COPING AND MENTAL HEALTH AMONG PATIENTS WITH END-STAGE PULMONARY DISEASE AND PRIMARY CAREGIVERS

DISSERTATION

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By

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Lung transplant candidates frequently experience functional limitations leading them to depend on caregivers to assist in activities of daily living. However, few studies have examined psychological functioning and quality of life among caregivers of lung transplant candidates. A principal aim of the present study was to evaluate coping, particularly problem-focused, emotion-focused, humor, and religious/spiritual coping (RSC) styles, and mental health (e.g., psychological functioning, quality of life) among lung transplant candidates and their primary caregivers. In addition, numerous lung transplant candidates are placed “on hold” for remediable contraindications (e.g., tobacco use) until the contraindication has been resolved (e.g., discontinued tobacco use for 6 months). Although research suggests that patients placed “on hold” have worse survival outcomes than patients initially listed for transplant, there is only one study examining “on hold” and “listed” transplant candidates. Therefore, another primary aim of the current study was to examine differences in coping and mental health among “on hold” lung transplant candidates compared to “listed” lung transplant candidates. A third aim of the study included examining the association between coping with mental health among lung transplant candidates and primary caregivers. A longitudinal, single-cohort study design was employed with a 6-month follow-up. Results indicated that patients experienced greater psychological distress and poorer quality of life than primary
caregivers. “On hold” lung transplant candidates experienced greater anxiety than “listed” lung transplant candidates, but the “on hold” and “listed” lung transplant candidates reported similar impairments in quality of life. Also, emotion-focused coping strategies were associated with greater stress and depression among patients, and emotion-focused coping and humor were associated with lower emotional quality of life among primary caregivers. In addition, negative religious coping was associated with greater depression among patients, and was associated with greater perceived stress among caregivers. This study highlights that both nonreligious coping styles and RSC styles can be conceptualized as adaptive or maladaptive. In addition, the study demonstrates that particular coping styles (emotion-focused coping, humor, and negative religious coping) are associated with poorer mental health outcomes among patients and primary caregivers during the lung transplant process. Thus, interventions may need to be directed towards reducing maladaptive coping strategies prior to transplant in order to improve quality of life.
Dedicated to my parents and godmother, all of whom have been my foundation:

Faye D. Brown

Charles E. Green, Sr. (April 5, 1951 – February 15, 2007)

Sheilah M. Lee (March 30, 1957 – July 12, 2008)
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CHAPTER 1

INTRODUCTION

Coping is a mental process utilized to manage life demands that are considered difficult or that surpass an individual’s current mental, physical, or social resources (Taylor, 2003). When an individual encounters a situation that is interpreted as threatening or challenging, the process of coping helps reduce the stress and demands of the situation by allowing the individual to reinterpret the situation as more favorable and less threatening (Hockenbury & Hockenbury, 2003; Pargament, 1997; Lazarus & Folkman, 1984). Coping strategies have been broadly categorized into problem-focused coping and emotion-focused coping (Snyder & Dinoff, 1999; Folkman & Lazarus, 1980). Problem-focused coping refers to doing something to alter the stressful situation, and it is often used when an individual views the situation as changeable (Carver, Scheier, Weintraub, 1989; Folkman & Lazarus, 1985; Folkman & Lazarus, 1980). Problem-focused coping includes acceptance, planning, positive reframing, and instrumental support (Carver & Connor-Smith, 2010; Wolf & Mori, 2009; Perczek, Burke, Carver, Krongrad, & Terris, 2002; Carver et al., 1989). Emotion-focused coping refers to reducing the emotional distress associated with the stressful situation, and it is mainly used when the situation is appraised as unchangeable (Carver et al., 1989; Folkman & Lazarus, 1980; Folkman & Lazarus, 1985). Emotion-focused coping includes denial, behavioral disengagement, substance use, venting, self-blame, self-distraction,
and seeking emotional support (Carver et al., 2010, Wolf et al., 2009; Perczek et al., 2002; Carver et al., 1989). The implementation of coping styles may change over time in the context of a chronic stressor, as observed in prior studies of cardiac surgery patients and college students (Crumlish, 1994; Folkman & Lazarus, 1985). Crumlish (1994) found that cardiac surgery patients used less emotion-focused coping after surgery than prior to surgery. Folkman and Lazarus (1985) found that college students used less problem-focused coping before an exam than during the waiting stage after the exam prior to grades being announced. Given the multidimensional structure of coping that has been documented in prior studies, and the tendency for coping strategies to change over time, longitudinal study of differing dimensions of coping is relevant for understanding individuals with chronic lung disease.

Lung transplant candidates experience chronic stress due to managing a life-threatening disease and pursuing lung transplantation (Bright, Craven, & Kelly, 1990). In the context of their illness, patients often experience reduced physical functioning resulting in decreased daily activities, loss of employment, and financial stress (Burker, Evon, Sedway, & Egan, 2004a; Burker, Carels, Thompson, Rodgers, & Egan, 2000). Patients also experience stressors associated with the lung transplant process including the expense of the medical procedure and of life-long medications, seeking eligibility to be listed for transplant, limited availability of organs, waiting for surgery after being approved, and recovery from surgery (Bright et al., 1990; Burker et al., 2004a). Thus, lung transplant candidates must cope with numerous stressors over an extended period of time, making it critical to understand their use of coping styles and changes in their use of coping over time.
Research suggests that coping strategies are associated with psychological functioning and quality of life among lung transplant candidates (Burker, Evon, Sedway, & Egan, 2004a; Myaskovsky, Dew, Switzer, Hall, Kormos, Goycoolea, DiMartini, Manzetti, & McCurry, 2003). Problem-focused coping is positively associated with psychological well-being and satisfaction with family life, whereas, emotion-focused coping is associated with overall disability, depression, anxiety, and poor quality of life (Myaskovsky, Dew, Switzer, McNulty, DiMartini, & McCurry, 2005; Burker et al., 2004a; Myaskovsky et al., 2003; Stilley, Miller, Manzetti, Marino, & Keenan, 1999a). Another aspect of coping associated with mental health includes religious and spiritual coping (RSC), particularly positive religious coping and negative religious coping. Positive religious coping refers to a sense of spirituality and spiritual connectedness to others, a secure relationship with God, and meaning in life (Pargament, Smith, Koenig, & Perez, 1998). Negative religious coping refers to a less secure relationship with God, a religious struggle, and a negative view of the world (Pargament et al., 1998). Positive religious coping is associated with better mental health, whereas, negative religious coping is associated with emotional distress (Pargament, Smith, Koenig, & Perez, 1998). Despite the growing interest and research literature on RSC and mental health, RSC has been scarcely studied among lung transplant candidates. In addition, caregivers of lung transplant patients are of particular interest because eligibility for lung transplant surgery is dependent on identifying a caregiver. In turn, caregivers experience many of the same stresses experienced by patients and may utilize a number of coping styles to deal with their stress (Myaskovsky et al., 2003; White & Grenyer, 1999).
The present study was designed to evaluate coping styles (e.g., problem-focused, emotion-focused, humor, and RSC), psychological functioning, and quality of life among lung transplant candidates compared to primary caregivers. An additional principal aim of the study was to examine coping styles, psychological functioning, and quality of life among “on hold” lung transplant candidates versus “listed” lung transplant candidates. “On hold” lung transplant candidates include all patients with end-stage pulmonary disease who are referred for lung transplantation but are placed “on hold” due to remediable contraindications. “Listed” lung transplant candidates include all patients with end-stage pulmonary disease who are referred for lung transplantation and are initially listed for transplant. Primary caregiver refers to the individual who provides the most assistance to the patient through the transplantation process. Thus, the caregiver can be a spouse, parent, sibling, child, other family member, friend, or romantic partner.

Outcomes of Lung Transplantation

Lung transplantation is a surgical procedure in which diseased lungs are replaced with healthier lungs from a deceased donor. Lung transplantation is the only treatment option for patients with end-stage pulmonary disease because there are no other medical or surgical options available for treating these patients (Baumgartner, Reitz, Kasper, Theodore, 2002; American Thoracic Society (ATS), 1998; TenVergert, Essink-Bot, Geertsma, van Enckevort, de Boer, & van der Bij, 1998). The survival rate following lung transplantation is greater than fifty percent, and transplantation often improves physical functioning, mental health, and quality of life (Trulock, Edwards, Taylor, Boucek, Keck, & Hertz, 2004; Rodrigue, Baz, Kanasky, & MacNaughton, 2005). However, lung transplantation is associated with worse outcomes (e.g., mortality) than
other solid organ transplantations, and research suggests that psychological adjustment (e.g., anxiety, depression) and quality of life prior to transplantation affects adjustment, survival, and quality of life after transplantation (Studer, Levy, McNeil, & Orens, 2004; Maurer, 2003; Limbos, Joyce, Chan, & Kesten, 2000; Cohen, Littlefield, Kelly, Maurer, & Abbey, 1998; Squier, Ries, Kaplan, Prewitt, Smith, Kriett, & Jamieson, 1995). Lung transplantation is commonly used among end-stage patients with any of the following conditions: chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis, cystic fibrosis, and alpha-1-antitrypsin deficiency emphysema (Trulock et al., 2004). The majority of lung transplant patients are diagnosed with COPD (Christie, Edwards, Aurora, Dobbels, Kirk, Rahmel et al., 2008).

Since the first human lung transplantation in 1963 at the University of Mississippi, more than 26,000 lung transplantations have been completed worldwide (Christie et al., 2008; Trulock et al., 2004). The number of lung transplantations performed has doubled in the past decade (Christie et al., 2008; Trulock et al., 2004; Hosenpud et al., 2000). The success of adult lung transplantations has improved in recent years and the one–year actuarial survival is 78% for total lung transplantations (Christie et al., 2008). Lung transplantation often improves physical functioning, mental health, and quality of life (Trulock, Edwards, Taylor, Boucek, Keck, & Hertz, 2004; Rodrigue, Baz, Kanasky, & MacNaughton, 2005). However, lung transplantation is associated with worse outcomes (e.g., mortality) than other solid organ transplantations, and research suggests that psychological adjustment (e.g., anxiety, depression) and quality of life prior to transplantation affects adjustment, survival, and quality of life after transplantation (Studer, Levy, McNeil, & Orens, 2004; Maurer, 2003; Limbos, Joyce, Chan, & Kesten,
Lung transplantation is considered a viable option for patients with end-stage pulmonary disease not only because it extends life, but also because it improves physical functioning, psychological functioning, and quality of life. Research suggests that health-related quality of life improves within one year of lung transplantation, regardless of gender and race, in the areas of physical functioning, role functioning, social functioning, mental health, vitality, and health perceptions (Rodrigue et al., 2005; Stavem, Bjortuft, Lund, Kongshaug, Geiran, & Boe, 2000; Limbos, Chan, & Kesten, 1997; Gross, Savik, Bolman, & Hertz, 1995; Ramsey, Patrick, Lewis, Albert, & Raghu, 1995). In addition, disease severity, particularly forced expiratory volume in one second (FEV$_1$) percent predicted (measure of airflow limitation), has been shown to be positively associated with health-related quality of life (Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007; Ståhl, Lindberg, Jansson, Rönmark, Svensson, Andersson et al., 2005;Engström, Persson, Larsson, & Sullivan, 2001). Lung transplant recipients have a better quality of life than pulmonary patients not seeking transplantation, but poorer quality of life compared to healthy individuals (Smeritschnig, Jaksch, Kocher, Seebacher, Aigner, Mazhar, & Klepetko, 2005). Following successful lung transplantation surgery, lung transplant recipients report improvements in overall adjustment, lower levels of depression, higher self-esteem, fewer pulmonary and cardiac symptoms, greater happiness, and increased
health satisfaction (Rodrigue et al., 2005; Limbos et al., 2000; Cohen et al., 1998; Gross et al., 1995). Pulmonary function and exercise tolerance also improve after lung transplantation (Limbos et al., 2000; Meyers, Lynch, Trulock, Guthrie, Cooper, & Patterson, 1999).

End-Stage Pulmonary Disease

Although lung transplantation yields increased survival and improved mental health and quality of life, outcomes may differ according to pulmonary diagnosis. Patients with COPD have a better survival outcome after transplantation than patients with idiopathic pulmonary fibrosis and pulmonary hypertension, but lower quality of life during the waiting period compared to patients with other end-stage pulmonary diseases (Studer et al., 2004; Burker, Carels, Thompson, Rodgers, & Egan, 2000). Patients with COPD tend to live longer, have poor functional capacity, and have a slow disease progression, whereas idiopathic pulmonary fibrosis and pulmonary hypertension progress more rapidly and thus are associated with a shorter survival rate and higher priority for consideration of lung transplantation (Nathan, 2005; Maurer, 2003). Cystic fibrosis patients report better health-related quality of life, mental health, social support, and more effective coping strategies than patients with other end-stage pulmonary diseases (Smeritschnig et al., 2005; Burker et al., 2000; Squier et al., 1995). Better mental health and coping strategies among cystic fibrosis patients may be due to patients being younger and more accustomed to managing the disease from an early age (Smeritschnig et al., 2005; Burker et al., 2000). Type of end-stage pulmonary disease also predicts survival during the waiting period (de Meester, Smits, Persijn, & Haverich, 1999). Patients with idiopathic pulmonary fibrosis and sarcoidosis, a disease characterized by inflamed cells
that effects many bodily organs including the lungs, have a high probability of dying while waiting to be transplanted, but patients with COPD are more likely to survive (Nathan, 2005; Studer et al., 2004; Tanoue & Elias, 2004; ATS, 1999; de Meester et al., 1999). The high probability of idiopathic pulmonary fibrosis and sarcoidosis patients dying during the waiting period may be due to the progressive course and rate of survival after diagnosis with idiopathic pulmonary fibrosis, and among sarcoidosis patients the late consideration and referral for transplantation (Nathan, 2005; Maurer, 2003). It is important to view outcomes among lung transplant patients in the context of the pulmonary diagnosis (Nathan, 2005; de Meester et al., 1999). Therefore, the pulmonary diagnoses that most often lead to lung transplantation will be briefly reviewed, including COPD, alpha-1 antitrypsin emphysema, cystic fibrosis, idiopathic pulmonary fibrosis, and pulmonary hypertension (Trulock et al., 2004).

COPD refers to obstructive lung diseases, specifically chronic bronchitis and emphysema, that cause the bronchial airways to narrow, resulting in limited airflow (Barnes, 2003). Alpha-1 antitrypsin deficiency is a genetic form of emphysema that occurs when insufficient alpha-1 antitrypsin enzyme is released to protect the respiratory tract (Alpha-1 Foundation, 2003; Hutchinson, 2003). In the lungs, cystic fibrosis is characterized by chronic bacterial infections in the bronchial airways that occur when mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) cause defects in lung function (Boucher, 2002). Idiopathic pulmonary fibrosis is a progressive and irreversible form of chronic fibrosing interstitial pneumonia that is characterized by inflammation, fibrosis (scarring), and damage to the lungs (King, 2004; Selman, King, & Pardo, 2001; ATS, 2000). Pulmonary hypertension refers to an elevated pulmonary artery
pressure in the blood vessels of the lungs of greater than 25 mm Hg at rest or greater than 30 mm Hg during exercise (Rounds & Klinger, 2004; Ghamra & Dweik, 2003).

There are a number of similarities in the symptoms and risk factors for various pulmonary conditions. Shortness of breath is a common symptom present in all pulmonary conditions (Yankaskas, 2004; Rounds & Klinger, 2004; Hutchinson, 2003; Halpin, 2002; ATS, 2000). Patients with COPD and alpha-1 antitrypsin emphysema experience symptoms of coughing, wheezing, chest pain, and changes in weight (Halpin, 2002; Alpha-1 Foundation, 2003; Hutchinson, 2003). In addition to the symptoms of dyspnea and coughing that are common among COPD and alpha-1 antitrypsin emphysema patients, cystic fibrosis patients experience pancreatic insufficiency, high sweat chloride levels, and malnutrition (Yankaskas, 2004). Pulmonary hypertension patients report experiencing chest pain, lightheadedness, palpitations, and fatigue (Rounds & Klinger, 2004; Cheever, 2005).

Smoking is a common risk factor for all of the pulmonary conditions excluding cystic fibrosis and pulmonary hypertension (Halpin, 2002; Needham & Stockley, 2004; ATS, 2000). Genetic risk is also a factor that is shared among all of the conditions (Needham et al., 2004; Robles & Shure, 2004; Yankaskas, 2004; ATS, 2000). The common risk factors for both COPD and alpha-1 antitrypsin include age, environmental factors, and respiratory infections. Risk factors for COPD include alpha-1 antitrypsin deficiency, a history of asthma, and low socioeconomic status (Halpin, 2002; Prescott & Vestbo, 1998; Needham et al., 2004). Diet drugs, particularly aminorex fumarate and fenfluramine derivatives, are additional risk factors for pulmonary hypertension, and
infectious agents are risk factors for idiopathic pulmonary fibrosis (Robles & Shure, 2004; ATS, 2000).

There are also differences between the various pulmonary conditions, particularly age of onset, prevalence of the disease between genders, and course of the disease. Patients with COPD and idiopathic pulmonary fibrosis are often diagnosed after 50 years of age, whereas cystic fibrosis patients are often younger because the disease is generally diagnosed in childhood (Burker, Evon, Sedway, & Egan, 2004b; Gilljam, Ellis, Corey, Zielenski, Durie, & Tullis, 2004; ATS, 2000). Pulmonary hypertension also tends to be diagnosed among younger individuals, particularly adults between the ages of 30 and 40 (Rounds & Klinger, 2004; Rich, Dantzker, Ayres, Bergofsky, Brundage, Detre, et al., 1987). In addition, pulmonary hypertension occurs more frequently among women, whereas idiopathic pulmonary fibrosis is more common among men (Robles & Shure, 2004; ATS, 2000).

Treatment interventions are similar across various pulmonary conditions. Smoking cessation, drug therapy, pulmonary rehabilitation, oxygen therapy, and lung transplantation are treatment options for most pulmonary conditions (Sandhaus, 2004; Trulock et al., 2004; Gildea, Arroliga, & Minai, 2003; Harvard Medical School, 2003; ATS, 2000; Scanlon, Connett, Waller, Altose, Bailey, & Buist, 2000; Emery, Hauck, Schein, & MacIntryre, 1998). An additional treatment is lung volume reduction surgery (Sandhaus, 2004; Hutchinson, 2003; Geddes, Davies, Koyama, Hansell, Pastorino, Pepper et al., 2000). Lung volume reduction surgery consists of removing parts of the damaged lung, and it has been shown to enhance lung function and quality of life (Geddes et al., 2000).
The Lung Transplantation Process

Patients with end-stage pulmonary disease progress through several phases after being told that lung transplantation is the only option for survival and improved physical functioning, mental health, and quality of life. The lung transplantation process consists of five phases: making the decision to be transplanted, the evaluation, the waiting period, transplantation, and recovery (Smolin & Aguiar, 1996). Although the evaluation and waiting phases were the focus of this study, each phase of the lung transplantation process will be described briefly below.

Making the Decision

The first phase consists of the physician informing the patient with end-stage pulmonary disease that transplantation is the only option, followed by the patient deciding to be transplanted (Smolin & Aguiar, 1996). The physician suggests lung transplantation as an option when the patient experiences a continuous decline in function, medical therapy is unsuccessful, and estimated survival is less than one year. The patient must be 60 years of age or younger in order to receive a bilateral lung transplant and age 65 or younger to receive a single lung transplant (ATS, 1998). Prior to referral, patients are evaluated to ensure the presence of lung disease, absence of other major organ dysfunction, and to assess lung function, exercise performance, and functional capacity. Patients who experience the following contraindications are not referred for lung transplantation: human immunodeficiency virus (HIV), hepatitis B antigen positivity, hepatitis C with liver disease, active malignancy within the past two years, excluding basal cell and squamous cell carcinoma of skin, and dysfunctions in other major organs, particularly renal dysfunction (ATS, 1998). However, patients with
corrective contraindications are referred for lung transplantation. After a physician has recommended lung transplantation to a patient with end-stage pulmonary disease, the patient decides whether or not to undergo lung transplantation. If the patient decides to be transplanted, he/she progresses to the second phase of the lung transplantation process, the evaluation.

**Evaluation**

Prior to being added to the lung transplant list in a lung transplant program, a patient with end-stage pulmonary disease is evaluated by physicians, a psychiatrist or psychologist, and a social worker (Craven, Bright, & Dear, 1990). The lung transplant surgeon and medical staff examine the patient to ensure that he/she meets the medical criteria for lung transplantation, as described above. The psychiatrist/psychologist and social worker examine the patient from a psychosocial perspective (Smolin & Aguiar, 1996). The psychiatrist/psychologist conducts a semi-structured interview and the patient usually completes several psychometric measures (e.g., Beck Depression Inventory, Minnesota Multiphasic Personality Inventory-II) to assess the patient’s mental health and health behaviors (Singer, Ruchinskas, Riley, Broshek, & Barth, 2001; Craven et al., 1990). Based on the psychological evaluation, recommendations are made for managing any psychological distress or problematic health behaviors (Craven et al., 1990). Studies indicate that applicants may experience significant psychological distress at the time of assessment (Singer et al., 2001; Craven et al., 1990).

Social workers usually examine the patient’s living situation, family functioning, social support, financial state, insurance, transportation, compliance, feelings about transplantation, and the patient’s coping strategies to ensure that the patient can meet the
demands of the lung transplant process (Craven et al., 1990; Smolin & Aguiar, 1996). If the patient with end-stage pulmonary disease lacks the resources necessary to adhere to the preoperative and postoperative management of their health condition, then the patient may be declined for enrollment on the lung transplant list (Craven et al., 1990). The evaluation period usually lasts a few months and the decision is made shortly thereafter (Smolin & Aguiar, 1996). However, some patients must wait several months before a decision is made and others are unable to complete the evaluation process for a specified period of time because they are exhibiting a corrective contraindication to transplantation.

Numerous end-stage pulmonary disease patients are placed “on hold” before, during, or after the evaluation phase because they exhibit contraindications to transplantation that are remediable, but the contraindications are also concerning to the transplant staff. Patients are placed “on hold” for the following reasons: continued smoking, current or recent history of substance abuse/dependence, underweight (i.e., Body Mass Index (BMI) <17) or obese (i.e., BMI> 30), low functionality (i.e., inability to walk 600 feet in six-minute walk distance), and too functional (i.e., expected survival time of more than 2 years). Smoking is a common risk factor for pulmonary disease, and research suggests that it is associated with decreased lung functioning over time (ATS, 2000; Muers, 1999; Fletcher, Peto, Tinker, & Speizer, 1976). Research suggests that patients who are interested in solid organ transplantation and have a current or recent history of substance abuse are highly distressed, difficult to manage, and are at heightened health risk after transplantation if they relapse (Stilley, Miller, Gayowski, & Marino, 1999b; Stilley, Miller, & Tarter, 1997). Therefore, lung transplant centers require that end-stage pulmonary disease patients discontinue smoking, consuming alcohol, or
using recreational drugs for at least 6 months before they are eligible for transplant (ATS, 1998). Weight is also a concern at lung transplant centers. Research indicates that underweight and overweight lung transplant patients experience reduced survival before and after lung transplantation (Karnasky, Anton, Rodrigue, Perri, Szwed, & Baz, 2002; Madill, Gutierrez, Grossman, Allard, Chan, Hutcheon, Keshavjee, and the Toronto Lung Transplant Program, 2001; ATS, 1998). Patients who are underweight or obese must lose or gain weight until they have a BMI $\geq 17$ and $\leq 29$ before they can be eligible for transplantation. Poor functioning patients with end-stage pulmonary disease must enhance their functioning through pulmonary rehabilitation and be able to walk 600 feet in the six-minute walk distance test before they are eligible for transplantation. Lung transplantation is not an option for patients who are too functional (i.e., expected survival time greater than 2 years) until their disease progresses further (i.e., expected survival is 2 years or less).

Prior studies have not evaluated end-stage pulmonary disease patients who were not initially eligible for lung transplantation. However, one recent study examined the frequency and impact of delayed decisions among heart transplant patients. Lewis and colleagues (2004) examined four groups of heart failure patients interested in undergoing heart transplantation including: (1) “eligible” patients who did not exhibit heart transplant contraindications and were thought to be good candidates and initially added to the waiting list; (2) “potentially eligible” patients who had contraindications that were of concern to the staff, but were possible heart transplant candidates; (3) patients with obvious contraindications and were considered “ineligible”; and (4) patients who either did not complete the evaluation process or were too functional to undergo transplantation.
and were considered “deferred”. They found that several of the “potentially eligible” patients were eventually listed, but they had worse survival outcomes compared to patients who were initially “eligible.” It is imperative that future research examine “potentially eligible” candidates for lung transplantation because some of these patients are later moved to the “eligible” list and undergo lung transplantation.

An examination of the “potentially eligible” population is also important because research suggests that pre-transplant psychological status and quality of life predict survival, quality of life, and psychological adjustment after transplantation (Cohen et al., 1998; Squier et al., 1995). Prior research suggests that maladaptive coping strategies among lung transplant candidates are associated with poor mental health, worse physical functioning, and reduced quality of life (Burker et al., 2004a; Myaskovsky et al., 2003). An investigation of “potentially eligible” lung transplant candidates’ ability to cope with psychological distress and the association between coping styles and mental health outcomes (e.g., health status, psychological functioning, and quality of life) prior to transplantation may provide insight into how to improve pre-transplant psychological status and quality of life.

The outcome of lung transplantation is also dependent upon the patient being compliant with, or adhering to, the medical advice and regimen recommended by the lung transplant program health care professionals (Bunzel & Laederach-Hofmann, 2000). Research indicates that noncompliance, obesity, and substance abuse prior to transplantation predict problems with compliance after transplantation (Bunzel et al., 2000). Because noncompliance and health behaviors predict post-transplant compliance and surgery outcome, it is imperative that researchers examine compliance and health
behaviors among end-stage pulmonary disease patients referred for lung transplantation, especially “on hold” lung transplant candidates who must demonstrate compliance and health behavior change before they are eligible for transplantation.

“On hold” lung transplant candidates’ ability to be compliant with changing their health behaviors may be influenced by perceived self-efficacy (i.e., confidence in one’s ability to achieve a particular goal, Bandura, 1977,) and dispositional optimism (i.e., the belief that outcomes will be positive, Scheier & Carver, 1985). Maddux and colleagues (1995) suggest that beliefs about self-efficacy influence people to endorse healthy behaviors and cease unhealthy behaviors (Maddux, Brawly, & Boykin, 1995). Research has shown that high perceived self-efficacy, the belief that one can achieve a particular goal, is associated with changes in health behaviors such as exercise, diet, and smoking cessation (Maddux, Brawley, & Boykin, 1995). For example, supermarket shoppers who had a high perceived self-efficacy about eating and buying healthier foods ate and bought healthier foods when they went shopping (Anderson, Winett, & Wojcik, 2000). Grembowski and colleagues (1993) found that older adults with high self-efficacy were able to meet their expectations for exercise, dietary fat, and weight control. Individuals who quit smoking and using drugs also tend to report a higher self-efficacy than individuals who are still using these substances (Shiffman, Balabanis, Paty, Engberg, Gwaltney, Liu, Gnys, Hickcox, & Paton, 2000; Coon, Pena, & Illich, 1998).

Dispositional optimism is also associated with health behaviors. Mulkana and Hailey (2001) found that dispositional optimism was positively associated with general health behaviors and intentions to engage in health-promoting behaviors. Among middle-aged and older adults, dispositional optimism is associated with nonsmoking,
moderate alcohol consumption, and participation in physical activities, including exercise and healthier dietary habits (Steptoe, Wright, Kunz-Ebrecht, & Lliffe, 2006; Kelloniemi, Ek, & Laitinen, 2005). Because high perceived self-efficacy and dispositional optimism are both associated with health behavior change and endorsing healthier behaviors, these factors should be examined among “on hold” lung transplant candidates who must demonstrate compliance and health-promoting behaviors.

The Waiting Period

After patients with end-stage pulmonary disease are enrolled on the lung transplant list, they move to the next phase of the lung transplantation process, the waiting period. The evaluation phase is stressful, but the waiting period is considered to be the most stressful phase of the lung transplantation process (Smolin & Aguiar, 1996). During the waiting period, lung transplant candidates may experience one or more of the following: transplantation, death while waiting, removal from the list because of worsening or improving health, or continued waiting for transplantation (de Meester et al., 1999). The median waiting time for lung transplantation in the United States is currently 46 months (Nathan, 2005). The number of lung transplant candidates far exceeds the number of organ donors available, therefore a large number of patients die while waiting for a lung transplant (Hertz, Taylor, Trulock, Boucek, Mohacsi, Edwards, & Keck, 2002; Fisher, Dark, & Corris, 1998). Although lung transplant candidates report being excited when they are added to the lung transplant list, over time candidates report feelings of stress, anxiety, and depression (Burker et al., 2000; Smolin & Aguiar, 1996; Craven et al., 1990). Lung transplant candidates report stress regarding finances, placement on the waiting list, finding a suitable donor, deterioration of health, death prior
to transplantation, and death of other patients on the waiting list (Burker et al., 2004a; Burker et al., 2000). Anxiety, depression, and reduced quality of life are often associated with limitations in physical, psychosocial, work, and recreational activities (Burker et al., 2000; TenVergert et al., 1998; Ramsey et al., 1995; Craven et al., 1990).

Although prior research indicates that the waiting period is the most stressful phase of the lung transplantation process, no research has been conducted on the period of time that patients wait to resolve their contraindications to surgery. Thus, it is unclear if the waiting period after the evaluation is more stressful than the waiting period after being placed “on hold”. It is also unclear if “on hold” lung transplant candidates use more maladaptive coping strategies and experience worse psychological functioning and quality of life than “listed” lung transplant candidates. Previous research among lung transplant candidates has not distinguished between patients who were placed “on hold” and patients who were “listed” for lung transplantation. Thus, the research findings on coping styles, psychological functioning, and quality of life among lung transplant candidates may include patients who completed two waiting periods instead of one waiting period. It may be important to distinguish between patients who complete one waiting period and those who effectively complete two waiting periods due to being initially disqualified when first evaluated.

Transplantation & Recovery

When an organ becomes available, the patient with end-stage pulmonary disease is contacted and told to report to the hospital to undergo lung transplantation. After arrival at the hospital, the patient is prepared for surgery. On occasion, the patient does not undergo lung transplantation because the lung is not adequate (Smolin & Aguiar,
1996). When this occurs, transplant candidates report experiencing disappointment about not being transplanted, but reassurance that they are high on the list (Smolin & Aguiar, 1996).

During the surgery, the patient receives anesthesia and lung ventilation while his/her chest is opened and one or both diseased lungs are removed and replaced with healthier lungs (Dark, 2003). After surgery, lung transplant recipients progress to the last phase of the lung transplantation process, recovery. In this phase, patients are released from the hospital and are provided with a regimen of medications, nutritional guides, and exercise recommendations (Smolin & Aguiar, 1996). During recovery, lung transplant recipients report experiencing excitement about going home, fear of infection and rejection, mood swings as a result of medications, and difficulty adjusting to role changes (Smolin & Aguiar, 1996). Recipients who experience medical and surgical complications must remain in the hospital for an extended period of time. Most recipients return to the hospital several times due to infections (Smolin & Aguiar, 1996). Infections and graft failure are the main contributors to death after surgery (Trulock et al., 2004).

The Effect of the Lung Transplantation Process on Caregivers

Chronically ill patients often experience functional limitations that cause them to depend on others, particularly caregivers, to assist them in completing activities of daily living (Martinez-Martin, Benito-Leon, Alonso, Catalan, Ponal, Zamarbide, Tobias, & Pedro, 2005; Schulz & Beach, 1999). The caregiver role in addition to individual responsibilities impacts psychological functioning, physical health, and mortality of caregivers (Martinez-Martin, Benito-Leon, Alonso, Catalan, Pondal, Zamarbide, Tobias,
& Pedro, 2005). Caregivers of patients with cancer, Alzheimer’s disease, and other dementias experience symptoms of depression and anxiety, low social support, caregiver burden/strain, and negative immunological changes (Tremont, Davis, & Bishop, 2006; Mahoney, Regan, Katona, & Livingston, 2005; Northhouse, Mood, Kershaw, Schafenacker, Mellon, Walker, Galvin, & Decker, 2002; Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Research on caregivers of Alzheimer’s patients suggests that experimental wounds heal more slowly than wounds among non-caregiver controls (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). Schulz and Beach (1999) found that spousal caregivers had a higher mortality risk than matched controls. The health of caregivers is not only affected by additional caregiver responsibilities, but also by the health status of the chronically ill patient for whom they are providing care. Empirical evidence suggests that the quality of life of patients with Parkinson’s disease and cancer is linked to caregiver quality of life, and quality of life among breast cancer patients is associated with family members’ physical symptoms (Martinez-Martin et al., 2005; Chen, Chu, & Chen, 2004; Northhouse et al., 2002). The empirical findings among caregivers of chronically ill patients may have implications for caregivers of patients with end-stage pulmonary disease referred for lung transplantation.

The process of lung transplantation has an impact on the life of the patient’s spouse. Spouses often feel that their life is put on hold because they are unable to complete activities other than caring for the lung transplant candidate (Kurz & Cavanaugh, 2001; Smolin & Aguiar, 1996). Spouses often assume numerous responsibilities that were performed by the lung transplant candidate (e.g., mowing lawn,
grocery shopping, housework) in addition to their own responsibilities, such as work and the demands of other family members (Kurz, 2002; Smolin & Aguiar, 1996). Statements about the lung transplantation process by both pre-transplant and post-transplant spouses reflect caregiver role strain, but pre-transplant spouses are more likely to make statements reflecting caregiver role strain than post-transplant spouses (Kurz, 2002). Spouses view the lung transplantation process as a “roller coaster ride” filled with chaos (e.g., adjusting to the lung transplant recipient’s physical health changes, relationship and role adjustments, social changes) that results in both the lung transplant recipient and spouse needing to make adjustments after transplantation (Kurz, 2001a).

The impact of the lung transplantation process on primary caregivers was of interest because research suggests that spousal/family adjustment, quality of life, and relationships are associated with patient adjustment, recovery, and quality of life before and after transplantation (Myaskovsky et al., 2005; Perez-San-Gregorio, Martin-Rodriguez, Asian-Chaves, Callego-Corpa, Correa-Chamorro, & Bernal, 2003; White & Grenyer, 1999). Although research in this area has focused mainly on spouses, the experiences of spouses are likely to be relevant to the experiences of non-spouse caregivers because these caregivers experience many of the same stressors of the transplantation process. The experience of caregivers during the lung transplant process has rarely been studied (Ullrich, Jansch, Schmidt, Struber, & Niedermeyer, 2004).

Myaskovsky and colleagues (2005) found that lung transplant candidates reported poorer physical functioning than family caregivers, but lung transplant candidates and caregivers were not different on self-reported mental health and emotional functioning. They also found that poor quality of life among lung transplant candidates was associated
with poor quality of life among caregivers. Ullrich and colleagues (2004) examined the experience of support persons involved in a lung transplant program. The support persons reported greater stress during the acute illness and recovery phase than during the waiting period, and they reported fear of the lung transplant candidate dying during the waiting period. Self-report of stress in this study was not assessed until five years post-transplant so recollections of stress during the waiting period may have been underestimated.

Although the literature on spousal/caregiver experience during the lung transplantation process is sparse, the experience of spouses during the heart transplantation process has been well documented. Because the lung transplantation process is similar in many respects to that of heart transplantation, it is useful to examine data from heart transplant studies. The pre-transplant period in the heart transplant literature is reported to be more stressful than the post-transplant period for spouses of heart transplant patients, and the spouses often experience more psychological distress than the patients (Bohachick, Reeder, Taylor, & Anton, 2001; Collins, White-Williams, & Jalowiec, 2000; Buse & Pieper, 1990). Spouses of heart transplant candidates report experiencing moderate to high levels of stress related to the possibility of their partner dying prior to transplantation, decisions regarding the partner’s care at home or at the hospital, the uncertainty of a suitable donor becoming available in time, increased responsibility, economic problems, and feeling that their own health is ignored (Collins et al., 2000; Collins, White-Williams, & Jalowiec, 1996a; Nolan et al., 1992). Research indicates a negative impact on the marital relationship because the spouse experiences declines in perceived health, role performance, communication, and emotional
involvement after transplantation (Collins et al., 2000; Bunzel, Laederach-Hofmann, & Schubert; 1999; Collins, White-Williams, & Jalowiec, 1996b).

Research among caregivers of chronically ill patients and heart transplant patients suggests that the caregiver role has a negative impact on caregivers’ psychological functioning, as reflected in his/her levels of stress, depressive and anxiety symptoms, and caregiver burden/strain (Tremont et al., 2006; Mahoney et al., 2005; Martinez-Martin et al., 2005; Kurz, 2002; Northhouse et al., 2002). More importantly, caregivers of heart transplant patients report experiencing greater psychological distress than the heart transplant patients themselves (Bohachick et al., 2001; Collins et al., 2000; Buse et al., 1990). Although previous studies of caregivers and lung transplant patients have not examined differences in psychological distress among caregivers and patients during the lung transplant waiting period, caregivers of lung transplant candidates are likely to have stress that are similar to those of heart transplant caregivers (Ullrich et al., 2004; Kurz & Cavanaugh, 2001).

Only two studies have examined the stress of lung transplantation on spouses/caregivers of lung transplant candidates. The psychological functioning and quality of life of caregivers prior to lung transplantation have not been adequately documented, nor has the utilization of RSC or the reciprocal effects of these factors among patients and caregivers. Further research evaluating the impact of the lung transplantation process on coping styles, psychological functioning, and quality of life among caregivers is necessary.
The Role of Coping in the Transplantation Process

Coping is an important aspect of the lung transplantation process because candidates and their caregivers experience a significant amount of stress that could negatively affect psychological functioning, quality of life, and physical health. Research indicates that organ transplantation candidates who use problem-focused coping to deal with stress report less emotional distress and better physical health (Stilley et al., 1999a). Among lung transplant candidates, problem-focused coping is positively associated with psychological and spiritual well-being and satisfaction, and it is associated with lower depressive symptoms among renal transplant patients (Christensen, Ehlers, Raichle, Bertolatus, & Lawton, 2000; Stilley et al., 1999a). However, emotion-focused coping among lung transplant candidates is associated with poor physical functioning, social functioning, and mental health, as well as physical disability and higher levels of fatigue (Burker et al., 2004a; Myaskovsky et al., 2003). Although lung transplant candidates tend to use more coping strategies than their primary caregivers (Myaskovsky et al., 2005; Kurz, 2001b), emotion-focused coping is also associated with poorer quality of life among caregivers. In addition, emotion-focused coping strategies are associated with poor quality of life and functional disability among other medical populations including patients with cancer, human immunodeficiency virus, and rheumatoid arthritis (Matsushuma & Maruyama, 2005; Swindells, Mohr, Justis, Berman, Squier, Wagener, & Singh, 1999; Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003).

More importantly, there appears to be a relationship between quality of life and coping styles among lung transplant candidates and caregivers. Myaskovsky and colleagues (2005) examined the reciprocal effects of patient and caregiver quality of life
and coping styles. They found that the utilization of emotion-focused coping among lung transplant candidates was associated with poorer health and physical functioning among caregivers. However, caregiver coping style was not associated with lung transplant candidate quality of life and coping style.

The relationship between coping styles and multiple aspects of mental health has not been intensively examined in a single study, nor have these factors been examined longitudinally among pre-transplant patients and primary caregivers. Only one study to date (Myaskovsky et al., 2005) has examined the reciprocal effects of patient and caregiver coping strategies on the partner’s quality of life. Although several nonreligious coping styles have been examined in prior studies, these coping styles can be broadly characterized as problem-focused coping and emotion-focused coping. The current study will examine nonreligious coping in the context of problem-focused coping and emotion-focused coping, and humor. Humor has been primarily associated with better mental health (Manne, Duhamel, Ostrofr, Parsons, Martinis, et al., 2003), however, there is research suggesting that it is associated with worse mental health (Aarstad, Aarstad, Heimdal, & Olofsson, 2005). Therefore, humor will be examined separately from either problem-focused coping or emotion-focused coping.

Prior studies of coping among lung transplant candidates and primary caregivers have largely excluded RSC, despite its association with health benefits among chronically ill populations and its influence on the ability of family caregivers to manage caregiving roles (Harrison, Koenig, Hays, Eme-Akwari, & Pargament, 2001; Chang, Noonan, & Tennstedt, 1998). Research on coping among medically ill and long-term care patients also suggests that RSC is a common coping strategy (Koenig, 1998, Ayele, Mulligan,
Gheorghiu, & Reyes-Ortiz, 1999). For example, Koenig (1998) found that 73% of a medically ill sample used RSC to deal with their illness and daily hassles. Although RSC refers to the transcendent, it is similar to nonreligious coping in that the various RSC strategies can be conceptualized as adaptive or maladaptive coping styles. In the research literature on nonreligious coping, adaptive coping refers to problem-focused coping and maladaptive coping refers to emotion-focused coping, whereas, in the religion and health literature, adaptive RSC styles refers to positive religious coping and maladaptive coping refers to negative religious coping. The exclusion of RSC in previous research may have resulted in a limited depiction of the coping styles being utilized by this population as well as a biased view of the types of strategies that may need to be included in future intervention studies. Because the current literature primarily focuses on nonreligious coping and mental health outcomes, coping interventions may not include RSC. The present study was designed to investigate the utilization of RSC and the association between RSC and mental health outcomes among lung transplant candidates and primary caregivers.

Religiosity and Spirituality

Religiosity and spirituality have been studied as psychosocial constructs predictive of many physical and mental health outcomes among chronically ill patients (Daaleman, Perera, & Studenski, 2004; Koenig, George, & Titus, 2004; Koenig, McCullough, & Larson, 2001; Koenig, George, & Peterson, 1998; Dein & Stygall, 1997). Although religiosity and spirituality are related, the two constructs are distinct. Religiosity refers to the beliefs, values, practices and rituals of a particular faith that individuals utilize to get closer to the transcendent (e.g., God, Allah, higher power,
ultimate truth) and to understand their relationship and responsibility to others (Koenig et al., 2001). Religiosity also includes searching for unsacred goals that can occur inside or outside of a religious setting (Koenig et al., 2001). It is community focused, observable, measurable, organized, behavior-oriented, authoritarian in terms of behaviors, and it is a doctrine that differentiates good and evil (Koenig et al., 2001). Spirituality, on the other hand, is concerned with the transcendent or transpersonal, it addresses ultimate questions about life’s meaning, it assumes that there is more to life than what we see or fully understand, and may lead to or arise from religious rituals (Fetzer, 1999; Koenig et al., 2001). Spirituality is understood at the level of the individual, does not rely on religious contexts, is subjective, emotion-oriented, less visible, less measurable, and less formal, and it is not authoritarian or doctrine oriented (Koenig et al., 2001; Miller, 1998). Religiosity and spirituality tend to be more openly utilized for coping among African Americans, women, and older adults (Argue, Johnson, & White, 1999; Ozorak, 1996; Donahue & Benson, 1995).

Although religiosity and spirituality are viewed and defined as distinct constructs, the dimensions of religiosity and spirituality are similar or the same in the research literature (Koenig et al., 2001). For example, prayer, a component of private religious practices, is a dimension of both religiosity and spirituality. Despite the dimensions of religiosity and spirituality being similar, it is important to distinguish between these two factors because individuals may identify experiences as spiritual, but not religious (Idler, Musick, Ellison, George, Krause, Ory et al., 2003).
The Connection Between Coping and Religiosity and Spirituality

The process of coping is distinct from religiosity and spirituality, yet there is overlap between coping and religiosity and spirituality. Coping is a process that occurs during a stressful experience (Pargament, 1997). Religiosity and spirituality are utilized in every day life in both stressful and non-stressful situations (Pargament, 1997). Religiosity and spirituality may influence many aspects of daily life, but religious and spiritual individuals do not necessarily rely on their religiosity and spirituality for coping with stressful events (Pargament, 1997). Coping often entails utilizing more resources than religiosity and spirituality, and religiosity and spirituality is likely to be used outside the context of coping (Pargament, 1997). Coping overlaps with religiosity and spirituality when individuals use religiosity and spirituality as coping mechanisms to deal with stressful situations (Pargament, 1997). Religiosity and spirituality are more likely to be used to cope if individuals are religious and/or spiritual, if religiosity and spirituality are the best coping resources available to the individual, or if religiosity and spirituality are accessible and compelling to an individual (Pargament, 1997).

Religious and Spiritual Coping

Religious and spiritual coping, like religiosity and spirituality, is multidimensional (Pargament, Smith, Koenig, & Perez, 1998). General religious and spiritual beliefs and practices are translated into a variety of specific RSC strategies. The following RSC strategies were the main focus of the current study because they have been frequently examined in the religion and health literature: organizational religiosity, private religious practices, religious beliefs (intrinsic religiosity), religious problem-solving styles, positive RSC, and negative RSC. Religious belief (intrinsic religiosity)
refers to whether an individual believes or does not believe in the transcendent (Allport & Ross, 1967; Koenig et al., 2001). Organizational religiosity refers to participation in a religious organization such as a church or synagogue (Koenig et al., 2001; Fetzer, 1999). Private religious practice, also known as nonorganizational religiosity, refers to participation in religious acts, such as prayer, inside or outside of a religious setting (Koenig et al., 2001; Fetzer, 1999). Religious problem-solving styles refers to the relationship between an individual and God as examined through three distinct styles of religious coping, specifically collaborative style, self-directing style, and deferring style (Pargament, Kennell, Hathaway, Grevengoed, Newman, & Jones, 1988). Collaborative style refers to the individual and God being responsible for the problem-solving process (Pargament et al., 1988). Self-directing style refers to the individual being solely responsible for solving the problem (Pargament et al., 1988). Deferring style refers to God being solely responsible for the problem-solving process (Pargament et al., 1988).

Prior research indicates that individuals use both positive RSC and negative RSC (Hills, Paice, Cameron, & Shott, 2005; Sherman, Simonton, Latif, Spohn, & Tricot, 2005). Theoretically, it is possible for individuals to use high or low levels or similar levels of positive and negative RSC. The items assessing positive RSC reflect a tendency to be seeking God, and items assessing negative RSC reflect a tendency to be questioning God. People who believe in a Higher Being and are going through a stressful or difficult situation may look to their faith for comfort and guidance, but at the same time question God by asking “why me.” Thus, individuals may simultaneously seek God and question God. It is important to examine the use of both positive and negative RSC in the context of the stress of being evaluated for lung transplant surgery, because lung transplant
candidates are likely to experience a prolonged period of stress and may rely on numerous strategies for coping.

Religious and Spiritual Coping among Lung Transplant Candidates and Caregivers

Three studies have addressed RSC among lung transplant candidates and spouses, but measures of religiosity and spirituality were not valid and reliable indicators of the spectrum of RSC in two of the studies (Myaskovsky et al., 2003; Kurz, 2001a; Burker et al., 2004b). Kurz (2001a) found that spouses of lung transplant candidates mentioned their religious faith and their faith in God as coping resources. However, Kurz (2001a) did not include a standard assessment of RSC. The spouses in the study openly expressed their feelings about the lung transplantation process during a telephone interview, but RSC was not assessed with a self-report questionnaire and the interviewers did not specifically ask about the spouse’s use of RSC. In addition, the study did not examine the use of RSC in relation to the spouse’s stress, psychological functioning, and quality of life.

Myaskovsky and colleagues (2003) found that increased religiosity was associated with fewer problems with social functioning among lung transplant candidates. Religious endorsement was assessed with a self-report questionnaire, but the measure consisted of only six items, each measured on a dichotomous scale (e.g., low religiosity and high religiosity). Thus, the measure did not provide scores for respondents who did not use RSC. The religious measure also did not take into account the multidimensionality of religiosity since it only measured participation in religious activities and religious beliefs.
Burker and colleagues (2004b) examined RSC among end-stage pulmonary disease patients. They found that most of the patients were religiously affiliated, and that several RSC strategies such as punishment appraisal, benevolent reappraisal, and seeking collaboration and support from God were associated with increased distress. However, there were several limitations of the study: (1) RSC strategies (e.g., private religious practices, organizational religiosity) that have been shown to be positively correlated with health outcomes among other transplant/surgery populations were not examined, and (2) quality of life was not assessed.

Although RSC has not been studied extensively among lung transplant candidates and caregivers, research among other surgery populations provides additional evidence of the importance of RSC during surgical procedures. Religious coping is associated with better adjustment among kidney transplant patients and caregivers (Tix & Frazier, 1998). Heart transplant recipients who participate in religious activities and have strong religious beliefs have better physical and emotional well-being, fewer health worries, and better medical compliance one year after transplantation (Harris, Dew, Lee, Amaya, Buches, Reetz, & Coleman, 1995). Coronary artery bypass graft (CABG) surgery patients report engaging in prayer, attending church services, and participating in church activities to cope with surgery and their condition (Saudia, Kinney, Brown, & Young-Ward, 1991; Ai, Bolling, & Peterson, 2000). Strong religious beliefs prior to CABG surgery have resulted in fewer complications, shorter hospital stays after surgery, and are associated with greater social support, higher levels of dispositional optimism, lower depressive symptoms, and less trait hostility (Contrada, Goyal, Cather, Rafelson, Idler, & Krause, 2004). Prayer is associated with enhanced postoperative emotional health among CABG
patients (Ai et al., 2000). Sears and colleagues (1997) examined collaborative, self-directing, and deferring religious problem-solving styles among heart transplant patient and found that patients who used each of these problem-solving styles reported better mental health and general health. Research also suggests that older adults with declining health report utilizing less organizational religiosity and greater private religious practices (Benjamins, Musick, Gold, & George, 2003).

The current research on RSC among surgery populations has not indicated a negative association between RSC and health outcomes, but there are aspects of RSC that are associated with negative mental health outcomes. For instance, negative religious coping strategies such as punishing God reappraisals, interpersonal religious discontent, and self-directed religious problem-solving style are associated with poor mental health and quality of life among medically ill hospitalized adults (Koenig, Pargament, & Nielsen, 1998). Thus, not all RSC strategies are associated with positive mental health outcomes.

At present, there are minimal quantitative data regarding the relationship between RSC and mental health outcomes among organ transplant candidates and recipients, especially lung transplant candidates and their caregivers (Harris et al., 1995; Burker et al., 2004b). In addition, very few studies have assessed RSC as a multidimensional construct or used valid and reliable measures of RSC (Harris et al., 1995; Siegel et al., 2001). Prior studies have not examined the degree to which RSC may predict psychological distress over and above the use of nonreligious coping, or changes in RSC that may occur over time during the chronic stress of the lung transplantation process (Burker et al., 2004b; Siegel et al., 2001; Tix & Frazier, 1998). Limitations in the religion
and health research literature and the small number of studies that have quantitatively examined RSC among patients with end-stage pulmonary disease and caregivers warrant further research in this area.

**Current Study**

Research has not been conducted on lung transplant candidates placed “on hold” despite the fact these patients are periodically added to the waiting list and undergo transplantation after their contraindications to transplantation are resolved. Most studies have examined only one aspect of health prior to transplantation (psychological distress, quality of life, pulmonary functioning). To date, prior studies have provided cross-sectional data on coping and mental health, but there are no longitudinal data available assessing lung transplant candidates and their primary caregivers prior to transplantation. In addition, the research literature on coping and mental health among caregivers is scarce, as well as the literature on the reciprocal effects of coping and mental health among lung transplant candidates and primary caregivers. An evaluation of factors associated with adjustment (e.g., stress, psychological functioning, coping) among lung transplant candidates and caregivers may assist in developing adequate interventions. The coping and mental health literature has focused mainly on nonreligious coping. Religious and spiritual coping has not been extensively studied among patients with end-stage pulmonary disease and their primary caregivers, despite documentation that higher levels of RSC are associated with mental health benefits among cardiac and kidney transplant patients. Further evaluation of coping, particularly RSC, and mental health outcomes among lung transplant patients and caregivers is warranted because of the importance of improving mental health prior to transplantation, the importance of better understanding
the utilization of coping styles, and evaluating the association of coping styles with mental health outcomes to determine areas for further study and intervention. The primary aims of the current study were to: (1) examine differences in coping strategies and mental health outcomes between patients and primary caregivers, (2) examine differences in coping strategies and mental health outcomes between “on hold” and “listed” lung transplant candidates, (3) evaluate the association of pulmonary functioning with quality of life among patients, (4) investigate the relationship of coping strategies, both nonreligious coping and RSC, with mental health outcomes among patients and primary caregivers, (5) evaluate change in coping strategies, both nonreligious coping and RSC, and mental health outcomes over time among patients and primary caregivers, and (6) investigate the reciprocal relationship of nonreligious coping and mental health outcomes among patients and primary caregivers. The secondary aims of the study included: (7) investigating the reciprocal relationship of RSC to mental health outcomes among patients and primary caregivers, (8) evaluating health behaviors and compliance, and (9) examining the degree to which dispositional optimism and self-efficacy predict health behaviors and compliance among “on hold” lung transplant candidates. The study hypotheses are enumerated below.

**Hypotheses of Primary Aims**

**Aim 1: Examine Differences in Coping Strategies and Mental Health Outcomes between Patients versus Primary Caregivers**

1) Patients with end-stage pulmonary disease were expected to utilize more problem-focused, emotion-focused, and humor coping strategies than caregivers. Prior
research suggests that lung transplant candidates tend to use more problem-focused, emotion-focused, and humor coping strategies than their caregivers (Mysakovsky et al., 2005; Kurz, 2001b).

2) Patients with end-stage pulmonary disease were expected to utilize private religious practices more than organizational religiosity, and primary caregivers would utilize organizational religiosity more than patients with end-stage pulmonary disease. According to Benjamins and colleagues (2003), older adults with declining health tend to decrease their use of organizational religiosity and increase their use of private religious practices.

3) Primary caregivers were expected to report better quality of life, specifically physical functioning, than patients. This hypothesis was based on prior data indicating that lung transplant candidates reported poorer physical functioning than family caregivers (Mysakovsky et al., 2005).

4) Psychological functioning and stress of primary caregivers was expected to be equivalent to that of patients. This hypothesis was consistent with the finding that lung transplant candidates and caregivers were not different on self-reported mental health and emotional functioning (Mysakovsky et al., 2005).

Aim 2: Examine Differences in Coping Strategies and Mental Health Outcomes among “On Hold” versus “Listed” Lung Transplant Candidates

5) “On hold” lung transplant candidates were expected to report greater stress, depression, and anxiety and utilize more coping styles (e.g., problem-focused, emotion-focused, humor, and RSC), compared to “listed” lung transplant candidates. However, “on hold” lung transplant candidates were expected to report equivalent

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quality of life (physical functioning) compared to “listed” lung transplant candidates. Although these two groups would likely have similar physical functioning, “on hold” candidates were expected to experience greater stress because the lung transplantation process was delayed for them and the time period in which they would be placed on the waiting list had been extended.

**Aim 3: Evaluate the Relationship between Pulmonary Functioning and Quality of Life among Patients**

6) Pulmonary functioning, particularly FEV$_1$% predicted, was expected to be positively associated with health-related and disease-specific quality of life among patients. This hypothesis is consistent with prior research among patients with chronic lung disease (Riekert et al., 2007; Ståhl et al., 2005; Engström et al., 2001).

**Aim 4: Investigate the Relationship between Coping Strategies and Mental Health Outcomes among Patients and Primary Caregivers**

7) Emotion-focused coping among patients was expected to be negatively associated with quality of life, particularly physical functioning, social functioning, and vitality, as well as psychological functioning. Problem-focused coping and humor were expected to be positively associated with psychological functioning. These hypotheses were consistent with prior literature among lung transplant candidates (Mysakovsky et al., 2003; 2005; Burker et al., 2004a; Stilley et al., 1999a).

8) Emotion-focused coping among primary caregivers was expected to be associated with poorer quality of life. This hypothesis was consistent with data from Myaskovsky and colleagues (2005).
9) Positive RSC, religious beliefs, prayer, and deferring religious problem-solving style were expected to be associated with better psychological functioning and quality of life, particularly physical functioning, social functioning, vitality, and general health, among patients and their primary caregivers. Negative RSC was expected to be associated with poorer psychological functioning and quality of life, particularly physical functioning, social functioning, vitality, and general health, among patients and their primary caregivers. Research on CABG surgery patients and cardiac and kidney transplant patients indicated that positive RSC and deferring religious problem-solving styles were associated with enhanced psychological functioning, emotional well-being, physical well-being, and general health (Contrada et al., 2004; Sears et al., 1998; Tix & Frazier, 1998; Harris et al., 1995). Research among medically ill hospitalized adults indicated that negative religious coping is associated with poorer mental health (Koenig et al., 1998).

Aim 5: Evaluate Change in Coping Strategies and Mental Health Outcomes over time among Patients and Primary Caregivers

10) Change in the utilization of coping strategies among patients and their primary caregivers over time were expected to be associated with change in health outcomes. Increased use of emotion-focused coping was expected to be associated with poorer mental health from baseline to 6-month follow-up, and problem-focused coping and humor were expected to be associated with better mental health. Positive RSC, religious beliefs, prayer, and deferring religious problem-solving were expected to be associated with better health, and negative religious coping was expected to be associated with poorer health from baseline to 6-month follow-up.
Aim 6: Reciprocal Effects of Nonreligious Coping and Mental Health Outcomes among Patients and Primary Caregivers

11) Patients’ nonreligious coping, specifically greater self-blame and less active, support-seeking, and acceptance coping, was expected to be associated with poorer quality of life among primary caregivers, particularly poorer general health and physical functioning. This hypothesis was based upon the findings of Myaskovsky and colleagues (2005), therefore nonreligious coping was examined using the nonreligious coping factors identified in the study by Myaskovsky and colleagues (2005). Myaskovsky and colleagues (2005) found that greater self-blame and less active, support-seeking, and acceptance coping among lung transplant candidates was associated with poorer caregiver quality of life, specifically general health and physical functioning.

12) Caregivers’ nonreligious coping was not expected to be associated with patients’ psychological functioning and quality of life. Myaskovsky et al. (2005) found that caregiver coping styles and quality of life were not associated with candidate coping styles and quality of life.

13) Caregivers’ health outcomes (psychological functioning, quality of life) were expected to be positively associated with patients’ health outcomes. Prior research has shown that psychological adjustment of spouses was associated with patient adjustment and recovery (White & Grenyer, 1999).

Hypotheses of Secondary Aims

Aim 7: Relationship of RSC among Lung Transplant Candidates to Mental Health Outcomes among Primary Caregivers
Patients’ negative RSC were expected to be negatively associated with primary caregivers’ psychological and physical functioning. Prior research has not examined the effects of RSC on health outcomes among lung transplant candidates and caregivers. However, because maladaptive nonreligious coping strategies among lung transplant candidates are associated with poorer health among caregivers, it was hypothesized that negative RSC among lung transplant candidates would be associated with poorer health among caregivers.

**Aim 8: Evaluate Health Behaviors and Compliance**

“At hold” lung transplant candidates were expected to report utilizing more positive health behaviors at follow-up than at baseline. This hypothesis had not been examined in previous research, but “at hold” lung transplant candidates must increase positive health behaviors over time to continue the transplantation process.

“On hold” lung transplant candidates were expected to comply with recommendations that they alter their health behaviors. Prior research has not examined compliance among “at hold” lung transplant candidates. Lewis and colleagues (2004) found that some “at hold” lung transplant candidates are not later added to the waiting list or transplanted because contraindications are not resolved due to noncompliance.

**Aim 9: Examine the Degree to which Dispositional Optimism and Self-Efficacy Predict Health Behaviors and Compliance**

High perceived self-efficacy and dispositional optimism at baseline was expected to be associated with better health behaviors at baseline and would predict better health behaviors and compliance at follow-up. Lung transplant candidates who were placed “at hold” for smoking and obesity were examined because these were primary
reasons for placing individuals on hold. Although previous research has not examined
the relationship of perceived self-efficacy and dispositional optimism to health
behaviors among “on hold” lung transplant candidates, prior research indicates that
high perceived self-efficacy and dispositional optimism are associated with positive
health behaviors in healthy adults (Steptoe et al., 2006; Kelloniemi et al., 2005;
Mulkana et al., 2001; Anderson et al., 2000; Maddux et al., 1995; Grembowski et al.,
1993).
CHAPTER 2

METHODS

Participants

A total of 88 lung transplant candidates from the Lung Transplant Program at the OSU Medical Center were contacted for recruitment into the study, as shown in Figure 1. Prospective patients were mailed recruitment materials including a cover letter, flyer, and postcard (see Appendix C). Twenty-two patients (16 “on hold” and 6 “listed” lung transplant candidates) did not respond to the recruitment materials for the following reasons: decided they did not want a transplant (n = 2), died (n = 3), could not be reached by the transplant staff (n = 12), or were permanently declined for noncompliance (n = 2), being too sick (n = 1), or had another major organ disease (n = 2). Ten patients (8 “on hold” and 2 “listed” lung transplant candidates) refused to participate in the study due to lack of time (n = 3), not interested in study participation (n = 3), the caregiver unwilling to participate or too busy (n = 3), or “too depressing to complete surveys about health” (n = 1). Twelve dyads dropped out of the study because the patient died (n = 2), decided they no longer wanted a lung transplant (n = 1), decided they no longer wanted to participate in the study due to lack of time (n = 3), or did not complete the consent form and baseline self-report packet of questionnaires (n = 6). Five dyads were excluded from all analyses due to completing the baseline self-report packet of questionnaires prior to lung transplantation (n = 2) or non-completion of the baseline self-report packet of
questionnaires by the primary caregiver (n = 3). The 39 patients who participated in the study were not significantly different from patients who refused, dropped out of the study, or were excluded from analyses in terms of age (F1,59 = .45, p=.51), gender (X²(1, n=64) = .783, p=.38), ethnicity (X²(2, n=64)=3.46, p=.18), or type of pulmonary disease (X²(5, n=51)=3.68, p=.60).

The sample (n = 39) included both “on hold” lung transplant candidates (n = 22), and “listed” lung transplant candidates (n = 17). The mean age of lung transplant candidates was 51.2 years (SD ± 9.2), and they were primarily Caucasian, female, married, and high school graduates who were unemployed and on disability, as shown in Table 1. Although the study sample was primarily female, most lung transplant patients nationwide are male (Health Resources and Services Administration, 2007). There were no significant demographic differences between “on hold” and “listed” lung transplant candidates, but “on hold” lung transplant candidates had poorer pulmonary functioning including forced expiratory volume in one second (FEV₁;F2,31= 4.20, p=.02), FEV₁/forced vital capacity (FVC) ratio (F2,31= 4.90, p=.01), and FEV₁% predicted (F2,31= 4.39, p=.02) compared to “listed” lung transplant candidates, as shown in Table 2. Mean age of primary caregivers was 47.0 (SD ± 13.2) years, and they were primarily Caucasian, female, with some college education, and employed full-time, as shown in Table 1. Primary caregivers were mainly spouses (41.0%) and parents (25.6%) of lung transplant candidates.

The following were inclusion criteria for lung transplant candidates: greater than 18 years of age or less than 65 years of age for single-lung transplantation; less than 55 years of age for double lung transplantation; irremediable end-stage lung disease,
unresponsive to alternative therapy, expected survival time of less than two years; no
other major organ disease; no significant untreated or unmanaged psychosocial problems;
participation in a pre-operative exercise rehabilitation program; able to speak, read, and
write English; completed at least an eighth grade education; and identification of a
primary caregiver. A subset of lung transplant candidates (“on hold” candidates) were
placed on hold by the OSU Transplant Program medical team because of one of the
following remediable contraindications to transplant surgery: recent (within past six
months) or current smoking, underweight (BMI<17), obese (BMI>30), recent (within
past year) or current substance abuse/dependence, poor pulmonary functioning (inability
to walk 600 feet during six-minute walk test), too functional (expected survival greater
than 2 years), insurance problems, or pending medical records. Lung transplant
candidates who were not placed “on hold” were listed as candidates for either single-lung
or bilateral lung transplant at OSU hospital.

“On hold” patients who were smoking or using illicit drugs were required to sign
a behavior contract stating that they would discontinue smoking, consuming alcohol, or
using recreational drugs and acknowledging that they needed to be abstinent from these
substances at least for 6 months before they would be reconsidered for lung transplant
surgery. Cessation of substances was verified with blood serum measures (e.g., serum
cotinine level, liver enzyme tests). Patients who were underweight had to achieve a BMI
of greater than 17, and patients who were obese had to achieve a BMI of less than 30
before they could be considered for transplant surgery. Body mass index was verified by
the primary family physician and/or OSU transplant staff. Patients who were placed “on
hold” for poor physical functioning had to participate in an exercise rehabilitation
program, and they could not continue the transplantation process until their functional
capacity improved (6-minute walk distance improved to at least 600 feet). Patients who
were “too functional” or who were placed “on hold” due to pending medical records or
insurance problems (e.g., out of network insurance) were excluded from this study.

Lung transplant candidates were asked to identify the primary caregiver who
would be assisting them through the transplantation process and indicate the primary
caregiver’s relation to them (e.g., spouse, parent, friend, sibling, child, romantic partner).
The criteria for all primary caregivers included being a caregiver for the lung transplant
candidate; able to speak, read, and write English; and completed at least an eighth grade
education. Voluntary consent of both the patient and primary caregiver was required for
participation in the study. Each caregiver was identified by the patient as the person
he/she would rely upon for help regardless of the number of hours per week spent in
caregiving duties.

Procedure

A longitudinal, single-cohort study design was employed. Prospective participants
were identified in consultation with the OSU Lung Transplant Program Team. Each
patient with end-stage pulmonary disease who was evaluated for lung transplant surgery
was informed of the opportunity to participate in the study. Prospective participants also
received a letter, flyer, and postcard advertising the study and soliciting participation in
the study (see Appendix C). In addition, announcements about the study were made at
monthly lung transplant support group meetings, and patients who were interested in
receiving further information about the study provided their contact information on a
postcard mailed to them by the lung transplant coordinator (see Appendix C). Prospective
participants were contacted by telephone to confirm their willingness to participate in the study and the availability of a caregiver to participate, following completion of a telephone screening form (see Appendix D). Prospective participants were also asked for permission to contact their primary caregiver to complete similar questionnaires concerning the caregiver’s coping styles, psychological functioning, and quality of life. Potential participants were also informed that questions on RSC were included in the self-report packet of questionnaires.

Upon agreeing to participate in the study, a cover letter, two consent forms, two Health Insurance Portability and Accountability Act (HIPAA) authorization forms, a self-report packet of questionnaires, and a self-addressed and stamped return envelope were mailed to participants. Participants were instructed to retain one consent form and HIPAA authorization form for their personal records, and to return the other consent form and HIPAA authorization form with the self-report packet of questionnaires within two weeks. Participants were contacted by telephone during the two-week period to (1) review the informed consent and HIPAA authorization form, (2) answer any questions, and (3) remind them to return the forms and self-report questionnaires. A second packet of self-report questionnaires and a stamped return envelope were mailed to participants 6 months following the baseline assessment (time 2). The Lung Transplant Program also required that a brief version of the medical evaluation be conducted at six-month intervals prior to transplantation to monitor the following medical variables: FVC (measure of airflow limitation), FEV$_1$ (measure of airflow limitation), FEV$_1$/FVC ratio (indicator of disease severity), FEV$_1$% predicted (indicator of disease severity), and body mass index (BMI). Participants who did not return their packets within two weeks
received a telephone call and/or a postcard reminding them to return the questionnaires, and they were contacted again if they did not return the materials after one month (see Appendix E).

**Measures**

The following demographic information was obtained from all participants: date of birth, gender, ethnicity, education, marital status, living arrangement, employment status, and income. Each patient also indicated a primary caregiver and the relationship to the caregiver (e.g., spouse, child). This measure is included in Appendix F.

**Measures of Health Status:**

1. The following data were transcribed from patient medical records: (1) pulmonary functioning data (FVC, FEV$_1$, FEV$_1$/FVC ratio, FEV$_1$% predicted), (2) flow rate of supplemental oxygen, (3) BMI, and (4) date referred to the OSU Lung Transplant Program. A spirometer was utilized to measure pulmonary functioning. Participants inhaled fully, then exhaled into the spirometer as hard and as fast as possible providing measure of the volume of air exhaled in the first second (FEV$_1$) and the total amount of air exhaled (FVC). Pulmonary functioning values and oxygen utilization were transcribed onto the forms included in Appendix G.

Participants completed all of the following self-report measures at each of the two assessments (baseline and 6 months).

**Measures of Coping:**

1. The COPE Questionnaire (Brief Form; Carver, Scheier, & Weintraub, 1989) is a 28-item self-report questionnaire assessing a broad range of coping strategies. It consists of 14 sub-scales, with two items per scale. The sub-scales include self-distraction,
active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. The subscales can be summed to produce an overall coping score. In the present study, the religious coping subscale was excluded from all analyses due to specific measures of RSC being utilized in the study. For most of the data analyses, the subscales were combined to create three factors including problem-focused coping, emotion-focused coping, and humor. Problem-focused coping included the following subscales: acceptance, planning, active, positive reframing, and instrumental support. Emotion-focused coping included the following subscales: denial, behavioral disengagement, substance use, venting, self-blame, self-distraction, and seeking emotional support. Humor consisted of the humor subscale. The COPE also consists of five factors: active coping, social support, avoidant coping, acceptance, and self-blame, according to prior research (Myaskovsky et al., 2005; Burker et al., 2004). The active coping factor consists of the active and planning subscales, as well as item 23 from the instrumental support subscale. The support factor consists of the venting, emotional, and religion subscales, in addition to item 10 of the instrumental support subscale. The avoidant factor consists of the denial, substance use, and behavioral disengagement subscales. The acceptance factor consists of the acceptance, self-distraction, positive reframing, and humor subscales. The self-blame factor consists of the self-blame subscale. Reliability of the COPE in this sample was adequate (Cronbach’s alpha = .82). This measure has also proven to be a reliable and valid measure of coping styles among college students (Carver et al., 1989). This measure is included in Appendix H.
2. The Brief Religious Coping Questionnaire (RCOPE; Pargament, et al., 1998) is a 14-item self-report questionnaire assessing religious strategies used to cope with an illness, and the extent to which the strategies are used. It consists of two sub-scales, with seven items per scale. The sub-scales include positive religious coping and negative religious coping. Reliability of the RCOPE in this sample was adequate (Cronbach’s alpha = .86). The RCOPE has demonstrated moderate to high internal consistency with Cronbach’s alpha ranging from .69 to .90 and adequate validity among college student and hospital patients (Pargament et al., 1998). This measure is included in Appendix I.

3. Duke Religion Index (DUREL; Koenig, Parkerson, & Meador, 1997) is a 5-item questionnaire that measures three dimensions of religiosity: organizational religiosity, nonorganizational religiosity, and intrinsic religiosity. The organizational and nonorganizational religiosity dimensions use a 6-point Likert scale with responses ranging from ‘more than once a week’ to ‘never.’ The intrinsic religiosity dimension uses a 5-point Likert scale with responses ranging from ‘definitely true of me’ to ‘definitely not true.’ The scale has shown adequate reliability and validity among Caucasian college students, and it has been used to examine religiosity among various medically ill samples (Koenig et al., 1997; Storch, Roberti, Heiderken, Storch, Lewin, Killiany, Baumeister, Bravata, & Geffken, 2004). It has also shown adequate reliability in this sample (Cronbach’s alpha = .89). This measure is included in Appendix J.

4. Religious Problem-Solving Scale Short Form (RPS-Short Form; Pargament et al., 1988) is an 18-item self-report measure that assesses the role of religion in the
problem-solving process. It consists of three religious problem-solving styles: collaborative, self-directing, and deferring. In the present study, the collaborative and self-directing religious problem-solving styles were excluded from analyses because the RCOPE provides measures of these dimensions in positive RSC and negative RSC, respectively. Items are scored on a 5-point Likert scale with responses ranging from ‘never’ to ‘always.’ This measure exhibited adequate reliability (Cronbach’s alpha = .80). This measure is included in Appendix K.

Measures of Stress and Psychological Functioning:

1. The Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) is a 10-item questionnaire that provides a self-report measure of appraised stress. Participants respond to statements such as, “In the last month, how often have you felt nervous and ‘stressed.’” The responses range from ‘never’ to ‘very often.’ The PSS has shown adequate internal consistency (ranging from .84 to .86) and concurrent and predictive validity among college student and smoking-cessation populations (Cohen et al., 1983). The PSS had adequate internal consistency (Cronbach’s alpha = .93) in the present study. This measure is included in Appendix L.

2. The Beck Depression Inventory (BDI; Beck, 1978) is among the most frequently used measures of depressive symptoms, consisting of 21 items that tap specific symptoms, or associated attitudes. Participants circle 1 of 4 statements that best describes how they have been feeling during the past week. Scores range from 0-63. The BDI has demonstrated high internal consistency and sufficient discriminant and content validity in both clinical and nonclinical populations (Beck, 1978). The BDI had
adequate internal consistency (Cronbach’s alpha = .91) in the present study. This measure is included in Appendix M.

3. The Beck Anxiety Inventory (BAI; Beck & Steer, 1987) is a 21-item self-report measure of anxiety. Participants rate their experience of anxiety symptoms, such as “Numbness or tingling.” The responses range from ‘not at all’ to ‘severely, I could barely stand it.’ Scores range from 0-63. The BAI has shown high internal consistency and stability, and adequate content, concurrent, construct, discriminant, and factorial validity in both clinical and nonclinical samples (Beck & Steer, 1987). This measure exhibited adequate reliability (Cronbach alpha = .77), and is included in Appendix N.

Measures of Quality of Life:

1. The Medical Outcomes Study Short Form-36 (SF-36; Ware & Sherbourne, 1992) provides 8 health-related quality of life dimensions including physical functioning, role functioning-physical, role functioning-emotional, social functioning, bodily pain, mental health, vitality, and general health perceptions. Transformed scores for each scale range from 0 to 100. Higher T-scores are indicative of better health-related quality of life. This measure has proven to be a reliable and valid measure of quality of life among medical patients (Ware & Sherbourne, 1992). This measure exhibited adequate reliability (Cronbach’s alpha = .89), and is included in Appendix O.

2. St. George’s Respiratory Questionnaire (SGRQ; Jones, Quirk, Baveystock, & Littlejohns, 1992) is a 76-item disease-specific quality of life measure. SGRQ provides a total score and three component scores: symptoms, activities, and impact. The symptom component indicates the level of symptomatology (i.e., frequency and
duration of breathlessness). The activities component indicates the physical activities that either cause or are limited by breathlessness. The impact component indicates factors affected by the illness such as employment and sense of control. The SGRQ has shown sufficient reliability and validity as a measure of impaired health among pulmonary patients (Jones et al., 1992). This measure exhibited adequate reliability (Cronbach’s alpha = .76), and is included in Appendix P.

Measures of Health Behaviors and Compliance:

1. The Health Behavior Questionnaire is a 31-item questionnaire that assesses the utilization of health behaviors. The following health behaviors were assessed in the questionnaire: smoking, eating, exercise, and illicit drug usage. The items were drawn from two valid and reliable measures of health behaviors, specifically the Health Behavior Inventory and Behavioral Risk Factor Surveillance System (Ransom-Flint & Mirels, 2005; U.S. Department of Health and Human Services, 2006). This measure is included in Appendix Q.

2. Seven-Day Physical Activity Recall (Blair, 1984) is an 8-item self-report measure that summarizes occupational and leisure activity during the prior seven days. Included in the instructions are examples of moderate, hard, and very hard physical activities. This measure is included in Appendix R.

3. Compliance was measured by examining the gradient of change in health behaviors over time. Compliance was defined by any amount of behavioral change in health outcomes in the expected direction (e.g., discontinuing smoking) at 6 month follow-up. Patients did not have to resolve the contraindication (free of tobacco use) at follow-up to be considered compliant.
Measures of Self-Efficacy for Health Behaviors:

1. Smoking Self-Efficacy Questionnaire (SEQ-12; Etter, Bergman, Humair, & Perneger, 2000) is a 12-item self-report questionnaire assessing the confidence of current and former smokers in their ability to abstain from smoking. The questionnaire consists of two sub-scales, with six items per scale. The first sub-scale is labeled “internal stimuli” and the second sub-scale is “external stimuli.” The responses range from ‘not at all sure’ to ‘absolutely sure.’ The SEQ-12 has demonstrated high internal consistency, test-retest reliability, and content, construct, and predictive validity (Etter et al., 2000). In this sample the internal consistency was adequate (Cronbach’s alpha = .87). This measure is included in Appendix S.

2. Weight Efficacy Lifestyle Questionnaire (WEL; Clark, Abrams, Niaura, Eaton, & Rossi, 1991) is a 20-item measure that assesses confidence about being able to successfully resist the desire to eat, rated on a 10-point scale ranging from 0 (not confident) to 9 (very confident). It consists of five situational factors: negative emotions, availability, social pressure, physical discomfort, and positive activities. The measure has shown adequate reliability and validity among both overweight and obese individuals (Clark et al., 1991). This measure also demonstrated adequate internal consistency (Cronbach’s alpha = .92). This measure is included in Appendix T.

3. Exercise Self-Efficacy Scale (Garcia & King, 1991) is 16-item measure of self-efficacy for exercise in a variety of situations. The responses range from 0% (I cannot do it at all) to 100% (Certain that I can do it). The scale has shown adequate
reliability and validity (Garcia & King, 1991) including in the present study (Cronbach’s alpha = .99). This measure is included in Appendix U.

Measures of Dispositional Optimism:

1. Life Orientation Test (LOT; Scheier & Carver, 1985) measures dispositional optimism with 13 items assessing an individual’s generalized outcome expectancies of future events. Items such as, “In certain times I usually expect the best,” and, “I hardly expect things to go my way,” are rated on a 5-point Likert scale ranging from ‘strongly disagree’ to ‘strongly agree.’ This measure has demonstrated sufficient internal consistency, test-retest reliability, and validity (Scheier & Carver, 1985). This measure demonstrated adequate internal consistency (Cronbach’s alpha = .85), and is included in Appendix V.

Lung transplant candidates completed pulmonary functioning testing and all self-report measures of coping, stress, psychological functioning, and quality of life. Lung transplant candidates placed ‘on hold’ for smoking, high or low weight, or low functional ability also completed assessments of health behaviors, dispositional optimism, and self-efficacy measures that corresponded to the health behaviors they were required to change in order to be eligible for transplantation. Primary caregivers completed all of the measures of coping, stress, and psychological functioning, in addition to the health-related quality of life measure (SF-36). The cover letter included with self-report questionnaires is included in Appendix W.
Data Analysis

Evaluation of study hypotheses was conducted in both cross-sectional data analyses and longitudinal data analyses, as described below.

Cross-Sectional Data Analysis

Due to positive skew in the distribution of negative religious coping, as measured by the RCOPE, log transformed data was utilized in analyses that included negative religious coping.

The study was initially designed to examine differences between patients and caregivers, specifically comparing “on hold” lung transplant candidates to their primary caregivers and “listed” lung transplant candidates to their primary caregivers. However, “on hold” candidates and their primary caregivers yielded similar findings to those of “listed” candidates and their primary caregivers when evaluating differences in coping and mental health outcomes at baseline. Also, the number of “on hold” lung transplant candidates recruited into the study was lower than expected reducing the sample size and power for the statistical analyses. Thus, data from “on hold” candidates and “listed” candidates were analyzed together, as were data from primary caregivers of both groups of patients.

Data Analyses among Patients versus Primary Caregivers:

Analysis of covariance (ANCOVA) was conducted to examine differences in coping (problem-focused, emotion-focused, humor, organizational religiosity, private religious practices) and mental health outcomes (perceived stress, depression, anxiety, physical quality of life, emotional quality of life) between patients and primary caregivers. Although “on hold” and “listed” lung transplant candidates did not differ on
demographic characteristics, “on hold” lung transplant candidates reported poorer pulmonary functioning, less RSC, and greater psychological distress than “listed” lung transplant candidates at baseline. Therefore, patient listing status (“on hold” versus “listed”) and length of time spent in the lung transplant process were controlled in all analyses that included both groups of patients.

Data Analyses among Patients:

Hierarchical regression analyses were utilized to evaluate the association between pulmonary functioning (FEV₁% predicted) and quality of life (physical quality of life, emotional quality of life, disease-specific quality of life) among patients. FEV₁% predicted was regressed onto patient listing status and length of time spent in the lung transplant process in step 1, followed by quality of life in step 2.

Pearson correlation analyses were conducted to examine the association of nonreligious coping (problem-focused, emotion-focused, and humor) with mental health outcomes (e.g., perceived stress, depression, anxiety, physical quality of life, and emotional quality of life) among patients. Pearson correlation analyses were also conducted to examine the degree of association among the RSC variables. In addition, Pearson correlation analyses were used to examine the association of RSC (positive religious coping, negative religious coping, religious beliefs, private religious practices, religious attendance, and deferring religious problem-solving) with mental health outcomes.

Hierarchical regression analyses were conducted to examine the association between nonreligious coping (problem-focused, emotion-focused, or humor) and mental health outcomes among patients. Five mental health outcomes (e.g., perceived stress,
depression, anxiety, physical quality of life and emotional quality of life) were regressed onto patient listing status and length of time spent in the lung transplant process in step 1, followed by nonreligious coping (problem-focused, emotion-focused, or humor) in step 2. A total of fifteen hierarchical regression analyses were conducted (3 indicators of nonreligious coping styles x 5 outcomes).

Prior research suggests that age, gender, income, and marital status may be confounded with the use of RSC and adjustment during stressful situations (Jenkins & Pargament, 1995). Also, dispositional optimism and self-efficacy may be confounded with the use of RSC and influence the relationship between RSC and mental health outcomes (Tarakeshaw, Vanderwerker, Paulk, Pearce, Kasl, & Prigerson, 2006; Callaghan, 2005; Contrada et al., 2004; Ai et al., 2002; Woods, Antoni, Ironson, & Kling, 1999). Pearson correlation analyses were conducted to evaluate the relationship of RSC with age, income, smoking self-efficacy, weight self-efficacy, exercise self-efficacy, and optimism. Analyses of variance (ANOVA) were conducted to examine the association of RSC with gender and marital status. Because negative religious coping, as measured by the RCOPE, was negatively associated with age (r = -.48, p < .01) among patients, age was entered in the first step of all hierarchical regression analyses that included negative religious coping.

Hierarchical regression analyses were conducted to examine the association between RSC and mental health outcomes among patients. Five mental health outcomes (e.g., perceived stress, depression, anxiety, physical quality of life and emotional quality of life) were regressed onto patient listing status and length of time spent in the lung transplant process in step 1, followed by six indicators of RSC (e.g., positive religious
coping, negative religious coping, religious beliefs, private religious practices, religious attendance, and deferring religious problem-solving) in step 2. A total of 30 regressions were conducted (6 indicators of RSC x 5 outcomes).

**Data Analyses among Caregivers:**

 Pearson correlation analyses were conducted to examine the association between nonreligious coping and RSC with mental health outcomes among caregivers. Procedures for analyzing the RSC and demographic characteristics relationships among caregivers were the same procedures utilized to evaluate these relationships among patients. Religious and spiritual coping was not associated with any demographic characteristics among caregivers.

**Data Analyses among Patient and Caregiver Dyads:**

 A principle aim of the present study was replication of the study by Myaskovsky and colleagues (2005) examining the reciprocal relationship of nonreligious coping and mental health outcomes among patient and caregiver dyads. Myaskovsky et al. (2005) utilized factor analysis to identify a five-factor model for the COPE Questionnaire. This five factor model of nonreligious coping was utilized in the present study. Three canonical correlation analyses were conducted to examine the interrelationship of nonreligious coping (e.g., active, support, avoidant, acceptance, and self-blame) and quality of life (physical quality of life, emotional quality of life, and disease-specific quality of life) among patient-caregiver dyads at baseline. The canonical correlation analyses also included patient listing status and length of time in the transplant process.

 Hierarchical regression analyses were conducted to examine the interrelationship of nonreligious coping, depression, and anxiety among patient-caregiver dyads. Two
patient mental health outcomes (e.g., depression, anxiety) were regressed onto patient listing status and length of time spent in the transplant process in step 1, followed by five caregiver nonreligious coping factors (e.g., active, support, avoidant, acceptance, and self-blame) in step 2. Thus, a total of ten regressions were conducted (5 nonreligious coping styles x 2 outcomes). To address patient predictors of caregiver distress, depression and anxiety were regressed onto patient listing status and length of time spent in the transplant process in step 1, followed by five patient nonreligious coping factors (e.g., active, support, avoidant, acceptance, and self-blame) in step 2. A total of ten regressions were conducted (5 nonreligious coping styles x 2 outcomes).

Hierarchical regression analyses were conducted to investigate the relationship between patient RSC (e.g., negative religious coping and self-directing religious problem-solving style) and caregiver mental health. Negative religious coping and self-directing religious problem solving style were the only RSC styles utilized in these analyses because the present study aimed to examine the negative aspects of RSC. Four caregiver mental health outcomes (e.g., depression, anxiety, physical quality of life and emotional quality of life) were regressed on patient listing status and length of time spent in the transplant process in step 1, followed by patient RSC in step 2. A total of eight regressions were conducted (2 indicators of RSC x 4 mental health outcomes).

Hierarchical regression analyses were used to evaluate the association between patient psychological functioning and caregiver psychological functioning among patient-caregiver dyads. Two mental health outcomes (e.g., depression, anxiety) among patients were regressed onto patient listing status and length of time spent in the transplant
process in step 1, followed by caregiver mental health outcomes (e.g., depression, anxiety) in step 2. A total of two regressions were conducted.

*Data Analyses among “On hold” versus “Listed” Lung Transplant Candidates:*

ANCOVAs were conducted to examine differences in coping (both nonreligious coping and RSC) and mental health outcomes between “on hold” lung transplant candidates and “listed” lung transplant candidates. Length of time spent in the lung transplant process and disease severity (FEV$_1$/FVC ratio) were controlled in all analyses. The FEV1/FVC ratio is the recommended measure of disease severity according to the Global Initiative for COPD (GOLD; Rabe, Hurd, Anzueto, Barnes, Buist, Calverley, et al., 2007), and it is utilized for both clinical and research purposes (Ståhl et al., 2005). In addition, the lung allocation score is calculated using FVC and not FEV1% predicted, thus, the measure of disease severity among lung transplant candidates should take into account FVC.

*Data Analyses among “On hold” Lung Transplant Candidates:*

Pearson correlation analyses were conducted to examine the association between self-efficacy, optimism, and weight at time 1. The association of tobacco use with self-efficacy and optimism could not be examined at baseline because no patients reported tobacco use at time 1.

**Longitudinal Data Analysis**

*Data Analyses among Patients:*

Multiple regression analyses were conducted to examine the association between change in nonreligious coping (problem-focused, emotion-focused, and humor styles) and change in mental health outcomes. Change scores were calculated for each of the
nonreligious coping factors over time. Five mental health outcomes (e.g., perceived stress, depression, anxiety, physical quality of life and emotional quality of life) at 6-month follow-up were regressed onto patient listing status, length of time spent in the transplant process, baseline mental health outcomes, and the change score of nonreligious coping. A total of fifteen multiple regression analyses were conducted (3 indicators of nonreligious coping styles x 5 outcomes).

There are a few concerns regarding the use of change scores including low reliability and negative correlation between change and initial status (Lacey & Lacey, 1962; Cronbach & Furby, 1970). However, recent research has shown that change scores are not unreliable, particularly when there are moderate test-retest reliabilities and individual differences in change exist (Rogosa, 1988; 1995). Low reliability of change scores is a reflection of an absence of change (Rogosa, 1995). In addition, change scores are not always negatively associated with initial status, but the association between change scores and initial status largely depends on the timing of the initial assessment (Rogosa & Willett, 1985). Change scores were utilized in the present study because it is a common way to examine change in longitudinal research with two time points.

Multiple regression analyses also were conducted to examine the association between change in RSC coping and change in mental health outcomes. Change scores were calculated for each of the RSC styles over time. Five mental health outcomes (e.g., perceived stress, depression, anxiety, physical quality of life and emotional quality of life) at 6-month follow-up were regressed onto patient listing status, length of time spent in the transplant process, baseline mental health outcomes, and change in six RSC styles (e.g., positive religious coping, negative religious, coping, private religious practices,
religious attendance, intrinsic religiosity, and deferring religious problem-solving). A total of thirty regressions were conducted (6 indicators of RSC x 5 outcomes).

Four repeated measures analyses of variance were conducted to examine change over time in pulmonary functioning (FEV₁, FVC, FEV₁/FVC ratio) and weight with listing status (“on hold” versus “listed”) as a between subjects factor.

Data Analyses among Caregivers:

Regression analyses were conducted to examine the association between change in nonreligious coping and change in mental health outcomes, as well as the association between change in RSC and change in mental health outcomes. Data analyses among caregivers followed the same procedure as described above for patients (without listing status and days spent in the transplant process in step 1).

Data Analyses among “On hold” Lung Transplant Candidates:

Descriptive statistics were used to document health behaviors at time 1 and time 2. Repeated measures ANOVA was used to examine change in weight over time among “on hold” lung transplant candidates using time 1 and time 2 assessments. In addition, multiple regression analyses were used to predict weight at time 2 from self-efficacy and dispositional optimism at time 1. Tobacco use was not examined in the repeated measures ANOVA or multiple regression analyses because no patients reported tobacco use at time 1 or time 2. A total of two regression analyses were conducted.

Missing Data:

Ipsative mean imputation was used to replace missing values when less than ten percent of item responses were missing from any measure. Four participants, two patients and two caregivers, did not complete the time 2 packets of self-report questionnaires.
Multiple imputation methodology was used to estimate missing data for these four participants to evaluate change in coping and mental health outcomes over time among patients and primary caregivers. A linear regression model was used to impute continuous, binary, or categorical missing values. The Markov Chain Monte Carlo (MCMC) method was utilized with 8 imputations, 100 default iterations, and 200 burn-in iterations to create 8 completed data sets using baseline and time 2 data. Standard statistical techniques were utilized to assess separately each of the 8 imputed data sets. The results were then combined to obtain the overall results for the multiple imputed data and to make valid statistical inferences. The final parameter estimates were averages of the estimates from the 8 imputed data sets, and the associated standard errors accounted for both within-and between-imputation variance. The multiple imputation procedures were conducted in SAS version 9.1.3 (SAS Institute, Cary, NC).
CHAPTER 3

RESULTS

The primary diagnosis among lung transplant candidates was COPD, they had severe pulmonary obstruction, and they required an average of 3.0 (SD ±1.3) liters of supplemental oxygen per minute, as shown in Table 2. Lung transplant candidates experienced mild symptoms of depression and anxiety as well as impaired quality of life, as shown in Table 3. Twenty-two lung transplant candidates were placed “on hold” for remediable contraindications including 6 patients for smoking (despite the fact that none of them acknowledged smoking), 11 patients for obesity, 3 patients for poor functional capacity in pulmonary rehabilitation, and 2 patients for consuming alcohol excessively at baseline. Primary caregivers experienced minimal depressive and anxiety symptoms, and no impairment in quality of life, as shown in Table 3.

Pearson correlation analyses were utilized to examine the association of nonreligious coping (e.g., problem-focused coping, emotion-focused coping, and humor) with mental health outcomes among lung transplant candidates at baseline. Greater use of emotion-focused coping was associated with greater emotional distress including perceived stress, depression, and anxiety, as shown in Table 4. Problem-focused coping and humor were not significantly associated with any mental health outcomes. Pearson correlation analyses were also conducted to examine the association among RSC variables in patients. All of the RSC variables including positive religious coping,
organizational religiosity, private religious activity, intrinsic religiosity, and deferring religious problem-solving style were positively inter-correlated except negative religious coping, as shown in Table 5. Negative religious coping was not significantly associated with any of the RSC variables among patients. Pearson correlation analyses were also conducted to examine the association of RSC with mental health outcomes among patients. Negative religious coping was positively associated with depression, as shown in Table 6. In addition, greater intrinsic religiosity and deferring religious problem-solving style were associated with less depressive symptoms among patients.

Cross-Sectional Analyses

Coping and Mental Health among Patients versus Caregivers:

It was hypothesized that lung transplant candidates would utilize less organizational religiosity and more nonreligious coping strategies and private religious practices than primary caregivers. Analyses of covariance revealed that patients did not differ from primary caregivers in their use of organizational religiosity, nonreligious coping, and private religious practices at time 1. Also, it was hypothesized that patients would report poorer quality of life, specifically physical functioning, and similar levels of stress and psychological functioning compared to primary caregivers. Analyses of covariance, controlling for patient listing and patient length of time spent in the transplant process, revealed that patients and primary caregivers reported similar levels of stress and emotional quality of life at time 1, but patients reported greater depression ($F_{3,66} = 4.98, p < .01$) and anxiety ($F_{3,64} = 6.69, p < .01$), as well as poorer physical quality of life ($F_{3,62} = 30.13, p < .01$) than primary caregivers, as shown in Table 6. Due to significant differences in physical quality of life between patients and primary caregivers, eight post-

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hoc ANCOVA analyses were conducted to examine differences between patients and caregivers on the eight SF-36 subscales. Analyses revealed significant differences in physical functioning ($F_{3, 66} = 48.42, p < .01$), role-functioning physical ($F_{3, 67} = 9.75, p < .01$), social functioning ($F_{3, 65} = 2.72, p = .05$), vitality ($F_{3, 67} = 3.34, p = .02$), and general health perception ($F_{3, 66} = 21.49, p < .01$).

**Nonreligious Coping and Mental Health among Patients:**

Emotion-focused coping was hypothesized to be negatively associated with quality of life and psychological well-being among patients. It was expected that problem-focused coping and humor would be positively associated with psychological well-being among patients. The results demonstrated that problem-focused coping, emotion-focused coping, or humor were not associated with quality of life among patients. Hierarchical regression analyses, controlling for patient listing status and patient length of time spent in the transplant process, indicated that emotion-focused coping was positively associated with stress ($F_{3, 30} = 3.11, p = .04$) and depression ($F_{3, 29} = 4.75, p < .01$) among patients as shown in Tables 7-8. Problem-focused coping and humor were not associated with psychological well-being.

**Religious/Spiritual Coping and Mental Health among Patients:**

It was expected that positive religious coping, religious beliefs, prayer, and deferring religious problem-solving styles would be associated with better psychological well-being and quality of life; and negative religious coping would be associated with poorer psychological functioning and quality of life among patients. The results provided limited support for these hypotheses. Negative religious coping, as measured by the RCOPE, was positively associated with depression ($F_{4, 27} = 3.22, p = .02$) and negatively
associated with physical quality of life (F\textsubscript{4,25} = 3.15, p = .02), particularly physical functioning (F\textsubscript{4,28} = 3.29, p = .01), as shown in Tables 9-11. Other forms of RSC, including positive religious coping, private religious activity, religious beliefs, and deferring religious problem solving styles were not associated with psychological well-being or quality of life among patients.

**Pulmonary Functioning and Quality of Life among Patients:**

Pulmonary functioning, specifically FEV\textsubscript{1} % predicted, was expected to be positively associated with health-related and disease-specific quality of life among patients. Results indicated no association between pulmonary functioning and either health-related quality of life or disease-specific quality of life among patients.

**Nonreligious Coping and Mental Health among Caregivers:**

It was hypothesized that emotion-focused coping would be associated with poorer quality of life among primary caregivers. Pearson correlation analyses revealed that emotion-focused coping (r = -.39, p = .02) and humor (r = -.42, p = .01) were associated with lower emotional quality of life among caregivers, as shown in Table 12. Problem-focused coping was not associated with emotional quality of life among caregivers, and problem-focused coping, emotion-focused coping, and humor were not associated with physical quality of life among caregivers.

**Religious/Spiritual Coping and Mental Health among Caregivers:**

It was hypothesized that positive religious coping, religious beliefs, prayer, and deferring religious problem-solving styles would be associated with better psychological well-being and quality of life, and negative religious coping would be associated with poorer psychological functioning and quality of life among caregivers. Negative religious
coping, as measured by the RCOPE, was positively associated with perceived stress ($r = .45, p < .01$), depression ($r = .36, p = .03$), and anxiety ($r = .35, p = .03$) among caregivers, as shown in Table 13. Other RSC strategies (e.g., positive religious coping, private religious activity, religious beliefs, and deferring religious problem solving styles) were not associated with psychological well-being or quality of life among caregivers.

Reciprocal Relationship of Nonreligious Coping and Mental Health among Patient-Caregiver Dyads:

Patient nonreligious coping, specifically greater self-blame and less active, support-seeking, and acceptance coping, was hypothesized to be associated with poorer quality of life among primary caregivers, particularly poorer general health and physical functioning. Caregiver nonreligious coping was not expected to be associated with patient psychological functioning and quality of life, but caregiver mental health outcomes were expected to be positively associated with patient mental health outcomes.

Canonical correlation analyses were conducted to evaluate the interrelationship of dyad mental health outcomes and nonreligious coping strategies at time 1. Three canonical correlation analyses were performed including: (a) patient nonreligious coping strategies with caregiver quality of life measures (using the component scores of the SF-36); (b) caregiver nonreligious coping strategies with patient quality of life measures (including both the SF-36 and the St. George’s Respiratory Questionnaire); and (c) the patient quality of life measures with the caregiver quality of life measures (using the component scores of the SF-36).

Patient non-religious coping strategies were not associated with caregiver quality of life, but results indicated a significant correlation of caregiver nonreligious coping
strategies with patient quality of life ($F_{21,63.7} = 2.11, p = .01$), as shown in Table 14. The caregiver nonreligious coping variant included an emphasis on active coping while using less support, avoidant, acceptance, and self-blame coping strategies, and was related to emotional quality of life of patients. Also, there was a significant correlation of patient quality of life with caregiver quality of life ($F_{8, 50} = 2.48, p = .02$), as shown in Table 15. The patient quality of life variant included an emphasis on emotional quality of life while using less physical quality of life, and was related to emotional quality of life of caregivers.

Hierarchical regression analyses, controlling for patient listing status and patient length of time spent in the transplant process, revealed that greater self-blame ($F_{7,26} = 5.50, p < .01$) and active ($F_{7,26} = 5.50, p = .02$) coping among caregivers was associated with higher levels of depression among patients. Also, greater self-blame coping among caregivers was associated with greater anxiety ($F_{2,35} = 13.52, p < .01$) among patients. In addition, caregiver depression was positively associated with patient depression ($F_{3,30} = 5.53, p < .01$), and caregiver anxiety was positively associated with patient anxiety ($F_{3,28} = 6.55, p < .01$).

*Religious/Spiritual Coping and Mental Health among Patient-Caregiver Dyads:*

It was hypothesized that patient negative religious coping and self-directing problem-solving style would be negatively associated with primary caregiver psychological and physical functioning. Hierarchical regression analyses, controlling for patient listing, patient length of time spent in the transplant process, and age, revealed that negative religious coping and self-directing problem-solving style among patients were not associated with caregiver psychological and physical functioning.
Coping and Mental Health between “On hold” Candidates and “Listed” Candidates:

“On hold” lung transplant candidates were hypothesized to report using more coping strategies, including both nonreligious coping and RSC, and were expected to exhibit greater stress, depression, and anxiety compared to “listed” lung transplant candidates. “On hold” lung transplant candidates also were hypothesized to report similar levels of quality of life compared to “listed” lung transplant candidates. Analyses of covariance, controlling for length of time spent in the transplant process, indicated that “on hold” lung transplant candidates reported less religious attendance ($F_{2,32} = 5.60, p < .01$) compared to “listed” lung transplant candidates at time 1. However, “on hold” and “listed” lung transplant candidates reported using similar levels of other RSC strategies and nonreligious coping at time 1, as shown in Table 16. “On hold” lung transplant candidates also reported greater anxiety ($F_{2,30} = 5.64, p < .01$) than “listed” lung transplant candidates, but there were no differences in levels of stress, depression, or quality of life at time 1, as shown in Table 16.

Longitudinal Analyses

Change in Pulmonary Functioning over Time among Patients

Repeated measures analysis of variance revealed that patients did not experience any changes in pulmonary functioning ($FEV_1$, FVC, $FEV_1$/FVC ratio) between baseline and the 6-month follow up.

Association of Change in Coping with Change in Mental Health among Patients:
It was hypothesized that increased use of emotion-focused coping and negative religious coping would be associated with worse mental health outcomes (e.g., stress, psychological functioning, quality of life) from baseline to 6-month follow-up among patients, whereas increased use of problem-focused coping and humor would be associated with better mental health. Also, it was expected that use of specific RSC styles (e.g., positive RSC, religious beliefs, prayer, and deferring religious problem-solving) would be associated with improved mental health outcomes (e.g., stress, psychological functioning, quality of life). Multiple imputation methodology was employed to account for missing data, particularly among patients who did not complete time 2 assessments. Less emotion-focused coping over time was associated with less perceived stress ($b = .44, \text{SE} = .08, p < .01$), depression ($b = .33, \text{SE} = .09, p < .01$), anxiety ($b = .24, \text{SE} = .10, p = .02$), and greater emotional quality of life ($b = -.35, \text{SE} = .09, p < .01$) among patients, as shown in Tables 17-20. Change in problem-focused coping and humor were not associated with change in mental health among patients. Decreased positive religious coping was associated with poorer emotional quality of life ($b = .29, \text{SE} = .09, p < .01$) over time among patients, as shown in Table 21. However, most RSC strategies (e.g., negative religious coping, private religious activity, religious attendance, intrinsic religiosity, and deferring) were not associated with change in mental health outcomes (e.g., perceived stress, depression, anxiety, or quality of life) over time among patients.

Association of Change in Coping with Change in Mental Health among Caregivers:

It was hypothesized that increased use of emotion-focused coping and negative religious coping would be associated with worse mental health, whereas increased use of problem-focused coping, humor, and the other RSC styles would be associated with
better mental health (stress, psychological functioning, quality of life) from baseline to 6-month follow-up among primary caregivers. Multiple imputation methodology was employed to account for missing data, particularly among primary caregivers who did not complete time 2 assessments. Reduced emotion-focused coping was associated with less perceived stress ($b = .46, \ SE = .08, p < .01$), depression ($b = .35, \ SE = .09, p < .01$), anxiety ($b = .23, \ SE = .10, p = .02$), and physical quality of life ($b = .14, \ SE = .07, p = .04$) among caregivers, as shown in Tables 21-25. Greater emotional quality of life was associated with less emotion-focused coping ($b = -.38, \ SE = .10, p < .01$) among caregivers, as shown in Table 26. Greater negative religious coping was associated with greater depression ($b = .24, \ SE = .09, p = .01$) over time, as shown in Table 27. Decreased positive religious coping was associated with poorer emotional quality of life ($b = .26, \ SE = .10, p = .01$) over time, as shown in Table 28. Change in other RSC strategies (e.g., negative religious coping, private religious activity, religious attendance, intrinsic religiosity, and deferring) was not associated with mental health outcomes (e.g., perceived stress, depression, anxiety, or quality of life).

*Health Behaviors and Compliance among “On hold” Candidates:*

High perceived self-efficacy and dispositional optimism were expected to be associated with endorsing positive health behaviors among “on hold” lung transplant candidates at time 1, but self-efficacy and dispositional optimism were not associated with weight at time 1.

It was hypothesized that “on hold” lung transplant candidates would utilize more positive health behaviors at 6-month follow-up than at baseline, and that they would comply with recommendations that they alter their health behaviors. All “on hold” lung
transplant candidates denied tobacco use at time 1 and time 2. Most “on hold” patients (63.6%) were trying to lose weight at time 1, and all of the patients were still trying to lose weight at time 2. Mean weight was 179.99 (SD±54.7) pounds at baseline and 177.3 (SD±55.1) pounds at time 2. Thus, despite efforts to lose weight, there was no significant change in weight during the 6-month period. At time 1, 41% of patients “on hold” for obesity reported being on a diet, 76% reported eating less fat or carbohydrates, 37% reported using physical activity or exercise, and 5% reported participating in a weight management program to lose weight. At time 2, 33% of patients reported being on a diet, 67% reported eating less fat or carbohydrates, 43% reported using physical activity or exercise, and 14% of patients reported participating in a weight management program to lose weight. Although only two patients were placed “on hold” for alcohol use, five patients reported consuming alcohol at time 1 and time 2. Among the two patients who were placed ‘on hold’ for alcohol use at time 1, one patient reported consuming ‘6 to 10 drinks per week’ and the other patient reported consuming ‘20 or more drinks per week.’ Although patients were not placed “on hold” for illicit drug use, one patient reported illicit drug use at both time 1 and time 2. The patient reported ‘daily’ illicit drug use at time 1, but did not specify the frequency of illicit drug use at time 2. In general, patients who were placed ‘on hold’ were not compliant at time 2 regarding abstaining from alcohol or successful weight loss.

It was hypothesized that high perceived self-efficacy and dispositional optimism at baseline would predict weight at follow-up. Regression analyses revealed that dispositional optimism, weight self-efficacy, and exercise self-efficacy at baseline did not predict weight at time 2.
CHAPTER 4
DISCUSSION

Results of this study provide novel data pertaining to the relationship of coping and mental health among patients being evaluated for lung transplant and their caregivers. The most salient findings include (1) patients and caregivers reported similar coping styles, (2) negative religious coping was associated with greater psychological distress and physical quality of life among patients and primary caregivers, (3) humor was negatively associated with emotional quality of life, (4) “on hold” lung transplant candidates reported less organizational religiosity and greater anxiety compared to “listed” lung transplant candidates, and (5) all “on hold” lung transplant candidates denied tobacco use at time 1 and time 2 despite biological markers indicating that several of the “on hold” candidates were still using tobacco.

In contrast to prior research (Myaskovsky et al., 2005; Benjamins et al., 2003), this study indicated that patients with end-stage pulmonary disease and their primary caregivers use similar levels of problem-focused, emotion-focused, humor, and RSC styles. However, despite similar levels of coping strategies, patients reported greater distress and poorer quality of life than caregivers. Also, the relationship of coping to mental health differed between patients and caregivers. For example, nonreligious coping styles were not associated with quality of life among patients, but emotion-focused coping and humor were associated with lower emotional quality of life among caregivers.
Although the absence of a significant association between nonreligious coping and
quality of life among patients was inconsistent with prior studies (Burker, Madan, Evon,
Finkel, & Mill, 2009; Taylor, Smith, Babyak, Barbour, Hoffman, Sebring, Davis, Palmer,
Keefe, Carney, Csik, Freedland, & Blumenthal, 2008; Myaskovsky et al., 2005;
Myaskovsky et al., 2003), the association between nonreligious coping and quality of life
may vary as a function of native lung disease. For example, Taylor and colleagues (2008)
found that problem-focused coping was associated with better physical quality of life
among patients with COPD, but not among patients with cystic fibrosis. The current
study included primarily patients with COPD, but there may have been additional
disease-related factors (e.g., treatment regimens, dependence on others) contributing to
the lack of association between nonreligious coping and quality of life. The current
findings indicate that the research literature examining coping among transplant
candidates and caregivers must expand beyond examining coping differences between
groups and focus on enhancing coping strategies among patients and caregivers.

Prior studies of religion and mental health have documented mental health
benefits of RSC with little attention focused on components of RSC that are associated
with poorer mental health. As observed among heart and stem cell transplant patients and
medically ill adults (Sherman, Plante, Simonton, Latif, & Anaissie, 2009; Sherman et al.,
2005; Koenig et al., 1998), negative religious coping in this study was associated with
psychological distress among both lung transplant candidates and primary caregivers, as
well as worse physical quality of life among lung transplant candidates. The relationship
of negative religious coping with poorer mental health warrants further investigation to
identify strategies that may minimize the negative mental health effects of negative RSC
or to identify strategies for modifying negative RSC. In addition, these findings underscore the importance of evaluating all aspects of RSC among lung transplant patients. According to Sulmasy (2009), health care professionals are often in the best position to ask patients and caregivers about religious and spiritual concerns and can make appropriate referrals to chaplains or clergy for pastoral counseling. It may be beneficial to identify patients and caregivers who may be experiencing a religious struggle early during the transplant process to minimize the effects of religious conflict on psychological well-being and quality of life. The moderate association between negative religious coping and depression may also reflect religious struggle that occurs in the context of depression which could indicate further reasoning to address religious concerns in the context of psychological assessment and intervention.

Findings regarding humor have been equivocal. Humor has been associated with reduced depression among mothers of pediatric bone-marrow transplant patients (Manne et al., 2003; Cupples, Nolan, Augustine, & Kynoch, 1998; Porter, Krout, Parks, Gibbs, Luers, Nolan et al., 1994). However, in the present sample of caregivers and in patients with head and neck cancer patients (Aarstad, Aarstad, & Olofsson, 2008; Aarstad et al., 2005) humor was associated with worse emotional quality of life. Also prior research has found that during serious medical encounters, patients were not receptive to physician use of humor (Penson, Partridge, Rudd, Seiden, Nelson, Chabner, & Lynch, 2005). Humor may not have been an effective strategy among caregivers in the present study due to profound consequences of possible outcomes (e.g., death or transplant) for the caregiver’s life. The present study provides further evidence that humor is not consistently associated
with better mental health and emphasizes the need to better understand humor, particularly instances in which humor is maladaptive.

No prior study has examined “on hold” lung transplant candidates or evaluated differences in coping and mental health between “on hold” and “listed” lung transplant candidates. In the present study, “on hold” and “listed” lung transplant candidates had severe pulmonary disease, as expected, but “on hold” lung transplant candidates had poorer lung function than “listed” lung transplant candidates. This observation is unique in documenting physical health differences between listed and on hold patients. The only prior study examining differences between “on hold” and “listed” transplant patients found no significant physical health differences (e.g., left ventricular ejection fraction – the capacity at which an individual’s heart is pumping) between on hold and listed heart transplant candidates. Further research is needed to explain how these physical health differences prior to transplant impact post-transplant physical health and survival.

Although it is expected that lung transplant candidates may experience decreased overall participation in activities (including attending religious services), reduced attendance at religious activities among “on hold” candidates compared to “listed” candidates may reflect a greater religious struggle among “on hold” patients or it may be a reflection of the greater functional impairment among “on hold” patients. According to Benjamins and colleagues (2003), older adults with declining health tend to decrease their use of organizational religiosity (religious attendance).

Greater anxiety among “on hold” candidates compared to “listed” candidates may be due to “on hold” candidates having to wait an extended period of time until they resolve their remediable contraindication to transplant prior to being listed. In addition,
greater anxiety among “on hold” candidates prior to transplantation may contribute to worse survival outcomes among “on hold” patients. These findings further highlight the importance of studying “on hold” and “listed” candidates in a longitudinal investigation with pre and post-transplant data.

There were no significant changes in health behaviors over time among “on hold” candidates in the present study. Two patients who were “on hold” were eventually listed for transplant, one of whom was “on hold” for smoking and another who was “on hold” for obesity. Two participants were not listed at follow-up due to continued tobacco use, despite their self-report that they were not smoking. One of the two was also drinking alcohol excessively. The discrepancy between patients’ self-report of tobacco use and their documented tobacco use (via biological makers) poses an interesting challenge. Patients are informed at the beginning of the transplant evaluation that tobacco use is a remediable contraindication to transplant and that they must be tobacco free for at least 6 to 12 months prior to being listed for transplant (Evon, Burker, Sedway, Cicale, Davis, & Egan, 2005). Therefore, patients occasionally deny their tobacco use out of fear of not being listed. Transplant programs typically require patients to complete a urinalysis to screen for cotinine to provide documentation of their abstinence. In the present study, no patient reported tobacco use at time 1 or time 2. Therefore, urinalyses to screen for tobacco use or other substances may be the only reliable method of determining smoking status among pre-transplant patients.

The discrepancy in reported tobacco use also reflects the difficulty patients may experience in changing a health behavior that is required to be listed for transplant. It is unclear if participants in the present study were unwilling to discontinue tobacco use or
attempted to quit but had difficulty doing so. There is limited research on tobacco use and compliance among lung transplant candidates, and the findings of the present study emphasize the importance of understanding health behaviors, compliance, and self-efficacy among transplant patients. Furthermore, continued tobacco use by some of the patients draws attention to the need for effective resources and strategies to help patients resolve contraindications to transplant, especially tobacco use.

Although most “on hold” patients were trying to lose weight, there were no significant changes in weight over time, despite reported changes in diet and participation in regular physical activity. There are multiple explanations for this finding. The 11 patients placed “on hold” for obesity reported ‘eating less calories’ or ‘eating less fat or carbohydrates’ to lose weight, as well as ‘using physical activity or exercise’ to lose weight. However, patients were not asked to indicate how much they changed their diet or physical activity level. It is possible that they may not have changed health behaviors enough to result in significant weight loss. In addition, less than one quarter of the sample reported participating in a weight loss program at baseline, and no patients reported participating in a weight loss program at follow-up. These data on weight management are unique in reflecting the difficulty pre-lung transplant patients experience in reducing weight, despite clear instructions to do so. This is a potential area for further research to examine strategies employed for weight loss in this population.

Additional findings of interest in this study include: (1) quality of life differences between patients and primary caregivers, (2) absence of association between pulmonary functioning and quality of life among patients, (3) association between mental health and both nonreligious coping and RSC among patients and primary caregivers, (4)
interrelationship of coping and mental health among patient-caregiver dyads, (5) change in coping and mental health over time among patients and caregivers, and (6) the association between optimism, self-efficacy, health behaviors and compliance among “on hold” lung transplant candidates.

The results of the present study are consistent with prior research indicating that patients evaluated for lung transplant surgery have poorer physical quality of life than caregivers but similar mental health and emotional quality of life, as assessed by the SF-36 (Myaskovsky et al., 2005). However, the current study indicated greater symptoms of depression and anxiety among patients, suggesting that general measures of emotional quality of life (such as the SF-36 mental health subscale) may not adequately reflect symptom differences between patients and caregivers.

The present findings were inconsistent with prior data indicating an association of FEV1% with health-related and disease-specific quality of life among patients (Riekert et al., 2007; Ståhl et al., 2005; Engström et al., 2001). Prior studies documenting the association between pulmonary functioning and quality of life focused on patients with severe disease, but not lung transplant candidates. The range of pulmonary function values in the present study was relatively restricted due to the severity of illness, thereby limiting the possible correlations with quality of life.

The findings of the current study are generally consistent with prior literature indicating that emotion-focused coping is associated with more psychological distress among patients and caregivers (Myaskovsky et al., 2003; 2005; Burker et al., 2004). Thus, reduction of emotion-focused coping may be beneficial for both patients and
caregivers, and coping interventions should focus on increasing problem-focused coping styles and reducing emotion-focused coping styles among patients and caregivers.

Private religious practices, religious beliefs, and religious problem-solving styles have been associated with better mental health among surgery populations (Contrada et al., 2004; Sears et al., 1997; Harris et al., 1995), but did not appear to be beneficial in this study. There are two possible reasons for the discrepancy in these results. First, prior research examined the relationship between RSC and mental health outcomes among post-transplant patients rather than pre-transplant patients, and research has shown that psychological well-being and quality of life significantly improve after transplant regardless of coping (Rodrigue et al., 2005; Cohen et al., 1998; Tix & Frazier, 1998; Harris et al., 1995). Second, this study used psychometrically sound measures of RSC, and prior studies have rarely utilized psychometrically sound measures of RSC (Kurz & Cavanaugh, 2001).

No prior studies have examined the interrelationship of coping and mental health among patient-caregiver dyads. The positive association between caregiver psychological well-being and patient psychological well-being in this study suggests that interventions focused on improving psychological well-being may need to include both patients and caregivers.

This was the first study examining the relationship of patient RSC with caregiver mental health. The null results may have occurred due to low power or they may reflect a true absence of association. Future research is needed to further examine this relationship in a larger sample.
Longitudinal findings of an association between nonreligious coping (e.g., emotion-focused coping) and mental health (e.g., emotional quality of life) over time are generally consistent with the cross-sectional findings of the present study and prior cross-sectional research studies among patients and caregivers (Myaskovsky et al., 2003; 2005; Burker et al., 2004a). Study results also support the importance of reducing emotion-focused coping and humor and may suggest that coping interventions should be directed toward both the patient and the caregiver.

Prior research has not examined the relationship of change in RSC and mental health outcomes over time. Although the positive association between negative religious coping and psychological distress was observed among caregivers, it was not evident among patients. Thus, religious conflict among patients may be resolved with time and may only acutely impact psychological well-being. In addition, several RSC styles were associated with psychological distress and emotional quality of life over time but were not related to mental health at baseline. These findings suggest that some RSC styles, particularly positive religious coping (a secure relationship with God) and deferring religious problem-solving (God being solely responsible for the problem-solving process) may not immediately impact psychological well-being and emotional quality of life in the presence of a stressor, but may affect mental health over time. The findings of the present study warrant further longitudinal research to better understand the relationship of RSC with mental health.

Self-efficacy and dispositional optimism were not associated with weight at baseline and did not predict weight loss or change in weight at follow-up. These findings should be interpreted cautiously due to the small sample size. Eleven patients were placed
“on hold” for obesity. Additional research examining the relationship of self-efficacy and optimism with weight and compliance among transplant patients is needed in light of the fact that patients are often placed on hold due to poor health behavior and resuming the poor health behavior post-transplant could have negative health implications.

Limitations

There were several limitations of the present study. First, the sample size of the study was relatively small. A priori power analyses indicated that a larger sample (n = 48) was needed to examine the association between RSC and mental health outcomes. Also, the association between health behaviors, compliance, and self-efficacy could not be adequately examined due to the small number of participants in the study who were placed “on hold” for tobacco use and obesity. Understanding this relationship is imperative among transplant patients because noncompliance is a major concern both pre and post-transplant due to possible effects on health (e.g., rejection, survival) and the potential relevance for determining appropriateness of candidates for transplantation.

In addition, numerous statistical analyses were conducted in the present study, and the reported findings did not include a correction to limit spurious findings. A Bonferroni correction was not applied to the reported findings because of the multiple concerns regarding using a Bonferroni correction, including (1) statistical comparisons interpreted differently based on the number of tests conducted; (2) risk of type II error not reduced; (3) meaningful results may be ignored due to the correction; and (4) the Bonferroni correction may be overly conservative (Perneger, 1998). Due to the large number of statistical comparisons, the findings examining the relationship between
nonreligious coping, RSC, and mental health among patients and caregivers, and the interrelationship of coping and mental health among patient-caregiver dyads, should be interpreted cautiously.

The present study also did not document the number of hours each caregiver spent performing caregiving duties. The responsibilities of the caregiver and the time spent in caregiver activities are likely to differ based upon the patient’s physical functioning. Although all of the patients in this study had end-stage pulmonary disease and reported impairments in quality of life, each participant’s physical functioning in daily activities likely varied. Therefore, primary caregivers of some patients may have had greater responsibilities and time commitments to caregiving duties than did others which, in turn, may impact their utilization of coping strategies and their psychological well-being. Documentation of the number of hours each caregiver spent performing caregiving duties in this study could help explain the levels of psychological distress (e.g., depression, anxiety) among caregivers.

**Future Directions**

This study extends the research literature on lung transplant candidates, caregivers, and the association of problem-focused coping, emotion-focused coping, humor, and RSC with mental health. First, “on hold” candidates experienced more psychological distress than “listed” candidates. This study supplements the findings of Lewis and colleagues (2004) and highlights the significance of further studying “on hold” and “listed” lung transplant candidates longitudinally. In addition, the apparent continued tobacco use among “on hold” lung transplant candidates underscores the difficulty that some patients have adhering to health recommendations even when faced with the
possibility of being denied surgery. Research examining compliance among lung transplant patients has primarily focused on post-transplant patients, but additional research is needed to examine compliance and health behaviors prior to transplant.

The literature on religion and health focuses primarily on the positive aspects of religious coping. The current study suggests that patients and caregivers may experience a religious struggle (negative religious coping) during the transplant process that may have a negative impact on psychological well-being. Thus, studies of religion and mental health should include assessments of negative aspects of RSC.

Patients reported worse psychological distress than primary caregivers despite equivalent use of problem-focused, emotion-focused, and humor coping styles. Coping and mental health among caregivers was also associated with patient mental health. Findings indicating that patients and caregivers differ regarding psychological distress are inconsistent with prior literature and suggest that specific measures of psychological functioning (e.g., depression, anxiety) in addition to measures of emotional quality of life should be utilized to assess and compare psychological well-being among patients and primary caregivers. This study also indicates that interventions that focus on enhancing problem-focused coping, diminishing emotion-focused coping and humor, and including RSC may be a valuable resource for lung transplant candidates. Because patients and primary caregivers experience the transplant process together, and their experiences (coping, emotions) may impact one another, interventions to improve coping strategies and psychological well-being should focus on both patients and caregivers.
Implications

The findings of the present study have several clinical implications. First, patients and primary caregivers should be included in interventions designed to improve mental health during the transplant process, and interventions should address problem-focused, emotion-focused, and humor coping styles. Second, patients and caregivers tend to benefit from using more problem-focused coping and less emotion-focused coping and negative religious coping. Patients may also benefit from the assessment of religiosity and spirituality, particularly religious conflict, and from being provided appropriate referrals when necessary. In addition, lung transplant patients may experience difficulty making significant health behavior changes (discontinuing tobacco use, losing weight) despite effects on life expectancy. It may be beneficial for transplant programs to identify resources available to patients to make these changes, provide or direct patients to resources to help make such changes, and document the effectiveness of programs being utilized in helping patients make health behavior changes. In conclusion, improving mental health prior to transplant for transplant candidates and their primary caregivers using interventions focused on coping including problem-focused coping, emotion-focused coping, humor, and religious/spiritual coping styles, as well as psychological well-being, and health behavior compliance may result in enhanced functioning of patient-caregiver dyads.
REFERENCES


Harris, R.C., Dew, M.A., Lee, A., Amaya, M., Buches, L., Reetz, D., & Coleman, G.


Ranson-Flint, T.M., & Mirels, H. (2005). Health Behaviors Inventory. Department of Psychology. Columbus, Ohio, The Ohio State University


<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Lung Transplant Candidates (n = 39)</th>
<th>Primary Caregivers (n = 39)</th>
</tr>
</thead>
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<tr>
<td>Age</td>
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<td>$47.0 \pm 13.2$</td>
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<td>84%</td>
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</tr>
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<tr>
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Table 1. Demographic Characteristics of Lung Transplant Candidates and Primary Caregivers
### Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Lung Transplant Candidates (n = 39)</th>
<th>“On Hold” Lung Transplant Candidates (n = 22)</th>
<th>“Listed” Lung Transplant Candidates (n = 17)</th>
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<tbody>
<tr>
<td>Age</td>
<td>51.2 ± 9.25</td>
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<td>86%</td>
<td>82%</td>
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<tr>
<td></td>
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<td>12</td>
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<tr>
<td>Marital Status</td>
<td>(% married) 56%</td>
<td>55%</td>
<td>59%</td>
</tr>
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<td>Education</td>
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<td></td>
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<td>Unemployed, retired 6</td>
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<td>Income (% less than $15,000)</td>
<td>32%</td>
<td>43%</td>
<td>19%</td>
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<td>FEV₁</td>
<td>0.93 ± 0.57</td>
<td>0.73 ± 0.43</td>
<td>1.16 ± 0.63*</td>
</tr>
<tr>
<td>FVC</td>
<td>1.84 ± 0.55</td>
<td>1.72 ± 0.64</td>
<td>1.98 ± 0.42</td>
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<tr>
<td>FEV₁% predicted</td>
<td>32.7 ± 19.68</td>
<td>25.4 ± 14.38</td>
<td>41.3 ± 21.90*</td>
</tr>
<tr>
<td>FEV₁/FVC ratio</td>
<td>0.50 ± 0.27</td>
<td>0.44 ± 0.23</td>
<td>0.59 ± 0.30*</td>
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<tr>
<td>Supplemental oxygen (L)</td>
<td>3.0 ± 1.31</td>
<td>3.1 ± 1.46</td>
<td>2.9 ± 1.20</td>
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<td>Pulmonary disease</td>
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</tr>
<tr>
<td></td>
<td>Alpha-1 3</td>
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<td>2</td>
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<tr>
<td></td>
<td>Cystic Fibrosis 1</td>
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<td>Syndrome 1</td>
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<td>Pneumonitis 1</td>
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Note: * p<.05, difference between “on hold” and “listed” candidates; FEV₁ = Forced Expiratory Volume in 1 second; FVC = Forced Vital Capacity

Table 2. Demographic and Pulmonary Characteristics of Lung Transplant Candidates
<table>
<thead>
<tr>
<th>Health Outcomes</th>
<th>Patients (n = 39)</th>
<th>Primary Caregivers (n = 39)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Stress Scale</td>
<td>14.8 ± 10.11</td>
<td>16.8 ± 8.37</td>
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<tr>
<td>Beck Depression Inventory</td>
<td>15.2 ± 12.58</td>
<td>8.2 ± 7.77**</td>
</tr>
<tr>
<td>Beck Anxiety Inventory</td>
<td>15.9 ± 12.34</td>
<td>8.4 ± 9.49**</td>
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<tr>
<td>SF-36 Physical Quality of Life</td>
<td>27.1 ± 6.25</td>
<td>49.4 ± 11.44**</td>
</tr>
<tr>
<td>SF-36 Emotional Quality of Life</td>
<td>48.3 ± 12.34</td>
<td>47.1 ± 14.41</td>
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<tr>
<td>Physical functioning</td>
<td>17.1 ± 14.08</td>
<td>79.3 ± 26.90**</td>
</tr>
<tr>
<td>Role-functioning physical</td>
<td>22.4 ± 38.39</td>
<td>76.3 ± 38.97**</td>
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<tr>
<td>Role-functioning emotional</td>
<td>49.1 ± 45.01</td>
<td>74.6 ± 39.85</td>
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<tr>
<td>Bodily Pain</td>
<td>57.2 ± 26.10</td>
<td>70.3 ± 26.36</td>
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<td>Social functioning</td>
<td>53.0 ± 31.49</td>
<td>76.7 ± 29.34**</td>
</tr>
<tr>
<td>Mental Health</td>
<td>73.8 ± 20.37</td>
<td>71.6 ± 21.12</td>
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<tr>
<td>Vitality</td>
<td>35.4 ± 23.66</td>
<td>55.9 ± 25.89**</td>
</tr>
<tr>
<td>General health perceptions</td>
<td>20.0 ± 19.03</td>
<td>63.4 ± 27.33**</td>
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Note: Values are means ± standard deviations. *p < .05, **p < .01; SF-36 = Medical Outcomes Study Short-Form - 36

Table 3. Health Outcomes among Patients versus Primary Caregivers
<table>
<thead>
<tr>
<th></th>
<th>Stress</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Physical Quality of Life</th>
<th>Emotional Quality of Life</th>
<th>Disease-Specific Quality of Life</th>
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<tbody>
<tr>
<td>Problem-focused Coping</td>
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<td>.04</td>
<td>.08</td>
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<td>.18</td>
<td>-.07</td>
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<td>Humor</td>
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<td>.05</td>
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Note: * p<.05, ** p<.01;

Table 4. Correlation of Nonreligious Coping with Mental Health Outcomes among Patients
<table>
<thead>
<tr>
<th></th>
<th>Positive Religious Coping</th>
<th>Negative Religious Coping</th>
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<th>Private Religious Practices</th>
<th>Intrinsic Religiosity</th>
<th>Deferring RPS</th>
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</table>

Note: *p < .05, **p < .01;  RPS = Religious Problem-Solving

Table 5. Correlation among Religious and Spiritual Coping Variables in Patients
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<thead>
<tr>
<th></th>
<th>Stress</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Physical Quality of Life</th>
<th>Emotional Quality of Life</th>
<th>Disease-Specific Quality of Life</th>
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<tr>
<td>Positive Religious Coping</td>
<td>-.22</td>
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<td>Negative Religious Coping</td>
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<td>Deferring RPS</td>
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Note: * p<.05, ** p<.01; RPS = Religious Problem-Solving

Table 6. Correlation of Religious and Spiritual Coping with Mental Health Outcomes among Patients
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<th>Perceived Stress</th>
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<th>Δ R²</th>
<th>β</th>
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<td>.12</td>
<td>2.69</td>
<td>1.54</td>
<td>1.75</td>
<td>.09</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>.12</td>
<td>.12</td>
<td>.01</td>
<td>.01</td>
<td>.63</td>
<td>.54</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>.24</td>
<td>.12</td>
<td>.51</td>
<td>.24</td>
<td>2.10</td>
<td>.04*</td>
</tr>
</tbody>
</table>

Note: * p < .05, **p < .01

Table 7. Hierarchical Regression Analysis of the Association of Emotion-Focused Coping with Perceived Stress among Patients
### Final Model Statistics

\[ F_{3,29} = 4.75, p < .01 \]

<table>
<thead>
<tr>
<th>Depression</th>
<th>Total R^2</th>
<th>Δ R^2</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Listing Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>.33</td>
<td>.19</td>
<td>.73</td>
<td>.26</td>
<td>2.88</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: *p < .05, **p < .01

Table 8. Hierarchical Regression Analysis of the Association of Emotion-Focused Coping with Depression among Patients
### Table 9. Hierarchical Regression Analysis of the Association of Negative Religious Coping with Depression among Patients

<table>
<thead>
<tr>
<th></th>
<th>Total $R^2$</th>
<th>$\Delta R^2$</th>
<th>$\beta$</th>
<th>SE</th>
<th>t</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Listing Status</td>
<td>2.83</td>
<td>1.71</td>
<td>1.65</td>
<td>.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>.01</td>
<td>.02</td>
<td>.73</td>
<td>.47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.16</td>
<td>.16</td>
<td>-.12</td>
<td>.21</td>
<td>-.60</td>
<td>.55</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative Religious Coping</td>
<td>.32</td>
<td>.16</td>
<td>6.59</td>
<td>2.59</td>
<td>2.55</td>
<td>.02**</td>
</tr>
</tbody>
</table>

Note: * $p<.05$, ** $p<.01$
## Physical Quality of Life

<table>
<thead>
<tr>
<th>Final Model Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>$F_{4,27} = 3.22, p = .03$</td>
</tr>
</tbody>
</table>

### Step 1
<table>
<thead>
<tr>
<th>Predictor</th>
<th>Total R²</th>
<th>Δ R²</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td></td>
<td></td>
<td>-2.23</td>
<td>1.17</td>
<td>-1.91</td>
<td>.07</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td></td>
<td></td>
<td>-.00</td>
<td>.01</td>
<td>-.11</td>
<td>.91</td>
</tr>
<tr>
<td>Age</td>
<td>.17</td>
<td>.17</td>
<td>.01</td>
<td>.14</td>
<td>.12</td>
<td>.91</td>
</tr>
</tbody>
</table>

### Step 2
<table>
<thead>
<tr>
<th>Predictor</th>
<th>Total R²</th>
<th>Δ R²</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Religious Coping</td>
<td>.33</td>
<td>.16</td>
<td>-4.41</td>
<td>1.80</td>
<td>-2.46</td>
<td>.02*</td>
</tr>
</tbody>
</table>

Note: * $p<.05$, ** $p<.01$

Table 10. Hierarchical Regression Analysis of the Association of Negative Religious Coping with Physical Quality of Life among Patients
<table>
<thead>
<tr>
<th>Physical Functioning</th>
<th>Final Model Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$F_{4,27} = 3.22, p = .03$</td>
</tr>
<tr>
<td></td>
<td>$R^2$</td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
</tr>
<tr>
<td>Patient Listing Status</td>
<td>-4.69</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>-.04</td>
</tr>
<tr>
<td>Age</td>
<td>.15</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
</tr>
<tr>
<td>Negative Religious Coping</td>
<td>.32</td>
</tr>
</tbody>
</table>

Note: * $p<.05$, **$p<.01$

Table 11. Hierarchical Regression Analysis of the Association of Negative Religious Coping with Physical Functioning among Patients
<table>
<thead>
<tr>
<th></th>
<th>Stress</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Physical Quality of Life</th>
<th>Emotional Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-focused Coping</td>
<td>.20</td>
<td>.16</td>
<td>.15</td>
<td>.32</td>
<td>-.21</td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>.52**</td>
<td>.49**</td>
<td>.54**</td>
<td>-.01</td>
<td>-.39*</td>
</tr>
<tr>
<td>Humor</td>
<td>.27</td>
<td>.37*</td>
<td>.24</td>
<td>-.05</td>
<td>-.42*</td>
</tr>
</tbody>
</table>

Note: *p<.05, **p<.01

Table 12. Correlation of Nonreligious Coping with Mental Health Outcomes among Caregivers
### Table 13. Correlation of Religious and Spiritual Coping with Mental Health Outcomes among Caregivers

<table>
<thead>
<tr>
<th></th>
<th>Stress</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Physical Quality of Life</th>
<th>Emotional Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Religious Coping</td>
<td>.09</td>
<td>.05</td>
<td>.16</td>
<td>.13</td>
<td>-.18</td>
</tr>
<tr>
<td>Negative Religious Coping</td>
<td>.45**</td>
<td>.36*</td>
<td>.35*</td>
<td>-.03</td>
<td>-.33</td>
</tr>
<tr>
<td>Organizational Religiosity</td>
<td>-.13</td>
<td>-.15</td>
<td>-.06</td>
<td>.10</td>
<td>-.00</td>
</tr>
<tr>
<td>Private Religious Practices</td>
<td>-.04</td>
<td>.04</td>
<td>.06</td>
<td>.17</td>
<td>-.20</td>
</tr>
<tr>
<td>Intrinsic Religiosity</td>
<td>-.01</td>
<td>.15</td>
<td>-.06</td>
<td>.03</td>
<td>-.01</td>
</tr>
<tr>
<td>Deferring RPS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *p < .05, **p < .01; RPS = Religious Problem-Solving
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Canonical Correlation</th>
<th>Multivariate F</th>
<th>Numerator DF</th>
<th>Denominator DF</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.74</td>
<td>2.78</td>
<td>15</td>
<td>74.937</td>
<td>0.0019**</td>
</tr>
<tr>
<td>2</td>
<td>0.55</td>
<td>1.66</td>
<td>8</td>
<td>56</td>
<td>0.1277</td>
</tr>
<tr>
<td>3</td>
<td>0.26</td>
<td>0.67</td>
<td>3</td>
<td>29</td>
<td>0.5745</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver Nonreligious Coping</th>
<th>Dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Active</td>
<td>-1.48</td>
</tr>
<tr>
<td>Support</td>
<td>0.55</td>
</tr>
<tr>
<td>Avoidant</td>
<td>-0.41</td>
</tr>
<tr>
<td>Acceptance</td>
<td>1.10</td>
</tr>
<tr>
<td>Self-blame</td>
<td>-0.71</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Quality of Life</th>
<th>Dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Physical Quality of Life</td>
<td>0.73</td>
</tr>
<tr>
<td>Emotional Quality of Life</td>
<td>1.08</td>
</tr>
<tr>
<td>Disease-Specific Quality of Life</td>
<td>0.75</td>
</tr>
</tbody>
</table>

Note: * p<.05, **p<.01

Table 14. Canonical Correlations of Caregiver Nonreligious Coping with Patient Quality of Life
### Dimension 1

<table>
<thead>
<tr>
<th>Canonical Correlation</th>
<th>Multivariate F</th>
<th>Numerator DF</th>
<th>Denominator DF</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.61</td>
<td>4.32</td>
<td>4</td>
<td>60</td>
</tr>
<tr>
<td>2</td>
<td>0.21</td>
<td>1.49</td>
<td>1</td>
<td>31</td>
</tr>
</tbody>
</table>

### Patient Quality of Life Variables

- Physical Quality of Life: 0.33, -0.97
- Emotional Quality of Life: 0.87, 0.55

### Caregiver Quality of Life Variables

- Physical Quality of Life: -0.22, 0.98
- Emotional Quality of Life: 0.98, 0.19

**Note:** *p < 0.05, **p < 0.01

Table 15. Canonical Correlations of Patient Quality of Life with Caregiver Quality of Life
<table>
<thead>
<tr>
<th>Variables</th>
<th>“On hold” Candidates (n = 22)</th>
<th>“Listed” Candidates (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cope Total</td>
<td>55.8 ± 11.66</td>
<td>57.6 ± 9.94</td>
</tr>
<tr>
<td>Positive Religious Coping</td>
<td>11.1 ± 5.48</td>
<td>12.2 ± 8.33</td>
</tr>
<tr>
<td>Negative Religious Coping</td>
<td>0.6 ± 0.85</td>
<td>0.3 ± 0.47</td>
</tr>
<tr>
<td>Private Religious Practices</td>
<td>3.0 ± 1.91</td>
<td>3.9 ± 1.92</td>
</tr>
<tr>
<td>Organizational Religiosity</td>
<td>2.3 ± 1.52</td>
<td>3.4 ± 2.16**</td>
</tr>
<tr>
<td>Intrinsic Religiosity</td>
<td>10.8 ± 3.49</td>
<td>12.6 ± 3.76</td>
</tr>
<tr>
<td>Collaborative RPS</td>
<td>15.3 ± 5.51</td>
<td>19.8 ± 8.93</td>
</tr>
<tr>
<td>Self-directing RPS</td>
<td>15.4 ± 6.46</td>
<td>16.5 ± 7.61</td>
</tr>
<tr>
<td>Deferring RPS</td>
<td>13.9 ± 6.43</td>
<td>17.6 ± 8.11</td>
</tr>
<tr>
<td>Perceived Stress Scale</td>
<td>21.3 ± 10.73</td>
<td>13.1 ± 6.60</td>
</tr>
<tr>
<td>Beck Depression Inventory</td>
<td>18.5 ± 10.92</td>
<td>10.2 ± 6.80</td>
</tr>
<tr>
<td>Beck Anxiety Inventory</td>
<td>20.4 ± 13.20</td>
<td>7.9 ± 7.01**</td>
</tr>
<tr>
<td>SF-36 Physical Component Scale</td>
<td>25.2 ± 5.81</td>
<td>29.3 ± 6.20</td>
</tr>
<tr>
<td>SF-36 Mental Component Scale</td>
<td>45.4 ± 13.7</td>
<td>51.6 ± 9.96</td>
</tr>
<tr>
<td>Disease-Specific Quality of Life</td>
<td>68.2 ± 19.1</td>
<td>58.7 ± 12.58</td>
</tr>
</tbody>
</table>

Note: Values are means ± standard deviations. * p<.05, ** p<.01; RPS = Religious Problem-Solving; SF-36 = Medical Outcomes Study Short-Form-36

Table 16. Coping and Health among “On hold” vs. “Listed” Lung Transplant Candidates
<table>
<thead>
<tr>
<th>Perceived Stress at Time 2 (Dependent Variable)</th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td>-.06</td>
<td>.09</td>
<td>-0.62</td>
<td>.54</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>.10</td>
<td>.09</td>
<td>1.16</td>
<td>.25</td>
</tr>
<tr>
<td>Perceived Stress at Time 1</td>
<td>.68</td>
<td>.08</td>
<td>8.36</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>.44</td>
<td>.08</td>
<td>5.42</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 17. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Perceived Stress Over Time among Patients
Table 18. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Depression Over Time among Patients

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td>-.06</td>
<td>.10</td>
<td>-0.55</td>
<td>.58</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>.13</td>
<td>.10</td>
<td>1.30</td>
<td>.20</td>
</tr>
<tr>
<td>Depression at Time 1</td>
<td>.72</td>
<td>.10</td>
<td>7.39</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>.33</td>
<td>.09</td>
<td>3.69</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: Δ = change score (time 1 – time 2); * p<.05, **p<.01
Anxiety at Time 2 (Dependent Variable)

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td>.11</td>
<td>.10</td>
<td>1.10</td>
<td>.28</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>.07</td>
<td>.10</td>
<td>.72</td>
<td>.47</td>
</tr>
<tr>
<td>Anxiety at Time 1</td>
<td>.68</td>
<td>.09</td>
<td>7.93</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>.24</td>
<td>.10</td>
<td>2.49</td>
<td>.02*</td>
</tr>
</tbody>
</table>

Note: Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 19. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Anxiety Over Time among Patients
### Table 20. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Emotional Quality of Life Over Time among Patients

<table>
<thead>
<tr>
<th></th>
<th>$\beta$</th>
<th>SE</th>
<th>t</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td>-.10</td>
<td>.09</td>
<td>-1.14</td>
<td>.25</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>-.28</td>
<td>.10</td>
<td>-2.71</td>
<td>.01</td>
</tr>
<tr>
<td>Emotional QOL at Time 1</td>
<td>.60</td>
<td>.08</td>
<td>7.17</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping $\Delta$</td>
<td>.36</td>
<td>.09</td>
<td>-4.12</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: QOL = Quality of Life; $\Delta$ = change score (time 1 – time 2); * $p<.05$, **$p<.01$
### Table 21. Multiple Regression Analysis of the Association of Change in Positive Religious Coping Over Time with Change in Emotional Quality of Life Over Time among Patients

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Listing Status</td>
<td>-.10</td>
<td>.10</td>
<td>-1.06</td>
<td>.29</td>
</tr>
<tr>
<td>Patient Time in Transplant Process</td>
<td>-.35</td>
<td>.10</td>
<td>-3.49</td>
<td>.00</td>
</tr>
<tr>
<td>Emotional QOL at Time 1</td>
<td>.62</td>
<td>.08</td>
<td>7.45</td>
<td>.00</td>
</tr>
<tr>
<td>Positive Religious Coping Δ</td>
<td>.29</td>
<td>.09</td>
<td>3.32</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: QOL = Quality of Life; Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 21. Multiple Regression Analysis of the Association of Change in Positive Religious Coping Over Time with Change in Emotional Quality of Life Over Time among Patients.
Perceived Stress at Time 2 (Dependent Variable)  

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Stress at Time 1</td>
<td>.67</td>
<td>.08</td>
<td>8.02</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>.46</td>
<td>.09</td>
<td>5.38</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 22. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Perceived Stress Over Time among Caregivers
### Table 23. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Depression Over Time among Caregivers

<table>
<thead>
<tr>
<th></th>
<th>( \beta )</th>
<th>SE</th>
<th>t</th>
<th>( p )-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression at Time 1</td>
<td>.67</td>
<td>.08</td>
<td>8.08</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping ( \Delta )</td>
<td>.35</td>
<td>.09</td>
<td>3.89</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: \( \Delta = \text{change score (time 1 – time 2)}; \) * \( p < .05, ** p < .01 \)
<table>
<thead>
<tr>
<th></th>
<th>$\beta$</th>
<th>SE</th>
<th>t</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety at Time 1</td>
<td>.73</td>
<td>.08</td>
<td>9.30</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping $\Delta$</td>
<td>.23</td>
<td>.10</td>
<td>2.36</td>
<td>.02*</td>
</tr>
</tbody>
</table>

Note: $\Delta$ = change score (time 1 – time 2); * $p<.05$, **$p<.01$

Table 24. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Anxiety Over Time among Caregivers
<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical QOL at Time 1</td>
<td>.87</td>
<td>.06</td>
<td>13.83</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>.14</td>
<td>.07</td>
<td>2.10</td>
<td>.04*</td>
</tr>
</tbody>
</table>

Note: QOL = Quality of Life; Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 25. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Physical Quality of Life Over Time among Caregivers
<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional QOL at Time 1</td>
<td>.60</td>
<td>.09</td>
<td>6.93</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-Focused Coping Δ</td>
<td>-.38</td>
<td>.10</td>
<td>-3.82</td>
<td>.00**</td>
</tr>
</tbody>
</table>

Note: QOL = Quality of Life; Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 26. Multiple Regression Analysis of the Association of Change in Emotion-Focused Coping Over Time with Change in Emotional Quality of Life Over Time among Caregivers
Table 27. Multiple Regression Analysis of the Association of Change in Negative Religious Coping Over Time with Change in Depression Over Time among Caregivers

<table>
<thead>
<tr>
<th></th>
<th>$\beta$</th>
<th>SE</th>
<th>t</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression at Time 1</td>
<td>.62</td>
<td>.09</td>
<td>6.72</td>
<td>.00</td>
</tr>
<tr>
<td>Negative Religious Coping $\Delta$</td>
<td>.26</td>
<td>.10</td>
<td>2.58</td>
<td>.01*</td>
</tr>
</tbody>
</table>

Note: $\Delta$ = change score (time 1 – time 2); * $p$<.05, **$p$<.01
<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>SE</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional QOL at Time 1</td>
<td>.62</td>
<td>.09</td>
<td>6.72</td>
<td>.00</td>
</tr>
<tr>
<td>Positive Religious Coping Δ</td>
<td>.26</td>
<td>.10</td>
<td>2.58</td>
<td>.01*</td>
</tr>
</tbody>
</table>

Note: QOL = Quality of Life; Δ = change score (time 1 – time 2); * p<.05, **p<.01

Table 28. Multiple Regression Analysis of the Association of Change in Positive Religious Coping Over Time with Change in Emotional Quality of Life Over Time among Caregivers
APPENDIX B:

FIGURES
Eligible Patients Sent Recruitment Materials (n = 88)

Recruited to Participate in Study (n = 56; 63%)

Refused (n = 32; 36%)
  Patients did not return recruitment materials (n = 22)
  Refused to participate (n = 10)

Completed Baseline Assessment Packet (n = 39; 70%)

Discontinued participating in study (n = 17; 30%)
  Death (n = 2)
  Did not want transplant (n = 1)
  Lack of time (n = 3)
  Did not complete baseline assessment packet (n = 6)
  Completed baseline assessment post-transplant (n = 2)
  Caregiver did not complete baseline assessment (n = 3)

Lost to Follow-Up (n = 4; 7%)
  Moved and could not be reached (n = 1)
  Did not return follow-up assessment packet (n = 2)
  Dropped out of study because patient died (n = 1)

Analyzed (n = 39; 70%)
  Multiple imputation was utilized for participants lost to follow-up (n = 4)

Figure 1. Study Profile
APPENDIX C:

RECRUITMENT FORMS
Dear Mr./Mrs. ______________,

We are writing to offer you an opportunity to participate in our research study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.” Participation in the research study does not require you to come to The Ohio State University (OSU) Hospital. Instead, we would like to mail you a packet of brief questionnaires to complete at home along with consent forms and HIPAA authorization forms. We would ask that you complete these forms and questionnaires at home and mail them back to us in a stamped, self-addressed envelope that we will provide. You will receive $30 for participating in the study! If you are interested in participating in the study, please complete the top portion of the stamped, self-addressed postcard that is enclosed with this letter and mail it to Marquisha Green. If you are not interested in participating in the study, please complete the bottom portion of the stamped, self-addressed postcard that is enclosed with this letter and mail it to Marquisha Green. Or, feel free to contact Marquisha at the telephone number or email address listed below.

We hope that you will be able to participate in this research study. Best wishes for 2006!

Thank you,

Marquisha R. Green, M.A.
Graduate Research Assistant
The Ohio State University
Office #: (614)-688-3895
Email Address: green.674@osu.edu

Charles F. Emery, Ph.D.
Principle Investigator
The Ohio State University
Office #: (614)-688-3061
Email Address: emery.33@osu.edu

Patrick Ross, M.D.
Co-Investigator
The Ohio State University Medical Center
PATIENTS WITH END-STAGE PULMONARY DISEASE AND THEIR PRIMARY CAREGIVERS NEEDED FOR RESEARCH STUDY

Researchers at The Ohio State University are looking for patients with end-stage pulmonary disease who are referred for lung transplantation at the OSU LUNG TRANSPLANT PROGRAM (and their caregivers) to participate in a research study examining coping styles, including religious/spiritual coping, and health.

Participation will involve completing a packet of self-report questionnaires at home. You will receive $30 for participating in the study!

For more information, or to volunteer, call Marquisha Green, M.A. or Charles Emery, Ph.D. at 614-688-3895
Marquisha Green, M.A.
The Ohio State University
Cardiopulmonary Behavioral Medicine Laboratory
169 Psychology Building
1835 Neil Ave.
Columbus, OH 43210
PLEASE CHECK ONE OF THE FOLLOWING:

_____ I am interested in participating in the study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.”

Name: _____________________ Telephone Number: _____________________

_____ I am not interested in participating in the study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.”

Name: _____________________ Age: _____________________
Race: _____________________ Gender: _____________________

I am not interested because (please circle one response):
1. Lack of time
2. Evaluation of religious and spiritual coping
3. Other, please specify __________________________________________________________________________

Pulmonary Disease: __________________________________________________________________________

PLEASE CHECK ONE OF THE FOLLOWING:

_____ I am interested in participating in the study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.”

Name: _____________________ Telephone Number: _____________________

_____ I am not interested in participating in the study “Coping and Health among End-Stage Pulmonary Disease Patients and Primary Caregivers.”

Name: _____________________ Age: _____________________
Race: _____________________ Gender: _____________________

I am not interested because (please circle one response):
1. Lack of time
2. Evaluation of religious and spiritual coping
3. Other, please specify __________________________________________________________________________

Pulmonary Disease: __________________________________________________________________________
APPENDIX D:

TELEPHONE RECRUITING INSTRUCTIONS AND SCREENING FORM
INSTRUCTIONS FOR RECRUITING
END-STAGE PULMONARY DISEASE PATIENTS

Investigator: Hello Mr./Mrs. _____________________, my name is ______________. I am calling you to provide further information about the study the OSU Lung Transplant Program staff informed you about. Is this a good time for me to talk with you for about 15 minutes?

Potential Participant: If the potential participant states, “yes,” then proceed with the telephone script. If the potential participant states, “no,” then ask what would be a good time to call him or her back to talk for about 15 minutes. Call the potential participant back during one of the available times he or she has given you.

Investigator: The primary goal of the study is to examine coping styles, stress, psychological functioning, and quality of life over time during the lung transplantation process. Participation in the study would consist of you completing a consent form, HIPAA authorization form, and a packet of self-report questionnaires at home on two different occasions: at the beginning of the study and at a 6-month follow up. The forms and questionnaires will be mailed to you, and a self-addressed stamped envelope will be provided for you to return the materials. Please note that some of the items may be considered sensitive or personal. It is anticipated that participation in the study would take approximately five hours of your time over a six month period. Participation in the study would help health professionals understand how end-stage pulmonary disease patients referred for lung transplantation adjust during the lung transplantation process and may provide insight for future interventions. In addition, you will receive a total of $30 for participating in the study. You will receive $15 after complete and return the questionnaires at the beginning of the study and $15 after you complete and return the questionnaires at the 6-month follow-up. Do you have any questions?

Potential Participant: If the potential participant states, “yes,” then clearly answer the questions. Be sure to emphasize that participation in the study would not require a substantial time commitment, the materials are completed in the comfort of his/her home, and participation in the study would provide information that could be beneficial for health professionals and end-stage pulmonary disease patients referred for lung transplantation. If the potential participant states, “no,” then proceed with the telephone script.

Investigator: Participation in the study is completely voluntary and refusal to participate will not influence current or future treatment in any way. Would you like to participate in the study?

Potential Participant: If the potential participant states, “no,” then ask if he/she would be interested in participating in the study at a later time. If the participant states, “no,” then note why the individual would not like to participate in the study and thank him/her for their time. If the participant states, “yes,” then ask what would be the best time to call.
them back about participation in the study, and write it down. Contact the participant about the study again during the time frame provided by the potential participant. If the potential participant states that he/she would like to participate in the study then proceed with the telephone script.

Investigator: We are also interested in how the lung transplantation process impacts the coping styles and health of caregivers. Can we contact your caregiver to complete similar questionnaires regarding coping styles, stress, psychological functioning, and quality of life?

Potential Participant: If the potential participant states, “no,” then inform him/her that we are interested in both patients with end-stage pulmonary disease referred for lung transplantation and their primary caregivers. For that reason, participation in the study requires consent from both then patient with end-stage pulmonary disease and their primary caregiver. Then ask again if we can contact their caregiver. If they state, “no,” then thank them for their time. If they state, “yes,” then proceed with the telephone script.

Investigator: Who is your caregiver? What is his/her contact information? The potential participant may want to ask the caregiver if he/she can give you the caregiver’s contact information before giving it to you. If this occurs, ask the potential participant when would be a good time to call him/her back to see if they can give the caregiver’s contact information to you. Write down the best time to call them back, and call them back at the suggested time. When you call them back, go through the entire recruiting instructions again. If this does not occur, proceed with the telephone script.

Potential Participant: The potential participant will provide the information requested, so write down the information in order to contact the caregiver.

Investigator: I will mail you a cover letter, two informed consent forms, two HIPAA authorization forms, a packet of self-report questionnaires, and a self-addressed stamped envelope today. The cover will include detailed instructions and my contact information in case you have any further questions or concerns. Please read the consent and HIPAA authorization forms before completing the packet of self-report questionnaires. You are to keep one copy of the consent form and HIPAA authorization form, and you are to send the other copy of the consent form and HIPAA authorization form back to me with the completed self-report questionnaires in the self-addressed stamped envelope provided. I will contact you within a week to review the consent form, HIPAA authorization form, and to answer any questions you may have. Do you have any questions?

Potential Participant: If the potential participant states, “yes,” then clearly answer the questions asked. Repeat the information above if necessary and emphasize that this information will be included in the cover letter and consent form which will be reviewed with him/her once they received the mailed packet. If the potential participant states, “no,” then proceed with the telephone script.
**Investigator:** Again, I will mail you the forms and questionnaires today. Thank you for your time.
INSTRUCTIONS FOR RECRUITING CAREGIVERS

Investigator: Hello Mr./Mrs. _____________________, my name is ______________. I am calling you to discuss your potential participation in a study at The Ohio State University involving patients with end-stage pulmonary disease referred for lung transplantation and their primary caregivers. I have already talked with (name of patient with end-stage pulmonary disease) about participating in the study, and I would to discuss the details of the study with you to determine if you are also interested in participating in the study. Is this a good time for me to talk with you for about 15 minutes?

Potential Participant: If the potential participant states, “yes,” then proceed with the telephone script. If the potential participant states, “no,” then ask what would be a good time to call him or her back to talk for about 15 minutes. Call the potential participant back during one of the available times he or she has given you.

Investigator: A primary goal of the study is to examine how the lung transplantation process impacts the health and coping styles of caregivers. Participation in the study would consist of you completing a consent form, HIPAA authorization form, and a packet of self-report questionnaires at home on two different occasions: at the beginning of the study and at a 6-month follow up. The forms and questionnaires will be mailed to you, and a self-addressed stamped envelope will be provided for you to return the materials. Please note that some of the items may be considered sensitive or personal. It is anticipated that participation in the study would take about five hours of your time over a six month period. Participation in the study will assist health professionals in becoming aware of how the lung transplantation process impacts caregivers. In addition, you will receive a total of $30 for participating in the study. You will receive $15 after complete and return the questionnaires at the beginning of the study and $15 after you complete and return the questionnaires at the 6-month follow-up. Do you have any questions?

Potential Participant: If the potential participant states, “yes,” then clearly answer the questions. Be sure to emphasize that participation in the study would not require a substantial time commitment, the materials are completed in the comfort of his/her home, and participation in the study would provide information that could be beneficial in understanding caregiver’s health and coping styles during the lung transplant process. If the potential participant states, “no,” then proceed with the telephone script.

Investigator: Participation in the study is completely voluntary and refusal to participate will not influence current or future treatment of the patient with end-stage pulmonary disease or you in any way. Would you like to participate in the study?

Potential Participant: If the potential participant states, “no,” then ask if he/she would be interested in participating in the study at a later time. If the participant states, “no,” then note why the individual would not like to participate in the study and thank him/her for their time. If the participant states, “yes,” then ask what would be the best time to call
them back about their participation in the study, and write it down. Contact the participant about the study again during the time frame provided by the potential participant. Emphasize that the study is designed to study both patients with end-stage pulmonary disease referred for lung transplantation and their primary caregivers. If the potential participant states that he/she would like to participate in the study then proceed with the telephone script.

**Investigator:** I will mail you a cover letter, two informed consent forms, two HIPAA authorization forms, a packet of self-report questionnaires, and a self-addressed stamped envelope today. The cover letter will provide you with detailed instructions and my contact information if you have any further questions or concerns. Please read the consent and HIPAA authorization forms before completing the packet of self-report questionnaires. You are to keep one copy of the consent form and HIPAA authorization form, and you are to send the other copy of the consent form and HIPAA authorization form back to me with the completed self-report questionnaires in the self-addressed stamped envelope provided. I will contact you within a week to review the consent form, HIPAA authorization form, and to answer any questions you may have. Do you have any questions?

**Potential Participant:** If the potential participant states, “yes,” then clearly answer the questions asked. Repeat the information above if necessary and emphasize that this information will be included in the cover letter and consent form that will be mailed to them. Also, inform them that this information will be reviewed when I contact them to review the consent and HIPAA authorization forms and answer questions they may have. If the potential participant states, “no,” then proceed with the telephone script.

**Investigator:** After returning the forms and self-report questionnaires, you will be mailed another packet of the same self-report questionnaires in 6 months. Do you have any questions?

**Potential Participant:** If the potential participant states, “yes,” then clearly answer the questions asked. Repeat the above information if necessary, and emphasize that this information will be included in the consent form which will be reviewed with him/her once they receive the mailed packet. If the potential participant states, “no,” then proceed with the telephone script.

**Investigator:** Again, I will mail you the forms and questionnaires today. Thank you for your time.
RECRUITING FORM

Potential Subject Name _______________________

Today’s Date ________________________________

1. Date to call individual back to review recruiting instructions
   ______________________________________________________________________

2. Date to call individual again to see if he/she wants to participate in the study
   ______________________________________________________________________

3. Reason the individual does not want to participate in the study
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

4. Caregiver Name
   ______________________________________________________________________

   Caregiver Telephone Number
   ______________________________________________________________________

   Caregiver Address
   ______________________________________________________________________

5. Date and time to call individual to get caregiver name and contact information
   ______________________________________________________________________
APPENDIX E:

TELEPHONE REMINDER SCRIPT AND POSTCARD
Investigator: Hello Mr./Mrs. _____________________, my name is ______________. I am calling you regarding your participation in the study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.” Thank you for agreeing to participate in the study. We have not received the packet of questionnaires and forms we mailed to you earlier. Do you have any questions about the materials we sent you?

Potential Participant: If the potential participant states, “no,” then proceed with the telephone script. If the potential participant states, “yes,” then clearly answer the questions. If the potential participant states, “I can no longer participate in the study,” note why the individual cannot participate in the study and thank him/her for their time.

Investigator: Please return the completed materials in the self-addressed stamped envelope we provided as soon as possible. If you have any further questions please feel free to contact me at 614-688-3895 or green.674@osu.edu. Thank you again for taking the time to complete these materials.
Dear (Name of Participant),

Thank you for agreeing to participate in the study “Coping and Health among Patient with End-Stage Pulmonary Disease and Primary Caregivers.” We have not received the packet of questionnaires and forms we mailed to you earlier. Please return the completed materials in the self-addressed stamped envelope we provided as soon as possible. If you have any questions or concerns, please feel free to contact Marquisha Green at 614-688-3895 or green.674@osu.edu. Thank you again for taking the time to complete these materials.
APPENDIX F:

DEMOGRAPHIC QUESTIONNAIRE
DEMOGRAPHIC INFORMATION FORM

Subject Number ____________________________

Today’s Date ______________________________

Date of Birth ______________________________

Please circle one numbered response for each of the questions below.

1. What is your gender?
   1. Male
   2. Female

2. With which ethnic group do you primarily identify?
   1. Black
   2. White
   3. Hispanic or Latino
   4. Asian
   5. American Indian
   6. Other (Please list) ______________________________

3. What is your marital status?
   1. Single, never married
   2. Married
   3. Divorced / separated
   4. Widowed

4. What are your living arrangements?
   1. Living alone
   2. Living with spouse or “significant other”
   3. Living with children
   4. Living with children and spouse or “significant other”
   5. Living with parent
   6. Living with friend(s)

5. What is your current work status?
1. Employed full-time
2. Employed part-time
3. Unemployed, on disability
4. Unemployed, looking for a job
5. Unemployed, not looking for a job
6. Retired
7. Homemaker, not employed outside the home

6. If you are retired, please state when you retired and why you retired.

___________________________________________________________
___________________________________________________________
___________________________________________________________

7. If you are unemployed and on disability, please state when you became unemployed, when you began receiving disability, and why you are on disability.

___________________________________________________________
___________________________________________________________
___________________________________________________________

8. How much education have you received?

1. Less than 9 grades
2. Some high school
3. Graduated from high school
4. Trade school or business school
5. Some college (including completion of junior college)
6. Graduated from a 4-year college
7. Post-graduate work at a University

9. What is your combined family income?

1. Less than 15,000 a year
2. 15,000 – 29,999
3. 30,000 – 44,999
4. 45,000 – 59,999
5. 60,000 – 74,999
6. 75,000 or greater

10. Are you trying to receive a lung transplant through the OSU Lung Transplant Program?
1. Yes
2. No (Skip to #17)

11. What is your relationship to the identified caregiver participating in the study?
   1. Spouse
   2. Parent
   3. Sibling
   4. Child
   5. Friend
   6. Romantic Partner
   7. Other, please list __________________

12. What is your pulmonary diagnosis? ______________________________

14. Are you using oxygen regularly?
   1. Yes
   2. No (Skip to #17)

15. What amount of oxygen do you use most often? ____________________

16. How long have you been using oxygen? ____________________

17. Have you previously experienced a mood disorder?
   1. No
   2. Yes, major depression disorder
   3. Yes, dysthymia disorder
   4. Yes, bipolar I disorder
   5. Yes, bipolar II disorder
   6. Yes, cyclothymic disorder

18. How many times have you experienced an episode of the mood disorder you identified in question 17? _________

19. When did you last experience a mood disorder? _________

20. Have you previously experienced an anxiety disorder?
   1. No
   2. Yes, panic disorder without agoraphobia
3. Yes, panic disorder with agoraphobia
4. Yes, agoraphobia
5. Yes, specific phobia
6. Yes, social anxiety disorder
7. Yes, generalized anxiety disorder
8. Yes, post-traumatic stress disorder
9. Yes, obsessive-compulsive disorder
10. Yes, acute stress disorder

21. How many times have you experienced an episode of the anxiety disorder you identified in question 20? __________

22. When did you last experience an anxiety episode? __________

23. Have you previously seen a psychologist or psychiatrist regarding your mental health?
   1. Yes
   2. No (Skip to #26)

24. How long did you see the psychologist or psychiatrist? __________

25. When was the last time you saw a psychologist or psychiatrist? __________

26. Have you previously experienced a mental disorder that was not included in the above questions?
   1. Yes
   2. No (Stop)

27. What mental disorder did you experience? __________

28. How many times have you experienced an episode of the mental disorder you identified in question 27? __________

29. When did you last experience an episode of the mental disorder? __________
APPENDIX G:

MEDICAL INFORMATION FORMS
MEDICAL INFORMATION FORM A

Subject Number _________________________

Today’s Date ___________________________

Please document the following information from the participant’s medical record. Make sure the most recent information is documented.

Date Referred to OSU Lung Transplant Program: ______________________________________

Date Placed on Hold for Contraindication: ______________________________________

Date Added to Waiting List: ______________________________________

Date Transplanted: ______________________________________

Forced Vital Capacity (FVC): ______________________________________

Forced Expiratory Volume in one second (FEV₁): ______________________________________

Static Lung Volumes: ______________________________________

Body Mass Index: ______________________________________

Serum Cotinine Level Test Results: ______________________________________

Level of Liver Enzymes Test Results: ______________________________________

Medical Diagnoses ______________________________________
Oxygen Level:

Length of Time on Oxygen:
MEDICAL INFORMATION FORM B

Subject Number _________________________

Today’s Date ___________________________

Please document the following the information from the participant’s medical record. Make sure the most recent information is documented.

Date Referred to OSU Lung Transplant Program: ___________________________________________________

Date Added on Waiting List: ___________________________________________________

Date Transplanted: ___________________________________________________

Forced Vital Capacity (FVC) ___________________________________________________

Forced Expiratory Volume in one second (FEV₁) _____________________________________________

Pulmonary Artery Pressure _____________________________________________________________

PaO₂ _____________________________________________________________

Body Mass Index _______________________________________________________________

Blood Sugar Level ______________________________________________________________

Blood Pressure: Systolic: ____________________ Diastolic: ____________________

6-Minute Walk Distance: __________________________________________________________

Pulmonary Capillary Wedge Pressure ________________________________________________
Creatinine Level

NY Heart Association Classification

Medical Diagnoses

Oxygen Level:

Length of Time on Oxygen:
APPENDIX H:
COPE QUESTIONNAIRE
COPE QUESTIONNAIRE

Subject Number ___________________________     Date ________________________

Instructions: These items deal with the ways you’ve been coping with stress in your life. We want you to know to what extent you have been doing the following things. Circle the number for each statement which best describes how often you felt or behaved this way.

1 = I haven’t been doing this at all
2 = I’ve been doing this a little bit
3 = I’ve been doing this a medium amount
4 = I’ve been doing this a lot

1. I’ve been turning to work or other activities to take my mind off things. 1 2 3 4
2. I’ve been concentrating my efforts on doing something about the situation I’m in. 1 2 3 4
3. I’ve been saying to myself “this isn’t real.” 1 2 3 4
4. I’ve been using alcohol or other drugs to make myself feel better. 1 2 3 4
5. I’ve been getting emotional support from others. 1 2 3 4
6. I’ve been giving up trying to deal with it. 1 2 3 4
7. I’ve been taking action to try to make the situation better. 1 2 3 4
8. I’ve been refusing to believe that it has happened. 1 2 3 4
9. I’ve been saying things to let my unpleasant feelings escape. 1 2 3 4
10. I’ve been getting help and advice from other people. 1 2 3 4
11. I’ve been using alcohol or other drugs to help get me through it. 1 2 3 4
12. I’ve been trying to see it in a different light, to make it seem more positive. 1 2 3 4
<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>I’ve been criticizing myself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I’ve been trying to come up with a strategy about what to do.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>I’ve been getting comfort and understanding from someone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I’ve been giving up the attempt to cope.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>I’ve been looking for something good in what is happening.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I’ve been making jokes about it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>I’ve been accepting the reality of the fact that it has happened.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>I’ve been expressing my negative feelings.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>I’ve been trying to find comfort in my religion or spiritual beliefs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>I’ve been trying to get advice from other people about what to do.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>I’ve been learning to live with it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>I’ve been thinking hard about what steps to take.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>I’ve been blaming myself for the things that happened.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>I’ve been praying or meditating.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>I’ve been making fun of the situation.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX I:

BRIEF RELIGIOUS COPING QUESTIONNAIRE
RCOPE QUESTIONNAIRE

Subject Number______________________    Date _____________________________

Instructions: There are many ways to try to deal with an illness. These are some ways you might have used religion or spirituality to help you to cope. Each item says something about a particular way of coping. We want to know to what extent you’ve been doing what the items say, how much or how frequently. Don’t answer on the basis of whether it seems to be working or not -- just whether or not you’re doing it. Try to rate each item separately from the others. Make your answers as true for you as you can.

0 = A great deal (e.g. very true)
1 = Quite a bit
2 = Somewhat
3 = Not at all (e.g., very untrue)

1. I looked for a stronger connection with God…………………..0     1     2     3
2. I sought God’s love and care……………………………………0     1     2     3
3. I sought help from God in letting go of my anger……………0     1     2     3
4. I tried to put my plans into action together with God…………0     1     2     3
5. I tried to see how God might be trying to strengthen me in the situation.
6. I asked for forgiveness for my sins…………………………0     1     2     3
7. I focused on religion to stop worrying about my problems.0     1     2     3
8. I wonder whether God had abandoned me…………………..0     1     2     3
9. I felt punished by God for my lack of devotion………………0     1     2     3
10. I wondered what I did for God to punish me…………………0     1     2     3
11. I questioned God’s love for me……………………………..0     1     2     3
12. I wondered whether my church had abandoned me…………0     1     2     3
13. I decided the Devil made this happen………………………0     1     2     3
14. I questioned the power of God……………………………..0     1     2     3
1) How often do you attend church or other religious meetings?
   1. More than once a week
   2. Once a week
   3. A few times a month
   4. A few times a year
   5. Once a year or less
   6. Never

2) How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?
   1. More than once a day
   2. Daily
   3. Two or ore times a week
   4. Once a week
   5. A few times a month
   6. Rarely or never

The following section contains 3 statements about religious belief or experience. Please mark the extent to which each statement is true or not true for you.

3) In my life, I experience the presence of the Divine (i.e., God).
   1. Definitely true of me
   2. Tends to be true
   3. Unsure
   4. Tends to not be true
   5. Definitely not true

4) My religious beliefs are what really lie behind my whole approach to life.
   1. Definitely true of me
   2. Tends to be true
   3. Unsure
   4. Tends to not be true
   5. Definitely not true

5) I try hard to carry my religion over into all other dealings in life.
   1. Definitely true of me
   2. Tends to be true
   3. Unsure
   4. Tends to not be true
   5. Definitely not true
APPENDIX K:

RELIGIOUS PROBLEM-SOLVING SCALE SHORT FORM
Religious Problem-Solving Scale Short Form

Following are the items included in the Religious Problem-Solving Scale. Items from the three subscales (Collaborative, Self-Directive, and Deferring) were mixed together to form a single questionnaire. Please indicate how often each of the following statements apply to you.

1) When I have a problem, I talk to God about it and together we decide what it means.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

2) Rather than trying to come up with the right solution to a problem myself, I let God decide how to deal with it.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

3) When faced with trouble, I deal with my feelings without God’s help.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

4) When a situation makes me anxious, I wait for God to take those feelings away.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

5) Together, God and I put my plans into action.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often
6) When it comes to deciding how to solve a problem, God and I work together as partners.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

7) I act to solve my problems without God’s help.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

8) When I have difficulty, I decide what it means by myself without help from God.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

9) I don’t spend much time thinking about troubles I’ve had; God makes sense of them for me.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

10) When considering a difficult situation, God and I work together to think of possible solutions.
    1. Never
    2. Almost Never
    3. Sometimes
    4. Fairly often
    5. Very often

11) When a troublesome issue arises, I leave it up to God to decide what it means for me.
    1. Never
    2. Almost Never
    3. Sometimes
    4. Fairly often
    5. Very often
12) When thinking about a difficulty, I try to come up with possible solutions without God’s help.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

13) After solving a problem, I work with God to make sense of it.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

14) When deciding on a solution, I make a choice independent of God’s input.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

15) In carrying out the solutions to my problems, I wait for God to take control and know somehow He’ll work it out.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

16) I do not think about different solutions to my problems because God provides them for me.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often

17) After I’ve gone through a rough time, I try to make sense of it without relying on God.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
5. Very often

18) When I feel nervous or anxious about a problem, I work together with God to find a way to relieve my worries.
   1. Never
   2. Almost Never
   3. Sometimes
   4. Fairly often
   5. Very often
APPENDIX L:

PERCEIVED STRESS SCALE
Thoughts and Feelings During the Last Week

The questions in this scale ask you about your feelings and thoughts during the past month. In each case, you will be asked to indicate how often you felt or thought in a certain way. The best approach is to answer each question fairly quickly. That is, don’t try to count up the number of times you felt a particular way, but rather indicate the answer that seems like a reasonable estimate.

Circle the appropriate number.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the last month, how often have you been upset because of something that happened unexpectedly?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. In the last month, how often have you felt that you were unable to control the important things in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. In the last month, how often have you felt stressed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. In the last month, how often have you felt confident in your ability to handle your personal problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. In the last month, how often have you felt that things were going your way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. In the last month, how often have you found that you could not cope with all the things that you had to do?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. In the last month, how often have you been able to control irritations in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. In the last month, how often have you felt that you were on top of things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
9. In the last month, how often have you been angered because of things that happened that were outside of your control?

0  1  2  3  4

10. In the last month, how often have you felt difficulties piling up so high that you could not overcome them?

0  1  2  3  4
The questionnaire consists of 21 groups of statements. After reading each group of statements carefully, circle the number (0, 1, 2, or 3) next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

1. 0 I do not feel sad.
   1 I feel sad.
   2 I am sad all the time and I can’t snap out of it.
   3 I am so sad or unhappy that I can’t stand it.

2. 0 I am not particularly discouraged about the future.
   1 I feel discouraged about the future.
   2 I feel I have nothing to look forward to.
   3 I feel that the future is hopeless and that things cannot improve.

3. 0 I do not feel like a failure.
   1 I feel I have failed more than the average person.
   2 As I look back on my life, all I can see is a lot of failures.
   3 I feel I am a complete failure as a person.

4. 0 I get as much satisfaction out of things as I used to.
   1 I don’t enjoy things the way I used to.
   2 I don’t get real satisfaction out of anything anymore.
   3 I am dissatisfied or bored with everything.

5. 0 I don’t feel particularly guilty.
   1 I feel guilty a good part of the time.
   2 I feel quite guilty most of the time.
   3 I feel guilty all of the time.

6. 0 I don’t feel I am being punished.
   1 I feel I may be punished.
   2 I expect to be punished.
   3 I feel I am being punished.
7. 0  I don’t feel disappointed in myself.
    1  I am disappointed in myself.
    2  I am disgusted with myself.
    3  I hate myself.

8. 0  I don’t feel I am any worse than anybody else.
    1  I am critical of myself for my weaknesses or mistakes.
    2  I blame myself all the time for my faults.
    3  I blame myself for everything bad that happens.

9. 0  I don’t have any thoughts of killing myself.
    1  I have thoughts of killing myself, but I would not carry them out.
    2  I would like to kill myself.
    3  I would kill myself if I had the chance.

10. 0  I don’t cry anymore than usual.
      1  I cry now more than I used to.
      2  I cry all the time now.
      3  I used to be able to cry, but now I can’t cry even though I want to.

11. 0  I am no more irritated now than I ever am.
      1  I get annoyed or irritated more easily than I used to.
      2  I feel irritated all the time now.
      3  I don’t get irritated at all by the things that used to irritate me.

12. 0  I have not lost interest in other people.
      1  I am less interested in other people than I used to be.
      2  I have lost most of my interest in other people.
      3  I have lost all of my interest in other people.

13. 0  I make decisions about as well as I ever could.
      1  I put off making decisions more than I used to.
      2  I have greater difficulty in making decisions than before.
      3  I can’t make decisions at all anymore.

14. 0  I don’t feel I look any worse than I used to.
      1  I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe I look ugly.

15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can’t do any work at all.

16. 0 I can sleep as well as usual.
1 I don’t sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17. 0 I don’t get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

19. 0 I haven’t lost much weight, if any, lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less.  Yes_____ No_____

20. 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
2 I am very worried about physical problems and it’s hard to think of much else.
3 I am so worried about my physical problems that I cannot think about anything else.
21. 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.
APPENDIX N:

BECK ANXIETY INVENTORY
BAI

DIRECTIONS: Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

<table>
<thead>
<tr>
<th></th>
<th>NOT AT ALL</th>
<th>MILDLY It did not bother me much.</th>
<th>MODERATELY It was very unpleasant, but I could stand it.</th>
<th>SEVERELY I could barely stand it.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Numbness or tingling.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Feeling hot.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Wobbliness in legs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Unable to relax.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Fear of the worst happening.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Dizzy or light headed.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Heart pounding or racing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Unsteady.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Feelings of choking.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Fear of losing control.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Difficulty breathing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Scared.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Indigestion or discomfort in abdomen.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Faint.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Face flushed.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Sweating (not due to heat).</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX O:

MEDICAL OUTCOMES STUDY FORM SHORT FORM-36
THE MOS 36-ITEM SHORT-FORM HEALTH SURVEY (SF-36)

INSTRUCTIONS: This survey asks you for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer that you can.

1. In general, would you say your health is:
   
   (Circle one)
   
   Excellent………………………………………………………………..1
   
   Very Good………………………………………………………………2
   
   Good…………………………………………………………………….3
   
   Fair………………………………………………………………………4
   
   Poor……………………………………………………………………...5

2. Compares to one year ago, how would you rate your health in general now?
   
   (Circle one)
   
   Much better now than one year ago……………………………………..1
   
   Somewhat better now than one year ago………………………………...2
   
   About the same as one year ago…………………………………………3
   
   Somewhat worse now than one year ago………………………………..4
   
   Much worse now than one year ago……………………………………..5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>YES Limited</th>
<th>YES Limited</th>
<th>NO, Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A Lot</td>
<td>A Little</td>
<td>At All</td>
</tr>
</tbody>
</table>


182
| a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports | 1 | 2 | 3 |
| b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 | 2 | 3 |
| c. Lifting or carrying groceries | 1 | 2 | 3 |
| d. Climbing several flights of stairs | 1 | 2 | 3 |
| e. Climbing one flight of stairs | 1 | 2 | 3 |
| f. Bending, kneeling, or stopping | 1 | 2 | 3 |
| g. Walking more than a mile | 1 | 2 | 3 |
| h. Walking several blocks | 1 | 2 | 3 |
| i. Walking one block | 1 | 2 | 3 |
| j. Bathing or dressing yourself | 1 | 2 | 3 |

4. During the past 4 weeks have you had any of the following health problems with your work or other regular activities as a result of your physical health?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cut down on the <strong>amount of time</strong> that you spent on work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>b. <strong>Accomplished less</strong> than you would like</td>
<td>1</td>
</tr>
<tr>
<td>c. Were limited in the <strong>kind</strong> or work or other activities</td>
<td>1</td>
</tr>
<tr>
<td>d. Had <strong>difficulty</strong> performing the work or other activities (for example, it took extra effort)</td>
<td>1</td>
</tr>
</tbody>
</table>
5. During the **past 4 weeks**, have you had any of the following problems with your work or other daily as a result of any emotional problems (such as feeling depressed or anxious) ?

   **YES** | **NO**
   --- | ---
   a. Cut down on the **amount of time** you spent on work or activities | 1 | 2
   b. **Accomplished less** than you would like | 1 | 2
   c. Didn’t do work or other activities as **carefully** as usual | 1 | 2

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

   (Circle one)
   
   Not at all………………………………………………………….1
   Slightly……………………………………………………………..2
   Moderately………………………………………………………..3
   Quite a bit…………………………………………………………4
   Extremely…………………………………………………………5

7. How much bodily pain have you had in the **past 4 weeks**?

   None………………………………………………………………1
   Very mild……………………………………………………….2
   Mild………………………………………………………………3
   Moderate………………………………………………………..4
   Severe……………………………………………………………..5
   Very severe……………………………………………………6

8. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?
9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give one answer that comes closest to the way that you have been feeling. How much of the time in the past 4 weeks:

<table>
<thead>
<tr>
<th>(Circle one number on each line)</th>
<th>All of the Time</th>
<th>Most of the Time</th>
<th>A Good Bit of the Time</th>
<th>Some of the Time</th>
<th>Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel full of pep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>b. Have you been a very Nervous person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>c. Have you felt so down In the dumps that Nothing could cheer You up?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>d. Have you felt calm and Peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>e. Did you have a lot of Energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>f. Have you felt Downhearted and blue?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>g. Did you feel worn out?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>h. Have you been a happy person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
i. Did you feel tired?  

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one)

All of the time…………………………………………………..1  
Most of the time……………………………………………….2  
Some of the time………………………………………………3  
A little bit of the time…………………………………………4  
None of the time……………………………………………….5  

11. How TRUE or FALSE is each of the following statements for you?  

(circle one number on each line)

<table>
<thead>
<tr>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don’t Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
</table>

a. I seem to get sick a Little easier than Other people  

   1 2 3 4 5  

b. I am as healthy as Anybody I know  

   1 2 3 4 5  

c. I expect my health to Get worse  

   1 2 3 4 5  

d. My health is Excellent  

   1 2 3 4 5
APPENDIX P:

ST. GEORGE’S RESPIRATORY QUESTIONNAIRE
THE ST. GEORGE’S RESPIRATORY QUESTIONNAIRE

Subject Number ___________________________     Date ________________________

INSTRUCTIONS: This questionnaire is designed to help us learn much more about how your breathing is troubling you and how it affects your life. We are using it to find out which aspects of your illness cause you the most problems, rather than what the doctors and nurses think your problems are.

Please read the instructions carefully and ask if you do not understand anything. Do not spend too long deciding about your answers.

Part 1

Questions about how much chest trouble you have had over the last year. Please circle one answer for each question.

1. Over the last year, I have coughed:

   Circle One

   Most days a week...........................................................1
   Several days a week......................................................2
   A few days a month......................................................3
   Only with chest infections.............................................4
   Not at all...........................................................................5

2. Over the last year, I have brought up phlegm (sputum):

   Most days a week...........................................................1
   Several days a week......................................................2
   A few days a month......................................................3
   Only with chest infections.............................................4
   Not at all...........................................................................5

3. Over the last year, I have had shortness of breath:

   Circle One
4. Over the last year, I have had attacks of wheezing:

- Most days a week
- Several days a week
- A few days a month
- Only with chest infections
- Not at all

5. During the last year, how many severe or very unpleasant attacks of chest trouble have you had:

- More than 3 attacks
- 3 attacks
- 2 attacks
- 1 attack
- No attacks

   Go to 7

6. How long did the worst attack of chest trouble last:

   Circle One

   A week or more
7. Over the last year, in an average week, how many good days (with little chest trouble) have you had:

No good days ........................................................... 1
1 or 2 good days ...................................................... 2
3 or 4 good days ...................................................... 3
Nearly every day is good .......................................... 4
Every day is good .................................................... 5

8. If you have a wheeze, is it worse in the morning:

No ............................................................... 1
Yes ................................................................. 2
Don’t have a wheeze .............................................. 3

Part 2

Section 1

9. How would you describe your chest condition:

Circle One

The most important problem I have .......................... 1
Causes me quite a lot of problems .......................... 2
Causes me a few problems .................................. 3
Causes no problem ............................................. 4

190
10. If you have ever had paid employment:

My chest trouble made me stop work .............................................1

My chest trouble interferes/interfered with my work or made me change my work.................................................................2

My chest trouble does not/did not affect my work .........................3

Never had paid employment ......................................................4

Section 2

Questions about what activities usually make you feel breathless these days. For each item, please circle either 1 for True or 2 for False as it applies to you.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Sitting or lying still:</td>
<td>1</td>
</tr>
<tr>
<td>12. Getting washed or dressed:</td>
<td>1</td>
</tr>
<tr>
<td>13. Walking around the home:</td>
<td>1</td>
</tr>
<tr>
<td>14. Walking outside on the level:</td>
<td>1</td>
</tr>
<tr>
<td>15. Walking up a flight of stairs:</td>
<td>1</td>
</tr>
<tr>
<td>16. Walking hills:</td>
<td>1</td>
</tr>
<tr>
<td>17. Playing sports or games:</td>
<td>1</td>
</tr>
</tbody>
</table>

Section 3

Some more questions about your cough and breathlessness these days. For each item, please circle either 1 for True or 2 for False as it applies to you.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. My cough hurts:</td>
<td>1</td>
</tr>
</tbody>
</table>
19. My cough makes me tired: 
20. I am breathless when I talk: 
21. I am breathless when I bend over: 
22. My cough or breathing disturbs my sleep: 
23. I get exhausted easily: 

Section 4

Questions about other effects that your chest trouble may have on you these days. For each item, please circle 1 for True or 2 for False as it applies to you.

<table>
<thead>
<tr>
<th>Circle One</th>
<th>TRUE</th>
<th>FALSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. My cough or breathing is embarrassing in public:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25. My chest trouble is a nuisance to my family, friends, or neighbors:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26. I get afraid or panic when I cannot get my breath:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27. I feel that I am not in control of my chest problem:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28. I do not expect my chest to get any better:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>29. I have become frail or an invalid because of my chest:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>30. Exercise is not safe for me:</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31. Everything seems too much of an effort:</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Section 5

32a. Do you take any medications: 

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Go to 36.
Questions about your medication. To complete this section, please circle either 1 for True or 2 for False as it applies to you.

<table>
<thead>
<tr>
<th>Circle One</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TRUE</strong></td>
</tr>
</tbody>
</table>

32. My medication does not help me very much: 1 2

33. I get embarrassed using my medication in public: 1 2

34. I have unpleasant side effects from my medication: 1 2

35. My medication interferes with my life a lot: 1 2

Section 6

These are questions about how your activities might be affected by your breathing. For each question, please circle 1 for True if one or more parts applies to you because of your breathing. Otherwise, circle 2 for False.

<table>
<thead>
<tr>
<th>Circle One</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TRUE</strong></td>
</tr>
</tbody>
</table>

36. I take a long time to get washed or dressed: 1 2

37. I cannot take a bath or shower, or I take a long time: 1 2

38. I walk slower than other people, or I stop for rests: 1 2

39. Jobs such as housework take a long time, or I have to stop for rests: 1 2

40. If I walk up one flight of stairs, I have to go slowly or stop: 1 2

41. If I hurry or walk fast, I have to stop or slow down: 1 2

42. My breathing makes it difficult to do things such as walk up hills, carrying things upstairs, light gardening, such as weeding, dance, play bowls, or play golf: 1 2

43. My breathing makes it difficult to do things such as carry heavy loads, dig the garden or shovel the snow, jog or walk at 5 miles per hour, play tennis or swim: 1 2
44. My breathing makes it difficult to do things such as very heavy manual work, run, cycle, swim fast or play competitive sports:  

1 2

Section 7

We would like to know how your chest trouble usually affects your daily life. Please circle either 1 for True or 2 for False as it applies to you because of your chest trouble. (Remember that True only applies to you if you can not do something because of your breathing.)

<table>
<thead>
<tr>
<th>Circle One</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRUE</td>
</tr>
</tbody>
</table>

45. I cannot play sports or games:  1 2

46. I cannot go out for entertainment or recreation:  1 2

47. I cannot go out of the house to do the shopping:  1 2

48. I cannot do housework:  1 2

49. I cannot move far from my bed or chair:  1 2

Here is a list of other activities that your chest trouble may prevent you from doing. (You do not have to circle these, they are just to remind you of ways in which your breathlessness may affect you):

- Going for walks or walking the dog
- Doing things at home or in the garden
- Sexual intercourse
- Going out to church, or place of entertainment
- Going out in bad weather or into smoky rooms
- Visiting family or friends or playing with children

Please write in any other important activities that your chest trouble may stop you from doing:

________________________________________________________________________
50. Now would you circle (only one) which you think best describes how your chest affects you:

Circle One

- It does not stop me from doing anything I would like to do…………..1
- It stops me from doing one or two things I would like to do……………...2
- It stops me from doing most of the things I would like to do…………..3
- It stops me from doing everything I would like to do………………….4

51. Date completed:

_______________________
APPENDIX Q:

HEALTH BEHAVIOR QUESTIONNAIRE
HEALTH BEHAVIOR QUESTIONNAIRE

1. Do you smoke cigarettes?
   1. Yes
   2. No (Skip to #4)

2. On the average, how many cigarettes do you smoke a day?
   1. Less than a pack a week
   2. ½ a pack a day or less
   3. 1 pack a day
   4. 1 ½ packs a day
   5. 2 packs a day
   6. 2 ½ packs a day
   7. 3 or more packs a day

3. How long have you smoked this amount? __________ (Answer and skip to #8)

4. Have you ever used cigarettes on a regular basis?
   1. Yes
   2. No (Skip to #8)

5. Prior to quitting, on the average, how many cigarettes did you smoke a day?
   1. Less than a pack a week
   2. ½ a pack a day or less
   3. 1 pack a day
   4. 1 ½ packs a day
   5. 2 packs a day
   6. 2 ½ packs a day
   7. 3 or more packs a day

6. How many years did you smoke? __________

7. How long has it been since you quit smoking? __________

8. Do you consume alcohol?
   1. Yes
   2. No (Skip to #11)

9. In the past month, about how many alcoholic drinks per week did you consume? (A drink is 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of hard liquor)
   1. Less than 1 drink per week
   2. 1 to 5 drinks per week
   3. 6 to 10 drinks per week
   4. 11 to 15 drinks per week
   5. 16 to 20 drinks per week
6. 20 or more drinks per week

10. How long have you consumed this amount of alcohol? __________ (Answer and skip to #15)

11. Have you ever consumed alcohol?
   1. Yes
   2. No (Skip to #15)

12. Prior to quitting, on the average, how many alcoholic drinks did you consume per week? (A drink is 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of hard liquor)
   1. Less than 1 drink per week
   2. 1 to 5 drinks per week
   3. 6 to 10 drinks per week
   4. 11 to 15 drinks per week
   5. 16 to 20 drinks per week
   6. 20 or more drinks per week

13. How long did you consume this amount of alcohol? __________

14. How long has it been since you quit consuming alcohol? __________

15. Do you use illicit drugs? (e.g., cocaine, marijuana)
   1. Yes
   2. No (Skip to #18)

16. How often do you use illicit drugs?
   1. Daily
   2. Weekly
   3. Monthly
   4. 3 to 4 times per year
   5. Other _____

17. How long have you used illicit drugs? __________ (Answer and skip to #22)

18. Have you ever used illicit drugs? (e.g., cocaine, marijuana)
   1. Yes
   2. No (Skip to #22)

19. Prior to quitting, on the average, how often did you use illicit drugs?
   1. Daily
   2. Weekly
   3. Monthly
   4. 3 to 4 times per year
   5. Other _____
20. How long did you use illicit drugs? __________

21. How long has it been since you quit using illicit drugs? __________

22. Are you trying to lose weight?
   1. Yes (Skip to #25)
   2. No

23. Are you trying to gain weight?
   1. Yes (Skip to #29)
   2. No

24. Are you trying to maintain your current weight, that is, to keep from gaining or losing weight?
   1. Yes (Skip to #32)
   2. No

25. Are you on a diet?
   1. Yes
   2. No

26. What type of diet are you on? _________________________

27. Are you eating less calories to lose weight?
   1. Yes
   2. No

28. Are you eating less fat or carbohydrates to lose weight?
   1. Yes
   2. No

29. Are you using physical activity or exercise to lose weight?
   1. Yes
   2. No

30. Are you participating in a weight management program to help you lose weight?
   1. Yes
   2. No

31. How long have you been trying to consistently lose weight? __________

32. Are you eating more calories to gain weight?
   1. Yes
   2. No
33. Are you eating foods high in fat to gain weight?
   1. Yes
   2. No

34. How long have you been trying to consistently gain weight? _________
APPENDIX R:

SEVEN-DAY PHYSICAL ACTIVITY RECALL
**7-Day Recall**

**Moderate Activities**
*Occupational Tasks:* Delivering mail or patrolling on foot, house painting, truck driving, making deliveries, lifting and carrying light objects.
*Household Activities:* Raking the lawn, sweeping and mopping, mowing the lawn with a power mower, cleaning windows.
*Sports Activities:* Volleyball, ping pong, brisk walking for pleasure or to work (3mph or 20min/mile), golf (walking and pulling or carrying clubs), calisthenic exercises.

**Hard Activities**
*Occupational Tasks:* Heavy carpentry, construction work, doing physical labor.
*Household Tasks:* Scrubbing floors.
*Sports Activities (actual playing time):* Doubles tennis, disco, square, or folk dancing.

**Very Hard Activities**
*Occupational Tasks:* Very hard physical labor (digging or chopping with heavy tools), carrying heavy loads, such as bricks or lumber.
*Sports Activities (actual playing time):* Jogging or swimming, singles tennis, racquetball, soccer

1. **On the average,** how many hours did you sleep each night during the last 5 weekday nights (Sunday – Thursday)? ______ Hours

2. **On the average,** how many hours did you sleep each night last Friday and Saturday nights? ______ Hours

3. How many **total hours** did you spend during the last **five weekdays** doing **moderate** activities or others like them as listed above? ______ Hours

4. Last **Saturday and Sunday,** how many **total hours** did you spend on **moderate** activities? ______ Hours

5. How many total hours did you spend during the last **five weekdays** doing **hard** activities or others like them as listed above? ______ Hours

6. Last **Saturday and Sunday,** how many **total hours** did you spend on **hard** activities? ______ Hours

7. How many total hours did you spend during the last **five weekdays** doing **very hard** activities or others like them? ______ Hours

8. Last **Saturday and Sunday,** how many **total hours** did you spend on **very hard** activities? ______ Hours
SMOKING SELF-EFFICACY SCALE

The following are some situations in which certain people might be tempted to smoke. Please indicate whether you are sure that you could refrain from smoking in each situation.

1) When I am nervous.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

2) When I feel depressed.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

3) When I am angry.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

4) When I feel very anxious.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

5) When I want to think about a difficult problem.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

6) When I feel the urge to smoke.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
4. Fairly sure
5. Absolutely sure

7) When having a drink with friends.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

8) When celebrating something.
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

9) When drinking beer, wine or other spirits
   1. Not at all sure
   2. Not very sure
   3. More or less sure
   4. Fairly sure
   5. Absolutely sure

10) When I am with smokers.
    1. Not at all sure
    2. Not very sure
    3. More or less sure
    4. Fairly sure
    5. Absolutely sure

11) After a meal.
    1. Not at all sure
    2. Not very sure
    3. More or less sure
    4. Fairly sure
    5. Absolutely sure

12) When having coffee or tea.
    1. Not at all sure
    2. Not very sure
    3. More or less sure
    4. Fairly sure
    5. Absolutely sure
APPENDIX T:

WEIGHT EFFICACY LIFESTYLE QUESTIONNAIRE
Listed below are a number of situations that lead some people to eat. We would like to know how confident you are that you would not eat in each situation.

Circle the number that best describes your feelings or confidence to not eat food in each situation according to the following scale:

<table>
<thead>
<tr>
<th></th>
<th>Not Confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Very Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I can resist eating when I am anxious (nervous).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>I can control my eating on the weekends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>3</td>
<td>I can resist eating when I have to say “no” to others.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>4</td>
<td>I can resist eating when I feel physically run down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>I can resist eating when I am watching TV.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>I can resist eating when I am depressed (or down).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>7</td>
<td>I can resist eating when there are many different kinds of food available.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>8</td>
<td>I can resist eating even when I feel it’s impolite to refuse a second helping.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>9</td>
<td>I can resist eating when I have a headache.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
10) I can resist eating when I am reading.
   0 1 2 3 4 5 6 7 8 9

11) I can resist eating when I am angry (or irritable).
   0 1 2 3 4 5 6 7 8 9

12) I can resist eating even when I am at a party.
   0 1 2 3 4 5 6 7 8 9

13) I can resist eating even when others are pressuring me to eat.
   0 1 2 3 4 5 6 7 8 9

14) I can resist eating when I am in pain.
   0 1 2 3 4 5 6 7 8 9

15) I can resist eating just before going to bed.
   0 1 2 3 4 5 6 7 8 9

16) I can resist eating when I have experienced failure.
   0 1 2 3 4 5 6 7 8 9

17) I can resist eating even when high-calorie foods are available.
   0 1 2 3 4 5 6 7 8 9

18) I can resist eating even when I think others will be upset if I don’t eat.
   0 1 2 3 4 5 6 7 8 9

19) I can resist eating when I feel uncomfortable.
   0 1 2 3 4 5 6 7 8 9

20) I can resist eating when I am happy.
   0 1 2 3 4 5 6 7 8 9
APPENDIX U:

EXERCISE SELF-EFFICACY SCALE
# Exercise Self-Efficacy Scale

Using the scale below as a yardstick, please answer the following: How confident are you that you could exercise under each of the following conditions over the next six months?

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I cannot do it at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderately certain that I can do it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>certain that I can do it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Rating**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could exercise</td>
<td>0 – 100%</td>
</tr>
<tr>
<td>a. when tired.</td>
<td>______</td>
</tr>
<tr>
<td>b. during or following a personal crisis.</td>
<td>______</td>
</tr>
<tr>
<td>c. when feeling depressed.</td>
<td>______</td>
</tr>
<tr>
<td>d. when feeling anxious.</td>
<td>______</td>
</tr>
<tr>
<td>e. during bad weather.</td>
<td>______</td>
</tr>
<tr>
<td>f. when slightly sore from the last time I exercised.</td>
<td>______</td>
</tr>
<tr>
<td>g. when on vacation.</td>
<td>______</td>
</tr>
<tr>
<td>h. when there are competing interests (like my favorite TV show)</td>
<td>______</td>
</tr>
<tr>
<td>i. when I have a lot of work to do.</td>
<td>______</td>
</tr>
<tr>
<td>j. when I haven’t reached my exercise goals.</td>
<td>______</td>
</tr>
<tr>
<td>k. when I don’t receive support from family/friends.</td>
<td>______</td>
</tr>
<tr>
<td>l. when I have not exercised for a prolonged period of time.</td>
<td>______</td>
</tr>
<tr>
<td>m. when I have no one to exercise with.</td>
<td>______</td>
</tr>
<tr>
<td>n. when my schedule is hectic.</td>
<td>______</td>
</tr>
<tr>
<td>o. when my exercise workout is not enjoyable.</td>
<td>______</td>
</tr>
</tbody>
</table>

In general, I believe I could exercise at my target heart rate three to five times per week for 30 to 40 minutes over the next 6 months. ______
APPENDIX V:

LIFE ORIENTATION TEST
**LOT**

**Instructions:**
Please answer the following questions about yourself by indicating the extent to your agreement with each statement. Be as honest as you can throughout, and try not to let your responses to one question influence your response to other questions. There are no right or wrong answers.

Circle the appropriate number

<table>
<thead>
<tr>
<th>Circle the appropriate number</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In uncertain times, I usually expect the best.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. It’s easy for me to relax.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. If something can go wrong for me it will.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I always look on the bright side of things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I’m always optimistic about my future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I enjoy my friends a lot.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. It’s important for me to keep busy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I hardly ever expect things to go my way.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Things never work out the way I want them.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I don’t get upset too easily.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I’m a believer in the idea that “every cloud has a silver lining.”</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I rarely count on good things happening to me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Overall, I expect more good things to happen to me than bad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
APPENDIX W:

MAILED COVER LETTER
Dear Mr./Mrs. ____,

Thank you for agreeing to participate in our study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.” Enclosed in this envelope are two consent forms, two HIPAA authorization forms, and several brief questionnaires. Please read the consent and HIPAA authorization forms, and sign each of them in the spaces that are highlighted. Please note that participation in this study is voluntary and refusal to participate will not influence current or future treatment in any way.

Next, complete the questionnaires enclosed. Please note that a few of the questionnaires pertain to religious and spiritual coping. Some of the items in the questionnaires may be considered personal or sensitive. Although we would like you to answer all items in order to help us with our research, please note that you may choose to skip without penalty any item that you feel is too personal or sensitive. Please do not discuss your answers with anyone until after you have completed the questionnaires.

Prior to returning the questionnaires by mail, we will contact you to review the informed consent and HIPAA authorization forms and to address additional questions or concerns. After we have reviewed the informed consent and HIPAA authorization forms with you by telephone, enclose one signed copy of the informed consent and HIPAA authorization forms and the questionnaires in the stamped envelope and mail them back to us as soon as possible.

If you have any further questions, please contact Marquisha Green at the telephone number or email address listed below.

Thank you again for taking the time to complete these forms and questionnaires! We believe that this study will help us better care for patients with end-stage pulmonary disease referred for lung transplantation and their primary caregiver.

Sincerely,

Marquisha R. Green, M.A.
Graduate Research Assistant
The Ohio State University
(Office #) 614-688-3895
green.674@osu.edu
Charles F. Emery, Ph.D.
Principal Investigator
The Ohio State University
(Office #) 614-688-3061
emery.33@osu.edu

Patrick Ross, M.D.
Co-Investigator
The Ohio State University Medical Center
Dear Mr./Mrs. _____,

Thank you for agreeing to participate in our study “Coping and Health among Patients with End-Stage Pulmonary Disease and Primary Caregivers.” Approximately six months ago you completed a consent form, HIPAA authorization form, and several brief questionnaires. At that time, we indicated that we would be sending you a second packet of questionnaires after six months. Enclosed in this envelope is the second (and final) packet of questionnaires.

Please complete the enclosed questionnaires as soon as possible. A few of the questionnaires pertain to religious and spiritual coping and some of the items in the questionnaires may be considered personal or sensitive. Although we would like you to answer every item you may choose to skip without penalty any item that you feel is too personal or sensitive. Please do not discuss your answers with anyone until after you have completed the questionnaires. After you complete the questionnaires, place the questionnaires in the stamped envelope and mail them back to us as soon as possible. You will receive your final payment, $15, for participating in the study after the packet of questionnaires are returned.

If you have any further questions, please contact Marquisha Green at the telephone number or email address listed below.

Thank you again for taking the time to complete these questionnaires! We believe that this study will help us better care for patients with end-stage pulmonary disease referred for lung transplantation and their primary caregiver.

Sincerely,

Marquisha R. Green, M.A.
Graduate Research Assistant
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