ADHERENCE AND QUALITY OF LIFE IN ADULTS WITH CYSTIC FIBROSIS: THE INFLUENCE OF SELF-EFFICACY AND COPING STYLE

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ABSTRACT

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Adherence and health-related quality of life in patients with Cystic Fibrosis (CF) are complex issues that may be influenced by a number of factors, including self-efficacy and coping style. This study seeks to further examine the relationship between self-efficacy, coping, adherence, and quality of life in individuals with CF. Adults diagnosed with CF were recruited through internet support websites and completed several surveys online that assessed participants' demographic and disease information, adherence to airway clearance, coping style,

self-efficacy, and health-related quality of life. Correlational and regression data analyses were utilized to explore the relationship between these different factors and how they interact and influence one another. Data analysis indicated several significant correlations between variables, as well as significant prediction models for quality of life and adherence to airway clearance techniques.

CHAPTER I

LITERATURE REVIEW

Overview

Cystic Fibrosis (CF) is a common genetic disease that affects multiple organ systems and occurs in approximately 1 in 3500 live births (Myers & Horn, 2006). In this disease, deficiencies in the transport of chloride across cell membranes results in the abnormal production of sticky secretions, which cause damage to several organs in the body, in particular the lungs and digestive system (Myers & Horn, 2006).

The disease causes increased susceptibility to respiratory infections, which in turn leads to decreased lung capacity and functioning (Myers & Horn, 2006). Generally, pulmonary functioning and disease severity in individuals with CF is assessed using spirometry tests, which produce an FEV1% value. FEV1% is the percentage predicted of FEV1 for an individual. FEV1 is the forced expiratory volume of air that is exhaled in one second from the level of total lung capacity. Determination of FEV1% through spirometry tests is a common aspect of CF clinic visits when patients are having routine checkups. This value is often used by the doctor and CF care team as a means for determining when more aggressive treatments (such as hospitalization or intravenous antibiotics) are needed (Wahl,

Rustoen, Hanestad, Gjengedal & Moum, 2005). The main cause of mortality in individuals with CF is respiratory failure (Quittner, Espelage, Levers-Landis, & Drotar, 2000). At present, there is no cure for the disease, although advances in medical treatment and other factors have lead to an increase in the median survival age into the 30s (Myers & Horn, 2006). Such increases in survival rate have lead to efforts to improve the quality of life of individuals who are living with the disease.

Adherence in Cystic Fibrosis

The complex issue of adherence to treatment regimens has been studied in a wide variety of chronic illnesses, including CF. Medical treatment of CF involves an extremely complex and time-consuming daily regimen which may include airway clearance, aerosolized medication, nutritional support, dietary supplements, and other medications such as antibiotics and anti-inflammatories (Wahl, Rustoen, Hanestad, Gjengedal, & Moum, 2005). Each aspect of the treatment regimen is designed to address a separate symptom of the disease. For instance, airway clearance, antibiotics, and aerosolized medications (i.e. Hypertonic Saline or Pulmozyne) are often utilized to prevent and treat respiratory infections, whereas nutritional support and dietary supplements (i.e. digestive enzymes, vitamins, or high-calorie drink supplements) are used to aid and promote digestion.

Airway clearance, also referred to in the literature as chest physiotherapy or Chest Percussion Therapy (CPT), is often an integral part of the treatment regimen for CF and typically involves two 30-minute sessions daily of either breathing techniques or percussion of the chest wall to loosen and expel secretions (Ricker, Delamater, & Hsu, 1998). Such techniques can include pounding the individual's

chest wall either manually or with a machine, huff coughing (much like fogging up a mirror), or devices that vibrate and create positive pressure as the individual breathes into them (e.g., PEP valve or Flutter®). When breathed through, both of these devices create positive pressure that opens up the airways in the lungs. In addition, the Flutter creates oscillations that vibrate the airways. Airway clearance is generally one of the most time-consuming therapies and often requires significant physical effort. Despite its importance in the treatment of CF, it ironically also has been found to have the lowest rates of adherence (Ricker, Delamater, & Hsu, 1998).

Research on adherence in individuals with CF has typically examined the various aspects of treatment separately in order to gain a more detailed understanding. Such research indicates that adherence to treatment in CF varies depending on the aspect of the regimen (Myers & Horn, 2006). Generally, it has been found that about 40-53% of patients were adherent to chest physiotherapy, 69-75% were exercising to a beneficial level, 81-97% were adherent to digestive enzymes, 46-90% were adherent to vitamin therapies, and 68-90% were adherent to oral antibiotics (Abbott, Dodd, Gee, & Webb, 2001). Obviously there is wide variability in adherence not only between the different types of therapies, but also between individuals and it seems that the most challenging therapies are those related to physiotherapy or airway clearance techniques (Myers & Horn, 2006). High rates of non-adherence are of concern for numerous reasons including the possibility of increased lung infections, faster disease progression, cost of wasted drugs, and potentially erroneous decisions on the efficacy of certain treatments (Abbott & Gee, 1998). Such concerns increase the need for research on the factors

that influence adherence rates in CF and methods for identifying and addressing such factors.

Unfortunately, few studies have examined the reasons for low rates of adherence to airway clearance in the CF population in depth. As proper use and adherence to airway clearance is an integral part of the CF treatment regimen, the current study will focus exclusively on adherence to airway clearance in order to provide a more detailed examination of its importance to quality of life in individuals with CF and the factors that influence such adherence.

Research on airway clearance adherence in CF has sought to identify variables that may influence whether or not an individual adheres to their prescribed therapy regimen, including environmental, personality, social, and psychological factors. Myers and Horn (2006) examined adherence to chest physiotherapy in adults with CF and found that participants' reasons for non-adherence generally fit into one of four categories: (1) emotional consequences of CP; (2) CP does not help; (3) fitting CP into lifestyle; and (4) physical consequences of CP. Other studies have grouped factors influencing non-adherence into four main categories: health, social, time, and emotional (Abbott & Gee, 1998). For instance, a patient may choose to not adhere because they feel well without the therapy (health), the therapy interferes with their ability to spend time with friends (social), they forget or are too busy (time), or the therapy acts as a painful reminder of their illness (emotional) (Abbott & Gee, 1998). The results of these studies suggest that numerous factors other than disease characteristics influence adherence to CP and such factors should be investigated in order to develop successful interventions for

improving adherence rates (Abbott, Dodd, Bilton, & Webb, 1994; Myers & Horn, 2006; Ricker, Delamater, & Hsu, 1998). Since psychosocial predictor variables often vary between individuals, they are often of interest in adherence research and may be targets of intervention. Two psychosocial factors that have been a focus of past adherence research in CF are self-efficacy and coping style (Abbott, Dodd, Gee, & Webb, 2001; Bartholomew, Parcel, Swank & Czyzeswki, 1993). Bandura's social cognitive theory defines self-efficacy as a person's belief about his or her ability to execute a required behavior in certain situations (Creer & Wigal, 1993). It has been suggested that an individual's self-efficacy and coping style in relation to their disease may play an important role in how well they adhere to their therapies, including chest physiotherapy.

Self-Efficacy

According to Bandura's theory, self-efficacy is not whether a person has the ability to perform a certain behavior, but their judgment of whether they have that ability. Such perceptions of ability and expectations of success are hypothesized to guide the individual's actual behavior by influencing their choices, motivation, thinking and other cognitive processes (Creer & Wigal, 1993). Thus, self-efficacy has been found in numerous situations to be highly correlated with performance of tasks, including adherence to treatment regimens. Bartholomew, Parcel, Swank, and Czyzewski (1993) investigated the role of self-efficacy in self-management behaviors of patients with CF. Their research in the development of a disease-specific measure of self-efficacy in CF found that self-efficacy predicted reported self-management behaviors (Bartholomew, Parcel, Swank, & Czyzewski, 1993).

Based on their findings, the authors suggest that interventions aimed at improving self-management should include a focus on improving self-efficacy. However, such research on the influence of self-efficacy on treatment adherence in CF remains scarce. It seems that it has been largely assumed that such a relationship exists and that high self-efficacy is related to higher adherence rates. The current study will seek to thoroughly investigate this assumption.

In addition, the influence of self-efficacy on quality of life has been examined in individuals with CF. Wahl, Rustoen, Hanestad, Gjengedal, and Moum (2005) investigated the relationships between self-efficacy, pulmonary function, perceived health status, and global quality of life in patients with CF. Their results indicated that self-efficacy significantly predicted perceptions of health status and global quality of life. Individuals with higher levels of self-efficacy demonstrated a higher global quality of life and better health status (Wahl et al., 2005). Since self-efficacy has been found to correlate with both self-management behaviors and quality of life in CF, this study will more thoroughly explore how these constructs interrelate.

Coping

When living with a chronic illness such as CF, an individual's ability to effectively cope with stressors related to the disease becomes increasingly important. In responding to the various emotional and physical demands of living with CF, individuals may employ a variety of behavioral, cognitive, and emotional techniques that allow them to effectively cope (Abbott, Hart, Morton, Gee, & Conway, 2008). Despite various terms and ways of measuring coping responses used in the literature, ways of coping with stressful situations are generally divided

into those that focus attention on the disease and those that divert attention away from it (Abbott, Hart, Morton, Gee, & Conway, 2008). Coping methods that focus attention on the disease are often termed approach, positive, optimistic, or problem-focused, whereas those that divert attention away from the disease are often termed passive, distraction, emotion-focused or avoidance (Abbott, Hart, Morton, Gee, & Conway, 2008). Generally, research has suggested that approach coping styles are more adaptive than avoidance strategies, and tend to predict better psychological adjustment (Abbott, Hart, Morton, Gee & Conway, 2008). However, in reality it is likely that adults living with a chronic illness often employ a variety of coping strategies depending on the situation or stressor that they are experiencing and in some instances, utilizing an avoidant coping strategy may be most appropriate and helpful (Abbott, Hart, Morton, Gee & Conway, 2008).

The influence of coping style on adherence and health-related quality of life has been examined in past research of CF. Research on the role of coping in treatment adherence has demonstrated mixed results. Whereas some studies report no relationship between adherence and coping, others have found that 'copers' had better adherence than 'non-copers', as evidenced by fewer hospital admissions (Abbott, Dodd, Gee, & Webb, 2001). However, it is difficult to determine if fewer number of hospitalizations for the 'copers' was actually due to increased adherence or a result of other factors, such as health-seeking behaviors or improved communication with physicians. Additionally, research suggests that increased treatment adherence is predicted by higher levels of optimism and self-efficacy, as measured by the Medical Compliance Incomplete Story Test (M-CIST) (Czajkowski &

Koocher, 1987). The M-CIST consists of different scenarios in which the main character must make a decision about whether or not to follow medical advice. Patients are asked to complete the story and determine the actions of the character for each scenario. This measure has been shown to discriminate between "non-compliant" and "compliant" groups (Czajkowski & Koocher, 1987). Despite evidence that more optimistic ways of coping seem to be related to higher adherence rates, there remains much to be examined in this area.

According to Abbott and colleagues (2008), little research has directly examined coping in individuals with CF, but such knowledge would have the potential to inform health psychology interventions to help these individuals more effectively manage and live with their disease.

Quality of Life

The study and treatment of chronic illnesses has consistently been focused not only on increasing survival rate, but also on improving quality of life. Health-related quality of life (HRQOL) is typically seen as being patient-centered and should reflect the individual's subjective evaluation of both their well-being and daily functioning (Quittner, Buu Messer, Modi, & Watrous, 2005). Measures of quality of life are multidimensional and go beyond objective measures of a disease by examining several different domains, including functional status, psychological and emotional state, disease state and physical symptoms, and social functioning (Quittner, Buu, Messer, Modi, & Watrous, 2005). According to Quittner and colleagues (2005) HRQOL serves several different purposes, including (1) measuring outcomes in clinical trials, (2) describing the impact of the illness on an

individual, (3) evaluating new pharmaceutical and surgical techniques, (4) aiding clinical decision making, and (5) estimating costs and benefits of medical interventions. Although generic HRQOL measures have been used in individuals with CF, recently measures specific to CF have been developed and utilized (Gee, Abbott, Conway, Etherington, & Webb, 2000; Quittner, Buu, Messer, Modi, & Watrous, 2005).

Abbott and colleagues (2008) conducted a study of the relationship between HRQOL and coping in cystic fibrosis. The results of their study showed a significant interaction between coping approach and HRQOL. Specifically, they found that optimistic acceptance was associated with higher quality of life ratings, whereas the use of distraction coping was associated with poorer quality of life (Abbott, Hart, Morton, Gee, & Conway, 2008). The authors also note that other literature has indicated a positive relationship between optimistic coping and adherence, further supporting the notion that how individuals with CF cope with their illness can significantly influence their health behaviors and overall subjective experience of the disease (Abbott, Hart, Morton, Gee, & Conway, 2008).

Another study that investigated quality of life in Cystic Fibrosis patients was conducted by Wahl, Rustoen, Hanestad, Gjengedal, and Moum (2004). Their research investigated a theoretical framework of the relationship between self-efficacy, pulmonary function, perceived health status, and quality of life. Their results indicated that the strongest predictors of quality of life were perceived health status and self-efficacy, in which those with higher self-efficacy and better reported health status demonstrated higher global quality of life (Wahl, Rustoen,

Hanestad, Gjengedal, & Moum, 2004). Interestingly, the results of this study suggest that objective disease factors (i.e., pulmonary function) do not have a very strong relationship to quality of life, but rather may influence it indirectly through perceived health status (Wahl, Rustoen, Hanestad, Gjengedal, & Moum, 2004). These authors suggest that health psychology interventions should aim to improve self-efficacy in patients with CF in order to improve quality of life.

While research on quality of life and treatment adherence in CF have often examined psychosocial factors such as self-efficacy and coping style, the results have been mixed. It remains unclear what the precise relationship is between these various factors. The current study will seek to contribute additional knowledge about how an individual's self-efficacy and coping style influences their adherence to airway clearance techniques and overall health-related quality of life.

CHAPTER II

PRESENT STUDY

Research Questions and Hypotheses

The purpose of the current study is to expand upon the existing literature by examining the relationships between disease-related factors, psychosocial variables (self-efficacy and coping), airway clearance adherence, and health-related quality of life in individuals with CF. Four main research questions are addressed in this study. First, in adults diagnosed with Cystic Fibrosis, how do coping style and self-efficacy relate to health-related quality of life? Based on prior research, those individuals with a more optimistic or hopeful style of coping or with greater self-efficacy are hypothesized to demonstrate better quality of life. Second, how do coping style and self-efficacy predict adherence to airway clearance techniques? It is predicted that, similar to quality of life, those individuals with more optimistic or hopeful coping styles and those with greater self-efficacy will display higher rates of adherence. Third, how does adherence predict health-related quality of life in this population? The answer to this question may depend on the reasons individuals with CF provide for not adhering to their airway clearance techniques. For instance, some

individuals may make a deliberate decision to not adhere to airway clearance because they feel that it interferes too greatly with their social functioning and thus, quality of life. However, it may also be that non-adherence for some individuals generates immediate consequences (i.e. hospitalization) that interfere with their ability to engage in everyday activities. Thus, such individuals might make the effort to be as adherent as possible in order to avoid such consequences. Due to these possible interactions, no specific hypotheses are made concerning this research question. Finally, what combination of psychosocial and disease variables (FEV1%, coping style, and self-efficacy) best predicts health-related quality of life in adults with CF? Ideally, knowledge of how disease severity, coping style, self-efficacy and adherence interact and influence one another and ultimately, quality of life, will allow professionals in the field to develop effective interventions for improving the overall treatment of individuals with CF. If certain factors are shown to better predict adherence or quality of life, health care professionals might be able to intervene in some instances to help improve adherence and health-related quality of life in this population.

CHAPTER III

METHODS

Design

This study utilized a cross-sectional design and assessed participants' demographic information, disease severity, coping style, self-efficacy, airway clearance adherence, and health-related quality of life. Analyses primarily explored the correlations and relationships between these variables.

Participants

Participants for this study were individuals over the age of 18 who had been diagnosed with Cystic Fibrosis (CF). Individuals who were under the age of 18, did not have a diagnosis of CF, or who did not speak English were excluded from study participation. Participants were not excluded from this study based on their specific genetic mutation of CF, disease severity, or geographical location. Study recruitment and data collection were conducted via the Internet, creating the possibility for wide variability in demographic characteristics of the sample.

Participants were recruited through various CF support websites and provided a link that connected to the consent form and questionnaires for the study. Due to this method of recruitment, participants in the study were self-selecting.

Messages were posted to the support websites asking adults with CF who were willing to participate in a study of adherence and quality of life to use the provided link to connect to the study questionnaires. All participants were asked to give informed consent for their participation in the study and told to contact the researcher with any questions or concerns they had after completion of the study questionnaires. Approval for this research was obtained from the Institutional Review Board at Texas State University and met ethical guidelines for research with human subjects.

Measures

Demographic Information. Age and gender were collected from each participant. Additionally, information about their disease was obtained, including age of diagnosis of CF (Abbott, Dodd, Bilton, & Webb, 1994), whether they are being treated at an accredited CF Center, and their most recent pulmonary function test results (FEV1%) (Appendix A). Whether an individual was diagnosed in early infancy or later in life (possibly even in adulthood), may influence the extent to which they have developed the ability to effectively cope with the illness. However, few studies have incorporated such a measure. As noted previously, FEV1% is the percentage predicted of FEV1 for an individual. FEV1 is the forced expiratory volume of air that is exhaled in one second from the level of total lung capacity. It is possible for different individuals to have the same FEV1, but different FEV1% because their predicted FEV1 values may be different. For instance, a short, low-weight female would most likely have a lower predicted FEV1 than a tall, high weight male. Thus, these two individuals may have the same FEV1, but the female

would have a higher FEV1% than the male. Therefore, the current study examined FEV1% instead of FEV1 as a measure of disease severity in order to have a standardized number for the sample. FEV1% is utilized in the current study as an objective measure of disease severity.

Airway Clearance Adherence. The adherence questions were modified from the Physiotherapy section of the Manchester Cystic Fibrosis Compliance Questionnaire (Abbott, Dodd, Bilton, & Webb, 1994). These 3 questions aim to assess how often airway clearance is prescribed for each individual, how adherent they are to that prescription, and reasons for non-adherence (See Appendix B).

Self-Efficacy. Participants' self-efficacy with regards to managing their disease was assessed using the Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001)(See Appendix C). This scale was designed to examine self-efficacy across several domains including symptom control, role function, emotional functioning, and communicating with physicians and has demonstrated high internal consistency reliability in past studies (Cronbach's alpha = 0.91). In the current study, this scale continued to demonstrate high internal reliability (Cronbach's alpha = .88).

Coping Style. Participants' coping style was determined using the Manchester Cystic Fibrosis Coping Questionnaire (Abbott, Dodd, Gee, & Webb, 2001) (See Appendix D). This 20-item questionnaire identifies 4 distinct coping styles: optimistic acceptance, hopefulness, distraction, and avoidance. Cronbach's alpha coefficients in validation studies were 0.74 (optimistic acceptance), 0.69 (hopefulness), 0.71 (distraction), and 0.76 (avoidance), demonstrating adequate internal reliability. In the current

study, Cronbach's alpha coefficients demonstrated high internal reliability for the optimistic acceptance scale (α = .79), fair reliability in the hopefulness and avoidance scales (α = .56 and .53, respectively) and poor reliability for the distraction scale (α = .35).

Quality of Life. Participants' health related quality of life was assessed using The Cystic Fibrosis Quality of Life Questionnaire (Gee, Abbott, Conway, Etherington, & Webb, 2000)(See Appendix E). This questionnaire consists of 52 items which evaluate quality of life across nine domains of functioning, including physical functioning, social functioning, treatment issues, chest symptoms, emotional responses, future concerns, interpersonal relationships, body image, and career issues. Cronbach's alpha coefficients in previous studies ranged from 0.72 to 0.92, demonstrating acceptable internal reliability of the measure. The questionnaire has also been found to have robust test-retest reliability and moderate to large discriminatory ability between different levels of disease severity (Gee, Abbott, Conway, Etherington, & Webb, 2000). In the current study, this quality of life measure demonstrated excellent overall internal consistency reliability (Cronbach's alpha = .96) and good internal reliability for each of the nine domains of functioning (Cronbach's alpha = .81 to .91).

Procedure

Data collection in this study occurred exclusively through online surveys that were composed on the website Surveymonkey.com. For this study, participants were recruited and asked to follow a website link that connected them to the online surveys. After certifying that they were 18 years of age or older, participants were

then provided with a consent form to read and at the end, asked to check a box that indicated that they either agreed or disagreed regarding participation in the study. They were told to print the consent form for their personal records.

Then, participants were asked to provide demographic information such as age and gender, and information about their Cystic Fibrosis such as age of diagnosis, and pulmonary function test results (FEV1%). The next questions asked participants for information related to their adherence to airway clearance techniques that were prescribed by their doctor, including how often airway clearance was prescribed for them, and how adherent they were to that prescribed routine over the past three months, and the reasons for missing airway clearance treatment sessions.

Participants then proceeded through the remainder of the surveys in the following order: Self-Efficacy for Managing Chronic Disease 6-Item Scale, Manchester Cystic Fibrosis Coping Questionnaire, and The Cystic Fibrosis Quality of Life Questionnaire (See Appendix). This order was chosen because it was expected that by completing the self-efficacy and coping surveys first, that individuals would be more accurately able to assess their health-related quality of life. It was expected that the process of answering questions related to disease severity, self-efficacy, and coping style would prime participants for examining their health-related quality of life in depth in the final survey. Additionally, it was expected that by having participants complete shorter questionnaires first, that fatigue related to completion of lengthy surveys would be lessened and that they would be more likely to complete all of the measures. Participants were expected to take approximately

30-45 minutes to complete all of the questionnaires. Data were collected and compiled using SurveyMonkey.com and analyzed using Statistical Package for the Social Sciences (SPSS) version 17.0. Correlational and multiple regression analyses were used to address the research questions of the study.

CHAPTER IV

RESULTS

Power Analysis

A power analysis was performed in order to determine the required sample size for a multiple regression analysis. Based on an alpha level of .05, anticipated effect size of 0.15, statistical power of 0.8, and 4 predictor variables, the desired sample size for this study was between 80 and 85 participants.

Data Collection and Scoring

Overall, 220 individuals attempted to access the survey online. Forty-three of these participants failed to meet inclusion criteria in that they were either not over the age of 18 or not diagnosed with Cystic Fibrosis. A total of 161 participants agreed to the consent form and 148 of these started the survey measures. Eighteen participants were excluded from data analysis as they either did not complete all of the survey measures or were missing a majority of data for any of the measures, leaving a total of 130 participants who were included in the data analysis of this study. After preliminary data analysis, a total of 126 participants were included in the final correlational and regression analyses. All data were analyzed using SPSS, version 17.0 Composite scores were calculated for the measures of self-efficacy,

coping, and quality of life. Composite score of self-efficacy was determined by calculating the mean of the six items, with higher scores indicating higher self-efficacy (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

For the Manchester Cystic Fibrosis Coping Questionnaire, a total score was calculated for each of the different coping styles (optimistic acceptance, hopefulness, distraction, and avoidance) by summing the items for each category, then dividing by the highest possible sum of the items in that category (# of items x 4), and multiplying by 100. For example, optimistic acceptance scores between 0 and 100 were derived by adding all 7 items/28 x 100. Composite scores for each coping style were on a scale of 0 to 100.

Similar calculations were performed for the Cystic Fibrosis Quality of Life Questionnaire. The quality of life measure is subdivided into nine domains of functioning: physical, social, treatment issues, chest symptoms, emotional functioning, concerns for the future, interpersonal relationships, body image, and career concerns. For each domain of functioning, a total score between 0 and 100 was derived by adding the item responses, then dividing by the highest possible sum of responses (# of items x 6), and multiplying by 100. For example, physical functioning score (10 items) was calculated using the following equation: ($\sum$ item responses/60) x 100. Finally, a total health related quality of life score was determined by calculating the mean of nine domain composite scores, again resulting in a total score between 0 and 100.

Responses to the adherence question, with six possible choices, were coded on a scale of 1 to 6, with 1 indicating lowest adherence rates and 6 indicating the highest.

Preliminary Data Analysis

Preliminary analyses were conducted to examine the data for outliers, skewdness, and scale reliability. Based on a very low Cronbach's alpha coefficient that indicated poor internal reliability, the distraction coping scale was eliminated from further analysis. The variable of participant age was positively skewed due to four outliers of individuals age 55 and older. These individuals were eliminated from further data analysis, which corrected the skewed distribution. Two other extremely skewed variables were gender and age of diagnosis. Although a majority of the present sample was female, there were no significant differences found between gender in either of the dependent measures under investigation (adherence and quality of life). Therefore, no changes were made to analyses or the data based on the gender skew. However, based on the extreme skew in age of diagnosis in which a majority of the individuals were diagnosed at birth, it was decided to not include this variable in any additional analyses for the present study.

Sample Characteristics

Frequencies and descriptive data were derived for the demographic and disease characteristics of the sample and for each of the variables of interest (self-efficacy, coping styles, and quality of life) (Table 1). The study sample was primarily female (82.5%) and the average age was 28.71 years.

There was wide variability in disease severity and age of diagnosis, with FEV1% ranging from 17 to 128, with 17 indicating the lowest degree of lung functioning and 128 being the highest (M=61.82, SD = 25.59). Generally, normal, healthy individuals without lung disease have FEV1% above 80.

Mean self-efficacy was calculated (M= 6.43, SD=1.91), as well as means for optimistic acceptance (M=82.96, SD=12.92), hopefulness (M=71.83, SD=14.32), and avoidance (M=49.60, SD=17.74).

Adherence Characteristics

In addition, the adherence characteristics of the sample were examined, including adherence rates and reasons for non-adherence. Table 2 provides information regarding self-reported adherence rates in the sample. Prescribed airway clearance ranged from 0 to 4 times daily (M=2.06). According to Abbott and colleagues (1994), individuals who endorse either items 1 or 2 are considered adherent/compliant, those who endorse items 3 or 4 are partially adherent/compliant, and items 5 or 6 non-adherent/non-compliant. Thus, in the present sample, a majority of participants were considered to be adherent (68.3%), 15.8% were partially adherent, and 15.9% were considered non-adherent.

When asked to indicate reasons for non-adherence, the most frequently endorsed reasons were "There isn't enough time" (54.8%), "I feel well without treatment" (33.3%), and "It interferes with my social life" (24.6%). The least frequently endorsed reasons for non-adherence were "I don't fully understand why I need to do airway clearance" (0%), "I don't know how to do it" (0%), and "I have difficulty doing my own airway clearance" (0.8%).

Correlations

Pearson correlation coefficients were calculated between all variables of interest (adherence, FEV1%, self-efficacy, optimistic acceptance, hopefulness, avoidance, and quality of life) (Table 3). Significant correlations were found between adherence and hopefulness ($r=.30$, $p<.01$), adherence and self-efficacy ($r=.18$, p,.05), FEV1% and self-efficacy ($r=.33$, $p<.01$), FEV1% and optimistic acceptance ($r=.19$, $p<.05$), self-efficacy and optimistic acceptance ($r=.52$, $p<.01$), self-efficacy and hopefulness ($r=.31$, $p<.01$), self-efficacy and quality of life ($r=.68$, $p<.01$), optimistic acceptance and hopefulness ($r=.56$, $p<.01$), optimistic acceptance and avoidance ($r=-.22$, $p<.05$), optimistic acceptance and quality of life ($r=.52$, $p<.01$), hopefulness and quality of life ($r=.20$, $p<.05$), and avoidance and quality of life ($r=-.12$, $p < .05$)

Overall, it appears that a higher quality of life was related to higher self-efficacy, optimistic acceptance, and hopefulness, as well as lower use of avoidance coping. Higher adherence rates were related to higher use of hopefulness coping strategies and self-efficacy. Generally, participants with higher ratings of self-efficacy also demonstrated higher use of optimistic acceptance and hopefulness coping. Finally, higher use of optimistic acceptance was associated with increased use of hopefulness coping strategies.

Multiple Regressions

Research Question #1: In adults diagnosed with Cystic Fibrosis, how do coping style and self-efficacy relate to health-related quality of life?

To examine the relationship between coping style and self-efficacy, and these variables' influence on quality of life, a multiple regression analysis was performed,

with quality of life as the dependent variable, and self-efficacy, optimistic acceptance, hopefulness, and avoidance entered as independent factors. Using a stepwise regression, two variables entered the model in the following order: self-efficacy and optimistic acceptance (Table 4). In the first model (Model 1), self-efficacy entered as a significant predictor variable, followed by optimistic acceptance entering the final model (Model 2). All other variables of interest were excluded. The current model, (Model 2) produced a significant F-value of 59.732 ($p<.01$). The overall correlation between the combination of these two variables and quality of life is 0.70. Together, self-efficacy and optimistic acceptance accounted for 49.3% of the total variance in quality of life. Self-efficacy was the most important variable in predicting quality of life and uniquely accounted for 22.8% of the variance in quality of life score. Higher levels of self-efficacy predicted higher quality of life. Optimistic acceptance was the second most important variable in predicting quality of life and uniquely accounted for about 3.6% of the variance, with higher scores predicting higher quality of life. Thus, approximately 22.9% of the accounted for variance in quality of life scores was shared among the two variables (self-efficacy and optimistic acceptance). The rest of the variance in quality of life scores was unaccounted for by the present data and measures.

Research Question #2: How do coping style and self-efficacy predict adherence to airway clearance techniques?

To examine the prediction of airway clearance adherence from coping style and self-efficacy, a stepwise multiple regression was run with adherence as the dependent variable and self-efficacy, optimistic acceptance, hopefulness, and avoidance as potential predictor variables (Table 5). The final regression model

only included hopefulness as a significant predictor of adherence and produced an F-value of 11.819 ($p<.01$), although avoidance score approached significance as a predictor of adherence ($t= -1.849$, $p=.067$). The correlation between hopefulness and adherence was .295, and hopefulness accounted for about 8.7% of the total variance in adherence ratings. Overall, higher use of hopefulness coping strategies was predictive of adherence in this sample.

Research Question #3: How does adherence predict health-related quality of life in this population?

To examine the relationship between airway clearance adherence and quality of life, a Pearson correlation was calculated between these two variables. The correlation between adherence and quality of life was not statistically significant ($r=-.04$, $p=.675$), indicating that there was no significant relationship between these two variables in this sample.

Research Question #4: What combination of psychosocial and disease variables (FEV1%, coping style, and self-efficacy) best predicts health-related quality of life in adults with CF?

Multiple regression was conducted to further examine how various psychosocial and disease variables predict quality of life in adults diagnosed with Cystic Fibrosis. Based on the previous finding that self-efficacy, and optimistic acceptance coping were predictive of quality of life, these two variables were definitively entered into the model, along with the possible disease-related predictor, FEV1%. The final regression model was significant and had a F-value of 37.27 ($p<.01$) (Table 6). The overall correlation between the combination of self-efficacy, optimistic acceptance, FEV1% and overall quality of life was .70.

Together, self-efficacy, optimistic acceptance, and FEV1% accounted for 49.3% of the total variance in quality of life. The most important predictor variable, self-efficacy, uniquely accounted for 18.0% of the variance in quality of life scores. Optimistic acceptance uniquely accounted for about 3.6% of the variance in quality of life. Finally, FEV1% uniquely accounted for about 1.1% of the total variance in quality of life in the current sample. Approximately 26.6% of the variance in quality of life scores that was accounted for in the model was shared among all four predictor variables. The remainder of the variance in quality of life scores (50.7%) was unaccounted for by the current data and measures.

Analyses Summary

Overall, the data analyses indicated several significant relationships among the variables of interest. First, it was found that a majority of the sample was adherent to their airway clearance prescription, with the most endorsed reason for non-adherence being a lack of time. Significant correlations were found between numerous psychosocial variables, such as FEV1% and self-efficacy, or self-efficacy and coping styles (i.e. optimistic acceptance and hopefulness). With regards to the first research question, it was found that self-efficacy and optimistic acceptance coping were significant predictors of health-related quality of life, which partly supported the original hypotheses. In analyses related to the second research question, hopefulness coping emerged as a significant predictor of airway clearance adherence. Contrary to initial expectations, self-efficacy was not a significant predictor of adherence. In analyses of the third research question, no significant relationship was found between adherence and quality of life. Finally, with regards

to the fourth research question, self-efficacy, optimistic acceptance, and FEV1% were predictors of health-related quality of life in the current sample.

CHAPTER V

DISCUSSION

Psychosocial Predictors of Quality of Life

The first research question of this study examined how self-efficacy and coping styles might help predict health-related quality of life. It was hypothesized that individuals with high self-efficacy and high use of optimistic acceptance or hopefulness coping strategies would display the highest total quality of life scores. This hypothesis was partially supported by the data in that higher ratings of self-efficacy and use of optimistic acceptance were predictive of higher quality of life. Contrary to expectations, hopefulness was not found to be a significant predictor of quality of life. These results seem to support the assertion of prior research and theories that approach coping strategies (i.e. optimistic acceptance) are generally more adaptive than avoidance strategies (i.e. distraction). Individuals who utilize more approach coping strategies in dealing with the stressors of their disease may be more likely to engage in self-care behaviors and may be more adept at directly dealing with stressors related to their disease (Abbott et al., 2008). Such abilities may, in turn, positively influence how an individual perceives the effects of the disease on their daily functioning. Further, the significant influence of self-efficacy in this model provides additional support to the common view that this construct is

important in subjective experiences of disease and illness. Research has suggested that high self-efficacy is related to better self-management behaviors in chronic illness (Bartholomew et al., 1993). Similar to approach coping strategies, the ability to manage one's disease may lead to improved functioning in multiple areas including physical, emotional and psychological. Individuals with high disease-related self-efficacy perceive themselves as being adept at controlling factors related to their disease process, which most likely influences how they feel the disease affects their daily functioning and quality of life.

Psychosocial Predictors of Adherence

The next research question of this study was to examine how self-efficacy and coping styles might influence adherence, specifically airway clearance techniques, which in this population are often time consuming and physically demanding. Prior to answering this question through data analysis, the overall rate of adherence of these participants, as well as their self-reported reasons for nonadherence, were addressed through descriptive analyses. Previous research has suggested that adherence rates in Cystic Fibrosis vary depending not only on the individual, but also on the specific therapy. It has often been suggested that the lowest adherence rates are typically those related to airway clearance. An interesting and promising finding of this study was that self-reported adherence to airway clearance seems to be very high in this sample, with a majority of participants being fully compliant. However, this finding may be the result of recruiting study participants from CF support websites. Participants recruited from support websites may be more likely to take an active role in the management of

their disease and thus, more likely to adhere to treatment prescriptions. Further, it is possible that individuals who completed the study measures were those who feel comfortable reporting their disease and health behaviors. Such individuals may also be more likely to be adherent to therapy. Overall, it is possible that the method of participant recruitment utilized in this study lead to self-selection of individuals who were adherent and attrition of those who were non-adherent. Individuals who were non-adherent may have felt guilty for not adhering and thus, may have either declined to participate in the study, or quit before they had completed all the measures. Thus, it is necessary that further research seek to obtain a more representative sample of CF patients, as well as uncover the various factors that influence and predict adherence in order to gain additional explanation for such high adherence rates as seen in this study.

In addition, the reasons for non-adherence provided valuable information. A majority of the reasons given for not adhering to prescribed airway clearance techniques were not enough time, feeling well without treatment, and interference with social life. These are all reasons that would probably be amenable to change in psychosocial interventions. For example, the fact that people may not adhere to airway clearance because it is time-consuming and they would rather be spending that time with friends or family could be addressed in an intervention by developing ways to incorporate pleasurable activities and time with friends into the time period in which they are performing airway clearance techniques. This might include chatting on the internet, catching up on emails, or playing games with family or friends during treatment time. Further, to address the issue of lack of time or

feeling well without treatment, cognitive behavioral strategies could be implemented to help patients with CF develop better time management skills in scheduling time for treatments, or identify and challenge cognitive distortions about only engaging in treatments as a form of acute rather than preventive care. Utilizing reasons for non-adherence to develop personalized interventions to increase adherence may be efficacious in adults diagnosed with this disease. On a positive note, several reasons for non-adherence that were infrequently or never endorsed seemed to revolve around knowledge of the treatment and its effects. This finding suggests that adults with Cystic Fibrosis are well educated on treatment options such as airway clearance, including the process and proposed benefits of such treatment and the positive outcomes of airway clearance on their symptoms and health status.

With regards to psychosocial predictors of adherence, it was hypothesized that, similar to quality of life, those individuals with the highest self-efficacy and higher use of optimistic acceptance and hopefulness coping would display the highest reported adherence rates. These expectations were not very well supported by the research here in that the only significant psychosocial predictor of adherence was hopefulness. Individuals with higher use of hopefulness strategies displayed higher rates of adherence. It remains a mystery as to why self-efficacy was not a significant predictor of adherence given the strong relationship shown between these two factors in past research. It is possible that in this current study, these two variables are highly correlated and thus, unable to be distinguished from one another. Another potential explanation is that individuals who were high in self-

efficacy were not generally more adherent to airway clearance because they feel confident in their ability to control the effects of their disease through other methods (i.e. exercise). Instead of adhering to airway clearance prescriptions, such individuals may use these other techniques to manage their disease. Additionally, it is possible that the measure of self-efficacy used in this study was not specific enough to the common treatment regimen of individuals with CF, in particular, airway clearance. Perhaps if individuals were specifically asked about their self-efficacy with regards to performing airway clearance, then a clearer relationship would have emerged with adherence to these techniques. Additionally, the regression model that was derived for this relationship explained very little of the variance in adherence, suggesting that other important factors (i.e., social support, patient-doctor communication, psychological distress, etc.) might be influencing adherence rates. Future research should more thoroughly explore this issue.

Adherence and Quality of Life

A third aim of this study was to investigate the relationship between airway clearance adherence and health-related quality of life in individuals with CF. No specific predictions were made and analysis with the present sample demonstrated no significant relationship between these two variables. In the past, researchers have proposed that adherence could influence quality of life either positively or negatively for a variety of reasons. For instance, individuals with CF may feel that the burdens that adherence to airway clearance can present (i.e. time consuming nature, physical effort, negative influences on social life, embarrassment, etc.) have a negative impact on their quality of life, and thus, make an active decision to not

adhere in order to avoid such consequences. On the other hand, some may view the beneficial effects of airway clearance (i.e. avoidance of hospitalization, easier breathing, etc.) as having a positive impact on their quality of life and thus, make the decision to be as compliant with their medical regimen as possible. It may be that in the present study, a number of factors, both positive and negative, mediate the relationship between adherence and quality of life, making it difficult for a definitive relationship to be deciphered. Future research might focus on determining what factors influence this relationship and the magnitude and direction of such influence. In addition, the fact that a majority of the sample in this study self-reported as being fully adherent may have made discovery of a significant relationship more difficult.

Predictors of Quality of Life

The final aim of this study was to determine which combination of disease and psychosocial variables best predicts health-related quality of life. In addition to the previous finding of the current study that self-efficacy and optimistic acceptance predict quality of life; FEV1% was added to the prediction model. The addition of FEV1% as a predictor of quality of life makes logical sense. Since FEV1% is often used as a measure of disease severity in this population, then it is understandable that less disease severity, as evidenced by higher FEV1%, would be related to greater functional status in multiple areas, resulting in a higher quality of life.

The fact that in this study, both psychosocial factors and objective measures of disease severity and progression contribute to quality of life highlights the multidimensional nature of this construct. This finding suggests that interventions

to improve quality of life for individuals with CF should focus not only on improvement of lung functioning through treatments such as airway clearance, but also should incorporate techniques to improve self-efficacy and the use of approach coping strategies (Abbott, et al., 2001; Wahl, et al., 2005). This prediction model also presents hope that, despite higher disease severity, individuals can still improve their health-related quality of life through other psychosocial methods. In fact, according to the current findings, FEV1% is not as important a determinant of quality of life as other factors, such as self-efficacy. This finding is useful for chronic illnesses, such as CF, in which disease severity is progressive and at times unpredictable, despite medical treatment.

Limitations

There are several limitations to the current study. First, recruitment methods may have presented a sampling bias. Because data were collected through support websites for CF, the participants were those who frequent such sites. Such individuals may display a more active approach to their disease management than those who do not visit such websites, which may explain some of the skewness of data, especially adherence rates and gender. Females in general may be more likely to seek social support for a disease through websites and discussion forums on the Internet.

An additional limitation of this study was the use of only subjective, self-report measures of disease severity, self-efficacy, coping, quality of life, and adherence. In particular, the measurement of adherence to medical regimens has often been the source of disagreement and controversy in the field of health

psychology (DiMatteo, 2004; Osterberg & Blaschke, 2005). Multiple definitions and methods for measuring adherence have been developed and there are incongruities as to what exactly is considered being fully adherent, partially adherent, or non-adherent (Quittner, Espelage, levers-Landis, & Drotar, 2000). In the current study, adherence was measured with a single, self-report question asking individuals to indicate the statement that best describes their adherence behavior. Participants may have self-reported higher adherence than what is the reality, in an effort to conform to expectations of the researcher. Further, the low internal reliability of the hopefulness, distraction and avoidance coping scales used in this study was a major limitation.

Additionally, the lack of counterbalancing of the measures used in this study may have created order effects in how participants answered the questions. For example, providing information related to disease severity early in the study may have influenced how participants answered the quality of life questions later, in either a positive or negative fashion depending on how they interpret the severity of their disease.

Strengths

There were also several important strengths of the present study. First, there was wide variability in some of the disease and demographic characteristics of the sample, particularly age and FEV1%, which enhanced the applicability of the present findings. Second, the use of the Internet as a data collection tool has shown its utility as a research method in this population and it is hoped that future research will continue to expand on this method and strengthen its efficacy. The use

of technology in this way can be very helpful in studying patients with chronic diseases such as CF in which accredited treatment clinics are not widely accessible and available. Many individuals with CF need to travel some distance in order to access medical care for their disease. Use of the Internet and other similar technologies (i.e. telephone, Skype, etc.) can help make this population more accessible for research and possibly even interventions. Finally, a strength of the current study is that it is examining the adult population with this disease. Due to the risk of earlier mortality in people with CF, a majority of past research has focused solely on children with CF (Lowton & Gabe, 2003). However, with advances in medical care, more and more individuals are living to adulthood with the disease. Thus, it is becoming increasingly important that researchers examine the effects of living with CF as an adult (Berge, Patterson, Goetz, & Milla, 2007; Hamlett, Murphy, Hayes & Doershuk, 1996). Hopefully, the current study has contributed some knowledge to this limited area of research.

Conclusion and Future Directions

Future research should seek to more thoroughly explore the link between adherence and quality of life, including how reasons for non-adherence might interact with how individuals experience the effects of their illness. Additionally, future research should improve upon the methodological limitations of the current study by obtaining a sample with more variability in rates of adherence. Such research might also consider utilizing multiple measurements of adherence, both objective and subjective, such as daily diaries or electronic monitors (Quittner et al., 2000).

The general findings of this study highlight the importance of psychosocial factors, such as self-efficacy and coping style, as well as disease-related factors in the health-related quality of life in adults diagnosed with Cystic Fibrosis. Both self-efficacy and the use of specific coping strategies (i.e. optimistic acceptance) have been shown to help predict quality of life. Based on these findings, it is expected that improvements to the quality of life in patients with this disease could be achieved through the development and integration of psychosocial interventions designed to improve self-efficacy and the use of approach coping methods. For instance, CF center social workers might be able to discuss self-efficacy and coping strategies with patients and work with the individual to develop more adaptive coping skills, which in turn might help them improve their confidence in their ability to treat their disease and improve their daily functioning. Education about the disease and how one can control the symptoms and work towards better functioning would be an important aspect of such interventions. Such interventions could also be tailored to the individual based on which aspects of their disease they are experiencing the most difficulty addressing. These interventions would best be applied within the health care system and CF care centers that these patients frequent for maintenance of their disease.

Table 1

Sample Characteristics

Characteristic	n	M	SD	Range
Male	22			
Female	104			
Age	126	28.71	7.23	18-48
FEV1%	119	61.82	25.59	17-128
Prescribed Airway Clearance (times per day)	104	2.06	.82	0-4
Total Self-Efficacy	126	6.43	1.91	2.5-10
Coping				
Optimistic Acceptance	126	82.96	12.92	57.14-100
Hopefulness	126	71.83	14.32	33.33-100
Avoidance	126	49.60	17.74	25-100
Quality of Life	126	67.23	14.75	24.36-95.51

Table 2

Airway Clearance Adherence

	Frequency	Percent
1. Do airway clearance # of times prescribed, every day	38	30.2
2. Occasionally miss 1 or 2 sessions	48	38.1
3. Often miss 1 or 2 sessions	10	7.9
4. Often miss several days of sessions	10	7.9
5. Only do when feel unwell	14	11.1
6. Never do airway clearance	6	4.8

Note. Participants' self-report of adherence to airway clearance prescription. Items 1 or 2 are considered adherent/compliant, items 3 or 4 are partially adherent/compliant, and items 5 or 6 non-adherent/non-compliant

Table 3

Pearson Correlations Demonstrating the Relationships Between Study Variables

Measure	1	2	3	4	5	6	7
1. Adherence	-	-.04	.18*	.15	.30**	-.15	-.04
2. FEV1%	-.04	-	.33**	.19*	.10	-.06	.32**
3. Self-Efficacy	.18*	.33**	-	.52**	.31**	-.14	.68**
4. Optimistic Acceptance	.15	.19*	.52**	-	.56**	-.22*	.52**
5. Hopefulness	.30**	.10	.31**	.56**	-	.04	.20*
6. Avoidance	-.15	-.06	-.14	-.22*	.04	-	-.12*
7. Quality of Life	-.04	.32**	.68**	.52**	.20*	-.12*	-

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

Table 4

Self-Efficacy and Coping Style Predictors of Quality of Life

	Quality of Life					
	Model 1			Model 2		
Variable	*B*	SE	β	*B*	SE	β
Constant	33.70**	3.42		18.48**	6.16	
Total Self-Efficacy	5.22**	.51	.68	4.32**	.58	.56
Optimistic Acceptance Score				.25**	.09	.22
R^2	.46			.49		
ΔR^2				.04		

Note. N=126. Regression analysis of self-efficacy and coping style as predictors of quality of life. All variables entered into model in stepwise fashion. from the following: self-efficacy, optimistic acceptance, hopefulness, and avoidance. Model 1 total self-efficacy entered as significant predictor. Final model (Model 2), included self-efficacy and optimistic acceptance score as significant predictors of quality of life.
**p <.01

Table 5

Coping Style Predictor of Adherence

	Adherence			
Variable	*B*	SE	β	R^2
Constant	2.31**	.66		
Hopefulness Score	.03**	.01	.30	.09

Note. N=126. Regression analysis of self-efficacy and coping styles as predictors of adherence. Hopefulness is only significant predictor of adherence. All variables entered into model in stepwise fashion.

**p <.01

Table 6

Psychosocial and Disease Predictors of Quality of Life

	Quality of Life		
	Model 1		
Variable	*B*	SE	β
Constant	17.13**	6.35	
Total Self-Efficacy	3.96**	.62	.52
Optimistic Acceptance	.25**	.09	.22
FEV1%	.06	.04	.11
R^2	.49		

Note. N=123. Model 1 all variables entered (Total Self-efficacy, and optimistic acceptance). Model 2 variables entered in stepwise fashion from the following: FEV1%, adherence, hopefulness score, and avoidance score.
** p <.01

APPENDIX A

DEMOGRAPHIC INFORMATION AND DISEASE SEVERITY

Age: _____

Gender: Male Female

Age at which diagnosed with CF: _____

Are you under the care of an accredited CF Care Center? Y N

Most recent FEV1% (Forced expiratory volume- percent of predicted): _____%

APPENDIX B

AIRWAY CLEARANCE ADHERENCE
(Abbott, Dodd, Bilton, & Webb, 1994)

How many times each day, has it been agreed between you and your physician, that you should do your airway clearance techniques (including therapy vest, acapella, flutter, huff-coughing, PEP, etc.)?

_____ times/day

Over the last three months, which of the following statements best describes you? : (check only one box)

- o I do my airway clearance the number of times my physician and I have agreed to, every day.
- o Occasionally, I miss one or two airway clearance sessions.
- o I often miss one or two airway clearance sessions.
- o I often miss several days of airway clearance sessions.
- o The only time I do my airway clearance is when I feel unwell.
- o I never do my airway clearance.

Please check the boxes which best describe you (may check more than one). When I miss my airway clearance, it is usually because:

- o I feel well without treatment.
- o It interferes with my social life.
- o There isn't enough time.
- o I have to rely on someone to help me.
- o I simply forget.
- o My CF isn't as serious as most of the other CF patients
- o It interferes with family routine commitments.
- o I can't always be bothered.
- o I don't believe that it does me any good.
- o I have too many different treatments to attend to, and airway clearance is the least of them.
- o It makes me feel worse.
- o I don't fully understand why I need to do airway clearance.
- o I do plenty of exercise, so I don't need to do airway clearance.
- o I don't know how to do it.
- o I have difficulty doing my own airway clearance.
- o I resent having to do it.
- o It's embarrassing.

APPENDIX C

SELF-EFFICACY FOR MANAGING CHRONIC DISEASE 6-ITEM SCALE
(Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001)

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

1 2 3 4 5 6 7 8 9 10
(not at all confident) (totally confident)

APPENDIX D

MANCHESTER CYSTIC FIBROSIS COPING QUESTIONNAIRE
(Abbott, Dodd, Gee, & Webb, 2001)

For each item, please indicate the extent to which you use that strategy in dealing with your Cystic Fibrosis. (1: not at all, 2: a little, 3: a moderate amount, 4: a great deal)

1. I make sacrifices in the short term because I know it will do me good

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

2. I try to do something positive

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

3. I try to look at it differently- to see the positive or funny side

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

4. I do what I can under the circumstances

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

5. I talk to a professional who knows about CF

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

6. I accept it

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

7. I'm just hoping it will be all right

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

8. I avoid it wherever possible

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

9. I treat myself to something special

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

10. I put it into perspective- it could be worse

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

11. I do something to take my mind off it

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

12. I have confidence in the doctors and treatment

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

13. I cry, eat, drink, or take drugs

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

14. I talk to my family and friends

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

15. I feel helpless, there is nothing I can do

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

16. I talk to others with CF

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

17. I try to put it out of my mind

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

18. I'm looking forward to a time in the future when it will be better

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

19. I pray

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

20. I feel optimistic

1	2	3	4
Not at all	A Little	A Moderate Amount	A Great Deal

APPENDIX E

THE CYSTIC FIBROSIS QUALITY OF LIFE QUESTIONNAIRE
(Gee, Abbott, Conway, Etherington, & Webb, 2000)

The following questionnaire is designed to find out how CF affects your life. Read each statement, and then indicate which response is closest to how you feel, by ticking ( ) one of the boxes after each statement. Please try to answer ALL the questions, as honestly as you can.

SECTION ONE:
How often, over the last two weeks, do you feel that your CF has affected the following aspects of your physical functioning/mobility?

1. Because of my CF, during the last two weeks, I have had difficulty doing heavy physical jobs. For example, digging, moving furniture, washing the car, vacuuming etc.
   - o All of the time
   - o Most of the time
   - o Good bit of the time
   - o Sometimes
   - o Occasionally
   - o Never

2. During the last two weeks, my CF has prevented me from getting out of the house to run errands. For example, paying bills, posting a letter, doing light shopping etc.
   - o All of the time
   - o Most of the time
   - o Good bit of the time
   - o Sometimes
   - o Occasionally
   - o Never

3. Because of my CF, over the last two weeks, it has been difficult for me to do light tasks around the house. For example, preparing a light snack, washing up, picking up the mail etc.
   - o All of the time
   - o Most of the time

- Good bit of the time
- Sometimes
- Occasionally
- Never

4. Over the last two weeks, getting around the house has been difficult because of my CF.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

5. For the last two weeks, CF has made it difficult to move from my bed or my chair.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

6. Despite CF, over the last two weeks I have got around and done what I like.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

7. During the last two weeks, there are places that I would like to have gone but didn't because of my CF.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

8. My CF has limited the type of sports and exercise I have been able to do over the last two weeks.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes

- Occasionally
- Never

9. During the last two weeks, my CF has made me feel lacking in energy.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

10. Over the last two weeks, I have found that my physical functioning and mobility have affected my quality of life by making life less enjoyable.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

SECTION TWO:
Over the past two weeks, has CF affected your social life in any of the following ways?

11. When I have been out socialising, over the last two weeks, I have behaved more cautiously than I would like to because of my CF.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

12. Because of my CF, during the last two weeks, I have tended to avoid visiting friends.
   - All of the time
   - Most of the time
   - Good bit of the time
   - Sometimes
   - Occasionally
   - Never

13. For the last two weeks, I have avoided going out and socialising because of my CF.
   - All of the time
   - Most of the time

- Good bit of the time
- Sometimes
- Occasionally
- Never

14. I find that the way in which CF affects my socialising interferes with my overall enjoyment of life.
- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

SECTION THREE:
The following questions ask you about symptom and treatment aspects of your CF. How have the following factors affected you over the last two weeks?

15. Over the last two weeks, I have found my treatments (ie physio, enzymes etc) very time consuming.
- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

16. During the last two weeks, my treatments have interfered with other things that I have wanted to do.
- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

17. Over the last two weeks, I have found that my treatments have interfered with my enjoyment of life.
- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

18. I have found my breathlessness troublesome, during the last two weeks.

- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

19. Over the last two weeks, I have found my coughing troublesome.
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

20. I have found my coughing embarrassing over the last two weeks.
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

21. For me, over the past two weeks, breathlessness / coughing have made life less enjoyable.
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

SECTION FOUR:
Over the past two weeks, I have found that my CF has made me feel:

22. Resentful:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

23. Angry:
    - All of the time
    - Most of the time

- Good bit of the time
- Sometimes
- Occasionally
- Never

24. Embarrassed:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

25. Irritable:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

26. So fed up that nothing can cheer me up:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

27. Anxious:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

28. Frustrated:
    - All of the time
    - Most of the time
    - Good bit of the time
    - Sometimes
    - Occasionally
    - Never

29. The way that my CF makes me feel emotionally interferes with my quality of life.

- All of the time
- Most of the time
- Good bit of the time
- Sometimes
- Occasionally
- Never

PLEASE NOTE, the remaining sections have a slightly different response scale, which asks you to indicate to what extent you either agree or disagree with each statement. Again, indicate which response is the closest to how you feel by ticking (√) one of the boxes after each statement. Please try to answer ALL questions as honestly as possible.

SECTION FIVE:
The next section asks you about any concerns that you may have for the future because of your CF:

30. It concerns me that I may not be able to have any/have more children.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

31. I have concerns about being assessed for a hear t-lung transplant.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

32. The possibility of needing a hear t-lung transplant worries me.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

33. I worry about CF shortening my life.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree

- Disagree
- Strongly disagree

34. In general thinking about the future makes me feel concerned / worried.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

35. The worries that I have about the future make life less enjoyable.

    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

SECTION SIX:
In general , do you agree or disagree that your CF has affected your relationships with other people in any of the following ways?

36. Establishing new relationships / friendships is difficult because of my CF.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

37. I find that my friends don't always understand the limits that my CF places on me.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree
    - Disagree
    - Strongly disagree

38. My CF makes it difficult for me to establish intimate relationships.
    - Strongly agree
    - Agree
    - Slightly agree
    - Slightly disagree

- o Disagree
- o Strongly disagree

39. My CF makes it difficult for me to maintain intimate relationships.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

40. I find that my CF interferes with me having a satisfactory sex life.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

41. I find that CF makes me feel different from other people my own age.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

42. My CF makes me feel isolated from other people.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

43. I am concerned that my CF is stressful for those who are close to me.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

44. I worry that, because of my CF, I will never be able to lead an independent life.
    - o Strongly agree
    - o Agree

- Slightly agree
- Slightly disagree
- Disagree
- Strongly disagree

45. The way in which CF affects my relationships with other people interferes with my quality of life by making life less enjoyable.
- Strongly agree
- Agree
- Slightly agree
- Slightly disagree
- Disagree
- Strongly disagree

SECTION SEVEN:
CF can affect your height/weight, in general how has this made you feel?

46. I believe that my CF has made me too small.
- Strongly agree
- Agree
- Slightly agree
- Slightly disagree
- Disagree
- Strongly disagree

47. I feel that because of my CF I am too thin.
- Strongly agree
- Agree
- Slightly agree
- Slightly disagree
- Disagree
- Strongly disagree

48. The way that my CF has made me look because of my height / weight makes life less enjoyable.
- Strongly agree
- Agree
- Slightly agree
- Slightly disagree
- Disagree
- Strongly disagree

SECTION EIGHT:
The next section asks you about problems you may experience at college, work OR school as a result of your CF. If you are no longer working or at college, please answer the questions in relation to your past experiences.

49. CF makes/has made, finding a suitable college course/job difficult.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

50. Holding down a job / college course is / has been difficult because of my CF.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

51. I am now unable to work / go to college because of my CF.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

52. I find that CF interferes with my career / college OR school life to such an extent that it makes life less enjoyable.
    - o Strongly agree
    - o Agree
    - o Slightly agree
    - o Slightly disagree
    - o Disagree
    - o Strongly disagree

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VITA

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