SPIRITUALITY AND WAYS OF COPING WITH CYSTIC FIBROSIS

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DEDICATION

I would like to dedicate this work to my cousin, Ashley, who has inspired my research into Cystic Fibrosis. Your endurance continually moves me.

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CHAPTER I

INTRODUCTION

The daily lives of adults with chronic illnesses such as cystic fibrosis (CF) are influenced by psychosocial as well as physical factors. While the physical impact of CF has been and continues to be thoroughly studied, the psychological and social factors associated with this disease have received little attention (Abbott, 2003; Abbott, Dodd, Gee, & Webb, 2001; Abbott & Gee, 1998; Latta, 1996). Coping and spirituality are factors that are receiving increased interest in the research literature; however, there have been a limited number of empirical studies conducted to gain a greater understanding of the relationship between spirituality and the way in which individuals with specific illnesses such as CF cope. Koenig (2004) explains that "a growing body of scientific research suggests connections between religion, spirituality, and both mental and physical health," showing that increased efforts into researching this area is crucial (p. 1194).

There is also a growing recognition that varying illnesses can have both physical and psychological stressors related to the specific illness (Sedway, 2003). As Rowe and Allen (2004) state, it is important to research and "explore the relationships between spirituality and coping with individuals who have the same or similar chronic illnesses" (p. 66). This idea supports a biopsychosocial approach with the chronic illness population, recognizing that an awareness of the biological, psychological, and social factors an individual encounters allows for a greater understanding of his or her individual experience.

Stress and Chronic Illness

Individuals with chronic illnesses such as CF face an increase in the frequency and severity of stressful situations (Falvo, 1999; Harowitz, 1986; Livneh & Antonak, 2005) compared to the general population without chronic illness. This increase stems from the need to cope with daily threats, including threats to a) one's life and well-being, b) body integrity, c) independence and autonomy, d) fulfillment of familial, social, and vocational roles, e) future goals and plans, and f) economic stability (Abbott, 2003; Levneh & Antonak, 2005, p. 83). Effective ways of coping can assist in dealing with these threats and increase the likelihood of adhering to required treatment regimens (Abbott, Bilton, & Webb, 1994; Abbott & Gee, 1998; Czajkowski & Koocher, 1987).

Factors that Influence Coping

Although research focusing on the way in which effective coping strategies influences health and well-being is growing in abundance, there is limited knowledge regarding factors that actually contribute to ways of coping. According to biopsychosocial approaches to stress and coping for those with chronic illnesses, it is important to gain insight into an individual's relevant personal factors in order to truly attempt to understand his or her particular experiences (Kaewsarn, Moyle, & Creedy, 2002; Molassiotis & Maneesakorn, 2004; Rowe & Allen, 2004; Thompson & Gustafson, 1996). For example, Folkman & Lazarus (1988) took this approach and found emotion to be an important factor related to coping.

Spirituality is a dimension that is no longer a taboo topic but continues to receive little attention in the empirical research literature (Fehring, Miller, & Shaw, 1997; Rowe & Allen, 2004; Narayanasamy, 2002). A growing number of professionals in the medical

field have recognized the need to increase research efforts into spirituality in order to better understand its connection to coping and overall health status (Astrow, Puchalski, & Sulmasy, 2001; D'Souza, 2002; Ellis, Campbell, Detwiler-Breidenbach, & Hubbard, 2002; Hall, Dixon, & Mauzey, 2004; Kaczorowski, 1989; Kliewer, 2004; Livneh & Antonak, 2005; O'Neill & Kenny, 1998; Orozco, 2004). Yangarber-Hicks (2004) indicates that spirituality can be seen as "offering great help by providing coping and problem-solving strategies, a source of social support, and a sense of meaning in the midst of tragedy and confusion" (p. 306).

Along with spirituality, it is important to develop a better understanding of the way in which other factors influence coping for those with chronic illnesses such as CF (Latta, 1996; Sedway, 2003). Particular demographic factors have received little attention in the research literature, even though they have been cited as being an important aspect of coping. Factors including spiritual/religious affiliation status, frequency of discussing spiritual issues with one's physician, disease severity, and lung transplant list status are factors that are in need of further research in order to understand the ways in which they relate to coping.

Purpose of the Study

The primary purpose of this study is to examine the relationship between spirituality and four ways of coping (optimistic acceptance, hopefulness, distraction, and avoidance) for adults with CF as measured by the Spiritual Involvement and Beliefs Scale-R (Hatch, Burg, Naberhaus, & Hellmich, 2001) and the Ways of Coping with Cystic Fibrosis (Abbott, Dodd, Gee, & Webb, 2001) scale. In addition, the following demographic factors will be examined to gain a further understanding of the nature of their own relationship with: spiritual/religious affiliation status, disease severity, lung

transplant list status, and frequency of discussing spiritual issues with one's CF physician.

Significance of the Study

The significance of this study relates to its prospective contribution to the empirical research literature as well as its potential contribution to clinical practice. First, exploring how spirituality relates to coping is often discussed in the research but rarely acted upon, especially with the chronic illness population. Results from this study could assist in identifying the significance of spirituality as a component of coping, which would not only enrich the literature but also provide valuable information to the doctors who work with adults with CF. Second, investigating the way in which demographic factors relate to coping would further enhance the understanding of how individual differences influence the way in which individuals with CF cope. Such an investigation would enhance the research literature and allow doctors to have a greater understanding of the way personal factors impact the health of adults with CF. This knowledge could support physicians as well as psychologists in helping patients identify factors that influence their ways of coping, possibly enhancing treatment adherence and quality of life.

Research Questions:

- 1. What is the relationship between spirituality and ways of coping for individuals with CF, as measured by the Spirituality Involvement and Beliefs Scale Revised (SIBS-R) and the Ways of Coping with CF (WCCF) scale?
- 2. What is the relationship between participant self-reported spiritual/religious affiliation status and ways of coping for individuals with CF, as measured by the WCCF scale?

- 3. What is the relationship between participant self-reported disease severity and ways of coping for individuals with CF, as measured by the WCCF scale?
- 4. What is the relationship between participant self-reported lung transplant list status and ways of coping for individuals with CF, as measured by the WCCF scale?
- 5. What is the relationship between participant self-reported frequency of discussing spiritual issues with one's CF physician and ways of coping for individuals with CF, as measured by the WCCF scale?

Hypotheses:

H₁: That there is a significant relationship between spirituality and the four ways of coping.

H₂: That there is a significant relationship between spiritual/religious affiliation status and the four ways of coping.

H₃: That there is a significant relationship between disease severity and the four ways of coping.

H₄: That there is a significant relationship between lung transplant list status and the four ways of coping.

H₅: That there is a significant relationship between frequency of discussing spiritual issues with one's cystic fibrosis (CF) physician and the four ways of coping.

Definition of Terms:

<u>Coping:</u> The constantly changing cognitive and behavioral efforts utilized to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person (Lazarus & Folkman, 1984).

Optimistic Acceptance: An optimistic, determined, and positive way of coping (Abbott et al., 2001).

Hopefulness: A hope that everything will turn out for the better (Abbott et al., 2001).

<u>Distraction:</u> An attempt to try and forget (Abbott et al., 2001).

Avoidance: An avoidant and passive way of coping (Abbott et al., 2001).

Spirituality: An underlying dimension of the conscious in which an individual strives for meaning and union with the universe and all things and extends to a power beyond us (Rowe & Allen, 2004). Spirituality is broader than religiosity; one can be spiritual and not be religious (Hatch et al. 1998).

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

Although research into psychological factors associated with chronic illnesses has increased over the past decade, evidence regarding these factors differs across specific illnesses (Sedway, 2003). Psychosocial factors associated with Cystic Fibrosis (CF) have received scarce attention in the area of psychological research. While the physical impact of CF on adults has been frequently studied, little research has been conducted to discover the ways in which individuals with CF cope with the stress and physical demands of daily life (Abbott, 2003; Lowton & Gabe, 2003). Similarly, spirituality has received little attention in the research literature, although it has been identified as an important factor in coping with chronic illness (Fehring, et al., 1997; Rowe & Allen, 2004; Narayanasamy, 2002). As the survival rate for those with CF increases, it is also important to increase research efforts into the factors associated with how adults with CF cope.

In support of increasing research efforts and awareness, the current literature review will explore issues related to the ways in which adults with CF cope. First, a review of the biopsychosocial approach will be presented. Second, a detailed overview of the symptoms and related health concerns of CF will be introduced to present a thorough review of the all-encompassing impact of the disease. This will be followed by a discussion of the literature and empirical research on coping. Also, a review of

spirituality and related empirical research will be presented. Next, a discussion of the research related to the relationship between coping and spirituality will be introduced. Finally, an exploration of the literature regarding relevant demographic factors will conclude this literature review.

Biopsychosocial Approach

While a biomedical model has been a dominant force in working with the chronic illness population, there is a trend toward developing a more synthesized approach.

Farmer, Clark, and Marien (2003) discuss how there has been a gradual paradigm shift in the past decade in how health service delivery is conceptualized, including expanding the focus to meet the medical, educational, social, and emotional needs. They also state that this focus shifts from illness to wellness, from provider as expert to a family-provider partnership, and from the person as the target of treatment to interventions that include environmental factors. Nicassio, Meyerowitz, and Kerns (2004) agree with this and state that the expansion towards a biopsychosocial model for the application of health psychology interventions has succeeded in promoting an interdisciplinary context for education and training opportunities. They particularly stress how this approach of expanding psychologists into the field of health psychology and working with those with chronic illnesses increases medical and allied health practitioners' awareness of the availability and effectiveness of a new range of intervention approaches for patients.

Related to the expanding focus of treatment strategies, transactional approaches to health care focus on the interplay between the person and the environment "in a dynamic, mutually reciprocal, bidirectional relationship" (Lazarus & Folkman, 1984, p. 293).

Lazarus and Folkman describe how what may be a consequence during an event can become an antecedent at another event, and the cause of the event can be either in the person or in the environment. Thompson's Transactional Stress Model is an expansion of

the ideas of Lazarus and Folkman regarding chronic illness and stress (Thompson & Gustafson, 1996). Thompson and Gustafson discuss that the goal of this framework is to use a biopsychosocial conceptual framework to integrate findings and guide the development of interventions. Included in this framework is Piaget's theory of cognitive development, which reflects the influence of biological and cognitive factors in development. Also, Erikson's theory of psychosocial development is referenced to address socioemotional concerns. Thompson and Gustafson further describe how systems-theory serves several useful purposes in this approach, including a) it allows exploration beyond a specific disease such as CF and focuses on multiple factors influencing development, b) it allows for the assessment of the impact of experience on the developing person or others in subsystems, and c) it forces the focus to be on the continuous interaction of constitutional and environmental factors and processes over time (p. 7). Thompson and Gustafson additionally stress the need for further experimental research to inform the biopsychosocial model across illnesses and conditions to "identify general and specific" processes influencing stress and coping. Although this framework primarily concerns chronic illness in childhood, the concepts and the biopsychosocial approach can be applied to adults as well.

Cystic Fibrosis

Until the past 30 years, cystic fibrosis (CF) had been considered a childhood disease because most people with CF rarely lived beyond childhood (Palmer & Boisen, 2002). CF is a genetic, multi-system disease characterized by chronic airway obstruction, subsequent infection of the bronchial airways, and maldigestion because of pancreatic dysfunction (Anderson, 2001). Incidence rates of CF are estimated at 1 in every 2500 live births among Caucasians and 1 in every 17,000 live births among non-Caucasians (Kepron, 2003), which make the disease the most fatal inherited disease in industrialized

nations (Sedway, 2003). Approximately 60 percent of those with CF are diagnosed within the first one to two years of life, with approximately 85 percent diagnosed by age 5 (Kepron, 2003). About 10 to 15 percent are over 18-years-old when diagnosed. Before 1940, 85% of CF patients died before reaching 2-years-old, but with improved technology and medical management, the number of patients reaching adulthood is steadily increasing (Sedway, 2002). With no cure at present, the current median age of survival is 35.5 years (Kepron, 2003).

In regards to diagnosis, recurrent lung infections are the common problem that prompts diagnosis, and lung abnormalities are the most common complications for those with CF and occur in 50% of patients (Cystic Fibrosis Foundation, 2004; Gjengedal, Rustoen, Wahl, & Hanestad, 2003; Kepron, 2003; Lowton & Gabe, 2003). The buildup of secretions, infection, and inflammation can lead to hemotysis (coughing up blood), permanent scar tissue, and pneumothorax (collapsed lung), which decreases lung function (Sedway, 2003). CF patients also commonly experience chronic nasal congestion due to hyperactive mucus-secreting glands, nasal polyps, and sinus disease, which are other indicators that prompt diagnosis.

CF and the Gastrointestinal System

Another crucial feature of CF relates to maldigestion and malabsorption of fats (Kepron, 2003). This faulty digestion and absorption occurs as a result of abnormal pancreatic functioning. In CF, the secretions of enzymes from the pancreas to the small intestine become thick. As a result, the cells of the pancreas related to enzyme production become damaged and are replaced by scar tissue, resulting in an inability to digest fat properly. Along with pancreatic functioning, mucus thickening can occur in the small and large intestines and the liver, affecting proper digestion.

Along with thick mucus impacting the digestive system, individuals with CF can experience gastroesphageal reflux disease (GERD) as their disease progresses (Cystic Fibrosis Foundation, 2004; Kepron, 2003, Lowton & Gabe, 2003). As lung functioning decreases and coughing increases, the likelihood of developing GERD increases. Also, some people with CF have smaller than normal gallbladders, increasing the likelihood of gallstones and liver disease.

CF and Nutritional Status

As a result of abnormal digestion, CF affects the absorption of vitamins, which can lead to malnutrition and difficulty maintaining healthy body weight (Cystic Fibrosis Foundation, 2004; Kepron, 2003). As those with CF get older, the incidence of developing diabetes increases. Diabetes can be brought on by pancreatic insufficiency along with medications used to treat CF, which can interfere with glucose metabolism. Also, the use of intravenous (IV) feeding to increase nutrition can trigger diabetes. For individuals with CF the onset of diabetes is typically milder and much slower, with fewer symptoms and complications than other types of diabetes.

CF and Fertility

As people with CF approach adulthood, a personal issue that can become an important concern is parenthood. CF affects the reproductive system differently for males and females (Cystic Fibrosis Foundation, 2004; Kepron, 2003; Lowton & Gabe, 2003). The testicles in males with CF develop normally and appear normal in both structure and function, allowing for a sexual relationship like anyone else. However, 95 percent of males are infertile because they lack epididymides, which collect sperm produced in the testicles, and they lack the collecting tubules and vas deferens, which pump sperm during sexual activity. For females with CF, there are no specific abnormalities in any of the

reproductive organs. However, increased malnutrition can lead to irregularities with menstruation.

Although those with CF, especially women, can experience parenthood, it is often cautioned and counseling is suggested (Kepron, 2003). For women, pregnancy can increase stress on the heart, lungs, and nutritional status of the mother and is only suggested for those with relatively mild CF symptoms. If the potential father is a carrier of the defected CF gene, there is also the possibility that the child could be born with the disease as well. A baby will experience no adverse effects from the mother's CF provided the mother stays in good overall health, and medications commonly used to treat CF do not increase risk for the baby. For both men and women, it should be realized that the average life expectancy for the CF parent is about 36-years-old, and the possibility exists that he or she may never see his or her children reach adulthood.

CF and Other Medical Complications

Other less serious medical complications can occur for those with CF and impact their daily lives. Osteoporosis, a bone disease characterized by a reduced bone mass, appears to be present in most all individuals that survive to early adulthood (Cystic Fibrosis Foundation, 2004; Kepron, 2003; Lowton & Gabe, 2003). Arthritis and joint pain are unusual in childhood CF, but up to 8 percent of adults develop complaints. Hepertrophic Pulmonary Osteoarthropathy (HPOA), a condition similar to arthritis where the layer of tissue that forms the surface layer of bone become thickened and causes pain or discomfort around the ends of the long bones such as the forearms or lower legs, is also seen in those who have advanced lung disease with low levels of oxygen in their blood. Rashes additionally can appear as joint pain first appears. These rashes typically cause no harm and eventually disappear on their own. Due to pancreatic problems and

malabsorption that results in high levels of a mineral called oxalate in the blood, adults with CF have a higher rate of developing kidney stones than average.

CF and Treatment Strategies

Due to the various physical complications of CF, there are a number of treatment strategies aimed at improving symptoms and maintaining health status. In order to remove mucus secretions in the airways, chest physiotherapy (CPT) is the major therapy of choice (Cystic Fibrosis Foundation, 2004; Kepron, 2003). During CPT, a physiotherapist or trained family member sharply percusses (taps) the chest of the patient in various positions for 30-60 minutes, at least twice a day. Throughout the years, various mechanical devices, such as vibrating vests, have been developed to enhance this process. This treatment assists in loosening secretions and drainage. Antibiotics in pill form and in nebulized form are also often utilized for the daily treatment of pseudomonas and bacteria, which influence infections and inflammation in the airways. For a severe flareup, intravenous (IV) therapy is often utilized in a hospital setting. When blood levels become low, additional oxygen is provided through an oxygen tank or special machine called an oxygen concentrator. For the treatment of maldigestion, various enzymes and vitamins are utilized. An individual with CF can often find herself or himself taking up to 80 pills a day along with other forms of treatment to manage symptoms.

CF and Lung Transplantation, Gene Therapy, and Medical Prospects for the Future

Along with improved treatment strategies, lung transplantation and gene therapy assist in increasing the life expectancy for those with CF (Lowton & Gabe, 2003). Lung transplantation is usually considered when someone has severe respiratory failure, deterioration of lung function and physical well-being despite medical compliance, and very poor quality of life and inability to carry out daily living (Kepron, 2003). On

average, lung transplantation expands one's life five or six years, with some recipients living 10 to 15 years after their transplant.

After the CF gene was discovered in 1989, work began to introduce gene therapy as a treatment option or possibly even a cure (Cystic Fibrosis Foundation, 2004; Kepron, 2002). Gene therapy includes inserting a normal gene into a virus, having the virus "think" the gene is part of its own genetic material, and introducing the gene to cells to override defective genetic material. As of yet, gene therapy provides only short-term results that decline over time. However, researchers continue to find ways to improve this system and possibly find other vectors to carry the genetic material to cells that would result in longer lasting outcomes.

Gene therapy continues to provide promise for treating CF (Kepron, 2003).

Although slower than initially anticipated, gene therapy provides promise for the future.

As treatment strategies and lung transplantation improve, the survival rate for those with CF is expanding. The significant number of physical symptoms and complications related to the disease remain, however, resulting in the need to explore the relevant psychological and social dynamics.

Coping

As the number of people with CF who enter adulthood continues to increase, it is significant for psychologists and other health care professionals to be aware of the experiences and issues faced by this population in order to develop comprehensive treatment strategies (Abbott & Gee, 1998; Czajkowski & Koocher, 1987; Gjengedal, Rustoen, Wahl, & Hanestad, 2003; Latta, 1996; Lowton & Gabe, 2003). An area of particular relevance to those with CF is coping, which can influence the way in which they physically and psychologically manage the disease. Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal

demands that are appraised as taxing or exceeding the resources of a person" (Lazarus & Folkman, 1984). Abbott et al. (2001) describe coping responses as the behaviors, thoughts, and feelings that are used to avoid harm resulting from life stressors.

Research including a broad spectrum of chronic illnesses such as cancer, rheumatoid arthritis, and diabetes has typically explored two broad categories of coping strategies, including disengagement and engagement strategies (Livneh & Antonak, 2005). Disengagement strategies are identified as "efforts that seek to deal with stressful events through passive, indirect, even avoidance-oriented activities such as denial, wishfulfilling fantasy, self- and other-blame, and resorting to substance abuse" (p. 83). Engagement coping strategies include efforts that resolve stressful situations through "active, direct, and goal-oriented activities such as information seeking, problem solving, planning, and seeking social support" (p. 83). Abbott et al. (2001) describes these two categories as "avoidance" and "active" ways of coping. Avoidance ways of coping are described as negative and maladaptive in healthy populations but especially maladaptive with the chronic illness population. Active ways of coping are described as positive and healthy for all populations.

Due to the uniqueness of the physical and psychological factors associated with specific chronic illnesses, researchers have acknowledged the need for insight into the unique experiences of those with specific illnesses (Kaewsarn et al., 2002; Molassiotis & Maneesakorn, 2004; Rowe & Allen, 2004; Thompson & Gustafson, 1996). As a result of little being known about the ways that individuals with CF cope, Abbott et al. (2001) developed the Ways of Coping with CF scale. During the development of their scale, the authors identified CF patient's specific concerns related to their illness and identified coping responses to those specific concerns. After empirical study, Abbott et al. identified four distinct ways of coping for people with CF. The first way of coping,

optimistic acceptance, reflects a confident, determined, and positive way of coping with CF. The second way, hopefulness, reflects a hope or desire for everything to turn out for the better. The third way, distraction, displays an attempt to try and forget CF. The final way, avoidance, includes an avoidant and passive way of coping.

It appears that since the Ways of Coping with CF scale (Abbott, et al., 2001) is a new measurement tool indicated for use with a specific population, little research has been performed with it. In fact, only one empirical study using this measure was discovered in this literature review. Abbott et al. (2001) utilized the CF coping questionnaire along with the Manchester Adult Cystic Fibrosis Compliance Questionnaire to examine the relationship between coping styles and treatment adherence. Sixty patients (25 females and 35 males) who regularly attended the Manchester Cystic Fibrosis Unit took part in the study. Results showed that those who were adherent to treatment scored higher on the optimistic acceptance and hopefulness scales than those who were non-adherent. Those who were partially adherent scored higher on the distraction scale than adherent or non-adherent patients, and non-adherent patients reported using avoidance strategies to a greater extent than those who were adherent. The researchers concluded that the degree of treatment adherence was related to a person's way of coping, and identifying effective coping strategies for those who are non-adherent to treatment should improve compliance.

Another study exploring whether coping was related to treatment adherence for patients with CF also examined the differences in coping behaviors (Czajkowski & Koocher, 1987). The Medical Compliance Incomplete Stories Test (M-CIST) and an assessment of coping behaviors were utilized with 40 (26 male and 14 female) adolescent and adult inpatients. The M-CIST is a set of five incomplete stories where the main character is confronted with a dilemma of whether or not to follow medical advice, and

the participant is asked to complete the story, predicting the outcome for the main character. The test is individually administered and scored separately using a set of objective criteria along the criteria of compliance/coping, optimism, and self-efficacy. Each of these dimensions yield a single score, and totaling the three scores together yield a "competency-compliant" score (p. 313).

After analyzing the data, the researchers discovered that participants identified as non-compliant to treatment expressed passive and resistant coping behaviors unlike the overt and direct behaviors of those identified as compliant (Czajkowski & Koocher, 1987). Even if participants identified as non-compliant reported stories where the main character was compliant, the compliance "tended to be passive and dependent in style" (p. 318). Czajkowski and Koocher also report that as participants got older, coping behaviors tended to change from behaviors and skills involving peer interactions in adolescence to behaviors and skills related more to autonomy and independence in adulthood. Further, males reported coping skills associated with achievement more frequently than females, and females reported skills that address relationships with others more frequently than males. The authors state that continuing to increase the understanding of coping skills and behaviors through studies such as theirs could assist in developing appropriate interventions for those with more avoidant and passive coping styles in order to improve treatment adherence.

While much of the literature on coping and chronic illness has focused on the role of coping in disease management or treatment adherence, Folkman and Lazarus (1988) introduced the importance of coping as a mediator of emotion in a study often cited in the health psychology and chronic illness literature. Similar to previous research, however, coping is described as including related thoughts, feelings, and behaviors, and it is described as being on a continuum from positive to negative. Folkman and Lazarus

evaluated the extent to which coping mediated emotions during stressful encounters for 191 males and females who indicated recently experiencing a stressful encounter. The ways the participants coped with the demands of their encounters and the emotions they experienced during two stages of those encounters were assessed through use of the Ways of Coping Questionnaire and through interviews regarding the extent to which participants experienced each of a number of emotions. The extent to which eight forms of coping (confrontive, distancing, self-control, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, and positive reappraisal) mediated each of four sets of emotions (worried/fearful, disgusted/angry, confident, and pleased/happy) was assessed by a series of hierarchical regression analyses. Coping was found to be associated with changes in all four sets of emotions, with four types of coping being strongly associated with changes in emotion. Planful problem-solving was associated with an improved and more positive emotion states. Confrontive coping was associated with worsened emotion states. Positive reappraisal was associated with improved emotion states for younger participants (mean age of women = 39.6, mean age of men = 41.4), however for older participants (mean age of women = 68.9, mean age of men = 68.3), positive reappraisal was associated with an increase in worry/fear. Distancing was associated with a worsened emotional state. Lazarus and Folkman conclude that some forms of coping may make "things" better or worse depending on population and context, and they state that "a full understanding of the differential effects is especially important if we are to make progress in developing effective coping-related interventions" (p. 474).

As can be seen by the cited literature, coping is an important aspect of chronic illness. The concentration of research in this area has been on treatment adherence and overall disease management, which has resulted in identifying coping as an important

component. The work by Folkman and Lazarus (1988), which involved emotion and coping broadened the focus from looking at ways that coping strategies influence health to looking at factors that influence coping. However, the research regarding factors that influence coping continues to be severely limited.

Spirituality

Among the many possible factors influencing coping, spirituality is one that has sparked growing discussion and debate (Astrow et al., 2001; D'Souza, 2002; Handzo & Koenig, 2004; Jenkins & Pargament, 1995; Johnson & Hayes, 2003; Kaczorowski, 1989; Koenig, 1994; Landis, 1996; O'Neill & Kenny, 1998). Spirituality is often identified as an important factor in maintaining health and well-being and in coping with chronic illness, however, it has been the focus of few studies (Ellis, M. R. et al., 2002; Fehring, et al., 1997; Hebert et al., 2001; Orozco, 2004; Yangarber-Hicks, 2004). Rowe and Allen (2004) state that although spirituality is thought to be an important strategy to help patients cope with the psychosocial stress associated with chronic illness, it is a dimension that is often left unattended. Similarly, Narayanasamy (2002) explains that while the significance of spirituality in patients' lives as they face illness is acknowledged in the emerging healthcare literature, "there is paucity of literature and research with regard to the lived experience of spiritual coping mechanisms in chronically ill patients" (p. 1461).

Philosophers have explored spirituality for centuries and have described it as an "underlying dimension of the conscious in which an individual strives for meaning and union with the universe and all things," as well as a dimension that "extends to a power beyond us" (Rowe & Allen, 2004, p. 62; Smith et. al., 1993). This description implies a subconscious component to the human psyche that influences one to seek meaning in his or her life as well as a belief in a power beyond one's control and striving for a union

with all creation. Rowe and Allen (2004) indicate that it is important to not confuse spirituality with religion, which may overlap but are not the same. Religion refers to "the external expression of faith, that is the inner beliefs or values that relate to God or any higher being" (p. 63). Further, religion is a type of spiritual experience that is an aspect of an organized belief system and practices. Spirituality can encompass more than religion, and a person can be spiritual without being religious (Hatch, Burg, Naberhaus, & Hellmich, 1998; Rowe & Allen, 2004). Despite centuries of philosophical exploration of this phenomenon, few empirical studies have been conducted, especially in regard to chronic illness.

In response to the lack of research into spirituality and to the encouragement of including spiritual variables into the biopsychosocial model of patient care, Hatch et al. (1998) developed the Spiritual Involvement and Beliefs Scale (SIBS), which is a 26-item scale that assesses spirituality based on 15 underlying principles such as purpose in life, faith, and trust. The authors also assert that the SIBS measures four factors of spirituality, including External/Ritual, Internal/Ritual, Existential/Meditative, and Humility/Personal Application. Hatch et al. state that they are hopeful that the availability of the SIBS will facilitate research into the relationship between spirituality and health. Relationship Between Coping and Spirituality

Acting upon the encouragement of Hatch et al. (1998), Rowe & Allen (2004) explored the relationship between spirituality and coping ability for those with various chronic illnesses such as cancer, diabetes, hypertension, and epilepsy. A total of 201 participants completed the Spiritual Involvement and Beliefs Scale (SIBS; Hatch et al., 1998) and the Coping Scale (Nowack, 1990). Data analyses resulted in a significant positive correlation between spirituality and the ability to cope. One particular style of coping, intrusive positive thoughts, resulted in a significant predictor of spirituality. The

authors state that their results suggest that "individuals who measure high in spirituality also tend to have a stronger and more diverse coping style and also tend to cope using a more positive outlook" (p. 62).

While limited, other research has been performed on the concept of spirituality and has also showed evidence that it is an important aspect of coping. Narayanasamy (2002) conducted a study to gain further understanding of the spiritual coping mechanisms of patients with chronic illness. Utilizing qualitative methods based on descriptive phenomenology, the author sought to gather the lived experiences of participants. After compiling information from unstructured interviews with 15 chronically ill (leukemia, chronic liver disease, lung cancer, etc.) patients, Narayanasamy discovered themes that suggested that those with chronic illness used the following spiritual coping mechanisms: faith, prayer, and related sources of support. Although this study offered one view of spiritual coping mechanisms, due to the majority of participants adhering to religious faiths, the author concludes that patients with chronic illness may benefit from "interventions that are sensitive, supportive, and responsive to their spiritual needs" (p. 1461).

Another study exploring spirituality and coping in chronic illness investigated to what extent brain tumor patients and their next of kin were able to cope, able to understand and create meaning out of their situation, and able to explore whether spirituality could be supportive (Strang & Strang, 2001). Also, the researchers analyzed whether these concepts are related to sense of coherence. Purposive, information-rich maximum-variation sampling was utilized. Twenty patients having malignant brain tumors of grade II-IV were interviewed with a focus on a) comprehensibility, b) manageability/coping strategies, c) meaningfulness, and d) whether spirituality contributes to a sense of coherence. The interviews were successively analyzed, where

incoming data was compared with previous interviews. After content and context analysis was performed using a hermeneutic approach, the researchers found comprehensibility was largely constructed by the patient's thoughts and theories; manageability was developed by actively seeking information; meaningfulness was central for quality of life and was created by close relations, faith, and work; and spirituality was related to meaning, although the value of religious faith was ambiguous. Traditional religion was not very important for participants, however; "they still had some kind of spiritual or existential experience that helped them to create meaning" (p. 132).

Related to coping, Kaczorowski (1989) explored whether anxiety is lower in individuals with cancer who identify themselves as highly spiritual. The relationship between spiritual well-being and state-trait anxiety was measured for 114 adults diagnosed with cancer. Kaczorowksi discovered an inverse relationship between spiritual well-being and state-trait anxiety, despite effects of gender, age, marital status, diagnosis, group participation, and length of time since diagnosis. The author concludes that this result supports the theory that individuals with high levels of spiritual well-being have lower levels of anxiety, which challenges the health care community to consider the healing potential of spirituality (p. 114).

After recognizing the importance of spirituality in coping with terminal illness, McClain, Rosenfeld, and Breitbart (2003) organized a study to assess the relation between spiritual well-being, depression, and end-of-life despair in terminally-ill cancer patients. During this study, 160 patients in a palliative care hospital with a life expectancy of less than three months were interviewed with various instruments including the Functional Assessment of Chronic Illness, the Spiritual Well-Being scale, the Hamilton Depression Rating Scale, the Beck Hopelessness Scale, and the Schedule of Attitudes

toward Hastened Death. Significant correlations were discovered between spiritual well-being and desire for hastened death, hopelessness, and suicidal ideation. Also, analyses showed that spiritual well-being was the strongest predictor of each outcome variable, and depression was highly correlated with desire for hastened death in participants with low levels of spiritual well-being but not those with high levels of spiritual well-being. McClain, Rosenfeld, and Breitbart conclude that spiritual well-being offers protection against end-of-life despair for those facing imminent death.

Another study focusing on spiritual well-being was conducted by Landis (1995). He explored spirituality and coping by examining the relationship between spiritual well-being and psychosocial adjustment to chronic illness. Ninety-four participants with diabetes mellitus completed four questionnaires (Mishel Uncertainty in Illness Scale, Spiritual Well-Being Scale, Psychosocial Adjustment to Illness Scale, and participant demographic survey). After data was analyzed, the predicted negative relationship between uncertainty of adjusting to health problems and spiritual well-being was supported. Landis reports that these findings suggest that spirituality and spiritual well-being may be an important component in coping and adjusting to uncertainty related to long-term health problems for those with chronic illnesses such as diabetes mellitus.

Fehring, Miller, and Shaw (1997) also explored the concepts of spiritual well-being and coping. The variables of religiosity and spiritual well-being were correlated with hope, depression, and mood states in 100 elderly patients with cancer in an inpatient oncology unit in the Midwestern United States region. Instruments utilized in this study include the Intrinsic/Extrinsic Religiosity Scale, the Spiritual Well-Being Index, the Miller Hope Scale, the Geriatric Depression Scale, the Profile of Mood States, and the Symptom Distress Scale. Data analyses showed a positive relationship between intrinsic religiosity and hope, positive mood states, and spiritual well-being and showed a negative

relationship between intrinsic religiosity and depression and negative mood states. Subjects with high spiritual well-being and religiosity also had significantly higher levels of hope and lower levels of negative mood states than subjects with low spiritual well-being and religiosity. Additionally, elderly people with cancer appear to use their religiosity as a way of coping when in distress. Fehring, Miller, and Shaw explain that people with an intrinsic religiosity view their lives in the context of spirituality, which is typically expressed through their faith. The researchers further state that their results support the "conceptualization of religiosity and spiritual well-being as they relate to coping with a chronic illness such as cancer" (p. 669).

Demographic Factors

Along with spirituality, gaining a greater insight into the way other factors influence ways of coping for those with chronic illnesses such as CF is also essential (Latta, 1996; Sedway, 2003). Also similar to spirituality, though, certain demographic factors have received little attention in the research literature, even though they have been considered to be important. Factors including spiritual/religious affiliation status, frequency of discussing spiritual issues with one's physician, disease severity, and lung transplant list status are factors that deserve further consideration in order to determine their relationship to ways of coping.

Spiritual/Religious Affiliation Status

The literature regarding whether or not being affiliated with a particular spiritual or religious denomination relates to coping is limited and fragmented. Discussion typically focus on the way people from types of affiliation cope, but rarely do authors discuss multiple affiliations at once. Rather, they typically focus on one or two particular affiliations. Pargament, Tarakeshwar, Ellison, and Welff (2001) explored the relationship between coping and well-being in a sample of Presbyterian clergy, elders, and members.

A total of 1,260 clergy, 823 elders, and 735 members completed measures of demographic variables, global religiousness, life stressors, positive and negative religious coping, and well-being (p. 497). Results were largely similar to the authors' predictions where clergy reported higher levels of positive religious coping than elders, and elders reported higher levels of positive religious coping than members. Also, positive religious coping was related to higher levels of well-being, and negative religious coping was related to lower levels of well-being. Additionally, positive and negative religious coping were more strongly related to well-being for clergy than for members. The researchers state that longitudinal studies of the long-term influence of positive and negative coping for particular religions are needed to further understand the true relationship.

While Pargament et al. (2003) discussed coping only for those identified as being affiliated with the Presbyterian denomination, Osborne and Vandenberg (2003) examined the situational and denominational differences in coping for those identified as being affiliated with either the Catholic church or Disciples of Christ church. The sample included 75 members of the Catholic church and 78 members of the Disciples of Christ church. Participants read hypothetical vignettes representing three types of stressful situations (the death of one's father, being in a sailboat during a storm, and a job promotion), and they were assessed on the types of coping strategies that they would use in each situation. Results indicated that both the type of stressful situation and the religious denomination significantly influenced participants' ratings of the extent to which they would engage in certain coping activities. For example, Catholics reported that they would engage in a larger amount of coping activities involving pleading with God and experiencing feelings of discontent than Disciples of Christ members. In both denominations, participants indicated that they would employ a greater number of coping strategies in response to the death of their father as compared to the two other vignettes.

A study that included several spiritual/religious affiliations in its investigation utilized affiliation as a potential moderator of coping (Tix & Frazier, 1998). The effects of coping, the potential moderation of effects by religious affiliation, and the potential moderation of effects by other factors (i.e., cognitive restructuring, social support, perceived control) were explored in patients and significant others coping with the stress of kidney transplant surgery. A total of 232 patients and 171 significant others (e.g., spouse, parent, friend, sibling, child, or romantic partner) completed the Coping Strategies Inventory, the Social Provisions Scale, the Internal Control and Chance Control subscales of the Multidimensional Health Locus of Control Scale, the Brief Symptom Inventory, and the Satisfaction with Life Scale 3 months and 12 months after surgery. Of these patients and significant others, respectively, 42% and 47% were Protestant, 36% and 36% were Catholic, 3% and 3% were Jewish, 10% and 8% were "other," and 9% and 6% reported no religious preference.

Although several denominations were indicated, the authors only assessed Protestant and Catholic denominations as potential mediators (Tix & Frazier, 1998). An explanation for this decision was not given. At both 3 and 12 months after transplantation, results indicated that the use of religious coping was generally associated with better adjustment both concurrently and over time in both patients and significant others. Also, these effects were moderated by religious affiliation, such that religious coping was more effective in promoting adjustment for Protestants than for Catholics. The authors state that the difference discovered between the affiliations could be due to the "fit" between the use of certain coping activities and certain stressful circumstances. For example, Protestants may be more likely to use specific coping activities that concentrate on faith and a sense of control that facilitates adjustment to stressors, whereas Catholics may be more likely to focus on activities that promote guilt reduction that may

facilitate adjustment. The authors further state that results of their study indicate that professionals should give consideration to how individuals differ in their use of religion and spirituality in different types of stressful situations.

Discussion of Spiritual Issues with Physicians

Another demographic variable that has been discussed in the literature on chronic illness but rarely studied is the frequency of discussing spiritual issues with one's physician. In fact, this literature review found no studies that actually examined the particular relationship between discussing spirituality issues with physicians and ways of coping. Rather, literature regarding the appropriateness of discussing spirituality with physicians was discovered.

Daaleman and VandeCreek (2000) discuss how the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) trial brought to light the issue of discussing spiritual or religious beliefs with physicians for chronically ill patients. They state that there has been an inconsistent orientation and lack of conceptual clarity accompanying the issue. Also, they highlight that the typical argument is whether it is the role of physicians or other members of a health care team (i.e., social workers, psychologists, clergy) to address these issues. Daaleman and VandeCreek cite that studies of quality of life indicate that discussing spiritual issues with physicians enhances personal meaning for the chronically ill. However, they also indicate that data from a US national survey suggests that more than 80% of physicians surveyed reported that they refer issues related to spirituality to clergy and pastoral care providers.

Ellis, Campbell, Detwiler-Breidenbach, and Hubbard (2002) explored the issue of whether or not physicians discussed spiritual issues with patients in their qualitative study. Thirteen family physicians were interviewed, and themes were extracted via

qualitative analysis. Results showed that six participants reported regularly addressing spiritual issues with patients; one reported intermediate involvement; six reported that they do not regularly address spiritual issues; and one was opposed to physicians' addressing spiritual issues with patients. Physicians who reported regularly addressing spiritual issues indicated they did so because of the primacy of spirituality in their lives and their belief in scientific evidence associating health with spirituality. The authors state that the physicians differed in their comfort and practice of addressing spiritual issues with patients; however their results provide a rationale for physicians to respond to patients' spiritual concerns.

Offering a patient perspective on this issue, Hebert, Jenckes, Ford, O'Connor, and Cooper (2000) conducted a study to identify preferences and concerns of seriously ill patients about discussing religious and spiritual beliefs with physicians (p. 685). Three focus group discussion with 22 patients hospitalized with a recent life-threatening illness were conducted. Through qualitative analysis procedures, the discussions were audiotaped, transcribed, and reviewed by two independent investigators to identify discrete comments for grouping into themes or domains. Almost all of the 562 comments were grouped into the domains of a) religiosity/spirituality, b) prayer, c) patient-physician relationship, d) religious/spiritual conversations, and e) recommendations to physicians. Spiritual beliefs were often mentioned as a source of comfort for participants, and all of the participants stressed the importance of physician empathy. Whether or not patients participated in spiritual discussions with doctors was closely related to the patientphysician relationship. Also, patients tended to agree that physicians must have "strong interpersonal skills for discussions to be fruitful," and physician-initiated discussion without a strong relationship was viewed as "inappropriate and as implying a poor prognosis (p. 685). Hebert et al. conclude that patients want physicians to ask about

coping and support mechanisms, and if patients disclose spirituality as being important in their lives, they would like physicians to respect these values.

A final study discovered in this literature review that relates to discussing spiritual issues with physicians explored whether or not patients expect psychiatrists to be interested in spiritual issues (D'Souza, 2002). The author conducted an empirical study, surveying the spiritual attitudes and needs of patents with a psychiatric illness. A questionnaire developed by the Centre for Excellence in Remote Psychological Medicine was administered to 79 patients (males = 28, females = 51). D'Souza found that 79% of the patients rated spirituality as very important and 82% thought their therapists should be aware of their spiritual beliefs and needs. Also, 69% of participants reported that spiritual needs should be considered by the therapist in treatment, and 67% stated that their spirituality helped them cope with their psychological pain. The author concludes that spiritually based "interventions and collaborations that can optimize treatment should be used so that we can achieve the goals of social and emotional well being and maintenance of good health for our patients" (p. 47).

Disease Severity

Disease severity is also a factor that is important to consider when working with the chronic illness population, but it has been scarcely researched in relationship to coping. The majority of the studies discovered in this review examined the way in which a particular coping style relates to disease progression. Mulder, Antoni, Duivenvoorden, Kauffmann, and Goodkin (1995) investigated what type of coping style predicts decreased clinical progression in homosexual men infected with the Human Immunodeficiency Virus (HIV). The associations between stressful life events, psychiatric symptoms, coping, and social support and disease progression one year later were explored in 51 asymptomatic and early symptomatic men. Clinical progression and

CD4 (lymphocyte count) counts served as the dependent variables. The measures utilized include the General Health Questionnaire, the HIV Life Events List, the HIV Coping List, and a self-report social network questionnaire. After analyses were performed, there was no association found between the psychosocial parameters and CD4 counts. An active confrontation coping style, however, was predictive of decreased clinical progression at one year follow-up. The authors assert that these results indicate that active coping strategies may have an effect on disease progression and could be mediated by greater treatment compliance.

Another study examining disease progression with HIV-infected men prospectively explored the effects of stressful events, depressive symptoms, social support, coping methods, and cortisol levels on progression of HIV (Leserman et al., 2000). Eighty-two homosexual men with HIV were studied every 6 months for up to 7.5 years. Disease progression was defined by CD4 counts or the presence of an Acquired Immunodeficiency Syndrome (AIDS) indicator condition. Participants completed the following questionnaires: the Psychiatric Epidemiology Research Interview, the Hamilton Depression Rating Scale, the Brief Support Questionnaire, the COPE scale. Additionally, cortisol was measured with a radioimmunoassay kit. Cox regression models with time-dependent covariates were utilized during analyses. Results found that progression to AIDS was associated with higher cumulative average stressful life events, coping by means of denial, and higher serum cortisol along with lower cumulative average satisfaction with social support. Leserman et al. state that further research is needed to determine if treatments based on these factors could alter the clinical progression of HIV.

Also looking at disease progression and coping, Moyer, Fontana, Hussain, Lok, and Schwartz (2003) researched the role of optimism and pessimism in health related

quality of life (HRQOL) in chronic hepatitis C patients. Participants included 123 outpatients with chronic hepatitis C. They completed the SF-36 quality of life instrument, the Brief Symptom Index (BSI) emotion functioning instrument, and an instrument that questioned patients' expectations with regard to the impact their disease would have on their lives. Those who said they would continue to stay healthy were recorded as optimists, and those who said they would become sick very rapidly and might die from liver disease in a few years were coded as pessimists (p. 42). The results discovered that pessimism was associated with lower scores on nearly all SF-36 subscales and higher scores on 6 BSI subscales, showing greater emotional distress. Also, pessimism was related to the presence of a psychiatric comorbidity and self-reported decline in health status. The authors' conclusions include the statement that these results suggest that pessimism can influence a person's coping style, overall emotional well-being, and health status.

Lung Transplant List Status

Of all the demographic factors included in this literature review, lung transplant list status was the scarcest in the literature. Further, exploring the literature for the relationship of transplant list status of any organ and any psychological factor resulted in virtually no related literature. Although transplant list status was occasionally mentioned in relation to disease severity, only one study was found that focused on transplant list status as a variable in and of itself. Sedway (2003) explored the differences of psychological distress based on lung transplant list status, disease severity, and adaptational factors for adults with cystic fibrosis. One hundred fifty adults with CF were administered several questionnaires, including the COPE inventory to measure coping strategy use, the Life Orientation Test to measure dispositional optimism, the Medical Outcomes Study Social Support Survey to measure perceived social support, the State

Trait Anxiety Inventory to measure anxiety, and the Beck Depression Inventory to measure depression. Demographic and health history surveys were also administered, and results of pulmonary functions test were retrieved from participants' medical charts. After employing hierarchical regression analysis techniques, the results found that adults with CF showed levels of depressive symptoms that were greater than the general population but similar to other chronic illness populations. Anxiety levels were equal to those found in the general population. Dispositional optimism and perceived social support were both strongly related to psychological adjustment, and active coping was related depressive symptoms and trait anxiety. Being considered for a transplant was related to lower levels of anxiety. Transplant status as well as pulmonary function, however, poorly predicted psychological adjustment. The author states that more investigation is essential to better understand the relationship of transplant status to coping and overall psychological adjustment.

Summary

Through the medical literature, it can be seen that CF can be extremely physically taxing on the individual with the disease. Due to its all encompassing nature, CF can create stress and other psychological demands as well. Coping has been shown to be an important aspect of managing the disease, however, the literature reveals that there is still much to be discovered regarding the particular factors that influence coping for specific illnesses such as CF. Spirituality is identified as a particular aspect of coping that deserves additional attention. Also, additional inquiry and research into how particular demographic factors relate to coping is essential, as research into these factors is severely limited. From the biopsychosocial perspective, continuing to gain awareness of the many dynamics involved in the lives of those with CF is crucial in order to truly gain insight into their unique experiences.

CHAPTER III

METHODOLOGY

Introduction

This chapter discusses the methodology followed in the current study of the relationship between spirituality and coping as well as the relationship between coping and the following demographic factors: spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician. The chapter provides a description of the participants, the instruments used to measure demographic information, spirituality, and coping, procedures followed, method of data collection, the study's proposed statistical analyses, and a restatement of the study's questions, goals, and hypotheses

Participants

Individuals, at least 18-years-old, with cystic fibrosis (CF) were recruited from two Midwestern CF clinics in the United States. A total of 100 surveys and five flyers announcing the study were sent to the clinic coordinators/directors of two different Midwestern CF clinics. The flyers and packets were displayed in clinic waiting areas, and adults with CF voluntarily took, completed, and returned packets. A total of 56 questionnaire packets were returned (56%), and 55 packets remained after removing incomplete questionnaires. The final sample consisted of 22 males and 34 females (Table 1). The participants were 18 to 37 years old with a mean age of 25.8 (SD = 4.87). The sample consisted of 91% Caucasian and 9% American Indian/Native American. The yearly household incomes were reported as: \$20,000 - \$30,000 (34%), \$30,000 - \$40,000

(25%), less than \$10,000 (13%), \$10,000 - \$20,000 (11%), \$40,000 - \$50,000 (9%), and over \$50,000 (9%). In this sample, the age at which one was diagnosed with CF ranged from 0 to 30 with a mean age of 3.6 (SD=6.5). The majority, 79%, of participants reported identifying with a particular spiritual/religious faith. The spiritual/religious affiliations were represented by Protestant at 54%, Catholic 14%, Agnostic 4%, Atheist 2%, other 9%, and none 18%. Marital status was reported as Single/Never Married 61%, Married 20 %, Separated 7%, With a partner 7%, Divorced 4%, and Remarried 2%. The majority, 71% identified themselves as having moderate disease symptoms, 18% as mild, and 11 % as severe. In this sample, 82% indicated they are not on a lung transplant list, 16% reported they have considered being listed, and 2% indicated they are listed. With regard to how often one speaks to his or her doctor about spiritual/religious issues, 32% reported sometimes, 32% never, 30% rarely, 4% usually, and 2% always.

Instrumentation

Participants completed the following forms and assessment instruments: a demographic information sheet, the Ways of Coping with CF scale (Abbott, Dodd, Gee, & Webb, 2001), and the Spiritual Involvement and Beliefs Scale-R (Hatch, Burg, Baberhaus, & Hellmich, 2001).

Demographic Information Sheet

After reading the letter/informed consent form (Appendix B), the participants completed the demographic information sheet (Appendix D). This instrument requested information regarding gender, age, ethnicity, education level, socio-economic status, marital status, number of children, spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician.

Ways of Coping with CF scale

The Ways of Coping with CF scale (WCCF; Abbott, et al., 2001; Appendix D) was used to determine the coping strategy utilized by the participants. The questionnaire is a relatively new 20-item self-administered instrument, which assesses coping. The WCCF scale was empirically developed from data collected from adolescents and adults with CF. Factor analysis of the WCCF scale conducted by its' developers revealed 4 factors, indicating four distinct ways of coping with CF.

The WCCF scale was developed in three phases. First, the identification of patient's specific concerns/worries regarding CF was obtained through interviews, and a list of 23 salient concerns was recorded (Abbott, et al., 2001). Second, the recorded concerns were administered by interview to patients, and a list of 24 coping responses to those concerns was recorded. In order to be included in the coping scale, at least 10% of subjects had to indicate using a particular coping response. Next, 174 (76 males and 98 females) adolescents and adults with CF completed the scale. The participants were asked to rate on a four point scale whether they used each strategy in dealing with their CF (not at all = 1, a little = 2, a moderate amount = 3, a great deal = 4), and factor analysis with varimax rotation was applied to the data.

After analyses, items loading greater than .50 for a factor and communalities greater than .30 were considered meaningful and retained for that factor (Abbott, et al., 2001). Results yielded a four-factor solution with 20 items comprising the final scale. Internal reliability was demonstrated with alpha coefficients of .74 (optimistic acceptance), .69 (hopefulness), .72 (distraction), and .76 (avoidance). Due to the avoidance subscale including only two items, a correlational analysis was conducted and confirmed a strong relationship (r = .72) between the items. A Pearson product moment

correlation matrix resulted in stronger item to domain correlations than item to unrelated domain correlations.

Participant response on the WCCF scale is based on a 4-point Likert-style scale (Abbott et al., 2001). The participants were asked to indicate to what extent they utilize a particular coping strategy. Responses include a) "Not at all," b) "A little," c) "A moderate amount," and d) "A great deal," with each response receiving a numeric value of 0, 1, 2, or 3, respectively. Items corresponding to a particular factor were totaled, resulting in a single score. Coping scores for each factor were transformed through an equation developed by Abbott et al., which enables comparisons among the 4 scores. Transformed scores translate to values between 0 and 100, with higher scores representing greater use of a specific way of coping.

Spiritual Involvement and Beliefs Scale-Revised

The Spiritual Involvement and Beliefs Scale, Revised (SIBS-R; Hatch, et al., 2001; Appendix D) was used to assess spirituality. The original 39-item version of the scale was designed to measure spirituality across a broad spectrum of spiritual orientations (Hatch et al., 1998). It includes 15 underlying principles of spirituality, such as purpose in life, faith, and trust. The SIBS also includes four factors of spirituality, including external/ritual, internal/ritual, existential/meditative, and humility/personal application. However, since the development of the instrument, the SIBS has undergone several revisions (Hatch, et al., 2001). The most current version is a 22-item questionnaire which has not been formally published, but permission was given to include it in the current study (R. L. Hatch, personal communication, March 31, 2005). A pilot test was conducted with the SIBS-R, utilizing a sample of recovering alcoholics (N=193). After seven days, test-retest reliability was established (.93). The coefficient alpha for the revised version was .92, and the correlation between the original 39-item

version and the 22-item version was .98. Additionally, the SIBS-R continued to measure four factors (core spirituality, spiritual perspective/existential, personal application/humility, acceptance/insight) although slightly renamed. The following are content areas covered by the SIBS-R: ability to find meaning, acceptance, application of beliefs and values, belief in/connection to/reliance on something greater than oneself, fulfillment, gratitude, hope, joy, love, meditation, connection to nature, prayer, relationship between spiritual health and physical health, relationship with someone who can provide spiritual guidance, serenity, service, spiritual experiences, spiritual growth, and spiritual writings.

Participant responses on the SIBS-R are based on a seven-point Likert-style scale. For questions 1-21, participants are asked to indicate how strongly they agree with statements regarding spirituality. Responses range from "Strongly Agree" to "Strongly Disagree." The final item on the scale requires participants to indicate their level of spirituality on the seven-point scale, with 7 being the most spiritual. Participants' item values are totaled, resulting in an overall score, with higher scores reflecting higher levels of spirituality.

Procedure

Participants were recruited from two different CF clinics located in large

Midwestern cities in the United States via convenience sampling. Potential participants

were recruited from January 2006 through April 2007. CF clinic coordinators/directors

were sent information announcing the purpose and procedure for the study via a flyer

(Appendix A) to provide to potential participants. Coordinators/directors placed the flyers

in clinic waiting areas along with packets containing a letter that briefly described the

study and consent information (Appendix B), a demographic information form

(Appendix D), the Ways of Coping with CF scale (Appendix D), the Spiritual

Involvement and Beliefs Scale (Appendix D), and a postage paid return envelope. The questionnaires were placed in each packet in random order to control for order effects. Also, the titles of the questionnaires were removed to control for response sets. It was estimated that the questionnaires took approximately 25 minutes in total to complete. Patients who chose to participate completed the forms in his or her home environment. There was no contact between the researcher and participants. Information provided by the participants was kept confidential, and data was placed in a locked file cabinet. Returned questionnaires were identified by number only for data entry and analyses purposes, and no identifying information was collected.

Statistical Analyses

Data analyses were performed with Statistical Package for the Social Sciences (SPSS) software. Each case of data was first assigned a coded number ID, entered, and then demographic characteristics were subjected to frequency distributions to facilitate describing the sample. There were some items on the scales that were reverse coded and required transformation. The SIBS-R and the Ways of Coping with CF scale were both subjected to factor analysis to establish construct validity, and to reliability analysis to establish internal consistency.

Subsequently, in order to better understand the relationship, discussed in the Research Questions and Hypothesis section, between spirituality and coping as well as specific demographic factors and coping, a Multiple Regression Analysis was utilized. This method was used to determine if the proportion of variance in spirituality, spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician predicted by the four ways of coping (optimistic acceptance, hopefulness, distraction, and avoidance) was likely to occur by chance or if it is truly a reflection of a systematic relationship between

coping and spirituality, spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician.

Research Goals:

The major goals of this study were to: (a) explore the relationship between spirituality and four ways of coping (optimistic acceptance, hopefulness, distraction, and avoidance) and (b) explore the relationship between the four ways of coping and specific demographic factors (spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician).

Research Questions:

- 1. What is the relationship between spirituality and ways of coping for individuals with cystic fibrosis (CF), as measured by the Spiritual Involvement and Beliefs Scale-Revised (SIBS-R) and the Ways of Coping with CF (WCCF) scale?
- 2. What is the relationship between participant self-reported spiritual/religious affiliation status and ways of coping for individuals with CF, as measured by the WCCF scale?
- 3. What is the relationship between participant self-reported disease severity and ways of coping for individuals with CF, as measured by the WCCF scale?
- 4. What is the relationship between participant self-reported lung transplant list status and ways of coping for individuals with CF, as measured by the WCCF scale?
- 5. What is the relationship between participant self-reported frequency of discussing spiritual issues with one's CF physician and ways of coping for individuals with CF, as measured by the WCCF scale?

Hypothesis:

H₁: That there is a significant relationship between spirituality and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between the WCCF scale and the SIBS-R.

H₂: That there is a significant relationship between spiritual/religious affiliation status and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

H₃: That there is a significant relationship between disease severity and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

H₄: That there is a significant relationship between lung transplant list status and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

H₅: That there is a significant relationship between frequency of discussing spiritual issues with one's cystic fibrosis (CF) physician and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between frequency of discussing spiritual issues with one's CF physician and the four ways of coping.

CHAPTER IV

Results

Introduction

This chapter will present the data and explain the results of the analyses conducted in this study. The analyses examined the following research questions and hypotheses:

Research Questions:

- 1. What is the relationship between spirituality and ways of coping for individuals with cystic fibrosis (CF), as measured by the Spiritual Involvement and Beliefs Scale-Revised (SIBS-R) and the Ways of Coping with CF (WCCF) scale?
- 2. What is the relationship between participant self-reported spiritual/religious affiliation status and ways of coping for individuals with CF, as measured by the WCCF scale?
- 3. What is the relationship between participant self-reported disease severity and ways of coping for individuals with CF, as measured by the WCCF scale?
- 4. What is the relationship between participant self-reported lung transplant list status and ways of coping for individuals with CF, as measured by the WCCF scale?
- 5. What is the relationship between participant self-reported frequency of discussing spiritual issues with one's CF physician and ways of coping for individuals with CF, as measured by the WCCF scale?

Hypothesis:

H₁: That there is a significant relationship between spirituality and the four ways of coping.

Analysis: A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between the WCCF scale and the SIBS-R.

H₂: That there is a significant relationship between spiritual/religious affiliation status

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

and the four ways of coping.

H₃: That there is a significant relationship between disease severity and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

H₄: That there is a significant relationship between lung transplant list status and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between spiritual/religious affiliation status and the four ways of coping.

H₅: That there is a significant relationship between frequency of discussing spiritual issues with one's cystic fibrosis (CF) physician and the four ways of coping.

<u>Analysis:</u> A multiple regression analysis will be used to test this hypothesis to determine the nature and magnitude of the relationship between frequency of discussing spiritual issues with one's cystic fibrosis (CF) physician and the four ways of coping.

Results of Statistical Analysis

Reliability analysis of the SIBS-R resulted in item to scale correlations ranging from .24 to .91, with a coefficient estimate of internal consistency at .95. Three items

(i.e., questions 4, 11, and 21) were deleted from the SIBS-R due to low (i.e., <.10) item to scale correlations, resulting in a scale with 19 items. Upon examination of the deleted items, it can be postulated why these items may have been unclear or confusing. For example, item 11 states, "I don't take time to appreciate nature." This is the only item in the scale referring to nature, which may not have appeared congruent with the rest of the scale. Similarly, item 21 states, "I examine my actions to see if they reflect my value," and since most of the items on the scale specifically use the term spiritual in some form, the connection this statement has to spirituality may not have been understood. Item 4 states, "I find serenity by accepting things as they are." It is possible that this item may not have been fully understood due to the use of the word serenity, whose meaning may have not been clear.

Based on the original theoretical factor structure of the WCCF scale, internal consistency estimates were lower than anticipated for the four subscales (optimistic acceptance, α = .55, n = 7; hopefulness, α = .42, n = 6; distraction, α = .33, n = 5; avoidance, α = .79, n = 2). The following are the item to scale correlation ranges for each of the subscales: optimistic acceptance, .20 to .31; hopefulness, <.1 to .48; distraction, - .15 to .37; and avoidance, .66 (both items). Results indicated that items 11 and 16, which were both under the hopefulness subscale, had low item to scale correlations and were subsequently deleted, and item 5 resulted in a reverse correlation with the distraction subscale. After examining the two deleted items, it can be suggested why these items may not have correlated with the hopefulness subscale as expected. Item 11 states, "I talk to a professional who knows about CF." This item is vague in what kind of "professional" the question is referring to. Also, many CF patients who are relatively healthy may not see any kind of professional related to CF for several months. Thus one might still be hopeful yet not speak to a "professional." Item 16 states, "I'm just hoping it will be all right."

Again, this question is vague as to what "it" is referring to. Similarly, item 5 may have resulted in a reverse correlation due to vague wording. It reads, "I feel helpless there is nothing I can do," with no reference to what one is feeling helpless about (i.e., diagnosis of CF, other personal problems, etc.) The resulting internal consistency estimates are as follows: optimistic acceptance, $\alpha = .55$, n = 7; hopefulness, $\alpha = .60$, n = 4; distraction, $\alpha = .47$, n = 5; avoidance, $\alpha = .79$, n = 2. Although improved, these estimates are still considered low and may affect the reliability of any results.

A series of five multiple regression analyses was deemed the most appropriate method of analysis to measure the relationship between the four ways of coping and spirituality, spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician. The results of the multiple regression analyses will be examined through exploring each of the research questions. It should be noted that although the bivariate correlations between optimistic acceptance and two other ways of coping (i.e., distraction and avoidance) appeared to indicate moderate levels of multicollinearity (appendix C, table 2), which could impact the interpretation of the multiple regression results, the variance inflation factors (VIFs) were all less than 3, indicating that multicollinearity did not affect the results. According to Pedhazur (1997), the VIF represents a measure of the inflation of variance of the regression coefficient (b) due to correlation between the independent variables. Perfectly uncorrelated variables produce a VIF of 1.0, with the general rule of thumb indicating further investigation of VIFs over 4.0.

Research Question 1

What is the relationship between spirituality and ways of coping for individuals with CF, as measured by the Spiritual Involvement and Beliefs Scale-Revised (SIBS-R) and the Ways of Coping with CF (WCCF) scale?

The hypothesis, that there would be a correlation between spirituality and ways of coping, was supported. The regression equation was significant with optimistic acceptance and hopefulness coping predicting spirituality, F(4, 50) = 10.50, p < .001, $R^2 = .46$, Adjusted $R^2 = .41$ (appendix C, table 3). The equation accounted for 41% of the variance. Optimistic acceptance coping, $\beta = .39$, b = .11, emerged as a significant positive predictor of spirituality, meaning that higher scores of optimistic acceptance predicted higher spirituality. Hopefulness coping, $\beta = .36$, b = 2.76, emerged as a significant positive predictor of spirituality, meaning that higher scores of hopefulness predicted higher spirituality. There was no significant correlation discovered between spirituality and the other two ways of coping (i.e., distraction and avoidance).

Research Question 2

What is the relationship between participant self-reported spiritual/religious affiliation status and ways of coping for individuals with CF, as measured by the Demographic Information Sheet and the WCCF scale?

The hypothesis, that there would be a correlation between participant self-reported spiritual/religious affiliation status and ways of coping was also supported. The regression equation was significant with hopefulness and avoidance coping predicting spiritual/religious affiliation status, F(4, 50) = 8.55, p < .001, $R^2 = .41$, Adjusted $R^2 = .36$ (appendix C, table 3). The equation accounted for 36% of the variance. Hopefulness coping, $\beta = -.51$, b, -.09, emerged as a significant predictor of self-reported spiritual/religious affiliation status, meaning that the higher scores of hopefulness predicted identifying with a spiritual/religious affiliation. Avoidance coping, $\beta = -.39$, b = -.11, emerged as a significant predictor of self-reported spiritual/religious affiliation status, meaning that higher scores of avoidance predicted identifying with a spiritual/religious affiliation. There were no significant correlations discovered between

spiritual/religious affiliation status and the other two ways of coping (i.e., optimistic acceptance and distraction).

Research Question 3

What is the relationship between participant self-reported disease severity and ways of coping for individuals with CF, as measured by the WCCF scale?

The data failed to support the hypothesis that there would be a relationship between participant self-reported disease severity and ways of coping. The regression equation, F(4, 50) = 2.23, p = .08, $R^2 = .15$, Adjusted $R^2 = .08$ was not significant (appendix C, table 3). The equation accounted for 8% of the variance.

Research Question 4

What is the relationship between participant self-reported lung transplant list status and ways of coping for individuals with CF, as measured by the WCCF scale?

The hypothesis, that there would be a correlation between participant self-reported lung transplant list and ways of coping was supported. The regression equation was significant with optimistic acceptance coping predicting self-reported lung transplant list status, F(4, 50) = 3.08, p = .02, $R^2 = .20$, Adjusted $R^2 = .13$ (appendix C, table 3). The equation accounted for 13% of the variance. Optimistic acceptance coping, $\beta = -.39$, b = -.06, emerged as a significant positive predictor of transplant list status, meaning that higher scores of optimistic acceptance coping predicted longer time periods of being on a transplant list. There were no significant correlation discovered between transplant list status and the other three ways of coping (i.e., hopefulness, distraction, and avoidance).

Research Question 5

What is the relationship between participant self-reported frequency of discussing spiritual issues with one's CF physician and ways of coping for individuals with CF, as measured by the WCCF scale?

reported frequency of discussing spiritual issues with one's CF physician and ways of coping was supported. The regression equation was significant, with hopefulness and avoidance coping predicting frequency of discussing spiritual issues with one's CF physician, F(4, 50) = 7.20, p < .001, $R^2 = .37$, Adjusted $R^2 = .32$ (appendix C, table 3). The equation accounts for 32% of the variance. Hopefulness coping, $\beta = -.40$, b = -.21, emerged as a significant positive predictor, meaning that higher hopefulness scores predicted a higher frequency of discussing spiritual issues with one's physician. Avoidance coping, $\beta = .36$, b = .24, also emerged as a positive predictor, meaning that higher avoidance scores predicted a higher frequency of discussing spiritual issues with one's CF physician. There were no significant correlations discovered between participant self-reported frequency of discussing spiritual issues with one's CF physician and the other two ways of coping (i.e., optimistic acceptance and distraction.)

The hypothesis, that there would be a relationship between participant self-

Summary

The purpose of this study was to explore the relationship between spirituality and four ways of coping as well as the relationship between demographic factors and four ways of coping. A total of 100 survey packets were given to two Midwestern CF clinics to be distributed to adults with CF. There was a net return rate of 56%, and 55 (N = 55) packets were utilized after removing incomplete surveys. The Spiritual Involvement and Beliefs Scale-Revised (SIBS-R) and the Ways of Coping with CF (WCCF) scale was first evaluated for reliability and internal consistency. The SIBS-R was determined to be satisfactory after deleting three items. There were two items deleted from the WCCF scale. A series of five multiple regressions was then conducted to answer each of the research questions. Optimistic acceptance and hopefulness coping emerged as significant positive predictors of spirituality. Hopefulness and avoidance coping were significant

positive predictors of spiritual/religious affiliation status. Optimistic acceptance coping was a significant positive predictor of lung transplant list status. Hopefulness and avoidance coping emerged as positive predictors of frequency of discussing spiritual issues with one's CF physician. These results will be discussed further in the following chapter.

CHAPTER V

Discussion & Conclusion

Discussion

The major goals of this study were to: (a) explore the relationship between spirituality and four ways of coping and (b) explore the relationship between the four ways of coping and specific demographic factors. This section will discuss the importance and implications of the findings and will present them as they pertain to Research, Education and Training, and Clinical Practice. In addition, the limitations of the current study and recommendations for future research will be discussed.

The results of this study provide support for the literature that suggests spirituality is important in the lives of adults with cystic fibrosis (CF). Spirituality appears to be especially related to optimistic and hopefulness coping with this population, where the more optimistic and hopeful one feels, the more spiritual he or she is also likely to feel. It also appears that if an adult with CF is affiliated with a spiritual/religious affiliation, he or she is more likely to have either a hopeful or avoidant way of coping. Another interesting finding is that the longer one remains on a lung transplant list, the more likely he or she is to have an optimistic acceptance way of coping. Additionally, the more frequent an adult with CF speaks with his or her physician regarding spiritual/religious issues, the more likely he or she is to have either a hopeful or avoidant way of coping.

Research

This study explored a number of articles from the literature related to spirituality and coping. These articles presented information to support the importance of spirituality in people's lives and ways of coping. Spirituality is believed by many to be an "underlying dimension of the conscious in which an individual strives for meaning and union with the universe and all things" (Rowe & Allen, 2004, p. 62). While it is often identified in the literature as an important factor in maintaining health and well-being and in coping with chronic illness, there have been few empirical studies (Ellis, M.R. et al., 2002; Fehring, et al., 1997; Herbert et al., 2001; Orozco, 2004; Yangarber-Hicks, 2004). The results of this study support the position that spirituality is an important part of the lives of adults with cystic fibrosis, particularly those who have an optimistic or hopeful way of coping. It was also discovered that a higher frequency of being affiliated with a spiritual/religious denomination was related to higher hopefulness and higher avoidance coping. It is unclear why a more positive way of coping such as hopefulness and a more negative way of coping such as avoidance was related to this variable. It may be that another variable is intervening and impacting results. For example, the intervening variable could be the belief system of the particular spiritual/religious denomination. A person who identifies with a denomination that promotes actively talking with others and engaging in positive activities when having problems and a person who identifies with a denomination that promotes keeping problems to oneself follow different belief systems, which could impact the way each person copes. Although previous literature has examined the way people from one or two particular denominations cope, there have rarely been studies that include a wide range of denominations, which could perhaps be very informative. The findings of the current study add to the much lacking body of

research regarding spirituality, coping, and chronic illness, and they indicate the need for further research.

Education and Training

The results also lead to implications for the education and training of practitioners in the psychology and counseling fields as well as the medical field. Understanding the way in which spirituality relates to coping could support physicians as well as psychologists in helping patients identify and measure their own ways of coping, which could enhance treatment adherence and quality of life. For example, given the findings that higher levels of spirituality and a higher frequency of discussing spiritual issues with one's physician were related to higher hopefulness coping, a physician or psychologist may choose to initiate the exploration of patients' coping abilities whether the patients' discuss spiritual issues during appointments or not. It is unclear whether hopefulness leads one to feel more spiritual and to speak more frequently with one's physician regarding spiritual issues or if being more spiritual and talking more frequently to a physician about spirituality leads to higher hopefulness. Similarly, higher avoidance scores were related to a higher frequency of discussing spiritual issues with one's physician, and the cause and effect relationship is unknown. Additional research could help to further investigate these relationships and possibly provide a greater understanding of why both a seemingly positive and negative way of coping were related to frequency of speaking with one's physician regarding spiritual issues. Gaining knowledge regarding spirituality and coping from research, such as the current study, during the education and training process would allow professionals to have a greater appreciation and understanding for the way spirituality and coping impact people's emotional and physical health.

Clinical Practice

While the relationship between spirituality and coping in adults with cystic fibrosis (CF) is not yet fully understood, enough support has been provided in the literature and through the results of this study to warrant the attention of clinicians working with this population. A greater knowledge and understanding of the importance of spirituality and coping could be useful in assisting adults with CF to positively deal with stressors in their lives. Addressing spirituality in routine mental health intake assessments as well as in the medical health care process could be very valuable. The emerging research and literature in support for addressing the importance of spirituality in the lives of adults with CF suggests that this is a significant issue that should not be ignored when working with adults with CF in any clinical or health care setting.

In the current study, a higher frequency of speaking with one's physician regarding spiritual issues was correlated with higher levels of hopefulness and higher levels of avoidance. As with spiritual/religious affiliation status, there could be an intervening variable impacting results. As in the previous example, the intervening variable could be one's belief system. A person's whose belief system actively promotes speaking to others regarding spirituality may be very comfortable talking to his or her physician about spiritual issues, and the more he or she engages in spiritual discussions with his or her physician, the more hopeful he or she may feel. However, a person whose belief system promotes keeping problems to oneself may not feel comfortable talking to his or her physician about spiritual issues, and the more frequent he or she engages in spiritual discussions with his or her physician, the more avoidant he or she may feel. Understanding this could be useful to professionals who work with this population so that they may look for other signs (i.e., non-verbal body language, demeanor, activity level, etc.) that could indicate one's comfort level. Additional research could further explore

possible intervening variables and provide additional support for the importance of professionals gaining a more enriched understanding of the connection between spirituality and coping. Further research could also explore whether if one's ability to cope is impacted by physicians initiating spiritual discussions versus patients initiating the discussion.

While important to be respectful and mindful of patient's individual belief system, it could be helpful for clinicians and physicians to routinely educate patients regarding findings such as those found in this study. Clinicians and physicians could approach the subject without being offensive and while keeping in mind that not all individuals will be comfortable with the topic. Due to the many stressors involved in the lives of those with CF, it is important for clinicians and physicians to attend to the factors, such as spirituality, that relate to coping styles and behaviors.

Another finding in the current study that could impact clinical practice was that higher optimistic acceptance coping scores were related to a longer duration of being on a lung transplant list. This could indicate that those who choose to be placed on a transplant list to begin with have a more positive outlook on life and more positive way of coping. However, it could also indicate that the longer one remains on a lung transplant list, the more positive his or her way of coping becomes. In clinical practice, a deeper understanding of this process (i.e., through additional research) would be valuable in assisting those on a transplant list deal with their stressors.

Limitations

Several limitations exist in this study. First, despite rigorous effort to obtain participants, the sample (N = 55) was small, which could impact the reliability of the results. Due to the low sample size, factor analysis could not be conducted on the measures used in this study. Factor analysis could have been useful to improve the

psychometric properties of the measures. In particular, it would have been useful to utilize factor analysis with the Ways of Coping with CF (WCCF) scale, whose internal consistency estimates were lower than anticipated. Even after reliability analysis, where two items were dropped from the scale, internal consistency estimates were low and could have impacted the reliability of the results. Thus, results should be considered tentative. Second, the sample consisted of participants from only two clinics in the same general area of the Midwest, which could also lead to questioning the generalizability of the results. Third, the sample included adults with CF who attend their local CF clinic. These individuals may not be representative of the general adult population of CF patients, which includes those who attend private physician offices rather than their local CF clinic. Also not included are those individuals who were hospitalized during the time the survey was available. Fourth, the participants were at different levels of disease severity and most likely varying levels of treatment, which could have influenced the results. While exploring disease severity's relationship to spirituality and coping was an important research question during this study, differing levels of severity and treatment may have influenced participants' moods and, subsequently, the way they respond to the instruments. A final limitation pertains to the nature of survey data, as participant response was based on self-report. Thus, results reflect the perceptions of the individual with CF with no substantiating reports of spirituality or ways of coping.

Conclusions

A major reason for initiating this study was to explore the possible efficacy of spirituality in coping for this population. After reviewing previous research that suggests a relationship between spirituality and coping, it seems as if spirituality could be a powerful tool in assisting adults with CF cope with their disease. It is encouraging that

the results of the current study also discovered a statistical connection. However, due to the limitations of this study, it is apparent that additional research is needed.

The current study began with internal consistency analyses of the SIBS-R and WCCF scale. Although some deletion of the survey items was necessary, improved alpha indexes were attained. A series of five multiple regressions were then conducted to answer each of the research questions. Optimistic acceptance and hopefulness coping emerged as significant positive predictors of spirituality. Hopefulness and avoidance coping were significant positive predictors of spiritual/religious affiliation status.

Optimistic acceptance coping was a significant positive predictor of lung transplant list status. Hopefulness and avoidance coping emerged as positive predictors of frequency of discussing spiritual issues with one's CF physician. While not all hypotheses were supported, the results were encouraging.

Recommendations

As a result of the heartening results, it is this researcher's hope that future studies will be initiated. In future studies, it is recommended that a larger sample be utilized. If a larger sample size is attained, it is recommended that factor analysis be conducted on the measures in order to further explore internal consistency. Additionally, including participants from varying regions of the United States as well as from varying countries would help strengthen the reliability of any results. Also, exploring spirituality and coping for children as well as adults could assist in even richer and more thorough results. Similarly, focusing on gender similarities and differences could also enhance results. Employing a sample that has a greater range of disease severity may also help to gain a greater awareness of how one's stage of disease is related to his or her way of coping and spirituality. Also, it is recommended that future studies not only replicate this

study but also utilize other instruments that define spirituality and coping differently to determine if the findings are similar.

Summary

The physical impact of cystic fibrosis (CF) has been thoroughly examined in the research literature. However, the psychological and social factors have received substantially less attention. Consequently, research such as the current study is needed in order to gain valuable information into the lives of adults with CF. This information is significant in helping individuals with CF cope with their disease as well as the daily stressors in their lives. Additionally, having a greater understanding of the connection between spirituality and coping may help to provide physicians and psychologists with the knowledge needed to assist individuals and families who are impacted by this disease in dealing more effectively with the stressors in their lives.

The outcomes of the current study show evidence of an important connection between spirituality and coping. Although there may be debate as to whether or not it is possible to study a variable such as spirituality, the current study provides support for additional studies. Ongoing research in this area is strongly encouraged, as understanding spirituality as it relates to the coping of individuals with CF may help to improve the quality of life of this population.

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APPENDIX A: Flyer

RESEARCH OPPORTUNITY

An opportunity to participate in research regarding the ways in which people with Cystic Fibrosis cope is now available. Participation should take no longer than 20 minutes.

If you are at least 18 years of age and interested in this opportunity, please contact your CF Clinic Coordinator/Director to obtain a research/survey packet.

APPENDIX B: Letter/Informed Consent

Dear Patient:

You are invited to participate in a study exploring how people cope with cystic fibrosis (CF). Participation in this study involves the completion of three questionnaires, which should take no loner than 20 minutes.

Possible benefits of participating in this study include an increased awareness of your experiences with CF. This survey contains potentially sensitive information regarding your experiences. However, because this survey is strictly anonymous, there are no foreseeable risks to you or any third party. The information from the study will assist in strengthening our understanding of coping with CF.

All information collected in this study is strictly confidential. No individuals will be identified. Surveys will be tracked by numbers only, and no identifying information will be collected.

Participation in this study is completely voluntary. Your consent to participate in this research will be implied by your return of the completed survey packet in the enclosed postage-paid envelope. There is no penalty for not participating.

Your participation in this study is greatly appreciated. If you have any questions concerning this study, please feel free to call Janna Westmoreland-Morgan, M.S., at 918-594-8568 or Teresa Bear, Ph.D. at 918-594-8516. You may also verify that this study has been approved by the Institutional Review Board (IRB) at Oklahoma State University by calling the IRB Compliance Office at 405-744-1676.

Sincerely,

Janna Westmoreland-Morgan, M.S. Oklahoma State University 2419 Main Hall Tulsa, OK 74106 jcherie15@aol.com 918-594-8568 Teresa M. Bear, Ph.D.
Asst. Professor
Oklahoma State University
2415 Main Hall
Tulsa, OK 74106
beart@okstate.edu
918-594-8516

APPENDIX C: Tables

Table 1

Demographic Characteristics of Participants

	Frequency	Percent
Gender	•	
Male	22	39.3
Female	34	60.7
Age*	11	10.6
18-21	11	19.6
22-25	14 15	25.0
25-28 28-31	10	26.8 17.9
32-37	6	10.7
$^*M = 25.8, SD = 4.9$		10.7
Age at Diagnosis**		
0-12 months	28	50.0
12-24 months	13	23.2
3-10 years	9	16.1
11-18 years	2	3.6
19-26 years	3	5.4
27-30 years	1	1.8
$^{**}M = 3.6, SD = 6.5$		
Ethnicity	51	01.1
Caucasian Native American	51 5	91.1 8.9
	<u> </u>	0.7
Marital Status Single/Never Married	34	60.7
Single/Never Married Married	11	19.6
Divorced	2	3.6
Separated	4	7.1
Remarried	1	1.8
With a partner	4	7.1
Number of Children		
0	49	87.5
1	5	8.9
2 Yearly Income	2	3.6
Less than \$10,000	7	12.5
\$10,000-\$20,000	6	10.7
\$20,000-\$30,000	19	33.9
\$30,000-\$40,000	14	25.0
\$40,000-\$50,000	5	8.9
Over \$50,0000	5	8.9
Identify with Faith		-0.5
Yes	44	78.6
No Spiritual/Policious Affiliation	12	21.4
Spiritual/Religious Affiliation None	10	17.9
Agnostic	2	3.6
Atheist	1	1.8
Catholic	8	14.3
Protestant	30	53.6
Other	5	8.9
Disease Severity	10	17.0
Mild Moderate	10	17.9
Moderate Severe	40 6	71.4 10.7
Transplant Status		10.7
Not Listed	46	82.1
Considering Being Listed	9	16.1
Listed Less than 6 Months	1	1.8
Discuss Spiritual/Religious Issues with CF		
doctor		
Always	1	1.8
Usually	2	3.6
Sometimes	18	32.1
Rarely	17	30.4
Never	18	32.1

Table 2

Correlation Matrix: Relatedness of Variables

	1	2	3	4	5	6 7	8 9***
Ways of Coping with CF							
1. Optimistic Acceptance	1	02	55**	50	.21	.1732*	41**12
2. Hopefulness		1	.16	.13	.61**	51** .22	.1851**
3. Distraction			1	05	09	.1011	2114
4. Avoidance				1	05	38** .23	.24 .26*
SIBS 5. Overall Score					1	.52**02	0657**
<u>Demographics</u>							
6. Spiritual/Religious Affiliation Status						118	2338**
7. Disease Severity						1	.44** .02
8. Lung Transplant List Status							103
9. Discussing Spirituality with Physician							1

p < .05. **p < .01. *** During analyses scores were reverse coded; thus lower scores on table indicate higher values

Table 3
Summary of Multiple Regression Analyses

	В	SE B	β	p (predictor)	VIF				
Research Question 1 Criterion: Spirituality, R^2 =	= .46, Adjusted	$R^2 = .41,$	p < .001						
Optimistic acceptance	2.76	1.15	.36*	.02*	2.13				
Hopefulness	5.89	.97	.65*	$.00^{*}$	1.05				
Distraction	-2.14	1.34	21	.12	1.65				
Avoidance	.49	1.96	.03	.80	1.49				
Research Question 2 Criterion: Spiritual/religious affiliation status, $R^2 = .41$, Adjusted $R^2 = .36$, $p < .001$									
Optimistic acceptance	03	.02	19	.24	2.13				
Hopefulness	09	.02	.51*	$.00^{*}$	1.05				
Distraction	.05	.03	.27	.06	1.65				
Avoidance	11	.04	39 [*]	.01*	1.49				
Research Question 3 Criterion: Disease severity	$R^2 = .15, Adj$	usted R ² =	: .08, p =	.08					
Optimistic acceptance	06	.04	31	.11	2.13				
Hopefulness	.04	.03	.20	.15	1.05				
Distraction	.01	.04	.03	.87	1.65				
Avoidance	.02	.06	.06	.73	1.49				
Research Question 4 Criterion: Transplant list st	tatus, $R^2 = .20$,	Adjusted	$R^2 = .13,$	p = .02					
Optimistic acceptance	06	.03	.38*	.05*	2.13				
Hopefulness	.03	.02	.17	.20	1.05				
Distraction	01	.03	03	.86	1.65				
Avoidance	.01	.05	.02	.89	1.49				
Research Question 5 Criterion: Frequency of discussing spiritual issues with physician, $R^2 = .37$, Adjusted $R^2 = .32$, $p < .001$									
Optimistic acceptance	.02	.05	.06	.72	2.13				
Hopefulness	21	.05	54 [*]	$.00^*$	1.05				
Distraction	03	.06	07	.63	1.65				
Avoidance	.24	.09	.36*	.01*	1.49				

APPENDIX D: Instruments

Demographic Information Sheet

Please check the response that best fits you:

What is your gender?	
a. Maleb. Female	
What is your current age?	
At what age were you diagnosed with Cystic Fibrosis?	
What is your ethnicity/nationality	
a. African Americand. Caucasian/White	
b. American Indian/Native Americane. Hispanic/Latino/Latina	
c. Asian/Asian Americanf. Other:	
What is the highest level of education you have completed?	
What is your total yearly household income?	
a. Less than \$10,000d. \$30,000 - \$40,000	
b. \$10,000 - \$20,000e. \$40,000 - \$50,000	
c. \$20,000 - \$30,000f. Over \$50,000	
What is your current marital status?	
a. Single/Never Marriede. Separated	
b. Marriedf. Remarried	
c. Widowedg. With a partner	
d. Divorced	
Do you have children?	
a. Yes (If Yes, How Many?)	
b. No	
Do you currently identify with a particular spiritual/religious faith?	
a. Yes	
b. No	
"Yes," please indicate your spiritual/religious affiliation.	
a. Agnosticf. Islamic	
b. Atheist g. Jewish	
c. Buddhist h. Protestant	
d. Catholic h. Other (Please Specify)
e. Hindu	
). How would you describe your current disease status?	
a. Mild (few symptoms resulting in visiting my CF doctor only for typical check	_
The symptoms resulting in the doctor only for typical check	

ups)	
b. Moderate (occasional symptoms, re	esulting in an increase in doctor's visits and
occasional hospital stays	s)
c. Severe (frequent symptoms, resulting	ng in frequent doctor's visits and hospital
stays)	
11. Please indicate your lung transplant state	us.
a. Not listed/Never been listed	d. Have been listed for 6-12
	months
b. Considering being listed	e. Have been listed for over 1 year
c. Have been listed for less than 6 mo	nthsf. Have already received a lung
	transplant
	(If so, how long has it been since
	you received the transplant?)
12. Please indicate how often you discuss is	sues related to your spirituality/religion
during your appointments with your primary	• • • •
a. Alwaysd. Rarely	,
b. Usually e. Never	
c. Sometimes	

Ways of coping with CF

People cope with CF in many different ways. Below is a list of ways (strategies) in which CF adults say they act, think or feel to help them deal with CF. For each strategy please check the box that best describes how much you act, think or feel this way (not at all, a little, a moderate amount, a great deal).

	Coping strategies	Not at all	A little	A moderate amount	A great deal
1	I talk to others with CF				
2	I feel optimistic				
3	I do something to take my mind off it				
4	I am looking forward to a time in the future when it will be better				
5	I feel helpless there is nothing I can do				
6	I talk to my family and friends				
7	I pray				
8	I try to put it out of my mind				
9	I accept it				
10	I cry, eat, drink or take drugs				
11	I talk to a professional who knows about CF				
12	I do what I can under the circumstances				
13	I try to look at it differently – to see the positive or funny side of life				
14	I avoid it wherever possible				
15	I put it into perspective – it could be worse				
16	I'm just hoping it will be all right				
17	I have confidence in the doctors and treatment				

18	I make sacrifices in the short-term because I know it will do me good		
19	I treat myself to something special		
20	I try to do something positive		

Abbott, et al. 2001

Items on subscales after item/reliability analysis:

Optimistic Acceptance: 2, 9, 12, 13, 15, 17, 20

Hopefulness: 1, 4, 6, 7

Distraction: 3, 5 (reverse coded), 10, 18, 19

Avoidance: 8, 14

Spiritual Involvement and Beliefs Scale – Revised (SIBS-R) (Hatch RL, Spring H, Ritz L, Burg MA, University of Florida)

How strongly do you agree with the following statements? Please circle your response.

		Strongly Mildly			Mildly		Strongly	
		Agree	Agree	Agree	Neutral	Disagree	Disagree	Disagree
1.	I set aside time for meditation and/or self-reflection	7	6	5	4	3	2	1
2.	I can find meaning in times of hardship.	7	6	5	4	3	2	1
3.	A person can be fulfilled without pursuing an active spiritual life.	7	6	5	4	3	2	1
4.	I find serenity by accepting things as they are.	7	6	5	4	3	2	1
5.	I have a relationship with someone I can turn to for spiritual guidance.	7	6	5	4	3	2	1
6.	Prayers do not really change what happens.	7	6	5	4	3	2	1
7.	In times of despair, I can find little reason to hope.	7	6	5	4	3	2	1
8.	I have a personal relationship with a power greater than myself.	7	6	5	4	3	2	1
9.	I have had a spiritual experience that greatly changed my life.	7	6	5	4	3	2	1
10.	When I help others, I expect nothing in	7	6	5	4	3	2	1

	return.							
11.	I don't take time to appreciate nature.	7	6	5	4	3	2	1
12.	I have joy in my life because of my spirituality.	7	6	5	4	3	2	1
13.	My relationship with a higher power helps me love others more completely.	7	6	5	4	3	2	1
14.	Spiritual writings enrich my life.	7	6	5	4	3	2	1
15.	I have experienced healing after prayer.	7	6	5	4	3	2	1
16.	My spiritual understanding continues to grow.	7	6	5	4	3	2	1
17.	I focus on what needs to be changed in me, not on what needs to be changed in others.	7	6	5	4	3	2	1
18.	In difficult times, I am still grateful.	7	6	5	4	3	2	1
19.	I have been through a time of suffering that led to spiritual growth.	7	6	5	4	3	2	1
20.	I solve my problems without using spiritual resources.	7	6	5	4	3	2	1
21.	I examine my actions to see if they reflect my values.	7	6	5	4	3	2	1

22. How spiritual a person do you consider yourself? (with "7" being the most spiritual)

7 6 5 4 3 2 1

APPENDIX E: IRB Approval Form

Oklahoma State University Institutional Review Board

Tuesday, May 02, 2006 Date:

IRB Application No ED06128

Spirituality and Ways of Coping with Cystic Fibrosis Proposal Title:

Reviewed and

Exempt

Processed as:

Status Recommended by Reviewer(s): Approved Protocol Expires: 5/1/2007

Principal Investigator(s

Janna Westmoreland-Morgan

John Romans 422 Willard

Rt. 1 Box 41

Stillwater, OK 74078

Boynton, OK 74422

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45

▼ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

- 1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.

 2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.

 3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and

 4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely.

Sue C. Jacobs, Chair Institutional Review Board

VITA

Janna Westmoreland Morgan

Candidate for the Degree of

Doctor of Philosophy

Thesis: SPIRITUALITY AND WAYS OF COPING WITH CYSTIC FIBROSIS

Major Field: Educational Psychology; Specialization area: Counseling Psychology

Biographical:

Education:

Received Bachelor of Arts degree in Psychology from University of Tulsa, Tulsa, Oklahoma in 1998, and completed the requirements for the Master of Science with a major in Counseling and Student Personnel with a specialization in Community Counseling at Oklahoma State University, Stillwater, Oklahoma, 2002. Completed the requirements for the Doctor of Philosophy at Oklahoma State University in December, 2007.

Experience:

2006-present, Therapist, CREOKS Behavioral Health Services, Tulsa, Oklahoma; 2005-2006, Psychology Intern, Oklahoma Health Consortium (APA Accredited), Norman, Oklahoma; 2004-2005, 2003-2005, Doctoral Practicum, Dick Conner Correctional Center, Hominy, Oklahoma and YWCA/Resonance Female Offenders Committed to Ultimate Success (FOCUS) program, Tulsa, Oklahoma; Assistant clinic Director, Counseling Psychology Clinic, Oklahoma State University, Tulsa, Oklahoma; 2002-2005, Teaching Assistant, 2002-2005, Oklahoma State University, Tulsa, Oklahoma; 2002-2003, Doctoral Practicum, Green Country Behavioral Health Services, Inc., Muskogee, Oklahoma; 2001-2002, Master's Practicum, Green Country Behavioral Health Services, Inc., Muskogee, Oklahoma.

Professional Memberships:

American Psychological Association (APA), Graduate Student Affiliate

Name: Janna Westmoreland Morgan Date of Degree: December, 2007

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: SPIRITUALITY AND WAYS OF COPING WITH CYSTIC FIBROSIS

Pages in Study: 79 Candidate for the Degree of Doctor of Philosophy

Major Field: Educational Psychology with an emphasis in Counseling Psychology

Scope and Method of Study: The daily lives of adults with chronic illnesses such as cystic fibrosis (CF) are influenced by psychosocial as well as physical factors. CF is a genetic, multi-system disease characterized by chronic airway obstruction, subsequent infection of the bronchial airways, and maldigestion because of pancreatic dysfunction (Anderson, 2001). With no cure at present, the current median age of survival is 35.5 years (Kepron, 2003). The primary purpose of this study was to examine the relationship between spirituality and four ways of coping (optimistic acceptance, hopefulness, distraction, and avoidance) as measured by the Spiritual Involvement and Beliefs Scale-Revised (Hatch, Burg, Naberhaus, & Hellmich, 2001) and the Ways of Coping with Cystic Fibrosis (Abbott, Dodd, Gee, & Webb, 2001) scale. In addition, the following demographic factors were examined to gain a further understanding of the nature of their relationship with coping: spiritual/religious affiliation status, disease severity, lung transplant list status, and frequency of discussing spiritual issues with one's CF physician. A multiple regression analysis strategy was utilized to gain insight into the way spirituality and the above cited demographic factors are related to the four ways of coping.

Findings and Conclusions: A total of 100 surveys were given to two Midwestern CF clinics to be distributed to adults with CF. There was a survey return rate of 56%. The SIBS-R and the Ways of Coping with CF scale was first examined for reliability and internal consistency, resulting in three items being deleted from the SIBS-R and two items being deleted from the WCCF scale due to low item to scale correlations. Multiple regression analysis was then conducted to answer each of the research questions. Optimistic acceptance and hopefulness coping emerged as significant positive predictors of spirituality. Hopefulness and avoidance coping were significant positive predictors of spiritual/religious affiliation status. Optimistic acceptance coping was a significant positive predictor of lung transplant list status. Hopefulness and avoidance coping emerged as positive predictors of frequency of discussing spiritual issues with one's CF physician.