Yale University EliScholar – A Digital Platform for Scholarly Publishing at Yale

Yale Medicine Thesis Digital Library

School of Medicine

January 2014

Is The Financial Burden Of Cancer Impacting Survivors' Quality Of Life?

Kathleen Fenn
Yale School of Medicine, kathleen.fenn@yale.edu

Follow this and additional works at: http://elischolar.library.yale.edu/ymtdl

Recommended Citation

Fenn, Kathleen, "Is The Financial Burden Of Cancer Impacting Survivors' Quality Of Life?" (2014). Yale Medicine Thesis Digital Library. 1875.

http://elischolar.library.yale.edu/ymtdl/1875

This Open Access Thesis is brought to you for free and open access by the School of Medicine at EliScholar – A Digital Platform for Scholarly Publishing at Yale. It has been accepted for inclusion in Yale Medicine Thesis Digital Library by an authorized administrator of EliScholar – A Digital Platform for Scholarly Publishing at Yale. For more information, please contact elischolar@yale.edu.



IS THE FINANCIAL BURDEN OF CANCER IMPACTING SURVIVORS' QUALITY OF LIFE?

A Thesis Submitted to the Yale University School of Medicine in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

> By Kathleen Marie Fenn MD, 2014



ABSTRACT:

Purpose: Little is known about the relationship between the financial burden of cancer and the physical and emotional health of cancer survivors. We examined the association between financial problems caused by cancer and reported quality of life in two samples of cancer patients.

Patients and Methods: Data from the 2010 National Health Interview Survey (NHIS) were analyzed. A multivariate regression model was used to examine the relationship between the degree to which cancer caused financial problems and the patients' reported quality of life. In a separate study, a cross-sectional survey was administered at a large academic breast center. Patients who had received a diagnosis of breast cancer between 6 and 18 months prior were eligible. Patients who qualified were invited to complete a survey including sociodemographic factors, and questions pertaining to their perceived quality of life and the financial burden of their cancer treatment. These data were correlated with tumor and treatment factors. Non-parametric statistical analyses were conducted using SPSS.

Results: In the NHIS data, of 2108 cancer patients who answered the survey question, "To what degree has cancer caused financial problems for you and your family?", 8.6% reported "a lot", while 69.6% reported "not at all". Patients reporting "a lot" of financial problems due to cancer were more likely to rate their physical health (18.6% vs. 4.3%, p<0.001), mental health (8.3% vs. 1.8%, p<0.001), and satisfaction with social activities and relationships (11.8% vs. 3.6%, p<0.001) to be poor compared to those with no financial hardship. On multivariate analysis controlling for all of the significant covariates on bivariate analysis, the degree to which cancer caused financial problems was the strongest independent predictor of quality of life. Patients who reported that cancer caused "a lot" of financial problems were four times less likely to rate their quality of life as "excellent", "very good", or "good" (OR=0.24; 95% CI: 0.14-0.40, p<0.001).

In the Yale Breast Center study, a total of 72 patients completed the survey. The mean age was 60 and mean tumor size was 2.3cm. When asked to what degree cancer caused financial problems, 18.1% responded "a lot", 12.5% "some", 18.1% "a little", and 44.4% "not at all". The majority (84.7%) self-reported their QOL to be "excellent", "very good", or "good", while 8.4% answered "fair" or "poor". On bivariate analysis, insurance status (p=0.029), education (p=0.013), family income (p=0.029), treatment history (chemotherapy, endocrine therapy, neither, or both) (p<0.001), and ER receptor status (p=0.037) were all significantly associated with the degree to which cancer caused financial problems.

Conclusion: Increased financial burden due to cancer was the strongest independent predictor of poor quality of life among cancer survivors in a nationwide population-based survey. We studied this relationship in a population of breast cancer patients at an academic center. Patients with hormone receptor-negative disease were more likely to report a large degree of financial problems. These patients represent a subset of patients with a poorer prognosis requiring more intensive therapy, These data support the need for increased clinician awareness of financial distress due to cancer, which may preferentially impact subsets of breast cancer patients.



Acknowledgements

I would like to thank Dr. Anees Chagpar for her dedicated, enthusiastic mentorship. I am grateful for her continued encouragement and patience throughout all phases of my thesis project.

Thank you to Dr. Suzanne Evans, Prof. Ruth Mc Corkle, Dr. Michael DiGiovanna, Dr. Lajos Pustai, Dr. Tara Sanft, Dr. Erin Hofstatter, Dr. Brigid Killelea, Prof. Tish Knobf, Dr. Donald Lannin, Dr. Maysa Abu-Khalaf, and Dr. Nina Horowitz, who all offered insightful ideas when drafting a manuscript reporting the results of the NHIS analysis.

Thank you to Gang Han for his guidance in identifying statistical methods for analysis of the Breast Center data.

Thank you to Karen Stavris, Meghan Butler, and Tina Adamczyk for their indispensable help in distributing surveys and compiling deidentified pathology reports for the Breast Center portion of this study. Thank you to all the clinicians who took the time to provide information on their patients' treatment history.



Table of Contents

Introduction	5
Statement of purpose	12
Methods	13
Aim #1: NHIS data	
Aim #2: Yale Breast Center data	15
Statement of student contribution	18
Results	19
Aim #1: NHIS data	19
Aim #2: Yale Breast Center data	21
Discussion	25
References	35

INTRODUCTION:

Contributors to Financial Distress in Cancer Patients

For a patient who receives a diagnosis of cancer, the financial impact of this diagnosis can be significant. The magnitude of the resulting financial burden is determined by a multitude of factors, including household income, socioeconomic status, insurance status, and extent of disease. Causes of cancer-related financial stress are multifactorial.

Treatment-related costs can be substantial, including costs of chemotherapy, radiation, and surgery, as well as home health care and travel to treatment centers (1). Patients who are employed may experience loss of productivity at work or total loss of employment and work-related benefits (2, 3). Household finances may suffer if the patient's family members take time away from work to help with their care (4). Other less apparent causes of financial burden include child care, domestic help, medical equipment, special foods, and nutritional supplements (1). In one cross-sectional survey sampling cancer patients in a region of the UK, costs of oil and heating, costs of food, and loss of income were the most frequently cited contributors to the financial impact of their disease (5).

Magnitude and Drivers of Cost of Cancer Treatment

Spending on cancer treatment has increased substantially during recent years, with more than a two-fold increase of direct medical costs relating to cancer treatment between the years of 1990 and 2008, after adjustment for inflation (6). Without taking into account the increase in expensive novel therapeutics, a projected growth in the population of elderly Americans will likely drive costs of cancer care in the upcoming years. Using data from the SEER database and assuming constant incidence, survival and cost, Mariotto et al



projected that the number of cancer survivors will increase by 4.3 million (31 percent) and yearly costs of cancer care would increase from 124.57 to 157.77 billion 2010 USD (27 percent) between 2010 and 2020 (7).

Most costs of cancer treatment billed to Medicare come during the first year after a cancer diagnosis; in the case of colorectal cancer, diagnoses of Stage II and III disease have the highest long-term aggregate cost billed to Medicare (8). Between 1991 and 2002, the cost of treatment for breast, lung, and colorectal cancer billed to Medicare increased after adjustments for inflation; the bulk of this increase was attributable to an increase in rates of surgical intervention, an increase in the rate of adjuvant therapy, and an increase in the cost of this treatment (9). Costs of cancer care in America continue to rise in this decade due to a variety of concurrent processes, including an increase in the elderly population, overutilization of therapy, and an increase the number of expensive innovative therapies available, with a proportion of these costs passed on to the patient (10).

Effects of Financial Burden

A high proportion of patients are affected economically by a cancer diagnosis. The SUPPORT study found that roughly one-third of families of seriously ill patients reported losing most or all of their family's savings (11). Ramsey et al. found in an analysis of patients in Washington state that cancer patients were 2.65 times more likely to file for bankruptcy in comparison with patients without a diagnosis of cancer (12).



Among American cancer patients, the degree of financial burden due to cancer can be variable. Low income patients have been shown to have disproportionately high expenses due to cancer (13). Insurance coverage can also affect an individual's cancer-related economic burden, with Medicare patients having more comorbidities but half the monthly expenditures of commercially insured patients in one study (14). Additionally, younger patients are more likely to experience financial distress. In the aforementioned study by Ramsey et al., younger patients had two to five times higher rates of bankruptcy when compared to cancer patients age 65 or older (12). Despite this finding, elderly patients are also affected. Cancer patients over the age of 70 are significantly more likely to have increased out-of-pocket expenditures for medical care in comparison with their cancer-free counterparts; the largest contributors to this increase in OOP expense comes in the form of prescription medications and home care services (15). Depending on an individual's particular financial and personal circumstances, the economic toll of cancer can be profound.

Financial problems related to cancer can adversely affect patients' compliance with treatment and access to care and, consequently, their future physical health. When analyzing NHIS data from 2003-2006, Weaver et al. found that patients with cancer were more likely than those without cancer to delay or forgo medical care (16). Through analysis of data found in the 2010 NHIS Cancer Supplement, Kent et al. found patients specifically reporting any degree of cancer-related financial problems were more likely to delay or forego medical care, including prescription medications, after adjusting for covariates (17). For example, among patients that were recently prescribed oral



oncolytics, those who were enrolled in pharmacy plans with a higher degree of costsharing were more likely to abandon therapy compared to those with plans requiring less cost-sharing (18).

Some patients experiencing financial distress will subsequently make financial decisions that have a substantial impact on the lives of themselves and their family. Among insured patients contacting a prescription drug assistance program, for example, 46% reported decreasing their amount of spending on food and clothing and 46% reported using a portion of their financial savings to defray costs of treatment (19). In a qualitative study of Irish cancer patients, patients also cited cutting back on food shopping and clothes shopping, in addition to reducing heat in their homes, and forgoing future medical treatment (20).

Financial Burden of Breast Cancer

The financial effects of a breast cancer diagnosis can be long-lasting. When assessing QOL in breast cancer survivors at an average of 12.5 years postdiagnosis, Hsu et al. found that breast cancer patients had EORTC financial impact subscores 6.3% higher than cancer-free age-matched controls (21). Similarly, when assessing long-term QOL longitudinally in breast cancer survivors in a region of Germany, Koch et al. found that reported financial difficulties for breast cancer survivors were significantly higher than those seen in controls, and even increased from year five to year ten post-diagnosis (22).

Financial burden can affect behavior in breast cancer patients. In a retrospective cohort study examining patients over 50 with resected breast cancer using mail-order prescriptions for aromatase inhibitors, higher prescription co-payments were significantly associated with nonpersistence and nonadherence to AI therapy, with this effect more pronounced in older women (23).

Instruments to Measure QOL

The financial burden of a cancer diagnosis may affect quality of life both on an immediate and long-term basis. Investigators interested in this outcome measure have available a variety of different methods for assessing quality of life. In a multidimensional model of health, physical, social, and mental components play a role along with morbidity and mortality. The World Health Organization (WHO) has defined quality of life as:

...the individual's perception of their position in life in the context of the culture and value systems in which they live and in relationship to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence and their relationships to salient features of their environment (24).

Some investigators choose to narrow their focus to health-related quality of life (HR-QOL); there are several validated instruments in use for measuring HR-QOL specifically in cancer patients. The European Organization for Research and Treatment of Cancer (EORTC) QLQ C-30 is a thirty item validated measure for quality of life in all cancer patients; it can be completed independently by patients and includes questions to assess physical, role, cognitive, emotional, and social functioning as well as global QOL (25). The QLQ-BR23 was designed as a breast cancer specific supplement to the QLQ C-30,



and assesses domains such as side effects from breast cancer, chemotherapy or radiation therapy, body image, and sexuality (26).

Both instruments have been validated clinically and cross-culturally and provide standardized measures of QOL, which are especially useful in clinical trials. However, quality of life is influenced by individual attributes and preferences, while standardized QOL measures typically give the importance of each item the same weight across surveys. This observation has led some researchers to suggest that a global self-reported assessment of both overall QOL and health-related QOL is an essential component to any QOL measure, because self-reported QOL takes into account the values of the individual in a way that many QOL survey items do not (27, 28).

Cancer-Related Financial Problems and QOL

The psychosocial effects of cancer-related financial strain are understudied. The degree to which cancer-related financial burden affects an individual's overall quality of life has not been commented on in the literature as frequently as numerical data on treatment costs. The subjective experience of cancer-related expenses, ie financial distress, can have an impact on a patient's overall well-being and satisfaction with life. In a qualitative study of Irish cancer patients, patients cited a variety of emotional effects resulting from the cost of their disease, including worry about shielding their children and spouses from the financial effects of their disease and anxiety about having to ask for financial assistance (20). The emotional toll of unexpected monetary costs may have a significant impact on quality of life.



Several studies have recently emerged reporting an association between increased economic burden due to cancer and decreased quality of life (29). In one, Meneses et al., using the QOL-BCS and Breast Cancer Finances Survey (BCFS) in a population of patients taken from an ongoing clinical trial, found that economic hardship events such as changes in motivation, productivity, or attendance at work, were negatively associated with QOL compared to baseline at 3 and 6 month follow-up on multivariate analysis (30). In another, Sharp et al. studied patients more than 6 months after a cancer diagnosis using a nationwide database in Ireland and found a threefold increase in depression risk among patients reporting increased cancer-related financial stress and financial strain (29). In addition, Gupta et al. examined this relationship with a case series of patients at a single American treatment center using QLQ C-30 to quantify financial distress and QLI to measure quality of life; using multiple regression analysis, every 10 point increase in financial difficulty score was significantly associated with a decline in every QOL domain, including physical, social/economic, spiritual, family, and overall function (31).

Taken together, these studies suggest a negative correlation between cancer-related financial problems and quality of life, including mental health. However, little has been published on this relationship in a nationwide sample of American cancer patients. Furthermore, there is a paucity of data on clinical factors that may impact this relationship, including pathologic features of disease and treatment history.



Statement of Purpose:

The aims of this study were as follows:

- 1. To characterize the relationship between cancer-related financial problems and self-reported quality of life through analysis of data from a nationwide population-based survey.
- 2. To examine the relationship between cancer-related financial problems and self-reported quality of life in a population of breast cancer patients at a large academic center, and to further elucidate the impact of clinicopathologic and treatment variables on this relationship.



Methods:

Aim #1: NHIS data

Data from the 2010 National Health Interview Survey (NHIS) were analyzed. The NHIS is the largest source of health information of US households, designed to reflect the nation's civilian noninstitutionalized population. It is a cross-sectional interview study administered annually by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. The NHIS uses a multistage sample design involving stratification and clustering techniques, and is designed to oversample Black, Hispanic, and Asian persons. The survey is administered face-to face by one of about 400 trained surveyors using computer assisted personal interviewing (CAPI), in which survey administrators enter data directly into a laptop computer at the time of interview.

The core of the survey contains four different segments: Household, Family, Sample Adult, and Sample Child. The Household segment collects demographic information on all members of the household from a single representative. The Family segment verifies and collects additional demographic information about individual member of the household. A sample adult and sample child (if applicable) are randomly chosen from each household and questionnaires are administered to collect additional information on health status, health service utilization, and health behaviors. Supplements to the survey are administered to address specific public health questions. The Cancer Control Supplement (CCS) collects information on cancer-related health behaviors and cancer screening. On years when the CCS is administered, it is given to the sample adult in each

selected household. The CCS was last administered in 2010. Further data on the NHIS are available elsewhere (32).

Respondents were asked if they had ever been told that they had cancer. For those who were 18 years of age or older, and who responded affirmatively, they were subsequently asked "To what degree has cancer caused financial problems for you and your family?". Possible responses were "a lot", "some", "a little", "not at all", "don't know", and "refused".

Data analysis

We analyzed the resulting data. Bivariate analyses were performed to examine whether the respondents who refused to answer or answered "don't know" to this question had statistically significant differences in their responses to other survey items examined in this study (Table 1). Those who answered the question informatively then formed the cohort of interest for our analyses.

The degree to which cancer caused financial problems was then evaluated in terms of its correlation with sociodemographic covariates, including sex, age, race, highest level of education completed, insurance status, family income, region of residence, and cancer type (Table 2). In addition, we evaluated the effect of cancer-related financial problems on respondents' perceived quality of life. In particular, respondents were asked to rate their quality of life in general, their physical health, their mental health, and their satisfaction with social activities and relationships. Possible responses included



"excellent, "very good", "good", "fair", and "poor" (Table 3). Furthermore, we evaluated respondents' perceived risk of recurrence ("What do you think the chances that your cancer will come back or get worse within the next 10 years?"), and their worry regarding the same ("How often do you worry that your cancer may come back or get worse?", Table 4).

A binary logistic regression model was created to determine the independent effect of cancer-related financial problems on quality of life, controlling for all of the sociodemographic factors found to be significant at p<0.1 on bivariate analysis (Table 5). All statistical analyses were performed with SUDAAN software (Release 9.0.1, Research Triangle Park, NC).

Aim #2: Yale Breast Center data

A survey study was conducted at the Breast Center at Smilow Cancer Hospital at Yale-New Haven. Because clinicopathologic information was not available from the NHIS cohort and many patients in that study were long-term survivors, we wanted to evaluate the effect of cancer-related financial problems and QOL in a cohort of recently diagnosed breast cancer patients in whom tumor and treatment data were available.

Patients attending follow-up appointments at the surgical oncology clinic who had received a diagnosis of breast cancer between 6 and 18 months prior were eligible. The survey items included questions about sociodemographic factors (age, race, marital status, education, sexual orientation, family income), financial problems due to cancer,



insurance status, out-of-pocket spending on medical expenses, and quality of life (including physical, mental, social, and overall QOL, as well as worry that cancer will return and self-reported chances of cancer returning or becoming worse), using language identical to the survey items included in the NHIS survey. An additional survey was given to the clinician, asking the clinician to report which type of surgery the patient had undergone and whether the patient had received treatment with conventional chemotherapy, radiation, trastuzumab, tamoxifen, or an aromatase inhibitor. Pathology reports for each patient were printed, deidentified, and attached to the survey document.

Including a validated QOL instrument for cancer patients, such as the EORTC QLQ-C30 or QLQ BR-23 for breast cancer specific QOL was considered. However, average length of time to complete QLQ BR-23 along with the QLQ-C30 is 9.2 minutes and it was felt that this addition to the length of time to complete the survey would be too onerous for patients, thus contributing to a decline in response rate (26). The outcome measure ultimately used was the answer to the survey item "In general, would you say your quality of life is...", as was used in the prior analysis of NHIS data.

Data analysis

When answering the question about insurance coverage, some patients marked that they had coverage with both Medicare and private insurance. In these instances, private insurance was considered to the primary coverage for purposes of data analysis.



After obtaining data from pathology reports, cancer type was categorized as either invasive (e.g. infiltrating ductal carcinoma, infiltrating lobular carcinoma, invasive squamous cell carcinoma) or non-invasive (e.g. DCIS) for purposes of data analysis.

Using clinician-provided data in the survey, a new "treatment history" variable was constructed. Patients were classified as having received systemic treatment (i.e. chemotherapy and/or trastuzumab) only, endocrine therapy (ie aromatase inhibitors or tamoxifen), both, or neither. Non-parametric statistical analyses were conducted using SPSS.



Statement of Student Contribution

With the input of my advisor, I devised a research question to be answered using data available in the NHIS survey database. I identified the variables of interest and with the assistance of my advisor, recoded them appropriately. My supervisor performed the statistical analysis of the data with SUDAAN software, and I learned the syntax and interpreted the results. I subsequently designed the survey to be administered in the Yale Breast Center and submitted it for HHC approval with the assistance of Karen Stavris, research nurse. During the duration of the survey, I reviewed patients scheduled to be seen in the breast surgical oncology clinic on a weekly basis. I submitted medical record numbers of patients who qualified for the study to two research coordinators and a patient care associate, who assisted in making physical copies of the survey and administering it to qualified patients. I gathered the data and entered it into an Excel database. I formulated the questions to be answered and worked with my advisor and Gang Han, PhD in choosing statistical methods and performing statistical analysis for the breast center survey data. For both components of the project, I interpreted the data and prepared the entirety of this written report.

Results from the NHIS data analysis were presented in an oral presentation at the Southwestern Surgical Congress in March 2013. A related manuscript is currently under revision after review by the Journal of Oncology Practice. Results from the Yale Breast Center study will be presented in poster format at the Miami Breast Center Conference in March 2014.



RESULTS:

Aim #1: NHIS Data

For the 2010 administration of the NHIS, the final response rate for the adult Sample Adult was 60.8% (32). Among the 2151 adult cancer survivors surveyed (representing 17,873,413 people in the population), 98.0% answered the question regarding the degree to which cancer caused them and their family financial problems. Among all people who were asked the question, 1.5% reported that they "didn't know" how cancer had financially impacted them or declined to answer. Comparing informative responders to those who responded "don't know" or declined to answer, no statistically significant differences were seen in terms of sociodemographic factors, suggesting that there was unlikely to be a systematic reporting bias in those who responded to the question of how cancer affected their financial life (Table 1). Those who refused to answer or didn't know how cancer affected their financial status did, however, had a significantly lower rate of worrying about their cancer coming back than those who provided informative answers (0% vs. 9.6%, p=0.005).

Of those who provided informative responses, 8.6% reported "a lot" of cancer-related financial problems, 11.7% reported "some", 10.3% "a little", and 69.6% "not at all". On bivariate analysis, compared to respondents who answered "not at all", respondents reporting "a lot" of financial problems were more likely to be female (63.5% vs. 55.9%, p=0.016), under the age of 65 (81.0% vs. 47.3%, p<0.001), of non-Caucasian race (18.8% vs. 7.4%, p<0.001), with less than a four-year college education (81.2% vs. 67.1, p=0.002), and a total combined household income of less than \$35,000 (51.6% vs. 32.4%,

p<0.001); Table 2. Subjects who reported "a lot" of cancer-related financial problems were also less likely to report Medicare as their primary health insurer (32.9% vs. 54.4%, p<0.001). The three types of cancer with the largest proportion of patients reporting "a lot" of financial problems were thyroid cancer (30.6%), ovarian cancer (25.3%), and lung cancer (23.7%) (p<0.001). Region of residence was not significantly correlated with degree of cancer-related financial problems (p=0.390).

Bivariate analyses were then performed to examine the association between degree of cancer-related financial problems and subjective evaluation of quality of life (Table 3). Compared to patients who answered "not at all", patients reporting "a lot" of cancer-related financial problems were more likely to report "poor" quality of life (p<0.001). This was true for self-assessment of general quality of life, as well as respondents' rating of their physical health, mental health, and social life. Additionally, patients reporting "a lot" of cancer-related financial problems were more likely to believe the chances of their cancer returning to be high and report a higher frequency of worry about their cancer returning in the future (p<0.001, Table 4).

For the multivariate analysis, we created an dichotomous outcome variable for quality of life, in which we compared "good", "very good", or "excellent" vs. "fair" or "poor". We found self-reported quality of life of "good" or better was inversely correlated with the degree to which cancer caused financial problems, independent of all sociodemographic variables found to be significant on bivariate analyses (Table 5). Patients with "a lot" of cancer-related financial problems carried a four-fold decrease in likelihood of reporting a

quality of life of "good" or better (OR: 0.24; 95% CI 0.14-0.40, p<0.001). Age, education, insurance status, and total combined family income were also significant independent predictors of quality of life.

Aim #2: Yale Breast Center Data

A total of 72 patients completed the survey. Of these, 5 respondents (6.9%) did not answer questions about quality of life and financial problems due to cancer. Clinician-provided information about treatment history was absent from two surveys (2.8%).

Of patients who responded, the mean age of respondents was 60.4 ± 12.3 years, with a median age of 61 years. Additional demographic information can be found in Table 6. In our sample, 42 (58.3%) had private insurance coverage, 16 (22.2%) had Medicare, 9 (12.5%) had Medicaid, and 2 (2.8%) were uninsured.

Clinicopathologic data is presented in Table 7. With regard to treatment history, the majority of patients had received a lumpectomy or partial mastectomy (n=44, 61.1%), with the rest having received a complete mastectomy. The majority had received radiation therapy (n=44, 61.1%). Less than half had received chemotherapy (n=29, 40.3%), trastuzumab (n=8, 11.1%), tamoxifen (n=16, 22.2%), or an aromatase inhibitor (n=29, 40.3%). For the 47 patients with an invasive component to their disease, mean tumor size was 2.3 ± 1.9 cm. The majority of patients (n=39, 54.2%) had node-negative disease. Though not all patients had information about Her2/Neu and receptor status included in their pathology report, of the 35 who did, 94.3% of tumors were negative



Her2/Neu by FISH. Additionally, out of 53 patients for whom this information was available, 42 (79.2%) were positive for estrogen receptor (ER), and 40 (75.5%) were positive for progesterone receptor (PR).

When asked to report out-of-pocket health-care related expenses over the last year, 22 (30.6%) reported expenses of \$500 or less whereas 12 (16.7%) reported expenses of \$5,000 or more. When asked to what degree cancer caused financial problems, 13 (18.1%) responded "a lot", 9 (12.5%) "some", 13 (18.1%) "a little", and 32 (44.4%) "not at all".

On bivariate analysis, the degree of association between demographic variables and cancer-related financial problems was evaluated (Table 8). Financial problems were significantly associated with insurance status (p=0.029); a greater proportion of patients with "a lot" of financial problems reported Medicaid coverage (41.7% vs 6.3%) and a lower proportion reported private insurance coverage (33.3% vs. 65.6%) or Medicare coverage (8.3% vs. 28.1%) compared to those with no financial problems. Age (p<0.001), education level (p=0.013), and family income (p=0.029) were also significantly associated with the degree of reported financial problems. Out-of-pocket spending on medical care approached a significant association with the degree of cancer-related financial problems (p=0.066). Race (p=0.150) and marital status (p=0.218) did not have a significant association.



On analysis of data from pathology reports, degree of cancer-related financial problems was significantly associated with ER receptor status (p=0.037, Table 8). A lower proportion of patients with "a lot" of cancer-related financial problems had ER-positive disease compared to those reporting none (44.4% vs. 84.0%). Cancer type (invasive vs. noninvasive, p=0.617), tumor size (p=0.650), tumor grade (p=0.103), node positivity (p=0.284), Her2/Neu FISH (p=0.480), PR status (p=0.150), and lymphovascular invasion (p=0.787) were all not significantly associated with financial distress.

The degree to which cancer caused financial problems was significantly associated with treatment history (systemic treatment only vs. endocrine therapy only vs. both vs. neither, p<0.001). Among survey respondents who reported "a lot" of financial problems, 9 (69.2%) had received systemic treatment only, 4 (30.8%) had received neither systemic nor endocrine treatment. No patients who had received endocrine treatment only or both types of treatment reported "a lot" of problems.

Surgery type approached significance (p=0.050), with patients reporting "a lot" of cancer-related financial problems reporting a lower rate of lumpectomy as opposed to mastectomy (50.0% vs 75.0%). Treatment with chemotherapy (p=0.121), radiation (p=0.885), or trastuzumab (p=0.146) was not associated with cancer-related financial problems.

The majority (n=61, 84.7%) self-reported their QOL to be "excellent", "very good", or "good", while 6 (8.4%) answered "fair" or "poor". Cancer-related financial problems



were associated with overall rating of QOL (p=0.004), as well as self-reported social QOL (p=0.004) (Table 9). Compared to patients reporting no cancer-related financial difficulty, a greater proportion of patients reporting "a lot" of cancer-related financial problems described their overall QOL as "poor" (7.7% vs. 0.0%). Cancer-related financial problems were also significantly associated with degree of self-reported worry that their cancer would return or get worse (p=0.003). A greater proportion of patients reporting "a lot" of cancer-related financial problems worried "all the time" that their cancer would return or get worse in comparison to patients reporting no financial problems (7.7% vs. 3.4%). The degree of cancer-related financial problems was not significantly associated with self-reported physical quality of life (p=0.095), mental quality of life (p=0.130), or belief that cancer would return or get worse (p=0.302). The proportion of patients reporting a quality of life of "good" or better by reported degree of financial problems is visually represented in Figure 1.



DISCUSSION:

As the cost of cancer care in the United States continues to increase and as the prevalence of cancer grows higher, the financial burden of a cancer diagnosis is becoming an increasingly important issue for cancer survivors. Cancer patients are especially vulnerable to economic hardship due to their disease, with evidence to suggest they face greater out-of-pocket health care expenses in comparison with patients suffering from other chronic diseases (15). This effect can be long-lasting. Beyond the physical and psychosocial impact of a cancer diagnosis, financial problems due to cancer can negatively impact survivors' quality of life.

We analyzed results of a nationwide health interview study and found that the degree of cancer-related financial problems was the strongest independent predictor of quality of life among a population of cancer survivors over the age of 18. Patients reporting "a lot" of financial problems were about four times less likely to report a quality of life that was "good" or better (OR: 0.24; 95% CI 0.14-0.40) compared to patients reporting no financial problems. The magnitude of cancer-related financial difficulty was a more significant predictor of quality of life than age, education, race, and family income. These findings highlight the potentially powerful impact of financial strain on a patient's perception of their overall well-being after a cancer diagnosis.

Like others, we found that increased cancer-related financial hardship is associated with lower household income (33, 34), female gender (35), and younger age (33, 19, 34). Several factors can be identified to help explain the gender disparity. In comparison with



men, terminally ill women have been found to be less likely to receive caregiving assistance from family and friends and thus more likely to have to pay for nursing care (35). Additionally, women may be disproportionately affected by childcare expenses; these expenses may contribute to increased financial burden after a cancer diagnosis.

Patients over the age of 65 reported fewer cancer-related financial problems. This is in accordance with findings by Shankaran et al, who noted that in a study of insured patients receiving adjuvant chemotherapy for colon cancer, younger age was associated with a greater degree of financial hardship independent of insurance status (34). Insurance status also plays a role, with patients covered by Medicare also reporting a lower degree of economic burden. Americans over 65 benefit from Medicare coverage, and are thus less likely than younger patients to be uninsured or underinsured, leading to increased financial protection from medical diagnoses requiring expensive treatment. Furthermore, older patients are more likely to have accrued financial resources and are less likely to have younger dependents.

Several studies have reported that financial difficulties and low income are associated with anxiety and depression in cancer survivors (36, 37, 38, 39). However, few have examined the relationship between *cancer-specific* financial problems and quality of life. Using survey data from patients on a cancer registry in Ireland, Sharp et al. found that cancer-related financial strain was associated with a roughly three-fold risk for depression (29). Similarly, among a group of breast cancer survivors from the Southeastern United States, Meneses et al. reported an association between cancer-related

financial events, such as decrease in work productivity and additional incurred out of pocket expenses, with decreased quality of life (30). A major strength of our study is the use of the NHIS data, which is designed to be representative of the entire population of the US, thus limiting population biases that may be present in institution-based or regional studies. This study is, to our knowledge, the largest, most contemporary population-based analysis of the financial impact of cancer on the self-reported quality of life of Americans.

We noted a relatively low proportion of patients claiming financial problems due to cancer in comparison to some prior studies. The majority of patients in our study (69.6%) claimed no financial problems at all, whereas much smaller proportions reported "a lot" (8.6%), or "some" (11.7%). Reported levels of cancer-related financial strain vary. For example, Sharp and colleagues found that 32% of patients more than 6 months post cancer diagnosis reported increased financial strain due to cancer (29). Similarly, we found that 30% of patients surveyed in our study reported some degree of cancer-related financial problems. However, Zafar et al. found that, even among a group of insured patients who did not request co-payment assistance, 85% reported at least some degree of financial burden from cancer-related expenses; for 27%, this burden was significant or catastrophic (19). Aspects of our study population may explain the lower reported rates of financial strain. The survey captured responses from patients who reported a diagnosis of cancer ever in their lifetime. Recall bias is likely to be present: patients for whom much time has elapsed since cancer diagnosis and treatment may be less likely to recall financial hardship, especially if they have reaccumulated resources lost during that time.



It is also possible that the survey population includes some patients who were diagnosed with childhood cancer and were thus, to a degree, protected from the financial toll due to their disease.

Because the NHIS is a cross-sectional study, no conclusions about causation can be drawn. Additionally, the survey does not provide any data on cancer stage and prognosis. Patients with more advanced disease may be more likely to have increased worry, lower quality of life, and increased financial difficulties; we are unable to examine this relationship with the available survey data. Furthermore, the survey included any patients who had ever been told they had cancer, and no temporal relationship between cancer diagnosis and emergence of financial difficulty can thus be elucidated from the data. This temporal relationship is also likely to confound data on quality of life and degree of worry that cancer may return; for example, patients for whom more time has elapsed since a cancer diagnosis may be less likely to worry about recurrence. Finally, the data do not report on the sources of financial difficulties for cancer patients, which could inform the types of interventions necessary to address this problem.

In order to address some of these limitations, we designed a cross-sectional survey study of breast cancer patients seen at the Breast Center – Smilow Cancer Hospital at Yale-New Haven Hospital. To decrease the possibility of recall bias, as seen in the NHIS data, we surveyed only breast cancer patients who had received their diagnosis between 6 and 18 months prior to survey administration. We found that, as seen in our analysis of data



from a population-based nationwide study, the degree to which cancer caused financial problems was significantly associated with poorer quality of life (p=0.004).

We observed that 30.6% of patients in this study reported "a lot" or "some" financial problems due to cancer. This rate is higher than that seen in the NHIS data and is more aligned with the 32% of patients that Sharp et al. observed who reported financial distress 6 months after a cancer diagnosis (29). Given that the majority of cancer-related cost of care to Medicare occurs in the first year after diagnosis (8), this finding is consistent with what would be expected in a population of patients 6-18 months post-diagnosis rather than the population of all cancer survivors captured by NHIS. As in the NHIS data, recall bias may contribute to this finding; patients with a newer cancer diagnosis may be more likely to self-report financial problems in comparison to patients who have had a diagnosis for a longer period of time.

The patient population in the Breast Center differs demographically in some respects to the American population as a whole. In comparison to an estimated 16.7% of Americans who are uninsured (40), only 2% of patients in our study reported no insurance coverage. Family income was roughly aligned with that expected in New Haven County; 45.9% of patients in this study reported a family income of \$75,000 or higher, whereas the median income for the county in which the breast center is located is \$60,549 (40). No data was obtained on the places of residence of survey respondents.

As was seen in the NHIS study, insurance status was significantly associated with cancerrelated financial problems, with fewer Medicare patients reporting "a lot" of financial burden. Younger age, too, was a significant covariate as seen in the NHIS data and other studies (33, 34).

The effect of family income on cancer-related financial problems has also been studied. Both Fortner et al and Shankaran et al found, similar to our NHIS findings, that income was a significant indicator of financial distress due to cancer (33, 34). In the Breast Center data, this variable was also significantly associated (p=0.029). It is worthwhile to point out that 15.8% of patients with annual household incomes above \$100,000 reported "a lot" or "some" financial problems due to cancer, indicating that moderate to high-income families are vulnerable to significant disease-related expense. Additionally, 40.0% of patients with annual household incomes below \$35,000 reported "a lot" of cancer-related financial problems, with an additional 15.0% reporting "some". Many of these patients likely qualify for "safety net" health insurance programs (e.g. Medicaid) intended to cover health expenses for low-income citizens. These relatively high rates of self-reported financial burden among low-income patients may be suggestive that such programs do not provide sufficient assistance to offset the financial toll of a cancer diagnosis.

When examining clinical and pathologic variables associated with cancer-related financial problems, we found that fewer patients with ER-positive disease and with a history of treatment with endocrine therapy reported cancer-related financial problems.



These variables are linked as diagnosis and treatment, and evidence suggests that aromatase inhibitors are a cost-effective treatment (41). Although ER-positive disease portends a better prognosis, we did not find that other prognostic factors, including tumor size, node status, and lymphovascular invasion were significantly associated with financial problems, suggesting that perhaps this association is due in part to the low cost of therapy available to patients with this diagnosis. In addition, it is possible that these patients were less likely to receive chemotherapy and may have been more likely to be recipients of Medicare benefits.

While a history of receiving chemotherapy was not on its own significantly associated with financial problems, we found that among patients who received systemic therapy (chemotherapy or trastuzumab) without endocrine therapy, 9 (64.3%) reported "a lot" of cancer-related financial problems. In contrast, no patient who received endocrine therapy either alone or in conjunction with systemic therapy reported "a lot" of financial problems. This data supports the hypothesis that patients with hormone receptor-negative disease are more vulnerable to financial burden. These patients have a poorer prognosis, are more likely to have a poorer functional status, and are more likely to undergo prolonged treatment regimens with systemic therapy.

While the Breast Center portion of this study (Aim #2) provided valuable insights into the impact of clinicopathologic and treatment variables on financial distress in breast center patients and aimed to minimize recall bias, it was limited by the small magnitude of the sample size that reduces the number of statistically significant observations that can be

made. The population in our academic center is demographically different from the population of cancer patients at large, so results cannot be directly extrapolated to apply to the population as a whole. However, these results complement the nationally representative work done with the NHIS data in Aim #1. Finally, as with the NHIS data, this is a cross-sectional study and thus no inferences about causation can be made.

Conclusions and Future Directions

Our data highlight the need to draw increased attention toward the economic burden caused by a cancer diagnosis and the impact this burden may have on a patient's overall well-being. In both aims of our study, consistent with findings in several prior studies, the degree to which cancer caused financial problems was significantly associated with decreased quality of life. Given this association, further attention toward interventions that may decrease the financial burden of a cancer diagnosis is warranted, especially for those most at risk of experiencing cancer-related financial problems.

Interventions to address this problem may be enacted at either the individual or systemic level. There has been some research directed at examining the nature of the physician-patient relationship and the patient's experience of financial burden of disease. Bullock et al. examined patient's attitudes toward discussing cost of care and found that while only a minority of oncologists reported feeling comfortable discussing costs of care with their patients, the majority of cancer patients wanted their oncologist to address these costs during their visit (42). This disparity between the expectations of patients and oncologists about communication regarding costs of care may be addressed by further education of



oncologists both on patient communication preferences as well as on specifics of treatment costs. Increased utilization of non-physician team members, such as social workers, who are knowledgeable about financial barriers to treatment, can also play an integral role by providing patients with up-to-date information and reducing physician workload.

On a larger scale, systematic changes to the American health care system are likely to affect the cost of cancer care as the Affordable Care Act (ACA) becomes progressively implemented. We noted in the NHIS data that uninsured patients were significantly more likely to experience "a lot" of financial problems due to cancer. By some estimates, the ACA will lead to a decrease in uninsured adults by 70%, thus portending a potential decrease in the financial burden of cancer on an individual basis (43). However, this estimate is not agreed upon by all researchers, and estimates are fluid as more information becomes available about utilization of health insurance exchanges. Additionally, the ACA will require more people to purchase insurance or, alternatively, pay a fine; this increased degree of cost-sharing may impose an additional financial burden.

Furthermore, continued research on methods to increase cost effectiveness on a systems level may lead to a decrease in the individual cancer patient's financial burden. As Zafar and Abernethy point out in their editorial on the subject, the ACA may ultimately contribute to decreased costs by shifting Medicare reimbursements away from a fee-for-service model and towards an encounter-based approach, thus incentivizing the use of

cost-effective treatment (44). However, expenditures on drug therapy continue to increase in oncology practice; increasing numbers of new, targeted therapeutic agents contribute to this phenomenon, in addition to the widespread use of drugs for off-label indications. One 2005 study estimated that up to 75% of drugs used in oncology are prescribed for off-label indications (45). Further research on the efficacy of drugs for off-label use may guide clinicians toward more cost-effective therapies. Incorporation of cost effectiveness considerations into the FDA drug approval process may also contribute to a decrease in this trend.

In summary, we found that lack of insurance coverage and lower family income is strongly associated with the degree of cancer-related financial problems. Subsets of patients for particular cancer types may be particularly susceptible to financial problems; such patients include those breast cancer patients with hormone receptor-negative disease, who are more likely to be younger and receive chemotherapy. Additional interventions to decrease personal costs due to cancer in the United States are worthy of further study, especially as the ACA in implemented over the next several years. Cost-effectiveness research to meticulously appraise the cost versus benefit of cancer therapies is needed, along with an increasing awareness on the part of clinicians of the impact that cancer related costs may have on the quality of life of their patients.

References

- 1. Brooks J, Wilson K, Amir Z. Additional financial costs borne by cancer patients: A narrative review. *European Journal of Oncology Nursing* 2011;15:302-310
- 2. Bradley CJ, Neumark D, Luo Z, et al. Employment and cancer: findings from a longitudinal study of breast and prostate cancer survivors. *Cancer Invest* 2007;25:47-54
- 3. Gordon L, Scuffham P, Hayes S, et al. Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psychooncology* 2007;16:1130-1139
- 4. Timmons A, Gooberman-Hill R, Sharp L. The multidimensional nature of the financial and economic burden of a cancer diagnosis on patients and their families: qualitative findings from a country with a mixed public-private healthcare system. *Support Care Cancer* 2013;21:107-117
- 5. Rogers SN, Harvey-Woodworth CN, Hare J, et al. Patients' perception of the financial impact of head and neck cancer and the relationship to health related quality of life. *Br J Oral Maxillofac Surg* 2012;50:410-416
- 6. Elkin EB, Bach PB. Cancer's next frontier: addressing high and increasing costs. JAMA 2010;303:1086-1087
- 7. Mariotto AB, Yabroff KR, Shao Y, et al. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst* 2011;103:117-128
- 8. Brown ML, Riley GF, Schussler N, et al. Estimating health care costs related to cancer treatment from SEER-Medicare data. *Med Care* 2002;40:IV-104-117
- 9. Warren JL, Yabroff KR, Meekins A, et al. Evaluation of trends in the cost of initial cancer treatment. *J Natl Cancer Inst* 2008;100:888-897
- 10. Zafar SY, Abernethy AP. Financial toxicity, Part I: a new name for a growing problem. *Oncology (Williston Park)* 2013;27:80-81, 149
- 11. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994;272:1839-1844
- 12. Ramsey S, Blough D, Kirchhoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)* 2013;32:1143-1152
- 13. Arozullah AM, Calhoun EA, Wolf M, et al. The financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol* 2004;2:271-278
- 14. Chang S, Long SR, Kutikova L, et al. Estimating the cost of cancer: results on the basis of claims data analyses for cancer patients diagnosed with seven types of cancer during 1999 to 2000. *J Clin Oncol* 2004;22:3524-3530
- 15. Bernard DS, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol* 2011;29:2821-2826
- 16. Weaver KE, Rowland JH, Bellizzi KM, et al. Forgoing medical care because of cost: assessing disparities in healthcare access among cancer survivors living in the United States. *Cancer* 2010;116:3493-3504
- 17. Kent EE, Forsythe LP, Yabroff KR, et al. Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer* 2013;119:3710-3717
- 18. Streeter SB, Schwartzberg L, Husain N, et al. Patient and plan characteristics affecting abandonment of oral oncolytic prescriptions. *J Oncol Pract* 2011;7:46s-51s
- 19. Zafar SY, Peppercorn JM, Schrag D, et al. The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient's Experience. *Oncologist* 2013



- 20. Timmons A, Gooberman-Hill R, Sharp L. "It's at a Time in Your Life When You Are Most Vulnerable": A Qualitative Exploration of the Financial Impact of a Cancer Diagnosis and Implications for Financial Protection in Health. *PLoS One* 2013;8:e77549
- 21. Hsu T, Ennis M, Hood N, et al. Quality of life in long-term breast cancer survivors. *J Clin Oncol* 2013;31:3540-3548
- 22. Koch L, Jansen L, Herrmann A, et al. Quality of life in long-term breast cancer survivors a 10-year longitudinal population-based study. *Acta Oncol* 2013;52:1119-1128
- 23. Neugut AI, Subar M, Wilde ET, et al. Association between prescription copayment amount and compliance with adjuvant hormonal therapy in women with earlystage breast cancer. *J Clin Oncol* 2011;29:2534-2542
- 24. O'Boyle CA. Measuring the quality of later life. *Philos Trans R Soc Lond B Biol Sci* 1997;352:1871-1879
- 25. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365-376
- 26. Sprangers MA, Groenvold M, Arraras JI, et al. The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. *J Clin Oncol* 1996;14:2756-2768
- 27. Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994;272:619-626
- 28. Covinsky KE, Wu AW, Landefeld CS, et al. Health status versus quality of life in older patients: does the distinction matter? *Am J Med* 1999;106:435-440
- 29. Sharp L, Carsin AE, Timmons A. Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer. *Psychooncology* 2012
- 30. Meneses K, Azuero A, Hassey L, et al. Does economic burden influence quality of life in breast cancer survivors? *Gynecol Oncol* 2012;124:437-443
- 31. Gupta D, Lis CG, Grutsch JF. Perceived cancer-related financial difficulty: implications for patient satisfaction with quality of life in advanced cancer. *Support Care Cancer* 2007;15:1051-1056
- 32. 2010 National Health Interview Survey (NHIS) Public Use Data Release. Hyattsville, MD: Division of Health Interview Statistics, National Center for Health Statistics
- 33. Fortner BV, Demarco G, Irving G, et al. Description and predictors of direct and indirect costs of pain reported by cancer patients. *J Pain Symptom Manage* 2003;25:9-18
- 34. Shankaran V, Jolly S, Blough D, et al. Risk factors for financial hardship in patients receiving adjuvant chemotherapy for colon cancer: a population-based exploratory analysis. *J Clin Oncol* 2012;30:1608-1614
- 35. Emanuel EJ, Fairclough DL, Slutsman J, et al. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med* 1999;341:956-963
- 36. Kim SH, Kang S, Kim YM, et al. Prevalence and Predictors of Anxiety and Depression Among Cervical Cancer Survivors in Korea. *International Journal of Gynecological Cancer* 2010;20:1017-1024
- 37. Dahl AA, Haaland CF, Mykletun A, et al. Study of anxiety disorder and depression in long-term survivors of testicular cancer. *J Clin Oncol* 2005;23:2389-2395
- 38. Kim SH, Son BH, Hwang SY, et al. Fatigue and depression in disease-free breast cancer survivors: prevalence, correlates, and association with quality of life. *J Pain Symptom Manage* 2008;35:644-655



- 39. Ell K, Xie B, Wells A, et al. Economic stress among low-income women with cancer: effects on quality of life. *Cancer* 2008;112:616-625
- 40. American FactFinder. U.S. Census Bureau:http://factfinder2.census.gov
- 41. Miller LA, Roy A, Mody R, et al. Comparative economic analysis of aromatase inhibitors and tamoxifen in the treatment of hormone-dependent breast cancer. *Expert Opin Pharmacother* 2007;8:1675-1691
- 42. Bullock AJ, Hofstatter EW, Yushak ML, et al. Understanding patients' attitudes toward communication about the cost of cancer care. *J Oncol Pract* 2012;8:e50-58
- 43. Schoen C, Doty MM, Robertson RH, et al. Affordable Care Act reforms could reduce the number of underinsured US adults by 70 percent. *Health Aff (Millwood)* 2011;30:1762-1771
- 44. Zafar SY, Abernethy AP. Financial toxicity, Part II: how can we help with the burden of treatment-related costs? *Oncology (Williston Park)* 2013;27:253-254, 256
- 45. M S. "Off-label" indications for oncology drug use and drug compendia: history and current status. *J Oncol Prac* 2005;1:102-105



Table 1: Demographic characteristics of informative responders vs. those refusing to answer or responding "Don't know" in NHIS population

	Informative Responders (%)	"Don't know" or refused to respond (%)	P-value
% total sample	98.5	1.5	
Sex			0.219
Male	44.0	39.3	
Female	56.0	60.6	
Race			0.450
White	90.6	90.4	
Black	6.7	7.5	
Asian	1.5	1.2	
All other races	1.2	0.4	
Age (years)			0.696
18-64	53.2	54.8	
<u>≥</u> 65	46.8	45.2	
Education			0.300
Less than grade 12	12.5	17.6	
High school graduate	27.5	25.4	
Some college/ Associate's	29.8	31.0	
Bachelor's	16.8	16.3	
Master's	9.1	7.0	
Professional/ Doctorate	4.4	2.8	
Insurance status			0.851



Medicare	51.0	51.1	
Medicaid	3.7	5.6	
Military	2.7	3.0	
Private	36.6	34.4	
Not covered	6.0	5.9	
Total combined family income			0.055
\$0-\$34,999	35.2	45.5	
\$35,000 -\$74,999	33.0	30.5	
\$75,000 -\$99,999	12.5	8.7	
\$100,000 and over	19.3	15.3	
Region			0.450
Northeast	17.1	22.9	
Midwest	25.0	23.7	
South	37.4	35.3	
West	20.5	18.1	
Cancer type			0.280
Breast	88.1	11.9	
Cervical	93.1	6.9	
Colorectal	89.3	10.7	
Lung	90.1	9.9	
Lymphoma/ leukemia	86.6	13.4	
Melanoma	91.0	9.0	
Ovarian	84.2	15.8	
Prostate	87.0	13.0	



Thyroid	94.7	5.3
Uterine	94.5	5.5
Other	92.0	8.0



Table 2: Degree to which cancer caused financial problems by demographic characteristics in NHIS population

	"A lot" (%)	"Some" (%)	"A little" (%)	"Not at all" (%)	P-value
% total sample	8.6	11.7	10.3	69.6	
Sex					0.016
Male	36.5	40.9	53.6	44.1	
Female	63.5	59.1	46.5	55.9	
Race					< 0.001
White	81.2	86.3	90.2	92.6	
Black	13.6	9.8	8.4	5.1	
Asian	2.7	2.7	1.4	1.1	
All other races	2.5	1.1	0.0	1.2	
Age (years)					< 0.001
18-64	81.0	65.5	55.7	47.3	
<u>≥</u> 65	19.0	34.5	44.3	52.7	
Education					0.002
Less than grade 12	16.2	13.5	19.5	10.8	
High school graduate	37.3	26.7	24.5	26.8	
Some college/ Associate's	27.7	32.5	30.2	29.5	
Bachelor's	12.1	17.6	14.1	17.7	
Master's	5.9	6.5	8.7	10.0	
Professional/ Doctorate	0.8	3.3	3.1	5.1	



Insurance status					< 0.001
Medicare	32.9	44.6	50.3	54.4	
Medicaid	8.4	2.6	4.3	3.2	
Military	5.2	1.1	2.8	2.6	
Private	37.7	43.5	37.3	35.3	
Not covered	15.9	8.2	5.2	4.6	
Total combined family income					< 0.001
\$0-\$34,999	51.6	36.7	38.0	32.4	
\$35,000 -\$74,999	29.5	33.6	34.8	33.1	
\$75,000 -\$99,999	11.4	15.4	11.9	12.3	
\$100,000 and over	7.8	14.3	15.3	22.2	
Region					0.390
Northeast	15.4	13.4	15.9	18.0	
Midwest	19.4	28.9	27.6	24.7	
South	46.2	38.0	38.3	36.1	
West	18.9	19.3	18.2	21.1	
Cancer type					< 0.001
Breast	12.0	16.6	10.0	61.4	
Cervical	5.5	13.5	10.3	70.6	
Colorectal	11.5	14.3	11.6	62.6	
Lung	23.7	8.8	19.6	48.0	
Lymphoma/ leukemia	11.9	27.6	10.8	49.7	
Melanoma	3.0	6.0	9.6	81.5	
Ovarian	25.3	16.8	6.5	51.4	



Prostate	4.0	8.0	14.8	73.2
Thyroid	30.6	10.8	5.5	53.1
Uterine	6.5	11.9	9.4	72.3
Other	6.8	9.0	8.8	75 4

Table 3: Bivariate analysis of degree to which cancer caused financial problems and quality of life ratings in NHIS population

	"A lot" (%)	"Some" (%)	"A little" (%)	"Not at all" (%)	P-value
Rating of general quality of life					< 0.001
Excellent	13.1	25.4	26.5	34.1	
Very good	18.2	29.7	31.0	35.1	
Good	33.6	29.8	28.5	22.4	
Fair	23.4	13.0	11.6	6.6	
Poor	11.7	2.0	2.5	1.8	
Rating of physical health					< 0.001
Excellent	6.1	11.8	10.6	16.0	
Very good	11.2	26.4	27.0	34.0	
Good	30.7	37.2	34.2	32.4	
Fair	33.4	16.3	17.5	13.3	
Poor	18.6	8.4	10.6	4.3	
Rating of mental health, including mood and ability to think					<0.001
Excellent	11.7	20.1	21.2	32.4	
Very good	21.5	35.7	36.3	34.8	
Good	35.9	30.2	34.9	23.8	
Fair	22.6	12.0	4.5	7.2	
Poor	8.3	2.1	3.2	1.8	
Rating of satisfaction with social activities and relationships					<0.001



Excellent	15.8	18.0	19.1	28.8
Very good	17.5	31.2	30.2	32.7
Good	37.4	35.6	34.7	28.7
Fair	17.6	11.6	10.0	6.2
Poor	11.8	3.6	6.0	3.6



Table 4: Bivariate analysis of degree to which cancer caused financial problems and ratings of worry in NHIS population

	"A lot" (%)	"Some" (%)	"A little" (%)	"Not at all" (%)	P-value
Belief the chances of cancer returning/ becoming worse in 10yr					<0.001
Very low	28.7	39.0	37.4	50.6	
Fairly low	10.4	22.5	20.1	15.6	
Moderate	29.2	25.6	22.4	22.4	
Fairly high	15.0	6.9	9.2	6.7	
Very high	16.7	6.0	10.9	4.6	
Frequency of worry that cancer may come back/get worse "all the time"					<0.001
Never	25.7	35.5	33.9	55.6	
Rarely	15.9	23.1	29.9	24.4	
Sometimes	25.3	28.2	19.2	15.1	
Often	12.7	7.1	12.3	3.3	
All the time	20.5	6.1	4.8	1.7	



Table 5: Multivariate analysis: quality of life of at least "good" by degree to which cancer caused financial problems and demographic characteristics in NHIS population

Variable	Adjusted OR (95% CI)	P-value
Degree to which cancer caused financial problems		< 0.001
A lot	0.24 (0.14-0.40)	
Some	0.57 (0.33-0.99)	
A little	0.67 (0.41-1.08)	
Not at all	Referent	
Sex		0.016
Male	Referent	
Female	1.54 (0.97-2.47)	
Race		
White	Referent	
Black	0.97 (0.60-1.57)	
Asian	0.40 (0.17-0.95)	
All other races	0.62 (0.18-2.14)	
Age		< 0.001
18-64	Referent	
≥65	2.17 (1.14-4.15)	
Education		0.002
Less than grade 12	Referent	
High school graduate	1.10 (0.70-1.74)	
Some college/ Associate's degree	2.09 (1.26-3.44)	
Bachelor's degree	3.16 (1.53-6.51)	
Master's degree	2.40 (1.08-5.30)	
Professional degree/ Doctorate	4.50 (0.88-22.87)	



Insurance status		< 0.001
Medicare	0.48 (0.23-1.02)	
Medicaid	0.63 (0.30-1.32)	
Military	0.53 (0.19-1.48)	
Private	1.65 (0.81-3.36)	
Not covered	Referent	
Total combined family income		<0.001
\$0-\$34,999	Referent	
\$35,000-\$74,999	2.24 (1.48-3.41)	
\$75,000-\$99,999	1.84 (0.93-3.63)	
\$100,000 and over	2.24 (1.01-4.98)	
Cancer type		< 0.001
Breast	Referent	
Cervical	0.97 (0.47-1.99)	
Colorectal	0.90 (0.41-2.02)	
Lung	0.38 (0.15-0.96)	
Lymphoma/ leukemia	0.91 (0.42-1.95)	
Melanoma	1.45 (0.53-3.97)	
Ovarian	1.24 (0.25-6.12)	
Prostate	1.53 (0.64-3.62)	
Thyroid	0.67 (0.17-2.57)	
Uterine	0.97 (0.47-2.01)	
0.1	1 10 (0 70 1 00)	

1.18 (0.70-1.99)



Other

Table 6: Sociodemographic characteristics, treatment history, and pathologic features of Yale Breast Center survey respondents

	Number of respondents (percentage total sample)
Race	vi
Caucasian	54 (75.0)
Black/African American	12 (16.7)
Asian	2 (2.8)
Other	4 (5.6)
Marital status	
Married	34 (47.2)
Widowed	9 (12.5)
Divorced	15 (20.8)
Separated	4 (5.6)
Never married	7 (9.7)
Living with partner	3 (4.2)
Education	
Less than grade 12	4 (5.6)
High school graduate	15 (20.8)
Some college/associate's degree	24 (33.3)
Bachelor's	10 (13.9)
Master's	14 (19.4)
Professional/ doctorate	5 (6.9)



Annual family income

\$0-\$34,999	22 (30.6)
\$35,000-\$74,999	16 (22.2)
\$75,000-\$99,999	13 (18.1)
\$100,000+	20 (27.8)
No response	1 (1.4)
Insurance	
Medicare	16 (22.2)
Medicaid	9 (12.5)
Private	42 (58.3)
Military	1 (1.4)
Not covered	2 (2.8)
Out-of-pocket health-care related	
expenses over the past year \$0-\$500	22 (30.6)
\$500-\$1,999	19 (26.4)
\$2,000-\$2,999	9 (12.5)
\$3,000-\$4,999	8 (11.1)
\$5,000+	12 (16.7)
No response	2 (2.8)



 Table 7: Treatment history and pathologic characteristics of Yale Breast Center patients

	Number of respondents
	(percentage of total sample)
Surgery type	
Lumpectomy/ partial mastectomy	44 (61.1)
Conventional mastectomy with no	10 (13.9)
reconstruction	
Skin-sparing mastectomy with	15 (20.8)
reconstruction	
No response	3 (4.2)
Chemotherapy received	
Yes	29 (40.3)
No	41 (56.9)
No response	2 (2.8)
Radiation received	
Yes	44 (61.1)
No	25 (34.7)
No response	3 (4.2)
Trastuzumab prescribed	
Yes	8 (11.1)
No	60 (83.3)
No response	4 (5.6)
Tamoxifen prescribed	
Yes	16 (22.2)
No	50 (69.4)
No response	6 (8.3)
Aromatase inhibitor prescribed	
Yes	29 (40.3)
No	39 (54.2)
No response	4 (5.6)



Cancer type

Cancer type	
DCIS	24 (33.3)
Infiltrating ductal	36 (50.0)
Infiltrating lobular	8 (11.1)
Other	4 (5.6)
Grade	
1	11 (15.3)
2	34 (47.2)
3	20 (27.8)
Data not available	7 (9.7)
Nodes positive	
Yes	17 (23.6)
No	39 (54.2)
Data not available	16 (22.2)
Her2/Neu FISH	
Positive	1 (1.4)
Negative	33 (45.8)
Equivocal	1 (1.4)
Data not available	37 (51.4)
Estrogen receptor	
Positive	42 (48.3)
Negative	11 (15.3)
Data not available	19 (26.4)
Progesterone receptor	
Positive	40 (55.6)
Negative	13 (18.1)
Data not available	19 (26.4)
Lymphovascular invasion	
Yes	9 (12.5)
No	59 (81.9)
Data not available	4 (5.6)



Table 8: Degree to which cancer caused financial problems by demographic characteristics and pathologic features among Yale Breast Center survey respondents

	"A lot" n (%)	"Some" n (%)	"A little" n (%)	"Not at all" n (%)	P-value
% total sample	13 (18.1)	9 (12.5)	13 (18.1)	32 (44.4)	
Race					0.150
White	8 (61.5)	7 (77.8)	11 (84.6)	24 (75.0)	
Black	2 (15.4)	1 (11.1)	1 (7.7)	7 (21.9)	
Asian	0 (0.0)	1 (11.1)	1 (7.7)	0 (0.0)	
All other races	3 (23.1)	0 (0.0)	0 (0.0)	1 (3.1)	
Education					0.013
Less than grade 12	1 (7.7)	0 (0.0)	0 (0.0)	3 (9.4)	
High school graduate	4 (30.8)	4 (44.4)	3 (23.1)	2 (6.3)	
Some college/ Associate's	6 (46.2)	3 (33.3)	6 (46.2)	8 (25.0)	
Bachelor's	2 (15.4)	1 (11.1)	2 (15.4)	5 (15.6)	
Master's	0 (0.0)	1 (11.1)	0 (0.0)	11 (34.4)	
Professional/ Doctorate	0 (0.0)	0 (0.0)	2 (15.4)	3 (9.4)	
Insurance status					0.029
Medicare	1 (8.3)	3 (33.3)	2 (16.7)	9 (28.1)	
Medicaid	5 (41.7)	1 (11.1)	0 (0.0)	2 (6.3)	
Military	4 (33.3)	4 (44.4)	10 (83.3)	21 (65.6)	
Private	1 (8.3)	0 (0.0)	0 (0.0)	0 (0.0)	
Not covered	1 (8.3)	1 (11.1)	0 (0.0)	0 (0.0)	
Marital status					0.218



Married	4 (30.8)	3 (33.3)	6 (46.2)	20 (62.5)	
Widowed	1 (7.7)	1 (11.1)	3 (23.1)	3 (9.4)	
Divorced	3 (23.1)	3 (33.3)	4 (30.8)	4 (12.5)	
Separated	1 (7.7)	1 (11.1)	0 (0.0)	2 (6.3)	
Never married	3 (23.1)	0 (0.0)	0 (0.0)	3 (9.4)	
Living with partner	1 (7.7)	1 (11.1)	0 (0.0)	0 (0.0)	
Total combined family income					0.029
\$0-\$34,999	8 (61.5)	3 (37.5)	4 (30.8)	5 (15.6)	
\$35,000 -\$74,999	4 (30.8)	1 (12.5)	1 (7.7)	9 (28.1)	
\$75,000 -\$99,999	0 (0.0)	2 (25.0)	4 (30.8)	6 (18.8)	
\$100,000 and over	1 (7.7)	2 (25.0)	4 (30.8)	12 (37.5)	
Out-of-pocket spending					0.066
\$0-\$500	3 (25.0)	2 (22.2)	2 (15.4)	13 (40.6)	
\$500-\$1,999	5 (41.7)	2 (22.2)	1 (7.7)	11 (34.4)	
\$2,000-\$2,999	0 (0.0)	2 (22.2)	3 (23.1)	3 (9.4)	
\$3,000-\$4,999	1 (8.3)	1 (11.1)	5 (38.5)	1 (3.1)	
\$5,000 or more	3 (25.0)	2 (22.2)	2 (15.4)	4 (12.5)	
Surgery type					0.050
Lumpectomy	6 (50.0)	4 (44.4)	10 (90.9)	24 (75.0)	
Mastectomy	6 (50.0)	5 (55.6)	1 (9.1)	8 (25.0)	
Treatment history					< 0.001
Chemotherapy only	9 (69.2)	2 (22.2)	2 (15.4)	1 (3.1)	
Endocrine therapy only	0 (0.0)	2 (22.2)	3 (23.1)	10 (31.3)	
Both	0 (0.0)	1 (11.1)	2 (15.4)	8 (25.0)	



Neither	4 (30.8)	4 (44.4)	6 (46.2)	12 (37.5)	
Radiation therapy					0.885
Yes	8 (66.7)	5 (55.6)	8 (72.7)	21 (65.6)	
No	4 (33.3)	4 (44.4)	3 (27.3)	11 (34.4)	
Cancer type					0.235
Non-invasive	6 (46.2)	5 (55.6)	3 (23.1)	8 (25.8)	
Invasive	7 (53.8)	4 (44.4)	10 (76.9)	23 (74.2)	
Grade					0.103
1	0 (0.0)	0 (0.0)	4 (30.8)	7 (24.1)	
2	5 (50.0)	4 (50.0)	6 (46.2)	15 (51.7)	
3	5 (50.0)	4 (50.0)	3 (23.1)	7 (24.1)	
Node status					0.284
Positive	5 (45.5)	3 (42.9)	4 (36.4)	4 (17.4)	
Negative	6 (54.5)	4 (57.1)	7 (63.6)	19 (82.6)	
Her2/Neu FISH					0.480
Positive	5 (100.0)	3 (75.0)	5 (100.0)	17 (94.4)	
Negative	0 (0.0)	0 (0.0)	0 (0.0)	1 (5.6)	
Equivocal	0 (0.0)	1 (25.0)	0 (0.0)	0 (0.0)	
ER status					0.037
Positive	4 (44.4)	5 (100.0)	8 (88.9)	21 (84.0)	
Negative	5 (55.6)	0 (0.0)	1 (11.1)	4 (16.0)	
PR status					0.150
Positive	4 (44.4)	4 (80.0)	8 (88.9)	20 (80.0)	
Negative	5 (55.6)	1 (20.0)	1 (11.1)	5 (20.0)	
Lymphovascular invasion					0.787
Present	1 (9.1)	1 (12.5)	3 (23.1)	4 (12.9)	



Absent	10 (90.9)	7 (87.5)	10 (76.9)	27 (87.1)	
Age (median, years)	45	51	61	66	p<0.001
Tumor size (median, cm)	2.20	2.30	1.65	1.60	p=0.650



Table 9: Bivariate analysis of degree to which cancer caused financial problems and quality of life ratings among Yale Breast Center survey respondents

	"A lot" n (%)	"Some" n (%)	"A little" n (%)	"Not at all" n (%)	P-value
Rating of general quality of life					0.004
Excellent	0 (0.0)	1 (11.1)	3 (23.1)	14 (43.8)	
Very good	4 (30.8)	3 (33.3)	8 (61.5)	12 (37.5)	
Good	6 (46.2)	2 (22.2)	2 (15.4)	6 (18.8)	
Fair	2 (15.4)	2 (22.2)	0 (0.0)	0 (0.0)	
Poor	1 (7.7)	1 (11.1)	0 (0.0)	0 (0.0)	
Rating of physical health					0.095
Excellent	0 (0.0)	1 (11.1)	2 (15.4)	8 (25.0)	
Very good	2 (15.4)	3 (33.3)	7 (53.8)	12 (37.5)	
Good	7 (53.8)	2 (22.2)	3 (23.1)	10 (31.3)	
Fair	3 (23.1)	3 (33.3)	1 (7.7)	2 (6.3)	
Poor	1 (7.7)	0 (0.0)	0 (0.0)	0 (0.0)	
Rating of mental health, including mood and ability to think					0.130
Excellent	0 (0.0)	1 (11.1)	2 (15.4)	11 (34.4)	
Very good	6 (46.2)	2 (22.2)	6 (46.2)	10 (31.3)	
Good	3 (23.1)	3 (33.3)	3 (23.1)	9 (28.1)	
Fair	3 (23.1)	3 (33.3)	2 (15.4)	2 (6.3)	
Poor	1 (7.7)	0 (0.0)	0 (0.0)	0 (0.0)	
Rating of satisfaction with social activities and					0.004



1		1	•
rΔ	atia	nck	11110
10	latio	1151	111125
			r-

Excellent	0 (0.0)	1 (11.1)	2 (15.4)	14 (43.8)
Very good	5 (38.5)	2 (22.2)	6 (46.2)	13 (40.6)
Good	5 (38.5)	2 (22.2)	4 (30.8)	5 (15.6)
Fair	2 (15.4)	3 (33.3)	1 (7.7)	0 (0.0)
Poor	1 (7.7)	1 (11.1)	0 (0.0)	0 (0.0)



Figure 1: Patients reporting a quality of life of "good" or better by reported degree of financial problems

