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Measurement of Self-Care in Patients with Cystic Fibrosis

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MEASUREMENT OF SELF-CARE IN PATIENTS WITH CYSTIC FIBROSIS

By

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ABSTRACT

MEASUREMENT OF SELF-CARE AGENCY IN
PATIENTS WITH CYSTIC FIBROSIS

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The purpose of this descriptive correlational study was to contribute to theory regarding the self-care agency in a population of Cystic Fibrosis (CF) patients ≥ 11 years of age (n=30). The following research questions were addressed: (1) what is the level of self-care in a group of CF patients; (2) what is the relationship between self-care and the basic conditioning factors of age, gender, years since diagnosis, and severity of illness; and (3) what is the relationship between locus of control and self-care.

Baker's Cystic Fibrosis Self-Care Practice Instrument was used to measure CF self-care. Wallston's Multidimensional Health Locus of Control (MHLC) Form A was used to measure general health beliefs, and Form C was used to measure health beliefs specific to CF. Shwachman score was used to measure severity of illness and demographic information was obtained on all subjects.

Results of this study indicate that those patients who viewed their CF physician(s) as controlling their health were the patients who scored highest on self-care. No significant correlations were found between self-care and age, gender, years with CF, and severity of illness.

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CHAPTER 1

INTRODUCTION

Chronic diseases bring patients into the health care system frequently for management of disease progression and palliative treatment for exacerbations of their disease. They interact with many health care disciplines including physicians, nurses, dietitians, and respiratory therapists. Health care providers involved with chronically ill patients may prescribe medications, alter diet, and recommend various life style changes. When evaluating patients to determine adherence to these recommendations/prescriptions, health care providers are dependent on self-report and the clinical assessment of a patient's condition. If the patient reports adherence, yet does not show an improvement in clinical condition, the health care provider may be perplexed as to further treatment. For some patients the ability or willingness to comply with these recommendations seems to be no problem, yet for others this is not true. If health care providers could predict, with some degree of certainty, which patients are less likely to follow recommendations, other methods to improve treatment adherence could be explored.

Cystic fibrosis (CF) is a chronic, progressively debilitating disease that is the most common lethal inherited disease of Caucasians. Affecting every race, this autosomal recessive disorder occurs approximately once for every

2,500 Caucasian births and once for every 17,000 African-American births. It is rarely seen in Asians and Native Americans. Affecting males and females equally, there are approximately 30,000 people living with CF in the United States with approximately 2,000 CF births each year. Although there is no cure for CF, great strides have been made to improve longevity. In the 1950's about half of those diagnosed with CF lived to be 5 years of age (Cunningham & Taussig, 1994). Today, the median survival for persons with CF is 30.1 years (CF Foundation).

The mutated gene responsible for the problems associated with CF is located on the long arm of chromosome 7 (Wilmott and Fiedler, 1994). This mutation causes an abnormality in the chloride conductance channel. The result is abnormally thick secretions affecting the lungs, pancreas, small bowel, liver, and reproductive organs, with excessive amounts of salt and water lost in the sweat glands. Although complications associated with CF vary with each patient, the most serious complication of CF is lung damage caused by the abnormal mucus and chronic infection resulting in disability, respiratory failure, and death in approximately 90% of CF patients. Mucus blocking pancreatic passages leads to serious problems with malabsorption and malnutrition in about 85% of CF patients. (Bartholomew & Schwartz, 1991).

The many complications associated with a chronic illness such as CF requires the patient to perform many home treatments including chest physical therapy, respiratory therapy, medications, and supplemental night

time feedings (Bartholomew, Parcel, Seilheimer, & Czyzewski, 1993). Self-management of this disease can impact the CF patient's health either positively or negatively. Exploring areas that can make self-care easier for the CF patient may also impact their future health.

The purpose of this study is to contribute to theory regarding self-care in a population of CF patients who attend the Michigan State University - Kalamazoo Center for Medical Studies Cystic Fibrosis Center. This theory building study will be the groundwork for future studies whereby interventions will be used to determine if patients have an affinity for varying levels of technology, techniques, and procedures that could result in an increased adherence to a prescribed regimen.

CHAPTER 2

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Many disciplines have researched and written about the concepts of self-care and self-management. Although each discipline defines these concepts somewhat differently, the underlying theme for all involves patients/clients taking an active role in their health.

Theoretical Framework

Dorothea Orem first published her concept of nursing theory including the concept of self-care in 1959 (as cited in Caley, Dirksen, Engalla & Hennrich, 1980). Since that time self-care nursing theory has evolved and now is used frequently in research and education.

This study utilized Orem's (1991) theories of self-care and self-care deficit. Orem (1991) defines self-care as "...the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 117). Self-care is learned behavior with characteristics of deliberate action of choice. "Self-care is a practical response to an experienced demand to attend to oneself" (p.124). Self-care requisite is the term used by Orem (1991, p.38) to express the desired outcome or goal of self-care. "Self-care requisites are expressions of the kinds of purposive self-care that individuals require" (p. 125). Orem identifies and defines three types of self-care requisites: universal, developmental, and

health-deviation (1991, p. 125).

> Universal self-care requisites are common to all human beings during all stages of the life cycle, adjusted to age, developmental state, and environmental and other factors. They are associated with life processes, with the maintenance of the integrity of human structure and functioning, and with general well-being.
>
> Developmental self-care requisites are associated with human developmental processes and with conditions and events occurring during various stages of the life cycle (e.g., prematurity, pregnancy) and events that can adversely affect development.
>
> Health-deviation self-care requisites are associated with genetic and constitutional defects and human structural and functional deviations and with their effects and with medical diagnostic and treatment measures.

Self-care demand refers to "the amount and kind of self-care that persons should perform or have performed for them within a time frame" (p. 135). Therapeutic self-care demand is conceptualized as being deliberate action.

According to Orem (1991) self-care deficit theory of nursing is a general systems theory that explains the relationship between the action capabilities and demands of self-care by individuals or the care demands of

their dependents. She refers to self-care agency as "human capabilities of individuals to perform actions to take care of themselves and others" (p. 145). Self-care agency varies throughout the lifespan from the very young to old age. Self-care agency is affected by basic conditioning factors such as age, gender, developmental and health state, sociocultural orientation, diagnosis and treatment factors, family systems factors, pattern of living, environmental factors and available resources (p. 136). Self-care agency is "...the complex acquired ability to meet one's continuing requirements for care that regulates life processes, maintains or promotes integrity of human

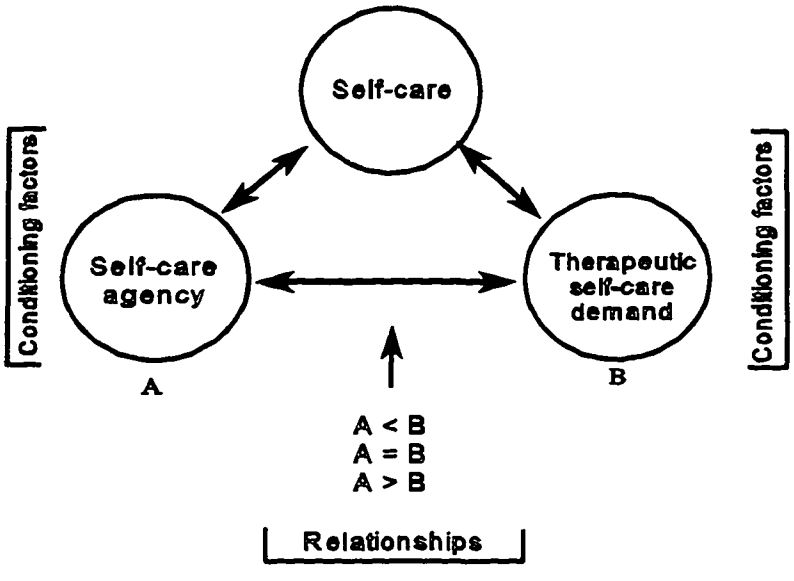


Figure 1. The relationship of self-care agency, therapeutic self-care demand, basic conditioning factors and self-care.

Source: Adapted from Orem, 1991, p. 146.

structure and functioning and human development, and promotes well-being" (p. 145).

Literature Review

An early study was conducted by Linn and Lewis (1979) on the attitudes of practicing physicians toward self-care. A thirteen item attitude scale was developed and administered to physicians (n=179) in the Los Angeles area. Those with the most favorable attitudes toward self-care were those physicians with an internal locus of control, Jewish religious background, under 46 years of age, and working in a group practice or clinic. Those with least favorable attitudes toward self-care were those who: came from Protestant backgrounds; were aged 46-63 years; practiced medicine alone and had external locus of control health beliefs.

Segall and Goldstein (1989) examined the range of self-care practices of 524 residents of Winnipeg, Canada and analyzed the correlates of self-care 'behavior'. They investigated three dimensions of self-care: symptomatic self-treatment responses, recent self-medication activity, and the use of home remedies. The following were also considered: sociodemographics, perceived health status, understanding of medical knowledge, attitudes toward medical care, and health maintenance/lifestyle beliefs and internal preventive control beliefs. The internal preventive control beliefs data were obtained using the Multidimensional Health Locus of Control (MHLC). The MHLC measures both internal and external dimensions of health locus of control, but only the internal preventive control belief subscale was used in the analysis of self-

care. The authors based this decision upon the findings of Wallston, who developed the MHLC, and reported that people who have an internal locus of control regarding health beliefs are more actively involved in their own care (p.157). Sociodemographics included; sex, age, marital status, education, income, religion and ethnicity. Results of the study indicated that females were more likely to be knowledgeable about the use of home remedies. Younger subjects were more apt to engage in self-care behavior. Education and income were not correlated very highly with self-care behavior. Stating no religious preference was associated with the use of home remedies. Ethnicity did not correlate with any of the self-care measures. No statistically significant relationships were found between internal preventive control health beliefs and the self-care behaviors under study. Surprisingly, there was an inverse relationship between health maintenance beliefs and self-treated symptoms and self-medication (Segall and Goldstein). The authors concluded that this finding signifies the importance of distinguishing between preventative and curative self-care beliefs and behavior (p.159).

McCaleb and Edgil (1994) utilized Orem's self-care model to describe the self-care practices of healthy adolescents (n=160). Their findings showed that adolescents aged 15-16 years are engaging in self-care practices and supported a link between self-concept and self-care.

Baker's (1991) descriptive multivariate correlational study sought to test Orem's self-care and self-care deficit theory in a group of adolescents with CF aged 12-22 (n=123). Subjects were recruited from three large

midwestern medical centers for children. Basic conditioning factors examined were age, gender, family income, family socioeconomic status, egocentric thought, satisfaction with family and severity of illness. Hollingshead Four Factor Index of Social Status was used to measure family socioeconomic status; Adolescent Egocentrism-Sociocentrism Scale measured egocentric thought; Family APGAR measured satisfaction with family and Forced Vital Capacity was used to measure severity of illness. The Cystic Fibrosis Self-Care Practice Instrument (CFSCPI) developed by Baker (1991) was used to measure health deviation self-care. Results revealed that basic conditioning factors were not significant predictors of self-care, yet the researcher suggests they may have an indirect effect on self-care. Baker (1991) recommended replication of her study using a "more multidimensional severity of illness measure which includes both pulmonary and nutritional data" (p. 176) to determine if severity of illness is a basic conditioning factor within Orem's model that could not be identified as such using the Forced Vital Capacity (FVC) as the measurement of illness severity.

Rubovits and Siegel (1994) studied self-care 'behaviors' in children with insulin dependent diabetes mellitus (IDDM), siblings of IDDM children, and normal healthy children. Their hypothesis that children with IDDM would score higher on disease management than the other two groups was supported.

Luder and Gilbride (1989) utilized Bandura's self-management principles while counseling cystic fibrosis patients about nutritional needs to

determine if CF patients who were counseled with a self-management focus could increase caloric intake and body mass index. Results supported a self-management focus in meeting nutritional needs of those with CF.

Wallston et al. (1983) found that persons who believe their health is controlled by powerful others are less likely to advocate self-treatment. Those with a strong internal locus of control had more positive attitudes toward self-treatment and active involvement in their own care. When evaluating patients with diseases such as diabetes, cancer, chronic pain and rheumatoid arthritis Wallston, Stein and Smith (1994) found that "internality" beliefs were strongest among persons with diabetes, and chance beliefs were strongest with cancer patients. It was theorized by the researchers that this may be due to the belief that cancer is frequently fatal, whereas diabetics realize their clinical status is dependent on actions they must take every day.

Purpose and Research Questions

The purpose of this study is to contribute to theory regarding the self-care of a population of CF patients who attend the Michigan State University - Kalamazoo Center for Medical Studies Cystic Fibrosis Center. The following research questions will be addressed:

1. What is the level of self-care in a group of CF patients?
2. What is the relationship between self-care and the basic conditioning factors (variables) of age, gender, years since diagnosis, and severity of illness?

3. What is the relationship of locus of control and self-care?

Definition of Terms

Self Care: "The practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 1991, p. 117).

Self -care Agency: "The complex acquired ability to meet one's continuing requirements for care that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well being" (Orem, 1991,p. 145).

Health Locus of Control: "Refers to a person's beliefs regarding where control over his/her health lies" (Wallston et. al, 1994).

CHAPTER 3

METHODOLOGY

Design and Sample

A descriptive, correlational design was used to measure self-care in cystic fibrosis (CF) patients aged ≥11 years attending the MSU-KCMS Cystic Fibrosis Center. CF patient records were reviewed for potential subjects meeting the age requirement to be eligible to participate in the study. It had been anticipated that there would be approximately 50 subjects eligible to participate in this study. All eligible CF patients were sent a letter describing the project and inviting them to take part or be approached by the investigator during visits to the CF Center for routine or illness follow-up. If qualifying patients were not seen in the clinic during the data collection phase of the study, they were contacted by phone to ascertain interest in study participation. This convenient sampling technique, which posed a threat to the external validity of the study, was necessary due to the limited number of available subjects. Further research is planned with this convenient sample of CF patients that will utilize study findings.

Inclusion criteria identified for this study were:

1. Diagnosis of cystic fibrosis for at least 2 years.
2. Attained age ≥ 11 years.

3. Use of English as first language.
4. Willing to sign informed consent if at least 18 years of age; parents willing to sign informed consent with patient assent if less than 18 years of age.
5. Willing and able to complete questionnaires.

Subjects who met the inclusion criteria and completed the informed consent process were asked to complete the Cystic Fibrosis Self-Care Practice Instrument (Appendix A) and the Multidimensional Health Locus of Control (MHLC) Forms A and C (Appendix B) with the God Health Locus of Control (GHLC) embedded within Form C. Demographic information was obtained on each subject by the investigator using data from the patient's medical record and verbal query (Appendix C). The severity of illness was measured with the Shwachman System of Clinical Evaluation of the Patient with Cystic Fibrosis (Appendix D). Scoring of this form was completed by the pediatric pulmonologists who routinely treat patients for exacerbations of their disease.

The above listed study instruments were given to each subject in a 9 X 12 envelope. Subjects were asked to complete the instruments in the following order: Cystic Fibrosis Self-Care Practice Instrument, Multidimensional Health Locus of Control Form C, Multidimensional Health Locus of Control Form A and completed last was the Patient Information form. This order allowed subjects to complete information on their health in

relation to cystic fibrosis first and their overall general health last. With the exception of the Patient Information Form, all instruments were coded with subject number only, and to ensure patient confidentiality no direct patient identifiers were placed on the instruments. After subjects completed all instruments, they were instructed to return them to the envelope and seal the envelope with a 1 X 3 label marked ' confidential'. A separate list identifying subject names with subject numbers was kept in a separate locked file in the investigator's office. The subjects were informed that the only person with access to this file was the investigator.

At the beginning of the study subjects were positioned in the large patient waiting room to complete the study instruments. However, it became apparent early in the study that the noise level was so high that it interfered with concentration for some subjects. Consequently, most subjects completed the study instruments in the examination rooms where a quiet environment could be assured.

Instruments

Cystic Fibrosis Self-Care Practice Instrument(CFSCPI). Baker's (1991) CFSCPI is a 28- item self-report questionnaire designed to measure health-deviation self-care behaviors necessary to meet the health-deviation self-care requisites associated with a diagnosis of cystic fibrosis. Each question is answered on a "ratio" scale of 0 to 100. Questions #24 and #25 are reverse coded and the total score is the mean of all the items. Content validity of this instrument was established using three techniques: (1) review by the

Orem research group at Wayne State University in Detroit, Michigan; (2) review by physicians and clinical nurse specialists working with CF patients; and (3) review by CF patient who did not take part in Baker's study (1991) . The reading level of this instrument was established as grade level five by the Flesch-Kincaid method (Baker, 1991). Construct validity of the CFSCPI yielded seven interpretable factors that accounted for 64% of the variance in health-deviation self-care scores (Baker, 1991). The sample size (n=123) was not deemed large enough to allow for a stable factor solution and factor scores were not used in subsequent analyses. Internal consistency resulted in a Cronbach alpha of .81 (n=123). Six subscales to the CFSCPI resulted in alpha coefficient values that ranged from .30 to .78. Baker suggests further instrument revisions before using the subscale scores as research variables.

Multidimensional Health Locus of Control (MHLC). This instrument has three forms, Form A/B, and Form C. Forms A and B are very similar with slightly different wording. Validation of Forms A and B was done with the general population. Form C was validated with a population of chronically ill subjects. Forms A and B have 18 items with three 6-item subscales that capture beliefs regarding the reinforcements of health-related behavior as being: (1) primarily internal (6 items); (2) a matter of chance (6 items); or (3) under the control of powerful others (6 items). Developed by Wallston et al. (1978) these scales resulted from earlier work with the general Health Locus of Control Scale which was based on Rotter's social learning theory as cited in Wallston, Stein and Smith, 1994. The

reading level of the MHLC (Forms A and B) was deemed to be at grade levels five-six using the Dale-Chall formula (Wallston, Stein & Smith, 1994). Although the MHLC was developed for adults using subjects over 16 years of age, no problems associated with administering this to subjects ≥ 11 years of age was anticipated . Alpha reliabilities for this instrument ranged from .673 to .767 when using the three 6-item scales. When the two Forms' (A and B) 6-item scales were combined the alpha reliabilities increased to .830 to .859. The development of Form C began in 1987 (personal correspondence K.A.Wallston, February 7, 1997). Form C has 18 items that also measures internality, powerful others externality, and chance externality. Unlike Forms A and B, which measures powerful others with 6 items, Form C measures powerful others with two 3-item subscales that address 'doctors' and 'other people' as powerful others. Form C is intended to be used with subjects who have an existing disease condition such as CF. Each statement is phrased with the term 'condition' and this term is substituted with whatever condition exists with the population being studied. Scoring the MHLC was done using a 6-point modified Likert scale ranging from 'Strongly Disagree' (1 point) to 'Strongly Agree' (6 points). Reliability and validity for the four subscales, Internality, Chance, Doctors and Other (powerful) People, within Form C was established with data collected on patients (n=588) with one of four diseases: rheumatoid arthritis; chronic pain; diabetes; or cancer. The internal consistency for the four subscales showed alpha values ranging from .70 to .85 with the lower alphas representing the two three-item

subscales. Embedded within the MHLC Form C were six statements that Wallston (personal correspondence Wallston, February 7, 1997,) has termed 'God Health Locus of Control (GHLC) Scale'. This subscale is designed to assess the belief that God is the locus of control of one's health in general, as measured with Forms A and B, or the locus of control of a specific disease state as measured with Form C (Wallston, 1997). This study provided the opportunity for beta testing the GHLC which will add to the current research that is being conducted elsewhere.

The GHLC was developed to explore behavioral aspects of rheumatoid arthritis (Wallston, 1997). Initially, the GHLC consisted of eight items with an alpha reliability >.90. Two items were dropped due to wording redundancy. The alpha reliability for the retained six items was .91.

System of Clinical Evaluation of Patients with Cystic Fibrosis. This instrument (Appendix D) determines severity of CF disease based on scores in four categories. A maximum score of 100 can be obtained by scoring patients in the areas of general activity, physical findings, nutritional status, and X-ray findings. A maximum of 25 points is possible in each of the four categories. Shwachman and Kulczycki (1958) followed 105 patients for five to fourteen years in developing this instrument which is widely used to determine severity of illness in cystic fibrosis patients. No information was given regarding reliability, however, this instrument has wide acceptance.

Procedures

This study was approved by the Grand Valley State University Human

Research Review Committee and the Bronson Methodist Hospital Human Use Committee prior to protocol initiation. Approval from the Bronson Methodist Hospital Human Use Committee was contingent upon removal of question #26 from the Cystic Fibrosis Self-Care Practice Inventory (CFSCPI) which asked "What percent of the time do you or your partner use birth control when you have sex? If you are not having sex, what percent of the time do you plan to use birth control when you begin having sex?" This question was removed from the instrument and the term "free space" was inserted for question 26.

After both committees approved the project, medical records were reviewed for subjects meeting study inclusion criteria. Thirty-five eligible subjects were identified during review of the Cystic Fibrosis Center records. One eligible subject had undergone recent lung transplant, and although this was not initially considered an exclusion criteria, this investigator chose not to ask the subject to participate. Attempts were made to contact thirty-four potential subjects. Letters to two potential subjects were returned 'undeliverable' and two subjects did not show for informed consent appointments. The remaining thirty eligible subjects were recruited for this study.

Written informed consent (Appendix F) was obtained from all subjects ≥ 18 years of age. Parents gave written informed consent with verbal patient assent on all subjects 11- 17 years of age. After the consent document was signed, each subject was given a packet containing the questionnaires and

instructed to complete them in the following order: Cystic Fibrosis Self-Care Practice Inventory (CFSCPI), Multidimensional Health Locus of Control Form C, Multidimensional Health Locus of Control Form A, and completed last was the patient information form. The total time required for completing all questionnaires ranged from 20-45 minutes, with most completing in less than 30 minutes. Questionnaires were checked for completeness by the investigator prior to subjects leaving the clinic and then returned to the envelope which was sealed with a 'confidential' label. Completed questionnaires were kept in a locked file in the investigator's office with access restricted to the investigator. All questionnaires were thoroughly completed by all 30 subjects with the exception of the demographics form on which ten subjects declined to answer the yearly income question.

Subjects were compensated $10.00 for the extra time they remained in the clinic to complete questionnaires. Subjects who agreed to come to clinic for study activity, but did not have an appointment to see the physician, were compensated an additional $10.00 for transportation.

CHAPTER 4

DATA ANALYSIS/RESULTS

Data Analysis

Data were analyzed using SAS statistical software (SAS Institute, Inc., Cary, NC). Questionnaires were checked for missing information when subjects turned them in to the investigator. All instruments were thoroughly completed by all subjects with the exception of the patient information (demographics) form on which ten (33%) subjects declined to answer the yearly income question. For this reason, no attempt was made to correlate income with other variables.

Descriptive statistics were used for the major variables. Correlations between self-care and locus of control subscales, and self-care with demographic variables were done using Pearson's product moment correlations. T-test procedures were used to evaluate differences between internal locus of control and powerful others locus of control for five self-care variables. Level of significance was set at $p \leq .05$.

Measurement of the internal consistency of the Cystic Fibrosis Self-Care Practice Instrument (CFSCPI) yielded a Cronbach alpha of .86 (n = 30). In order to calculate the internal consistency reliability some modifications had to be made in the calculations for the Cronbach alpha technique. This

was necessary because not all items in the CFSCPI applied to all subjects. For instance, some subjects did not require enzyme supplementation as part of their prescribed regimen, which resulted in a 'not applicable' answer for that question. When calculating the Cronbach alpha, there must be a score for each item, for every subject. Whenever 'not applicable' was the answer, this was substituted with that subject's mean CFSCPI score for that particular question.

Results

As seen in Table 1, the ages of participants ranged from 11 to 44 years with a mean of 18.5 (SD = 6.7).

Table 1

Age Distribution (n=30)

Age	n	%	Mean	Median	SD
11	1	3.3	18.5	17.0	6.7
12	4	13.3			
14	3	10.0			
15	2	6.6			
16	2	6.6			
17	5	16.6			
18	2	6.6			
19	3	10.0			
21	3	10.0			
25	1	3.3			
28	3	10.0			
44	1	3.3			

The sample (n = 30) consisted of 16 males (53.3%) and 14 females (46.7%). This distribution is consistent with the national statistics maintained by the Cystic Fibrosis Foundation Patient Registry which show

53.6% males and 46.4% females affected (Cystic Fibrosis Foundation, 1995). Three (10%) of the 30 subjects were married; the remaining 27 (90%) were single. The sample included twenty nine (96.7%) Caucasians and one (3.3%) Hispanic. The number of years with a diagnosis of CF ranged from 2 to 44 years,with a mean of 16.3, SD 7.6 and median 16.5 (not shown). Other demographic information collected included number of siblings with CF, number in household, head of household, religion and income (see Table 2).

Table 2

Characteristics of Sample (n=30)

Group	n	%
Gender		
Male	16	53.3
Female	14	46.7
Ethnic Origin		
Caucasian	29	96.7
Hispanic	1	3.3
Marital Status		
Single	27	90
Married	3	10
Siblings with CF		
0	25	83.3
1	4	13.3
2	1	3.3
Head of Household		
Father/Stepfather	21	70
Mother/Stepmother	3	10
Self	6	20
Total Number of Persons in Household		
1-2	7	23.3
3-4	15	50
5-6	6	20
7-8	2	6.7
Income (dollars per year)		
Declined to answer	10	33.3
<15,000	8	26.7
15-25,000	3	10
26-35,000	2	6.7
36-45,000	4	13.3
≥46,000	3	10
Religion		
Protestant	12	40
Catholic	7	23.3
Jehovah's Witness	1	3.3
Other	5	16.7
None	5	16.7

Subjects were queried regarding the number of visits they made to their CF physician for illness and routine follow-up over the past 12 months. If subjects were unsure of the number of visits, the clinic chart was reviewed for the actual number (see Table 3).

Table 3

Physician Visits

Visits	n	%	Mean	Median	SD
CF Physician Visits in Past Year					
Illness					
00-04	13	43.3	6.5	5	6.2
05-09	7	23.3			
10-14	6	20.0			
15-19	1	3.3			
20-24	3	10.0			
Routine Follow-Up			3.6	3.5	3.2
00-04	23	76.7			
05-09	4	13.3			
10-14	3	10.0			
Total Visits			10.2	7.5	7.4
0-4	8	26.6			
5-9	10	33.3			
10-14	5	16.6			
15-19	3	10.0			
20-24	3	10.0			
25-29	0	0			
30-34	1	3.3			
Non-CF Physician Visits in Past Year					
Total Visits			2.2	1	15.04
0-4	26	86.6			
5-9	2	6.6			
10-14	1	3.3			
15-19	1	3.3			

This study sought answers to three research questions: (1)What is the level of self-care in a group of CF patients? (2)What is the relationship between self-care and the basic conditioning factors (variables) age, gender, years with CF, and severity of illness? and(3) What is the relationship between locus of control and self-care?

Measurement of self-care was done using Baker's (1991) Cystic Fibrosis Self-Care Practice Inventory (CFSCPI). Severity of illness was measured with Shwachman's (1958) System of Clinical Evaluation of the Patient with Cystic Fibrosis. Locus of control was measured with Wallston's (1978, 1994) Multidimensional Health Locus of Control Form A (general health) and Form C (cystic fibrosis).

Research question 1, what is the level of self-care in a group of CF patients was answered. The CFSCPI scores ranged from 22.6 to 92.8 ($M = 63.5$, $SD = 15.7$, $Mdn = 62.1$) with a possible range of 0 to 100. When adherence to five areas of CF self-care (medications, enzymes, diet, exercise and chest physical therapy) was analyzed, it was found that subjects were more likely to take their medications than do chest physical therapy. The order of adherence beginning with the most adherent and ending with the least adherent were: medications, enzymes, diet, exercise and chest physical therapy.

Research question 2, what is the relationship between self-care and the basic conditioning factors (variables) age, gender, years with CF, and severity of illness was answered. Pearson product moment correlations

yielded no statistically significant relationships. The correlations were r = -.03, p = .88 for self-care and age; r = .24, p = .19 for self-care and gender; r = -.05, p = .80 for self-care and years with CF; and r = -.21, p = .25 for self-care and severity of illness. However, self-care and illness visits to the CF clinic showed a weak correlation (r = .33, p = .07), although it was not statistically significant.

Research question 3, what is the relationship between locus of control and self-care was answered. Locus of Control was measured for CF (Form C) and general health (Form A). Scores were obtained on both forms for the three subscales (internality, chance, and powerful others). When Pearson product moment correlations were used to compare the three subscales of both forms, strong positive relationships were noted indicating concurrent validity (see Table 4).

Table 4

Correlations between Cystic Fibrosis and General Health Locus of Control Subscales

	General Health		
Subscale	Internal	Chance	Powerful Others
Internal	0.39*		
Chance		0.67**	
Powerful Others			0.66**

*p = .03 **p =.0001

The powerful others subscale on the Locus of Control Form C was broken

down to doctors and other people resulting in 4 subscales, internal, chance, doctors and other people. When correlation analysis was done, self-care and doctors (as locus of control for CF) showed moderate strength ($r = .37$, $p = .04$),. When self-care was correlated with powerful others (locus of control for general health) a trend towards a weak positive relationship was demonstrated ($r = .33$, $p = .07$). The locus of control instrument that was used for general health (Form A) did not break the powerful others subscale down into doctors and other people as was done with the locus of control for CF (Form C). Consequently, it cannot be determined if "doctors" was the influencing variable leading this trend for general health as occurred with CF.

Locus of control for each subject was determined by the scores on the three subscales. Subjects were considered to have a strong locus of control if s/he scored highest on the same subscale for general health (Form A) and CF (Form C). Eleven subjects scored highest for internal locus of control on both forms while six subjects scored highest on powerful others locus of control on both forms. Data collected on these 17 subjects were pulled out to create a subgroup. In order to determine the level of self-care relating to adherence to prescribed medication, prescribed exercise, prescribed chest physical therapy, and prescribed enzyme supplementation for this subgroup, questions specific to these behaviors were identified in the CFSCPI. One question for each behavior that asked 'what percent of the time do you' perform the prescribed behavior was identified. As seen in Table 5, the t-test procedure was used to

Table 5

Self-Care Variables and Locus of Control

Variable	n	M	SD	t	df	p
Exercise				-.008	15	.99
Internal	11	76.5	28.2			
Powerful Others	6	76.6	28.9			
Medications				-1.54	11.9	.14
Internal	11	78.8	33			
Powerful Others	6	95	7.7			
CPT				-.65	15	.52
Internal	11	59.9	40.3			
Powerful Others	6	73.3	40.8			
Enzymes				-2.02	9.5	.07
Internal	10	76.3	32.5			
Powerful Others	6	97.5	4.1			
CFSCPI				-2.60	15	.02*
Internal	11	53.9	14.7			
Powerful Others	6	71.4	9.5			

*statistically significant

compare the two groups, powerful others locus of control and internal locus of control, for adherence to medications, exercise, chest physical therapy (CPT), enzyme supplementation and CFSCPI scores for both groups. Although the means for the two groups indicated disparity for four of the five variables (medications, CPT, enzymes, CFSCPI, but not exercise), only the CFSCPI result reached significance. The CFSCPI scores were significantly different for the two groups ($t = -2.60$, $df = 15$, $p = .02$) indicating that the subjects who

viewed powerful others as controlling their health were performing more self-care than the group who controlled their own health (internal locus of control). Because Form A of the MHLC did not include a 'doctors' subscale as did Form C, it is not possible to conclude that physicians were the powerful others directing this relationship. The difference in the two groups, strong powerful others or strong internal locus of control, with respect to adherence to prescribed enzyme supplementation approached significance at p=.07.

CHAPTER 5
DISCUSSION AND IMPLICATIONS

Discussion

Chronic diseases such as CF require patients to perform numerous daily activities related to their illness. Active participation and treatment adherence is essential to health maintenance. This study sought answers to three research questions: (1)What is the level of self-care in a group of CF patients; (2)What is the relationship between self-care and the basic conditioning factors (variables) age, gender, years with CF, and severity of illness; and(3) What is the relationship between locus of control and self-care.

The finding that cystic fibrosis patients were more likely to take medications than perform chest physical therapy (CPT) was not expected in answering research question 1. Certainly taking medications is very important, however daily performance of CPT is also essential in preventing respiratory complications. CPT ranked last out of the five self-care variables (medications, enzymes, diet, exercise and CPT).

The finding of no statistically significant correlations between self-care and the basic conditioning factors of age, gender, years with CF, and severity of illness was not unexpected and consistent with Baker's (1991) findings. The finding of a weak correlation between self-care and illness visits is perplexing. One would expect those who are performing higher on

self-care to have fewer illnesses.

Research question three which asked what is the relationship between locus of control and self-care revealed that those patients who viewed their CF physician(s) as controlling their health were the patients who reported increased adherence to prescribed treatment. This finding seems incongruent with nursing's focus on empowering the patient whereby nurses encourage patients to 'take charge of your health'. Numerous questions arise as a result of this study: 1) How would these findings compare with other chronic illnesses; and 2) Is the CF patient-CF physician relationship different from other patient-physician relationships due to the early entrance of the physician. Clearly the number of subjects (n = 30) in this study was small, however, Abbott, Dodd and Webb (1996) had similar findings with 60 adults with CF. They found that adherence to chest physical therapy, enzyme supplementation, and vitamin regimens increased as their level of worry about their CF increased. Also, when they compared those who had an internal locus of control with those who believed their health was controlled by others, it was found that those subjects who viewed their health as controlled by others had greater adherence. They concluded that worrying about CF and the perception of having little personal control over CF increased treatment adherence. It might be hypothesized that those with an internal locus of control are making an unconscious decision not to perform those activities associated with self-care. Although there was a trend toward a weak positive relationship between the number of CF illness visits to the

clinic and the CFSCPI self-care scores, severity of illness did not correlate with self-care. Baker (1991) also found no correlation between severity of illness, as measured by FVC, other basic conditioning factors and self-care. Her recommendation to use a multidimensional measure for severity of illness was taken for this study through the use of the Shwachman System of Clinical Evaluation of the Patient with Cystic Fibrosis, but did not yield statistically significant correlations.

Implications for Nursing

Administration

Nurses spend a great deal of time with chronically ill patients. The results of this study indicate that nurses working with CF patients need to be cognizant of the patient-physician relationship which may be different, for CF patients and their CF physician, than other physician-patient relationships.

Education

Obtaining self-care scores on all CF patients may be beneficial in determining where patients are having problems adhering to recommendations. The nurse educator can quickly ascertain what areas the CF patient is having problems with regarding adherence and together with the patient set measureable goals as appropriate.

Research

This study emphasizes the need to continue to conduct research with chronic illnesses such as CF. While this study adds to the body of knowledge,

there are no definitive answers regarding questions of adherence. This is a complex issue that warrants ongoing, continuous research.

Limitations

The primary limitations of this study are the small sample size and the convenience sampling technique used. Although thirty of the thirty five eligible subjects participated, the small sample size restricts generalizability. When the subgroup for the 'strong' locus of control was determined, this limited generalizability even further. The convenient sampling design poses a threat to the external validity of the study.

Baker (1991) found that CF patients who were dissatisfied with family functioning and had low socioeconomic status were most likely to not participate in self-care behaviors. Due to the high number of subjects refusing to answer the yearly income question on this study, no data analysis could be performed using subjects' income. It is possible that important information was lost as a result of this.

All subjects completed the questionnaires in the same order which involved completing the CF specific questionnaires first. It had been hypothesized prior to study initiation that subjects might view their CF as separate from their overall health. This uniformity of questionnaires was thought to be a method of determining if indeed this was true, but this technique could have introduced response set bias.

Recommendations

Larger studies are needed to explore the interrelationships of locus of

control and self-care with cystic fibrosis patients. Further research needs to examine if there are factors specific to CF that impacts the physician-patient relationship unlike other chronic diseases.

This study did not explore the concepts of trust versus dependency as confounding factors related to the patient-physician relationship. It is possible that these may be relevant to this population. Future studies might examine the role of trust and dependency in CF patients.

Appendix A

Cystic Fibrosis Self-Care Practice Instrument

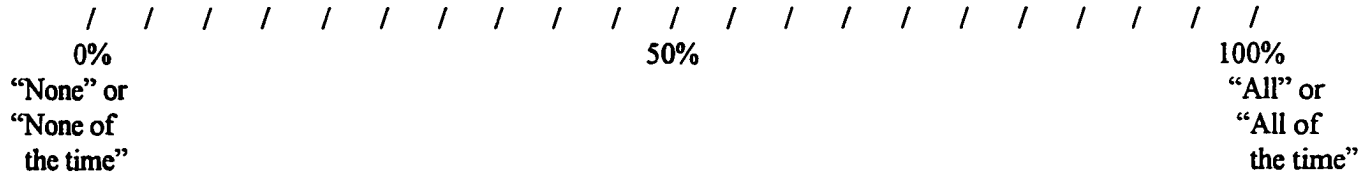
Appendix A

CYSTIC FIBROSIS SELF-CARE PRACTICE INSTRUMENT

Baker, 1990

A. PLEASE FILL IN THE NUMBER THAT BEST ANSWERS EACH QUESTION FOR YOU.
B. THERE ARE NO RIGHT OR WRONG ANSWERS.
C. PLEASE FEEL FREE TO WRITE IN COMMENTS.

FOR EACH QUESTION WRITE IN THE PERCENT (%) FROM 0 TO 100 THAT BEST ANSWERS THE QUESTION FOR YOU. 0% MEANS "NONE" OR "NONE OF THE TIME", 50% MEANS "HALF" OR "HALF OF THE TIME",AND 100% MEANS "ALL" OR "ALL OF THE TIME". NUMBERS IN BETWEEN MEAN AMOUNTS BETWEEN NONE OR ALL. YOU MIGHT WANT TO THINK ABOUT IT AS A LINE WITH 0% AT ONE END, WITH 100% AT THE OTHER END, AND WITH THE OTHER NUMBERS IN BETWEEN LIKE THIS:



EXAMPLE:
____% WHAT PERCENT OF THE TIME DO YOU GET UP IN THE MORNING AS SOON AS YOUR ALARM RINGS?

_____% 1. What percent of the time do you do the chest physical therapy that you need to do?

_____% 2. What percent of the time do you give yourself an aerosol treatment before you do your chest physical therapy?

2a. Are you supposed to be using oxygen? Yes No (Circle your answer)
(If yes, continue with question 3. If no, go on to question 4).

_____% 3. What percent of the time do you use oxygen as recommended?

_____% 4. What percent of the time do you eat a high calorie, high protein diet?

_____% 5. What percent of the time do you take enzymes with your meals?
(If you are not supposed to take enzymes, put an "X" in the blank)

_____% 6. What percent of the time do you eat high calorie, high protein snacks in between meals and at bedtime?

_____% 7. What percent of the time do you take enzymes with your snacks?
(If you are not supposed to take enzymes, put an "X" in the blank)

_____% 8. What percent of the time do you check for too much fat in your bowel movements?

_____% 9. What percent of the time do you adjust your fat intake or increase your enzymes if your bowel movements contain too much fat?

_____% 9a. Are you supposed to give yourself tube feedings? Yes No (Circle your answer)
(If yes, continue with question 10. If no, go on to question 11.

_____% 10. What percent of the time do you give yourself the recommended type and amount of tube feeding?

_____% 11. What percent of the time do you increase your salt intake when you perspire a lot?

/ /

0% "None" or "None of the time"

50%

100% "All" or "All of the time"

_____% 12. What percent of the time do you drink at least 6 to 8 glasses of liquid each day? (If you have been instructed to limit your fluid intake, place an "X" in the blank)

_____% 13. What percent of the time do you take the prescribed medications for your CF (other than your enzymes)?

_____% 14. What percent of the time do you watch for the side effects of medications that you take?

_____% 15. What percent of the time do you participate in active exercise such as walking, biking, sports? (If you are not supposed to be actively exercising, put an "X" in the blank)

_____% 16. What percent of the time do you watch yourself for weight loss, fever, increase in shortness of breath, or change in cough or sputum production?

_____% 17. What percent of the time do you go to your doctor within one week of experiencing weight loss, fever, increase in shortness of breath, or change in cough or sputum production?

_____% 18. What percent of the time do you keep your routine follow-up appointments at the outpatient clinic or your doctor's office?

_____% 19. When you have to miss school because of your CF, what percent of the time do you "make-up" the work you missed? (if you are out of school, answer this for when you were attending school)

_____% 20. What percent of the time do you do things that help you decrease the boredom or discomfort you have with chest physical therapy or any other CF self-care that you do?

_____% 21. With what percent of people that you don't know very well do you talk to about your CF?

_____% 22. With what percent of your friends do you talk about your CF?

_____% 23. With what percent of your friends do you share how hard it is to have CF?

_____% 24. What percent of the time do you keep your CF a secret when you're with people you don't know very well?

_____% 25. What percent of the time do you keep your CF a secret when you're with your friends?

26. Free space

_____% 27. What percent of the time do you tell yourself that you're "ok" even though you have CF?

_____% 28. What percent of your CF self-care are you personally responsible for now?

CFSCPI, 1990
LKB

FOR THE REMAINING QUESTIONS, CIRCLE YOUR ANSWER.

29. How much of a problem is having CF for you now?

Not a problem	Sometimes a problem	Usually a problem	Always a problem

30. How satisfied are you with the amount of responsibility you have for your CF self-care?

Very Dissatisfied	Dissatisfied	Satisfied	Very Satisfied

31. I think the amount of responsibility I have for my CF self-care now is:

Too little	About Right	Too Much

32. Is there anything else that you think I should know about reasons you might or might not be involved in CF self-care (actions that you need to take because you have CF)?

THANK YOU FOR YOUR TIME

Appendix B

Multidimensional Health Locus of Control

Appendix B

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL- FORM A

PLEASE PLACE AN "X" IN THE BOX WHICH BEST FITS YOUR AGREEMENT WITH EACH STATEMENT.
Answer these questions in relation to your general health.

STATEMENT	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
If I get sick, it is my own behavior which determines how soon I get well again.						
No matter what I do, if I am going to get sick, I will get sick.						
Having regular contact with my physician is the best way for me to avoid illness.						
Most things that affect my health happen to me by accident.						
Whenever I don't feel well, I should consult a medically trained professional.						
I am in control of my health.						
My family has a lot to do with my becoming sick or staying healthy.						
When I get sick I am to blame.						
Luck plays a big part in determining how soon I will recover from an illness.						
Health professionals control my health.						
My good health is largely a matter of good fortune.						
The main thing which affects my health is what I myself do.						
If I take care of myself, I can avoid illness.						
When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking care of me.						
No matter what I do, I'm likely to get sick.						
If it's meant to be, I will stay healthy.						
If I take the right actions, I can stay healthy.						
Regarding my health, I can only do what my doctor tells me to do.						

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL- FORM C

PLEASE PLACE AN "X" IN THE BOX WHICH BEST FITS WITH YOUR AGREEMENT WITH EACH STATEMENT. Answer these questions in relation to your Cystic Fibrosis.

STATEMENT	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
If my CF worsens, it is my own behavior which determines how soon I feel better again.						
As to my CF, what will be will be.						
If I see my doctor regularly, I am less likely to have problems with my CF.						
If my CF worsens, it is up to God to determine whether I will feel better again.						
Most things that affect my CF happen to me by chance.						
Whenever my CF worsens, I should consult a medically trained professional.						
I am directly responsible for my CF getting better or worse.						
Most things that affect my CF happen because of God.						
Other people play a big role in whether my CF improves, stays the same, or gets worse.						
Whatever goes wrong with my CF is my own fault.						
Luck plays a big part in determining how my CF improves.						
God is directly responsible for my CF getting better or worse.						
In order for my CF to improve, it is up to other people to see that the right things happen.						
Whatever improvement occurs with my CF is largely a matter of good fortune.						
The main thing which affects my CF is what I myself do.						
Whatever happens to my CF is God's will.						
I deserve the credit when my CF improves and the blame when it gets worse.						
Following doctor's orders to the letter is the best way to keep my CF from getting any worse.						

STATEMENT	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
If my CF worsens, it's a matter of fate.						
Whether or not my CF improves is up to God.						
If I am lucky, my CF will get better.						
If my CF takes a turn for the worse, it is because I have not been taking care of myself.						
The type of help I receive from other people determines how soon my CF improves.						
God is in control of my CF.						

Appendix C

Patient Information

Appendix C

PATIENT INFORMATION

Subj#_____ D.O.B._____/_____/_____ Age_____

Gender:_____M Years with CF_____ #Siblings with CF____
_____F

Total # living in household_____
#Adult males living in household_____ #Adult females living in household_____

(Circle one) Head of Household: mother father stepmother stepfather other_____

Marital Status: _____Single (never married)
_____Living Together
_____Married
_____Separated
_____Divorced
_____Widowed

Race:_____Caucasian
_____Black
_____American Indian
_____Asian or Pacific Islander
_____ Multiracial
_____ Other

Total number of illness visits to CF Clinic over past 12 months_____
Total number of routine f/u visits to CF Clinic over past 12 months_____
Total number of illness visits to other clinic/MD over past 12 months_____
Total number of routine f/u visits at other clinic/MD over past 12 months_____

(Circle one) Religion: Protestant Catholic Jewish Muslim Other None

Income: _____< $15,000/year
_____ $15,000-$20,000/year
_____ $20,001-$25,000/year
_____ $25,001-$30,000/year
_____ $30,001-$35,000/year
_____ $35,001-$40,000/year
_____ $40,001-$45,000/year
_____ $45,001-$50,000/year
_____ >$50,000/year

Other relevant information:

Appendix D
System of Clinical Evaluation of the Patient with Cystic Fibrosis

Appendix D

Subj #_____ SCORE: General Activity_____/25

Date___/___/___ Physical Exam_____/25

circle **Inpatient Outpatient** Nutrition _____/25

Xray findings _____/25

Total Score_____/100

System of Clinical Evaluation of the Patient with Cystic Fibrosis

Grading	Points	General Activity	Physical Examination	Nutrition	X-Ray Findings
Excellent (86-100)	25	Full normal activity; plays ball, goes to school regularly, etc.	Normal; no cough; pulse and respirations normal; clear lungs; good posture	Maintains weight and height at above 25th percentile; well-formed stools, almost normal; good muscle mass and tone	Clear lung fields
Good (71-85)	20	Lacks endurance and tires at end of day; good school attendance	Resting pulse and respirations normal; rare coughing or clearing of throat; no clubbing; clear lungs; minimal emphysema	Weight and height at approximately 15th to 20th percentile; stools slightly abnormal; fair muscle tone and mass	Minimal accentuation of bronchovascular markings; early emphysema
Mild (56-70)	15	May rest voluntarily during the day; tires easily after exertion; fair school attendance	Occasional cough, perhaps in morning upon rising; respirations slightly elevated; mild emphysema; coarse breath sounds; rarely localized rales; early clubbing	Weight and height above 3rd percentile; stools usually abnormal, large and poorly formed;very little, if any, abdominal distention;poor muscle tone with reduced muscle mass	Mild emphysema with patchy atelectasis; increased bronchovascular markings
Moderate (41-55)	10	Home teacher; dyspneic after short walk; rests a great deal	Frequent cough, usually productive; chest retraction; moderate emphysema; may have chest deformity; rales usually present; clubbing 2 to 3+	Weight and height below 3rd percentile; poorly formed, bulky, fatty, offensive stools; flabby muscles and reduced mass; abdominal distention mild to moderate	Moderate emphysema; widespread areas of atelectasis with superimposed areas of infection; minimal bronchial ectasis
Severe (40 or below)	5	Orthopneic; confined to bed or chair	Severe coughing spells; tachypnea with tachycardia and extensive pulmonary changes; may show signs of right-sided cardiac failure ; clubbing 3 to 4+	Malnutrition marked; large protuberant abdomen; rectal prolapse; large, foul, frequent, fatty movements	Extensive changes with pulmonary obstructive phenomena and infections; lobar atelectasis and bronchiectasis

Appendix E

Permission to Use Cystic Fibrosis Self-Care Practice Instrument

CEDARVILLE
COLLEGE
P.O. Box 601, Cedarville, OH 45314
513-766-2211 FAX 513-766-2760

Chris Fooy, RN, BSN
MSU KCMS
1000 Oakland Dr
Kalamazoo, MI 49008

Chris,

It was good to meet you "over the phone" and to learn of your study in which you are examining the self-care of persons with CF. As per our phone conversation, you have permission to use the Cystic Fibrosis Self-Care Practice Instrument [CFSCPI] (Baker, 1990) in your study.

To score the CFSCPI, you must first reverse code items # 24 and 25. The total score is then the mean of all the items. Although the CFSCPI can be broken down into conceptual subscales representing the various health deviation self-care requisites, further instrument development/revision is needed before using subscale scores as research variables. As you will note on page 104 of my dissertation, the reliabilities for some of the subscale scores were low. Therefore, I would caution against using the subscale scores for your study. Any information that you glean about subscale scores, however, would be helpful to me for future revisions of the instrument.

Items # 29-32 were for my information and are technically not part of the CFSCPI. If you want to use them, please feel free to do so, but you would not be required to do so.

Please let me know if I can be of any further assistance to you. I would love a copy of your study when you are finished.

Sincerely,

[redacted]

Lois K.Baker, RN, PhD, CPNP
Associate Professor, Nursing

Appendix F

Consent Form

Appendix F

CONSENT FORM

Introduction:

You are being asked to take part in a research project. The purpose of this study is to obtain information about how patients with cystic fibrosis care for themselves and the beliefs they may have about their health. To qualify for this study you must meet the following:

1. Have cystic fibrosis.
2. Be at least 11 years of age.
3. Use English as first language.
4. Willing to sign informed consent if at least 18 years of age; parents willing to sign informed consent with patient assent if less than 18 years of age.
5. Willing and able to complete questionnaires.

As a participant on this study I understand that:

1. participation in this study will involve completing questionnaires.
2. participation in this study will involve approximately 30 minutes of my time.
3. there are no benefits to me for participating on this study.
4. there are no known risks associated with participation on this study.
5. no names will be presented with the data.

Family Acknowledgement

"I have been given an opportunity to ask questions regarding this research study, and these questions have been answered to my satisfaction. I understand that if I have any additional questions I can contact Chrysanthe Fooy, R.N., John H. Marks, M.D. or Douglas N. Homnick, M.D. at 616-337-6450."

"In giving my consent, I understand that I/my child's participation in this research project is voluntary, and that I may withdraw myself/him/her at any time without affecting my/my child's future medical care. I also understand that the investigator in charge of this study, with my/my child's welfare as a basis, may decide at any time that I/he/she should no longer participate in this study."

"I hereby authorize the investigators, Chrysanthe Fooy, R.N., John H. Marks, M.D. or Douglas N. Homnick, M.D. to release the information obtained in this study to the medical science literature. I understand that I/my child will not be identified by name. Additionally, I understand that the Food and Drug Administration (FDA) may inspect Bronson Methodist Hospital's research

files and may wish to interview me regarding my/my child's participation in this study."
"In the event of physical injury or illness resulting from the research procedures, Bronson Methodist Hospital and/or the investigators, Chrysanthe Fooy, R.N., John H. Marks, M.D. or Douglas N. Homnick, M.D. will provide or arrange to provide for all necessary medical care to help me/my child recover, but they do not commit themselves to pay for such care, or to provide any additional compensation. I also understand that neither Bronson Methodist Hospital nor the investigators Chrysanthe Fooy, R.N., John H. Marks, M.D. or Douglas N. Homnick, M.D., agree to bear the expense or medical care for any new illness or complications which may develop during my/my child's participation in this study, but are not a result of the research procedures. If

I have further questions or concerns regarding my/my child's participation in this study, I may direct them to Chrysanthe Fooy, R.N., John H. Marks, M.D. or Douglas N. Homnick, M.D. at 616-337-6450. If I have questions about research subjects' rights, I may direct them to Robert H. Hume, M.D., Chairman, Bronson Methodist Hospital Institutional Review Board at (616) 341-7988 or Professor Paul Huizenga, Chair, Grand Valley State University Human Research Review Committee @ 616-895-2472. "

"I acknowledge that I have read and understand the above information, and that I agree to allow myself/my child to participate in this study. I have received a copy of this document for my own records."

_____ _____

Signature of Patient Date

If minor is older than five (5) years of age, was assent obtained? Yes ____ No ____

_____ _____

Signature of Legal Guardian/Parent Date

_____ _____

Signature of Legal Guardian/Parent Date

If both parents/guardians do not provide informed consent for their child to participate in this study, please explain why: _____

_____

_____

"I have witnessed that the information in this Patient Consent Form was adequately explained to the patient."

_____ _____

Signature of Witness Date

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