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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

Quality of Life, Religious/Spiritual Coping, Demoralization and Depression in
Heart Failure Patients

by

Terry Larsen PhD, RN, CNS

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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In partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

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Quality of Life, Religious/Spiritual Coping, Demoralization and Depression in
Heart Failure Patients

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Background: Research suggests that the heart failure (HF) population is particularly vulnerable to depression. Other factors may also affect quality of life such as religious/spiritual coping, and demoralization.

Purpose: The purpose of this descriptive correlational study was to examine factors that predict health-related quality of life (HRQoL) in adults with heart failure. *Specific Aims:* (1) to examine level of religious/spiritual coping, spiritual distress, demoralization, depression and HRQoL among adults with heart failure; (2) to examine the relationships of religious/spiritual coping, spiritual distress demoralization, depression and selected demographic variables (age, gender, race/ethnicity and length of living with HF) with HRQoL.

Methods: A cross-sectional correlation design conducted at a large regional cardiomyopathy clinic in Southern California (N=115). Participants completed a survey containing demographic questions, the Duke University Religion Index, Religious Coping Scale, the Demoralization Scale, the Beck Depression Inventory-II and the Kansas City Cardiomyopathy Questionnaire.

Results: T-tests revealed significant differences for positive religious/spiritual coping $t(113) = 2.72, 95, 84, p < .05$ by gender. Women reported lower mean HRQoL scores 58.86 (SD 26.59) than men 68.57 (SD 24.77); and used more positive religious coping 20.95 (SD 4.97) than men 18.05 (SD 6.20) $p < .05$. Correlation analysis found depression and demoralization to be positively correlated ($r = .801; p < .05$). A significant negative relationship between depression and HRQoL ($r = -.645, p < .001$), demoralization ($r = -.507; p < .001$) and spiritual distress ($r = -.218; p < .05$) was found. There is a trend towards statistical significance with Hispanics 21.26 (SD 5.04) more likely to use positive religious/spiritual coping than non-Hispanic participants 17.96 (SD = 6.42, $p = 0.54$). Regression analysis indicate the overall model significantly predicted HRQoL $R_2 = 0.424, F(4,110) = 20.267, p < .001$. The model found depression accounted for 42% of the variance in HRQoL.

Implications: A holistic approach to managing HF patients that considers the varied human responses of stress and coping that is culturally sensitive and gender appropriate would be beneficial. Future qualitative research methods may capture the phenomenon of spiritual coping more completely. Also, use of other HF quality of life scales may find other significant factors important to patient management.

Copyright May 2010

Dedicated to the memory of my father, Richard Irving Smith,

who always wanted me to become a nurse.

The intuitive mind is a sacred gift and the rational mind is a faithful servant. We have created a society that honors the servant and has forgotten the gift.

Albert Einstein

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Chapter 1

The Problem

Nearly 5 million Americans are living with Heart Failure (HF), and it is the only cardiovascular condition that is on the rise (Duffy, Hoskins, & Dudley-Brown, 2005; Heart, 2008). The incidence of HF has more than doubled since 1979 reaching epidemic proportions, leading the cause of hospital readmissions. Concurrently, the aging population along with advanced cardiac technology has added to the prevalence and chronicity of HF, putting additional strain on our already over-burdened Medicare system (American Heart Association, 2006; Barnes et al., 2006).

Since the 1970's researchers have been finding strong relationships between those who are depressed and cardiovascular disease. Increased cardiovascular mortality among the depressed has been found in nine out of ten studies (Koenig, 2001). For those who are living with heart disease, studies have found that outcomes are significantly worse for those with depression (Rumsfeld et al., 2003). According to Sumner (1998) recognizing and responding to emotional as well as physical factors are equally important for improving quality of life with HF.

The disabling symptoms of HF can demand major long-term lifestyle alterations resulting in decreased quality of life through role limitations, physical activity, cognitive impairment, social functioning, and HRQoL. Required lifestyle changes with diet, exercise, complicated medical regimes, and the addition of health promotion activities can be overwhelming (Duffy et al., 2005). Consequently, there is a high rate of emotional distress with HF due to the inability to cope with disabling symptoms, and recurring setbacks (Koenig, 2002). The nature of distress may be psychological, social, and spiritual, having a profound impact on a person's ability to cope (Oates, 2004).

Compounding the problem, the dangerous neurohormonal responses of the body to stress are being recognized as an increased risk for further physiological damage and immune suppression with HF (Coma-Canella, Macias, & Iborrala, 2005; Kubzansky, 2007; Rutledge, Reis, Linke, Greenberg, & Mille, 2006). If some of these responses are not resolved over time, the demoralization of living with chronic illness can lead to major depression and poor outcomes (Kissane, 2004). Additionally, the paucity of literature on this subject makes it difficult to disentangle the complexity of psycho-cardiologic symptoms and its possible synergistic effects with HF (Pelle, Gidron, Szabó, & Denollet, 2008).

HF carries an uncertain illness course with a survival rate worse than many types of cancer and there is no cure (Barnes, 2006; Green, 2008). Sudden death can occur without warning in patients who are asymptomatic with the incidence rate up to 50% in patients with New York Heart Association Classification (NYHA) class II and III (Heart Failure Society, 2006) (see Appendix A). Research findings show survival rates for

optimally managed HF patients with refractory symptoms are less than one-year (Oates, 2004). Unfortunately, the major difficulty of planning hospice care for HF patients resides in the difficulty of projecting the trajectory of the disease. To date there are few standardized treatment plans for HF in hospice and literature on end-of-life care for HF patients is sparse.

Background and Significance

The chronic nature of heart failure along with recurring setbacks can lead one to question his/her self-efficacy and life's priorities, triggering spiritual distress (Sumner, 1998; Westlake & Dracup, 2000). Additionally, strong emotions such as fear and anxiety often elicit the stress responses of the body causing increasingly severe symptomology and fatal cardiac arrhythmias (Veith et al., 1993). Symptom perception is what the person experiencing it believes it is, within their physical and psycho-social-spiritual context and worldviews (Posey, 2006). Particular ways that people cope with stressful life events may be critical to understanding how they are able to prevent or buffer depressive symptoms (Koenig, 2001).

Interestingly, research suggests the majority of HF patients engage early in complementary medical modalities in order to cope. Some studies found that a multifaith group of respondents preferred religious involvement such as prayer to medication and psychotherapy for anxiety and depression (Rajagopal, Mackenzie, Bailey & Lavizzo-Mourey, 2002). Additionally, up to 64% of clients seek alternative therapy for chronic cardiovascular disease according to Marshall, Walizer, and Vernalis (2004), these

methods include Tai Chi, meditation, herbal supplements, yoga, prayer, and biofeedback among others. Spiritual well-being is associated with decreased perception of pain and is an essential component of good palliative care (Puchalski, Lunsford, Harris, & Miller, 2006).

Within the study of religion and health literature; religious beliefs and behaviors have shown to have inverse relationships with depression and risk factors for heart disease (Koenig, 2001; 2008b). HF patients have been found to have more hospitalizations than those who are not depressed (Jiang et al., 2001). The few studies done on the relationships between religiousness and heart disease suggest that religious involvement is independently associated with lower death rates and better outcomes (Jaffe, Eisenbach, Neumark, & Manor, 2005; Koenig, 1998; 2001; 2006). Religious and spiritual involvement has been described as healthy stress and coping mechanisms for many people giving them meaning, hope and strength during times of disease and crises (Carson & Koenig, 2008; Murray, Kendal, Grant et al., 2007 Thomas et al, 2008). Thus, research up to this point warrants closer examination of the factors that might possibly be antecedents and modifiers of depression in living with HF (see Appendix B).

Purpose of the Study

The significance of this study relates to the Heart Failure Society of America's guidelines (2006) for the evaluation of patients with HF. The two main goals of its management are prevention of further disease progression and the alleviation of patient suffering (Green, Porter, Bresnahan, & Spertus, 2000). The overall purpose of this study

will be achieved through the following aims: Aim I - explore spiritual coping in persons living with HF examine its effects on spiritual distress, demoralization, depression and HRQoL. Aim II - examine the relationships of selected demographic of age, gender, length of living with HF, ethnicity and religious/spiritual coping, spiritual distress, demoralization, depression, with HRQoL. The research questions that are the focus of this study are:

Question 1: What is the level of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL among HF patients?

Question 2: What is the relationship of demographic variables of age, gender, race/ethnicity, length of living with HF, religious/spiritual coping, spiritual distress, demoralization, and depression, with HRQoL?

Definition of Terms

Heart Failure is a complex clinical syndrome resulting from any cardiac etiology resulting in the impairment of the ventricle's ability to eject blood. The three hallmark physical manifestations are dyspnea, fatigue, and fluid retention. The results of these abnormalities often lead to decreasing functional abilities and ultimately quality of life for individuals and their families. Heart failure has a deteriorating illness trajectory often requiring multiple hospitalizations and death. Sudden death is a continual threat in living with HF (Evaluation of Heart Failure, 1999). For the purposes of this study the following definitions are given for the variables to be examined:

Religious/Spiritual Coping is defined as a positive reframing of one's life circumstances and understood to be a more basic concept of spiritual support. The phenomena of religious involvement and spiritual coping are meant to describe efforts made by patients in a search for meaning and purpose by turning to the sacred (Pargament, Koenig, & Perez, 2000). Positive religious coping will be assessed by the measurements of the Duke University Religion Index (Koenig, Meador, & Parkerson, 1997) (see Appendix C).

Spiritual Distress is defined as struggles one is experiencing within his/her relationship with the Transcendent/God (Koenig, 2008). Spiritual distress is an important developmental end-of-life issue in palliative care philosophy (Ferrell & Coyle, 2006). Acknowledging that not all religious coping is of positive benefit for mental health, the 7 negative items of the RCOPE Brief (Religious Coping) instrument developed by Pargament, Koenig, & Perez (2001) has been chosen to measure spiritual distress for this study (see Appendix D).

Demoralization is defined as a syndrome distinct from depression that characterizes a breakdown in coping that causes feelings of helplessness, hopelessness, existential distress and the desire to give up on life (Boscaglia, 2007; Kissane, 2004b). It will be measured by Kissane's Demoralization Scale (DS) a 24-item, 5-point response, self-report questionnaire with acceptable validity (see Appendix E).

Depression is defined as a mood disorder characterized by a loss of interest or pleasure in living that is socially disabling (Crawford & Robinson, 2008; Venus, Thomas, Eagan, Morelli, & Houska, 2001). Depression affects people's physical health, quality of life,

and mortality (Jiang et al., 2001). Its effects on patient's compliance make it difficult for clinicians to manage their care and makes caregiving more burdensome. In order to measure depression in HF patients, the Beck Depression Inventory (BDI-II) will be used (Segal, Coolidge, Cahill, & O'Reilly, 2008) (see Appendix F).

Health-related Quality of Life (HRQoL) is defined as the perception of the biomedical, psychosocial, and spiritual issues people living with HF experience. Research shows that with HF, perception of illness and functional status are directly correlated with their HRQoL (Doris, Yu, & Lee, 2004). It will be assessed within the context of the Kansas City Cardiomyopathy Questionnaire (KCCQ) The KCCQ provides a more accurate description of HRQoL previously used measures and is disease specific for HF (Green et al., 2000) (see Appendix G).

Contribution to Nursing Knowledge

As Watson (2005) so eloquently describes; when we touch the body of another, we are also touching their spirit; holding their healing in our hands. The very act of caring locates us in a place where we share each other's humanity that is dynamic and reciprocal. This vulnerability is a sacred place that has the ability to heal or destroy during the moments of greatest vulnerability. Thus, the philosophical underpinning of nursing praxis is grounded in the ethical demand of preserving and promoting the human dignity of those we care for (Logstrup, 1997). Caring relationships recognize the value, importance and dignity of both the client and the nurse. (Rafael, 2000). According to Ferrell (2005) true compassion is a spiritual act.

Ethical and moral issues often arise during times of illness. Considerations for individual patient needs are primary in spiritual care and closely related to ethics and morality. Values and beliefs reflect spirituality evidenced by questions that query what the right thing to do is and what one ought to do (Taylor, 2002). Critical decision making during illness is based on the patient's and family's beliefs that should be understood and supported by healthcare practitioners. However, despite compelling research data, ethical concerns continue to be debated regarding what constitutes appropriate behavior in addressing spiritual issues (Sloan, Bagiella, & Powell, 1999).

HF often reaches a point where medical treatment alone does not provide adequate symptom relief (Deaton & Grady, 2004). Living with HF and its uncertainties make the trajectory of HF difficult to predict, begging for a holistic approach (Oates, 2004). Therefore, continual development of spirituality is critical within HF management, in order to relieve suffering and distress, as there is no cure for this disease (Bekelman et al., 2007). Renewed interest on the topic of spirituality that promotes client comfort improves quality of life through spiritual understanding and growth (Kennedy & Cheston, 2003).

This study is a marriage of empirical reasoning and intuitive reasoning: the cornerstone of building nursing knowledge (Meleis, 2007). Identification of core assumptions have developed based on years of clinical nursing practice. Research knowledge gleaned from analysis of research literature over time have led to discovery of conceptual themes within the context of HF. Ontological assumptions and epistemological approaches of those concepts created the context and guiding theoretical

framework for developing the research questions. Findings from this study will add to the body of research evidence for future theoretical development and research on the nature of distress in living with HF which currently has very little data to draw from.

Chapter 2

Literature Review

The relevance of this study was identified as an important issue in a cardiomyopathy clinic at a large medical center in Southern California during my Clinical Nurse Specialist preceptorship in graduate school. Clearly, religious and spiritual factors play an important role in many people's lives influencing health and health outcomes including those suffering with HF (Koenig, 2001; Shuman & Meador, 2003). Widespread interest in spirituality has been growing most recently in the last twenty years throughout journals of nursing, medicine, religion, sociology, psychology, psychosomatic medicine, public health, and gerontology.

The literature for this study was searched from the online library located at a university in Southern California. Data bases were accessed through Academic Search Elite, ERIC, PubMed, CINAHL, PRECINAHL, OVID, PsychInfo, Alta Religion

Databases, Sociology Index, Healthsource, Health Watch, and the Google search engine from a period from 2006-2010. It includes classic nursing theory literature as well as research and supportive literature, using a multidisciplinary approach.

Key terms used were: conceptual analysis, depression, heart failure, palliative care, quality of life, spiritual assessment, spiritual care, spiritual distress, spiritual and religious coping, and transcendence. The literature was critiqued and categorized according to the variables being measured; religious/spiritual coping, spiritual distress, demoralization, depression, and health-related quality of life. This study postulates that spiritual distress, demoralization, and depression all play a part in the perception of the HF patient's quality of life. Additionally, it seeks to elucidate the unique process that religious/spiritual coping has on the outcome of HRQoL.

This literature review is a reflection of the diverse views and scientific results of these publications. It begins with descriptions of the physiological background factors that pertain to the relationships of stress on the cardiovascular system and its relationship to spiritual coping. Although this is not the focus of this study, it bears important consideration highlighting HF patient's vulnerability to stress (Rumsfeld et al., 2003). Second, a description is given of a holistic framework that informs the philosophical approach guiding this study. A multidimensional perspective conducted by the Fetzer Institute (John E. Fetzer Institute, 2003) recommends beginning with conceptual clarity as essential in the study of linking religious/spiritual coping to health outcomes. Therefore, conceptualization issues of the variable "spiritual distress" due to its highly

subjective meanings and ambiguity will be discussed in the third section. Thus, relationships of the variables that are considered threats to HRQoL will then be considered. Finally, the concept of spiritual/religious coping as a unique coping strategy is brought to light through pertinent research studies that have informed the development of this study.

The Neurohormonal Responses to Stress on the Cardiovascular System

Considerable progress in the understanding of the pathophysiology of HF has elucidated its etiology more clearly within the last 2 decades. Chronic heart failure is characterized by neurohormonal derangement. Neuroendocrine activity primarily refers to the hypothalamic-pituitary-adrenal (HPA) axis and sympathetic nervous system (SNS) activity and their central role in regulating homeostatic regulatory processes of the body to changing stimuli in the environment. Excessive activation of these pathways has been linked with increased risk for hypertension, cardiovascular disease and diabetes. The postulated link between neuroendocrine activity and health risks is termed “allostatic load” (Seeman & McEwen, 1996 p. 460). It describes the cumulative strain on the body, by repeated fluctuation of physiologic responses which are continually challenged impacting activity in the entire body’s regulatory systems

Neurohormonal derangement sets off a chain of bodily events progressing a cardiac condition into a systemic life-threatening disease. The renin-angiotensin-aldosterone system (RAAS) and the sympathetic nervous system are activated by various

cardiac events and diseases. Subsequently, specific neurohormones are produced that exert biologic and hemodynamic effects on the left ventricle and vascular bed adversely affecting vascular compliance and ventricular dysfunction (Buvat de Virginy, 2006). Decreased renal artery perfusion activates the RAAS system that results from decreased cardiac output causing increased retention of sodium and water reabsorption. Thus a murderous relationship between the kidneys and the heart creates further cardiac remodeling through a complex cascading process involving proinflammatory cytokines, inflammation and many other deleterious metabolic processes (Armour, 2007; Emdin, et al., 2003). Additional decompensation of ventricular function can also occur from poor self-maintenance, compliance and comorbid conditions (Onwuanyi & Taylor, 2007).

A review of the literature done by Esch et al., (2002) has found that stress is a complex process calling for consideration of the subjective and individual differences in the stress response. Variables such as the patient's history, duration of the stressors influence and genetic components may all have positive or negative effects on how stress is processed in an individual. Generally the effects of stress are deleterious. Highlighted are the data showing close relationships between stress and the cardiovascular system in order to inform modern medical practices and new therapeutics. Stress management techniques focusing on mental, behavioral and psychosocial stressors all have future importance in the dealing with stress' affects of cardiovascular disease. It is concluded that stress has a major impact on the circulatory system playing a significant role in susceptibility, progress, and outcome of cardiovascular diseases.

Deeply anchored beliefs affect attitudes, behaviors, and interpersonal skills, resulting in mind-body interactions with illness and treatment choices (Tu, 2006).

Psychoneuroimmunology studies show that when a person responds to an event, they do so with their entire body and person, showing complete connected integration and communication of the mind, body and spirit. Our endocrine systems and immune responses are reflective of the state of our minds and hearts resulting from the ascribed meanings we give to the demands of illness (Halldorsdottir, 2007). Doering and associates (2006) found that negative emotions act through numerous pathological pathways such as neurohormonal dysfunction, immune suppression, coagulopathy, and endothelial dysfunction, exacerbating cardiac disease and crises. Buvat de Virginy (2006) states that neurohormonal derangement and its damaging myocardial effects occur long before a person becomes symptomatic with HF.

Jekell et al., (2005) conducted a case-controlled study on the effects of thioredoxin (Trx) in chronic heart failure (CHF). Trx is a multipotent protein and key regulator responsible for gene regulatory activity for several transcription factors including glucocorticoids receptors, DNA binding and cytokine mediating factors. The rationale for conducting the study was based on the poor prognosis of CHF and the need for better understanding of underlying inflammatory mechanisms as essential for design of novel therapy strategies. The syndrome of CHF involves a series of neuroendocrine responses affecting the sympathetic nervous system and glucocorticoids. These complex reactions are responsible for maintaining homeostasis within the body's system for stress

adaptation, having multiple effects on immune cells and molecules. CHF patients have elevated adrenocortical hormone release that elevates cortisol levels, lipid peroxides, and other biochemical reactions. The researchers found higher than expected levels of Trx in CHF patients, concluding its importance as a biochemical marker increasing with advancing disease. Additionally, psychological, cardiovascular, and metabolic factors were found to correlate with free salivary cortisol and stress recovery (Roy, Kirschbaum, & Steptoe, 2001; Thomas, 2008).

Stress is a universal human experience but the intensity, duration, frequency, and nature of stressors and their impact is highly individualistic effecting different areas of the brain according to a study conducted by Soufer and Burg (2007). The long-term consequences of stress are determined by the role that these individualistic responses play including their impact on health, positively or negatively. A person's perceptions of stressful events are influenced by past experiences and one's physiological and behavioral response to those events (Armour, 2007; Courtney Devries, Craft, Gasper, Neigh, and Alexander, 2007).

An award-winning study conducted by Courtney Devries et al., (2007) postulated that increasing stress levels have deleterious consequences in cardiac arrest and wound healing with corresponding increases in corticosteroids acting on glucocorticoids receptors. The researchers paired mice together following induced stroke. Mice that were paired together were found to have less cerebral ischemia than mice that were alone. It was found that cytokine regulation is vital to ischemic outcome with important

therapeutic and preventive implications for stroke. Courtney Devries et al., (2007) argue that positive social interactions can suppress the body's reactivity to stress and suppress the inflammatory response with cerebral ischemia. These studies suggest that the biochemical component to stress has definite cardiovascular effects that could be mediated with positive social interactions improving health outcomes. There are strong similarities between existing human and rodent data. Positive social support is an important resource to coping with heart failure and the lack of emotional support is a strong predictor of cardiac events and hospitalization (Bean, Gibson, Flattery, Duncan, and Hess, 2009; McMahan, 2002).

Religion and Spiritual Coping May Counter Stress Reaction

Seeman and McEwen's (1996) research maintains that perceived support by God or members of a religious congregation may reduce one's reaction to a stressor. Sharing of sympathy, encouragement and assistance with tasks, materials and finances are some of the perceived benefits of church attendance (Idler et al., 2003). Positive social bonds are thought to modulate neuroendocrine responses through cognitive-emotional interpretations of stimuli and the neocortical and limbic centers. Information is carried through the sensory systems and fed through the temporal lobe to the amygdala and the (HPA) axis. This process ultimately results in emotional and behavioral responses to environmental stimuli including fear, anxiety and more general body-wide neuroendocrine arousal, highlighting the impact of the social environment on individuals (Seeman & McEwen, 1996). However, there are many dimensions to religiousness and

spirituality that could relate to health outcomes in various ways especially among various stages of life. It is thought that people with religious or spiritual resources may sidestep some of health risks or minimize the effects disease (Idler et al., 2003).

Religious/spiritual coping is a unifying and integrating essence, creating wholeness between mind-body and soul (Manning, 2006). Religious/spiritual practices can elicit a relaxation response that changes sympathetic activation to parasympathetic processes reducing allostatic load. Prayer, repetitive words, music, sounds, and images may trigger changes in brain wave activity that lowers blood pressure and heart rate, improves oxygenation, reduces muscle tension, in addition to alteration of brain wave activity and function. The experience of deep inner peace has been associated with a shift from sympathetic arousal to a parasympathetic relaxation response (Idler et al., 2003). The dampening of physiological reactions is thought to provide a cushion in dealing with both major and minor stressors (John E. Fetzer Institute, 2003). Immediate coping methods are based on existing individual's religious orientation that has health implications (Pargament, Smith, Koenig, & Perez, 1999). Koenig and colleagues (1997) conducted a study that examined the relationships of religious attendance and biological immune responses in 1718 subjects over 65 years old. The results showed a consistently inverse relationship between religious attendance and high level of Interleukin-6 and other biological processes of immune function.

Social support gained through religious attendance and coping processes could be significant factors in living with heart disease. From a socio-cultural perspective, religion

and spirituality are especially relevant in older minority populations, particularly concerning end-of life issues (Daaleman & Frey, 2004). Due to the prevalence of depression with HF and its negative outcomes, it is important to explore determinants and modifiers of psychosocial factors that influence adjustment. The influence of social support likely exerts a protective effect on coping, enabling people to manage stressful life situations (Park, Fenster, Suresh, & Bliss, 2006).

McMahan (2002) conducted a literature review on twenty-three psychological factors relating to heart failure in order to learn more about coping styles used by patients. The review revealed that levels of social support and style of coping help to ameliorate depression and anxiety acting as prognostic indicators for those with HF. Reducing morbidity and mortality in the HF patient is the primary objective in treatment and ultimate proof of therapeutic effectiveness (Murberg & Bru, 2001). Changing treatment paradigms from pharmacological interventions to a more holistic approach may result in reducing numbers of hospitalizations and improved outcomes.

A Biopsychosocial-Spiritual Model Framework

This study is viewed through the lens of Sulmasy's "Biopsychosocial-Spiritual Model for Health Care at End of Life" (Sulmasy, 2002). It is a holistic model seeking to move beyond addressing the biological, psychological, social, and the spiritual as distinct dimensions of the person. Rather, it addresses the whole person with the assumption that all people have a spiritual history, helping to shape the identity of the individual. This

history affects all aspects of the whole person when life-threatening illness occurs. The cornerstone of this model is that all people are intrinsically spiritual. This holistic view acknowledges that many people's spiritual history includes a religious tradition that helps shape the individual.

Sulmasy's model states that illness disturbs relationships inside and out. Physically, the disturbances inside the body affect the relationships of biological, biochemical processes including the relationship between body and mind. Outside the body includes the relationships between the individual and their environment, socially and spiritually. Healing consists of the restoration of right relationships, inside and outside the body. At the end of life when the inside of the body "milieu interior" (p. 26) can no longer be healed, spiritual growth and healing can still take place "milieu divin" (p.26). Spiritual issues often arise in the dying process. Questions of relationships arise, such as the need for forgiveness and reconciliation for example. Questions of meaning are associated with the concept of hope. Believing one's life has had no meaning is the ultimate human indignity, characterizing complete hopelessness (Sulmasy, 2002).

The medical profession today must move beyond historical dualism of separation of mind and body that was touted by Descartes during the Age of Enlightenment, argues Cassell (1991). Cartesian philosophy which espoused the separation of mind and body has long overshadowed the medical and nursing professions, viewing suffering and distress as primarily a physical manifestation (Hall, Koenig & Meador, 2004). Sulmasy purports that holding the paradigm of the reductionism of medicine, and the larger truths

about the patient as a human being, is an enormous challenge for today's health care practitioner. Symptom management and facilitation of reconciliation with friends and family is the path to genuine healing (Sulmasy, 2002).

Conceptual Considerations of Spiritual Distress

The concept of spiritual distress is a complex phenomenon and is best described by clusters of concepts. Murray (2004) argues that the spiritual dimension is often ignored due to lack of conceptual clarity, agreed upon definitions, epistemological concerns, and research funding issues. Therefore it is suggested that spirituality's epistemology is inherently ambiguous based on an individual's culture and belief system. Spiritual distress is often closely confounded with psychological distress, anxiety, suffering, psychosocial distress, depression and demoralization. Distress and spiritual distress have overlapping components of both concepts making it difficult to isolate them. O'Brien (2003) found seven concepts associated with "alterations of the spirit"; (p. 67) spiritual pain, alienation, anxiety, guilt, anger, and spiritual loss within the nursing diagnosis literature.

Nevertheless, the meaning of spiritual distress is unique within the context of illness. Factors threatening to spiritual integrity are related to pathophysiologic, treatment modalities, and situational domains. Firstly, issues of human relationships such as grief, loss, emotional and physical pain are significant factors determining how people respond to stress (Carson & Koenig, 2004). Immobility resulting from debilitating disease,

terminal illness, pain, traumas and stigma may challenge belief systems causing separation from spiritual ties and practices. Secondly, prescribed treatment regimens may conflict with beliefs, such as blood transfusions, dietary restrictions, surgery, medical procedure, and medications among others (Koenig, 2007). Lastly, personal and/or environmental situations embarrassment of practicing spiritual rituals due to lack of privacy, beliefs opposed by family members, peers, and healthcare providers can be spiritually distressing (Puchalski, 2006; Taylor, 2002). Spiritual distress adds the existential concern to distress often expressed as “Why me” (Taylor, 2002, p.114) questions and puzzlement of one’s purpose in life and self-worth. In contrast, spiritual well-being describes a sense of connectedness as experienced or perceived by the individual that promotes health and well-being. Chaturevedi (2007) asserts that spiritual distress requires spiritual healing.

The etymological meaning of spirituality is derived from the L. *spiritualis*, adjective, meaning ‘of breathing, of the spirit’ (Harper, 2001). It is believed to be a primary motivational force, intrinsic to human nature that leads to transcendence, giving meaning in the face of life-threatening illness, and improving quality of life through connectedness with self-others, God or nature (Ferrell & Coyle 2006; Murberg & Bru, 2001; Philip Greenway, Phelan, Turnbull, & Milne, 2007). Carson and Koenig (2004) postulate that spirituality is the individually defined philosophy of life that is not necessarily religious and is integral to one’s cultural beliefs and values. Spirituality defines the context, not the content of personhood and is the lived experience, not an

intellectual process (Miner-Williams, 2006). Conceptual confusion and the covariant relationship of religion and spirituality make it difficult to articulate their meanings (Shuman & Meador, 2005).

Distress is a non-specific biological and/or emotional response to a perceived stressor that may be threatening to the individual (Ridner, 2004). Distress has also been used to describe spiritual discomfort according to Ridner (2004). Webster's (2007) defines distress as being "cut to the heart" giving metaphorical, if not literal meaning with HF. The concept of the heart being the center of the soul and one's spiritual essence may give spiritual distress with HF added significance (Oates, 2004; Pearsall, 1998). Health is more than the absence of disease argues Shuman & Meador (2005).

The terms of religion and spirituality are often used interchangeably but are not always synonymous. Religion is defined as an organized system of beliefs, outwardly expressed through group worship, education, fellowship, and rituals. It is a path towards spiritual growth for many people. Wright (2005) states that all people have spirituality inside, but not all people are religious. Townsend, Kladder and Mulligan (2002) found that religion is a source of comfort to some, but not to everyone, according to the systematized review of literature on the impact of religion on health. However, 94% of Americans claim to have belief in God (Townsend, Kladder, & Mulligan, 2002). There is a growing realization that religion and spirituality may affect every aspect of a person's life (Hills, Paice, Cameron & Shott, 2005; Oates, 2004).

Recently, many nursing scholars are challenging the restrictive view of religion and spirituality in order to expand its applicability to fit everyone. Contemporary spirituality is eclectic and individualistic situated on the sacred-secular continuum seeking many paths to meaning (Paley, 2006). In contrast, Swinton (2006) describes religion and spirituality as coexistent. He warns that attempting to separate the two concepts of religion and spirituality is a form of reductionism and commodification, downgrading the ultimate significance of a particular religion. Some scholars state that the entire concept of spirituality lacks a precise theoretical or conceptual definition within the nursing profession, (Manning, 2006, Sawatsky & Pesut, 2005). Whereas, Marstolf and Mickley (1998) wrote that research in spiritual care in nursing needs to consider the differences in world-views espoused in nursing conceptual models and theories.

Underscoring its conceptual complexity Pargament, Meggar-Russel, and Murray-Swank (2005) suggest that religious beliefs have such a rich multidimensional underpinning which is so diverse and varied that uniformity of beliefs is impossible. Meaningful advances in the fields of religion and health will depend on the capacity to conceptualize religion and spirituality that requires a cultural-linguistic approach (Hall, et al., 2004). Highlighting the challenges of clear conceptuality of spirituality, Cavendish et al., (2004) posits that nurses must distinguish the difference between religion and spirituality and use it consistently in education, practice and research.

The profession of nursing has traditionally held The North American Nursing Diagnosis Association (2006) description of spiritual distress as a state in which a person

is experiencing a disturbance in his/her belief system that provides strength, hope and meaning to life. According to Koenig (2008a), a leading researcher of theology, spirituality and health, when conducting research with spiritual distress as a variable, it should be defined as within the context as one's relationship to God or the Transcendent. This research perspective taken by Koenig (2008a) creates conceptual clarity and consistency within the spirituality/religion research. It also highlights the theological aspect that many people experience when dealing with illness that is distinctly spiritual not psychosocial (Carson & Koenig, 2008, Pargament, Tarakeshwar, Ellison, & Wulff, 1998). When spirituality is measured using instruments with indicators for good mental health, the associations are contaminated by tautology making the results meaningless. Thus, spirituality should be measured with instruments that describe its unique and distinct contribution to the coping process (Koenig, 2008a).

Possible Factors Affecting Health-related Quality of Life with HF

Historically, healthcare professionals believed that there was no relationship between religion and health. However, a large body of literature has emerged legitimizing its link to better health through psychological and social mechanisms that are related to less depression, anxiety and emotional problems. People who are involved in religious activity generally live longer and have less cardiac disease. Biological mechanisms affecting the immune, endocrine systems, genetic factors, and central nervous system influences are being studied to shed greater light on how religious involvement provides

hope, optimism, and well-being to those who suffer from chronic illness (Carson & Koenig, 2008).

Individuals with chronic illness often deal with a wide array of intense psychological and emotional stressors causing pain, uncertainty, change in biography, role conflicts within the family system, and changes in one's personal well-being. Each person's response to illness is individual rating quality of life differently, depending on their sense of coherence, spirituality and worldviews (Delgado, 2007; Leninger, 1988). Depression is a common mental health disorder and is common with chronic illness. Even a mild case of it can disrupt normal functioning and adversely affect quality of life (Fu & Parahoo, 2008). Religious/spiritual coping provides a buffer against life's stressors by providing meaning, strength, and the ability to transcend life's circumstances (Pargament, 1997).

Paying closer attention to factors that positively and negatively affect HRQoL may reduce health service utilization and morbidity (Bosworth et al., 2004). Physically, HF is characterized by slowed and erratic physical functioning including an increasingly shrinking social world that includes repeated hospitalizations and forced dependency. Additionally, employment, financial, and emotional losses often lead patients down the path to spiritual distress and major depression affecting overall quality of life. Spiritual well-being relates to the individual's circumstance associated with illness and his/her personal values and expectations as an essential component of health-related quality of life (Atkinson, Wishart, Wasil, & Robinson, 2004).

The chronic nature of heart failure along with recurring setbacks can lead one to question his/her self-efficacy and life's priorities, triggering spiritual distress (Sumner, 1998; Westlake & Dracup, 2000). Westlake and Dracup (2001) conducted a qualitative phenomenological study which sought to uncover how HF patient's spirituality affecting patients with advanced heart failure adaptation to illness. The multidimensional construct of health-related quality of life was used to guide the content of the questions. The researchers framed the study also on how the individual's sense of self can erode through the chronicity of heart failure. Spirituality is a primary motivational force that can lead to transcendence giving meaning in the face of life-threatening illness, improving quality of life. Many participants also cited the importance of spirituality, religion, family, and friends as sources of hope. This study was said to support the importance of optimism for the future for heart failure patients. It brought to light the role of nursing in providing social support, communication, and compassionate care for patients and their families (Westlake & Dracup, 2001).

Regrets about the past, search for meaning in experiencing HF and hope for the future were reported as recurrent themes. The search for meaning and purpose in life may bring about unresolved interpersonal conflicts, leading to greater anxiety ultimately causing spiritual distress (Westlake & Dracup, 2001). Empirical studies have shown that unresolved spiritual struggles can lead to physical decline and be predictive of greater mortality risk (Pargament & Ano, 2006). Viewing spiritual crises as a developmental

stage in the dying process deserves consideration within the specialty of HF management (Kennedy & Cheston, 2003).

The concept of suffering is closely associated with existential distress as the result of a person's powerlessness over their symptoms and hopelessness over their prognosis (Clarke & Kissane, 2002; Puchalski, 2006). Demoralization is described as a process that starts when a significant threat is perceived that leads to helpless, hopelessness and desire to die, due to the loss of meaning in one's life with chronic illness. It may accompany illness crises in those without depression and is characterized by a breakdown in coping, however, over time it can lead to major depression (Rickelman, 2002).

Thus, demoralization is considered a distinct and separate phenomenon from depression and can be identified as an antecedent if experienced for a length of time, studied and identified only in cancer patients thus far, (Kissane, 2004b). This condition is relevant to end-of life decision making and its potential interference with the informed consent process (Kissane, 2004a).

Heart failure patients suffer from major long-term lifestyle alterations resulting in decreased quality of life through role limitations, decreased physical activity, mental health, social functioning and spiritual well-being. Required changes in diet, exercise, self-care challenges relating to complicated medical regimes, and the addition of health promotion activities can be overwhelming causing grief, and isolation according to a study conducted by Duffy et al., (2005). Negatively perceived events such as these

occurring in the face of terminal illness can be demoralizing through a combination of feelings of helplessness and existential distress (Chochinov, 2003; Kissane, 2004a). It is a process in which the personal experience of helplessness and not knowing what to do that attacks one's self esteem and self-efficacy (Clarke & Kissane, 2002).

Ferrell (2005) explains that suffering threatens the core of a person involving spiritual distress and existential crises. Suffering without meaning is demoralizing and those who feel demoralized are at risk for suicide due to the overall perception of hopelessness (Chochinov, 2003). The absence of meaning in life is characterized by alienation from one's self and the world and what is held sacred (Daaleman & Frey, 2004; Pargament et al., 2005). According to Frankl (2006) the greatest task in life is the quest for meaning; whose life experience is illustrative. As a holocaust prisoner, Frankl found survival possible under the most dire circumstances as long as there was meaning to his suffering; "having a Why to live for enabled them to bear almost any How" (p. 104). A feminist theology book written by Raphael, (2003) also reports memories of Holocaust survivors and how they survived. Even the smallest acts of kindness by fellow prisoners provided motivation to endure the most horrific situations, by instilling faith in humanity and God. Regardless of gender, race, or class, all humans have the innate need for healing amidst suffering according to Georges (2002).

Bosworth et al., (2004) conducted a qualitative study on what constituted quality of life for HF with New Your Heart Association Classification (NYHA) class I-IV. Recurrent themes found the changes of life are not as significant as the methods of

coping with HF as important opportunities for personal growth. Whereas, a review of randomized clinical trials found that both pharmacological and nonpharmacological treatments can have a positive impact on HRQoL (Leidy, Rentz & Zyczynski, 1999).. Additionally, HRQoL is quite possibly the primary indicator of treatment effectiveness (Leidy et al., 1999).

Perceived control has been found to reduce negative emotions and positively influence comeback from cardiac events (Doering et al., 2004). Current literature shows that stress and anxiety management along with self-mastery are crucial in the HF patient population, because psychosocial factors can be significant prognostic indicators (Seskevich, 2005). Subsequently, anxiety often accompanies depression creating diagnostic confusion and can be very difficult in determining what is normal or abnormal (Pelle et al., 2008). Anxiety is characterized as a negative emotion with an element of fear that has psychoneuroimmunological manifestations (Jiang et al., 2004).

Heart Failure and Depression

Depression is a common disability affecting up to 121 million people worldwide (Fu & Parahoo, 2008). According to the DMS-9 manual describes depression has being linked to many psychiatric conditions (American Psychiatric Association, 2000). People who are depressed are significant users of medical services and at increased risk for suicide. It is also a condition that often goes unrecognized in the clinical settings Almeida and Almeida (1999). Depression is known to be a strong predictor in those with severe

heart failure resulting in poor outcomes, recidivism and mortality (Duffy et al., 2005; Gusick, 2008; Koenig, 2006; Norra, Skobel, Arndt, & Schauerte, 2008; Rumsfeld et al., 2003; Sayers et al, 2007; Sullivan, Newton, Hecht, Russo, & Spertus, 2004).

Jiang and colleagues (2001) followed 374 participants with HF for over one year examining the effects of depression. Those with major depression had more than double the risk of mortality at 3 months and at one year. Thomas et al., (2008) postulate the shared physiological changes of heart failure and depression potentiates the progression of both diseases. In addition, there is overlapping symptomology of HF and depression that includes fatigue, hypersomnia, decreased appetite, and lack of interest in pleasurable activities. The high impact of depression with HF results in 2 to 3 times more hospital admissions than those who are not depressed (Norra et al., 2008). Bennet, Sauve, and Shaw (2005) state that as many as 40% of those who have NYHA Class IV status suffer from depression, with concurrent cognitive deficits.

Faller et al., (2007) discusses depression in HF as a frequent comorbidity. In a study on gender differences in depression and survival in HF results showed that major depression was associated with increased mortality risk. Interestingly, as the severity of NYHC increased and prevalence of depression increased, it was found more commonly with women. It is also mentioned that depression may influence mortality through behavioral pathways and directly via biological mechanisms involved in HF. Unfortunately, studies are lacking linking treatment of depression to improvement of survival.

A mixed method study conducted by Gary (2006) found that women were generally in the supporter role rather than being supported by others. Consequently, functional disability in doing household chores due to increasing dyspnea and fatigue had the most influence in quality of life. Gary noted that depression was prevalent in the respondents that reduced self-care practices and the motivation to perform them. Additionally, higher prevalence rates of depression have been linked to being female, functional impairment, and perceived lack of social support (Zauszniewski & Bekhet, 2008). In a study conducted by Whipple et al., (2009) higher levels of hopelessness are associated with greater subclinical atherosclerosis independent of age, race, income, cardiovascular disease risk factors, and depressive symptoms among middle-aged women (Whipple et al., 2009). Women with HF have more symptomology, comorbidities, longer hospital stays and the SOLVD study suggested a worse 1 year cardiac mortality outlook than men (Petrie, Dawson, Murdoch, Davie, & McMurray, 1999).

A new diagnosis of HF is known to cause considerable emotional stress due to the inability to cope (Koenig, 2002) and depression has been shown to empirically predict a desire for death and increased desire for physician assisted suicide (Chochinov, 2003). Sayers et al., (2007) recommend changes in clinical practice including routine screening for psychiatric disturbances in older patients with HF. Koenig, Vandermeer, Chambers, Burr-Crutchfield, and Johnson (2006) report the outcome of minor depression in HF is dependent on physical factors whereas major depression is more intrinsically related, suggesting the experience of spiritual distress. Beery, Bass, Fowler & Allen, (2002) states

that spiritual distress may wear the mask of depression; going unrecognized or misinterpreted in the clinical setting.

Interestingly, a psychological crises that has been misunderstood by the medical profession, but has no organic etiology is called a “spiritual emergency” (p. 133) and presents with symptoms of distress such as depression, anxiety, and even altered states of consciousness and hallucination (Kennedy & Cheston, 2003). Religious/spiritual problems are currently recognized in the Diagnostic and Statistical Manual of Mental Disorders DSM-IV (American Psychiatric, 2002). Actions which support rather than suppress this event are the most beneficial in fostering the resolution of spiritual distress (Kennedy & Cheston, 2003). Patients who use avoidance-type coping styles have been found to have higher mortality rates. The literature review suggests that an active approach in managing HF is vital to adaptation and lowering anxiety and mortality (Murburg & Bru, 2005).

Taylor (2002) states that there is a growing body of research showing predictive relationships between aspects of religiosity or spirituality and enhanced well-being, less depression and psychological distress, reduced mortality and delayed morbidity. However, Sloan et al., (1999) state that the association is weak and inconsistent. A meta-analytical review of the prevalence and magnitude of depression in HF related to clinical outcomes was conducted by Rutledge et al., (2006). Findings indicate a moderate to high prevalence of depression with reductions in symptoms resulting from various treatment interventions..

Religious/Spiritual Coping is a Unique Coping Strategy

The adaptive qualities of coping should be evaluated within the stressful context which they occur, according to Folkman and Lazarus (1986). Folkman and Lazarus' Stress and Coping Theory explains coping as a major mediating factor between "stressful events and adaptational outcomes such as depression, psychological symptoms, and somatic illness" (p.1). Folkman and Lazarus' work described coping as having two central components: Problem-focused coping and emotion-focused coping. In exploration of the debate and criticism of coping research, Folkman and Moskowitz (2004) sought to discover new developments in why some individuals fared better than others when encountering stress in their lives. They asserted that in studying coping styles within a given culture, effective interventions may be developed to ameliorate stress. Individual coping strategies used are diversely complex and not inherently good or bad. They concurred with Dr. Kenneth Pargament's research (2001) identifying that religious coping is distinct from secular coping, which can have either positive or negative outcomes. Folkman and Moskowitz (2004) state that spiritual/religious coping is a unique method of coping that gives individuals enhanced ability to cope with adverse circumstances. When first diagnosed with illness many first turn to their faith for comfort, strength, hope and meaning in order to counter anxiety and stress (Pargament, 1997).

Religious involvement and spiritual coping can have a significant impact on patient's quality of life. An entire body of research has emerged maintaining that religion

reduces the impact of stress by providing enhanced coping skills for anxiety, depression and other psychosocial distress relating to chronic illness (Koenig, 2007; Meyerstein, 2005; Pargament, 1997; Philip Greenway et al., 2007; Rowe & Allen, 2004). Religious coping studied with cancer patients found a greater use of positive religious coping was related to greater quality of life but also more physical symptoms (Tarakeshwar et al., 2006). Immediate coping methods are based on existing individual's religious orientation that has health implications (Pargament, 1997).

Transcendence of one's circumstances is an essential component of spirituality. It has been empirically identified as an important predictor of mental health and well being found by Ellerman and Reed (2001) in a correlational study of middle-age adults. Webster describes the meaning of "spiritual" as "characterized by the ascendancy of the spirit, showing much refinement of thought and feeling" (Webster's, 1980, pg. 1373). Self-transcendence has been consistently found to be beneficial in older depressed adults and is an essential dimension of spirituality. Spiritual growth and maturity that facilitates a broadening perspective validates meaning and purpose during challenging life circumstances that characterizes a developmental process (Bean & Wagner, 2006). Spiritual coping provides transcendence through a connectedness with God or higher power that helps counter the uncertainty that presents major problems with chronic illness causing of fear, discomfort, pain and suffering (Coyle, 2002).

Both Positive and Negative Coping Affects Health

Sustaining one's spirit and identity in the face of chronic illness can be very challenging for patients, family and caregivers. Thus, positive religious/spiritual coping provides hope in the midst of despair (Puchalski, 2006). Connectedness with God or higher power helps counter the uncertainty that present major problems with chronic illness causing fear, discomfort, pain and suffering (Coyle, 2002; Taylor, 2002). Religious coping is an important coping mechanism that helps buffer against the harmful effects of stress by enabling individuals to reappraise life's obstacles as opportunities for growth or part of a divine plan (Schanowitz & Nicassio, 2006). Using the Brief RCOPE in examining positive psychosocial functioning of older adults, Schanowitz and Nicassio, 2006) found that religious coping positively correlated with positive affect and self-acceptance but other studies have found positive relationships between positive religious coping and beneficial health outcomes (Koenig, 2008).

Since medical illness often brings the spiritual dimension into focus, many first turn to faith for comfort strength hope and meaning. Others, though fewer in number are beset with spiritual struggles that trigger a decline in physical illness, mental health including depression (McConnell, Pargament, Ellison, & Flannelly, 2006; Pargament & Ano, 2006). Illness can precipitate a search for meaning and spiritual struggles are connected with psychological distress in illness (Mako, Galek, & Poppito, 2006). Subsequently, negative religious coping in response to stressful life events can be very problematic and distressing (Tarakshwar et al., 2006). Moreover, it is associated with

unfavorable physical and mental outcomes such as greater functional disability, lower quality of life and depression and increased mortality (Koenig & Meador, 2004; Pargament et al., (2005). For example, negative religious coping might include perceived harsh truths regarding punishment, abandonment or unforgiveness with eternal consequences.

Pargament, Koenig, Tarakeshwar, and Hahn (2001) conducted a 2 year longitudinal study of medically ill elderly patients and their religious coping methods. It was concluded that religious struggles over time can increase health-related risks and are predictive of declines in health. A study of 577 hospitalized patients found that negative religious coping behaviors was associated with overall poor health and decreased quality of life (Koenig, 1998). On the other-hand, others find new meaning and purpose for living within illness that helps them to emotionally survive, care of themselves, recover and rehabilitate, using their religious or spiritual beliefs (Koenig & Meador, 2007). After controlling for the effects of social support, religious coping is a significant predictor of psychosocial adjustment (Vandecreek, Pargament, Belavich, Cowell, & Friedel, 1999).

A qualitative study conducted by Gall, et al. (2005), found that when physical illness presents, many elderly turn to their long held spiritual and religious beliefs for coping. A cross-sectional survey of 838 hospitalized patients over 50 years old revealed that adults tend to consistently show increasing involvement in religious activities with age. As a person matures the world of spirit becomes more important (Martsolf &

Mickley, 1998) a concept that is congruent with the framework of this study and reflective of developmental factors along the life cycle.

Moreover, religious involvement was related to fewer past psychiatric illnesses, especially with depression and alcohol according to Koenig (2002) who studied the religious involvement of congestive heart failure (CHF) and chronic pulmonary disease (CPD). Results showed that 98% had religious affiliation, 48% attended weekly services, 70% reported praying and reading religious material at least daily, and greater than 85% reported religious beliefs and attitudes. The study concluded that CHF and CPD patients commonly have religious beliefs and practices and are related to less severe illness and disability, along with fewer mental illnesses and less psychotropic drug use.

A report by the Institute of Medicine highlights the domains of quality supportive care for life-limiting conditions (Institute of Medicine, 1997). Domains found to promote optimal care were overall quality of life; physical well-being and functioning; psychosocial well-being and functioning; spiritual well-being; patient perception of care and family well-being and functioning (Chochinov, 2003). There is a growing understanding that religion pervades every aspect of an individual's life (Hills et al., 2005).

Nurses are uniquely positioned at the bedside to recognize and respond to individual's specific spiritual needs. Establishing collaborative relationships between clinical nurse specialists, palliative care coordinators, and cardiology services will

produce mutually beneficial outcomes for patients and their families (Barnes et al., 2006) Working with the interdisciplinary team to achieve the common goals of realistic and optimal patient/family coping has been shown to decrease readmission rates for HF patients to the hospital. (Duffy et al., 2005).

People acquire their religious meaning systems from their cultural backgrounds (Park, 2005). Thus, investigating ways to improve communication with our clients honoring their culture and belief systems has the potential to improve patient satisfaction, better self-management, levels of depression thus improving quality of life (Kristellar, Rhodes, Cripe, Sheets, 2005). HF specialists Heywood, Elatre, Ramdas, Fabbri, and Huiskes, (2005) assert that patients and their caregivers need and want guidance in their personal and professional lives due to the poor prognostic outlook. Preserving client's autonomy shows respect for the client and is important to their care (Hardin & Hussey, 2003).

The compelling relationships of religious coping, depression and health have been studied intensively over the past 20 years by physicians, nurses and psychologists. However, research data thus far suggest that the study of spiritual/religious coping and heart failure patient's adaptation to illness is in its infancy. The comorbidity of depression has been well established with CHF; however it is the field of oncology that contains the majority of the spirituality and illness research. Few HF studies have addressed spiritual coping and spiritual distress and their impact on quality of life, showing a gap in the literature.

Chapter 3

Methodology

Building on previous research conducted on this topic, both qualitative and quantitative, this study will examine relationships among religious/spiritual coping, spiritual distress, demoralization, and health-related quality of life (HRQoL). This study is a cross-sectional correlation design conducted at a large regional cardiomyopathy clinic in Southern California. It investigates the level of the variables and the relationships among them in a population in which these issues have received very little research and attention.

Identification of Sample

A convenience sample (N=115), was recruited from a large regional cardiomyopathy clinic in Southern California. Respondents who met the inclusion criteria were approached to participate in the study during clinical hours. Inclusion criteria were all patients over the age of 18 yrs old, male and female, and enrolled in the Cardiomyopathy

Clinic and able to speak, read and write English. Exclusion criteria were any serious comorbid medical diagnosis such as renal failure requiring dialysis, current malignancy, or debilitating cognitive impairment. The rationale for this method of sampling in this study is that homogenous sampling reduces variation permitting a more focused inquiry.

Human Subjects Protection

Ethical considerations have been made throughout this research proposal by obtaining IRB approval and informed consent. Both the researcher and the research assistant completed the most recent version of the National Institutes of Health (NIH) Office of Extramural Research's "Protecting Human Research Participants" training course. The research design does not pose any foreseen threats to any participants. The sample is well defined and does not unwittingly exclude minorities. Participants are recruited equitably and without coercion. The data collection process was conducted as to minimize respondent burden and confidentiality ensured from the outset of the study. It was important to explain this to each participant prior to signing the consent due to the personal nature of the topic. The research assistant was trained in the research protocol and to be sensitive and courteous to each respondent, valuing respondent's diversity (see Appendix H). Reporting of the research participant's identities will be adequately protected during the reporting of the study (Polite & Beck, 2004).

Application was made and approval granted by the Institutional Review Board (IRB) from the University of San Diego for this study. IRB #2008-12-059 (see Appendix

I). Application for the IRB at Loma Linda University Medical Center was approved. IRB #590356 (see Appendix J).

Duke University Religion Index (DUREL)

The DUREL is a 5 item scale used to measure positive religious coping methods. Understanding the role of religious beliefs and practices are important to understanding psychosocial adjustment to illness (Storch et al., 2004, Koenig et al., 1997). The DUREL assesses organization, non-organizational and intrinsic religious dimensions of religiousness. It has excellent internal consistency with Cronbachs alpha ranges of .75 - .91 (Storch et al., 2004; Cotton et al., 2006). It is comprised of 3 subscales. Item 1 (DUREL 1-r) measures religious attendance. Item 2 (DUREL 2-r) measures private religious activity. Scoring is based on a 6 item Likert scale. Items 3-5 (DUREL 3-r) measure intrinsic religiosity. Scoring is based on the sum of the responses within each of the 3 categories on a 5 item Likert scale. Religious/spiritual coping items were reverse scored (1= 6, 2= 5, 3= 4, 4=3, 5= 2, 6=1) then totaled for each respondent. Higher scores indicated higher religious/spiritual coping. Overall religiosity scores consisted of the sum of the reversed scores.

Religious Coping Scale (Brief RCOPE)

Pargament, Koenig, & Perez, (2000) developed a 14 item questionnaire designed to measure positive and negative religious coping methods with good internal consistency. This tool has been chosen because older adults tend to be more religious as they age with higher levels of church attendance than other age groups. The RCOPE assesses the extent to which participants use religious coping strategies in dealing with

stressful life events. The first seven questions reflect positive religious coping styles and the last seven focus on negative coping styles. Only the negative coping items will be used in order to measure spiritual distress. (Cronbach's alpha ranges from .58 - .73) (Pargament et al., 1998). Scores of the seven subscale items are summed, with the higher the score representing greater spiritual distress (Tarakeshwar, 2006).

How a person's functioning and health in relation to religious dimensions is of great interest to scholars of many disciplines. However, the study of spirituality as it is defined in the bulk of the religion and health literature presents many challenges. Pargament et al., (2005) argues that confirming or disconfirming the unseen or can be studied by measuring the paths that lead people to perceive their ultimate truths. Experiences, rituals, relationships and perceptions are factors that can be examined personally, socially and culturally. In developing the RCOPE as a research measurement, Pargament et al., (2000) explains that keener understanding of religious coping could lead to better integration of religious issues for assessment, education and counseling interventions.

The Demoralization Scale (DS)

Kissane, (2004b) developed a 24-item, 5-point response, self-report questionnaire with acceptable validity (Cronbach's alphas 0.89-0.71). Subscales demonstrate satisfactory internal coherence, and have sufficient differentiation from one another. Pearson's matrix showed high significance for convergent validity of its constructs, differentiating demoralization from depression in palliative care and psycho-oncology patients. Subscales included were dysphoria, loss of meaning and purpose

disheartenment, helplessness and sense of failure. Scoring will be based on the sum of the subscales. The DS was developed using a factor analysis of several pertinent scales: McGill Quality of Life, Patient Health Questionnaire, Beck Depression Scale, Beck Hopelessness Scale, Hunter Opinions and Personal Expectation Scale and Schedule of Attitudes Toward Hastened Death. The DS has divergent ability to differentiate a subset of patients who are demoralized but not yet clinically depressed.

Beck Depression Inventory-II. (BDI-II)

The BDI-II is a widely used screening tool to measure depression with those who are 13 years and older and medically ill. It is an upgraded version of the Beck Depression Inventory that included many somatic items, resulting in artificially elevated depression score. The updated version is considered a more valid version for those with medical illness and its items correspond more closely to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (Steer, Ball, Ranieri & Beck, 1999; Segal, et al. 2008). It has been found to have significant correlations with the Geriatric Depression Scale for older adults, and the Center for Epidemiologic Studies Depression Scale (CES-D) used for the general population. The BDI-II is a 21 item self-report depression screening tool with good internal consistency ranging from ($\alpha = .85$ for older adults $-.92$ for older adults), showing solid psychometric properties. Each item is rated on a Likert scale ranging severity of depressive symptoms from 0-4 with higher scores indication greater depression. The measures ask respondents to rate their symptoms as to how they have felt within the past 2 weeks. Scoring is the sum of the subscales with the maximum score being 63. The cut off points ≥ 10 for minimal depression and ranges of 14-19 for mild

depression, 20-28 for moderated depression and 29-63 denoting severe depression (Aben, Verhey, Lousber, Lodder, & Honig, 2002; Segal et al., 2008).

Kansas City Cardiomyopathy Questionnaire (KCCQ)

The KCCQ is a self-administered 23 item questionnaire that quantifies disease-specific physical limitations, symptoms frequency, severity and changes over time, quality of life, social interference and self-efficacy. It uses a Likert scale with clinically meaningful gradations between categories. It takes on average 4-6 minutes to complete. Cronbach's alpha for the relevant domains addressed by the KCCQ are: physical limitations (0.90) symptoms (0.88), quality of life (0.78) social limitation (0.86), self-efficacy (0.62), KCCQ functional status (0.93), KCCQ clinical summary (0.95). It provides 10 scaled scores and is scored 0-100 (Green et al., 2002).

The KCCQ is a more recently developed instrument and has been chosen for the measurement of health-related quality of life (Green et al., 2002). It is a valid, reliable and responsive health status measure for patients with HF. It was developed with the two primary goals of preventing further disease progression and alleviating suffering. The KCCQ is a way to measure indicators of living with HF that has the capacity to erode one's quality of life (Rumsfeld et al., 2003). Due to the depth and complexity of the concept of quality of life this instrument was created to address the limitations and lack of responsiveness to clinical changes. It provides a more accurate measurement of responsiveness to clinical change that is three times larger with HF, than the Minnesota Living with Heart Failure Questionnaire and the Chronic Heart Failure Questionnaire. Other advantages are that its questions include gender neutral language, clarity and

interpretability to other languages (Sullivan et al., 2004). Studies used to validate the KCCQ have suggested that lower KCCQ scores are associated with poor health status (Rumsfeld et al., 2003). The overall summary score will be calculated to determine HRQoL for this study. It includes the KCCQ quality of life and social limitation scores in addition to the functional status score which correlates with New York Heart Association Classification. The English language version was used for this study (Green et al., 2002).

Data Collection Procedures

Respondents were recruited face to face in Cardiomyopathy clinic waiting room by use of a flyer, which was handed out at the front desk by the clinic's staff (see Appendix K). Upon verbal consent, the patient was then introduced to the researcher or the research assistant and the study was explained in an empty private room. Informed consent was obtained prior to survey administration by the investigator (see Appendix L). A packet including the demographic questionnaire and 5 scales were administered that included the Duke University Religion Index, (DUREL), Religious Coping Scale (RCOPE), Demoralization Scale (DS), Beck Depression Scale - II and the Kansas City Cardiomyopathy Questionnaire (KCCQ). Demographic and background information, including age, gender, race/ethnicity, religious affiliation, marital status, and length of living with HF, comorbidities and financial resources were collected from the study participants (see Appendix M). The self-administered questionnaires given to the respondent lasted approximately 30 minutes in a private room. Respondents were then given \$10.00 in cash along with a thank-you note for their participation.

All analyses were conducted using the Statistical Package for Social Sciences (SPSS). Initially, demographic data were analyzed using descriptive statistics which included frequency, means, and standard deviations. To examine the reliability of the measures used in the study, Cronbach's alpha were computed and compared to values reported in the literature.

The analytic approach for each of the research questions was the following:

Question 1: What is the level of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL among HF patients?

Descriptive statistics (e.g., frequency, means and standard deviations) were calculated in order to describe the levels of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL in the sample of HF patients.

Question 2: What is the relationship of religious/spiritual coping, spiritual distress, demoralization, depression, and demographic variables with HRQoL?

First, correlational analysis was used to exam the relationships among the variables of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL. Pearson's r was used to examine the bivariate relationships between these quantitatively measured (continuous) variables. Correlational analysis was used to examine the relationships of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL with continuous demographic variables of age, gender, race/ethnicity and length of living with HF.

T-tests and analysis of variance were used to examine the relationships between the variables of religious/spiritual coping, spiritual distress, demoralization, depression, HRQoL and categorical demographic variables.

Second, a multiple linear regression analysis was conducted in order to examine the relationships of the predictor variables of religious/spiritual coping, spiritual distress, demoralization, depression, and key demographic variables with the dependent variable, HRQoL. Significance of the overall model and significance of each predictor variable was examined. This research design provides the advantage of immediate and economical acquisition of research data and is appropriate for determining the relationship between the variables at one point in time.

Chapter 4

Findings

The purpose of this study was to examine the relationships among religious/spiritual coping, spiritual distress, demoralization, depression, and health-related quality of life (HRQoL) in heart failure patients. In this chapter the study findings are presented. First a descriptive profile of participants, including their scores on the independent variables of religious/spiritual coping, spiritual distress, demoralization, depression, and the dependent variable of health-related quality of life (HRQoL) is presented. The chapter concludes with the findings related to specific research questions.

Description of Sample

A purposive sample of 115 heart failure patients was recruited from a large regional cardiomyopathy clinic located in Southern California. Ages ranged from 25 to 85 and older. The largest age group was in the 55- 64 yrs category (22.6%). The sample was predominately male (65.2%), Caucasian 67 (58.3%), and married 65 (56.5%).

Slightly more than a third had some education at the college level 41 (35.7%). There was a total of 14 religious denominations represented; the largest category was Catholic 32 (27.8%); 3 (2.6%) described affiliation as non-denominational, and 26 (22.6%) claimed no religious affiliation.

Those living with HF for 10 years or more were the largest category (N = 35; 30.4%). Additionally, 59 (52.2%) participants have been hospitalized 3 or more times. Other diagnosed illnesses were grouped in body system categories for this study. Those who have been diagnosed with other illnesses totaled 80 (69.6%) with the majority (N = 42; 36.5%) reporting endocrine disorders followed by vascular problems (N = 25; 21.7%). Approximately two-thirds felt they had the financial resources to pay for their healthcare (N = 72; 62.6%), despite the fact that 95 (82.6%) respondents were unemployed (see Table 1).

Table 1

Participant Demographics

	<i>n</i>	%
Gender (<i>n</i> =115)		
Female	40	34.8
Male	75	65.2
Age (<i>n</i> =115)		
25-34 yrs	5	4.3
35-44 yrs	10	8.7
45-54 yrs	24	20.9
55-64 yrs	26	22.6
65-74 yrs	19	16.7
75-84 yrs	24	20.9
85 and older	7	6.1
Marital status (<i>n</i> =115)		
Married	65	56.5
Separated	19	5.2
Widowed	18	15.7
Divorced	13	11.3
Single	13	11.3
Currently Employed (<i>n</i> =115)		
No	95	82.6
Yes	20	17.4
Highest level of Education (<i>n</i> =115)		
8 th grade	9	7.8
12 th grade	27	23.5
Some college	41	35.7
College degree	23	20.0
Graduate school	15	13.0
Ethnic background (<i>n</i> =115)		
African American	21	18.3
Asian	3	2.6
Caucasian	67	58.3
Hispanic	23	20.0
Middle Eastern	1	.9

Table 1 *Participant Demographics (continued)*

	<i>n</i>	%
Religious Affiliation (<i>n</i> =115)		
Baptist	6	5.2
Buddhist	1	.9
Catholic	32	27.8
Christian	18	15.7
Holyness	2	1.7
Jewish	1	.9
Latter Day Saints	1	.9
Lutheran	1	.9
Methodist	2	1.7
None	26	22.6
Non-denominational	3	2.6
Pentecostal	3	2.6
Presbyterian	2	1.7
Protestant	11	9.6
Seventh-Day Adventist	4	3.5
United Church of Christ	2	1.7
Number of Times Hospitalized (<i>n</i> =115)		
None	6	5.2
1 time	25	21.7
2 times	25	21.7
3 or more times	59	51.3
How long living with HF (<i>n</i> =115)		
Less than 1 yr	6	5.2
1-3 yrs	27	23.5
4-6 yrs	28	24.3
7-9 yrs	19	16.5
10 or more years	35	30.4
Other diagnosed illnesses (<i>n</i> =115)		
No	35	30.4
Yes	80	69.6
Endocrine	42	36.5
Gastro-Intestinal	6	5.2
Hematological	11	9.6
Musculoskeletal	9	7.8
Neuromuscular	6	5.2

Table 1 *Participant Demographics (continued)*

	<i>n</i>	%
Oncological	6	5.2
Renal	8	7.0
Respiratory	17	14.8
Sensory	2	1.7
Urological	3	2.6
Vascular	25	21.7
Other	16	13.9
Financial resources (<i>n</i> =115)		
No	43	37.4
Yes	72	62.6

Finding Related to Research Questions

Question 1:

What is the level of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQOL among HF patients?

Descriptive statistics (e.g., means, standard deviations) were calculated in order to describe the levels of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL in the sample of HF patients (see Table 2).

Positive Religious/Spiritual Coping (DUREL)

The independent variable religious/spiritual coping was measured by the DUREL (Koenig, Meador & Parkerson, et al. 1997), a 5 and 6 item Likert type scale. Scores for subscale 1, religious attendance ranged from 1 to 6; subscale 2, private religious activity ranged from 1-6, subscale 3, intrinsic religiosity subscale score ranged from 6-18. The first item, (DUREL-1r) examining religious attendance was $M = 3.42$ ($SD = 1.76$); DUREL- 2r private religious activity $M = 3.50$ ($SD = 1.83$) and the mean DUREL intrinsic religiosity (comprised of items 3-5) reflects religious belief or experience $M = 12.14$ ($SD = 3.45$). Overall Religious/Spiritual coping $M = 19.06$ ($SD = 5.95$). The reliability coefficient of the DUREL overall religiosity in this study was .847. The DUREL 3r subscale was .88.

Negative Spiritual Coping (RCOPE)

Spiritual distress was measured by the 7 negative RCOPE religious coping items; $M = 9.01$ ($SD = 2.98$) range of 7 to 25. Examination of the distribution of the RCOPE scores revealed that it was positively skewed. Square root transformation was conducted on the RCOPE total score. The transformed variable remained positively skewed.

Demoralization (DS)

Demoralization was measured with the DS. Mean score for subject's responses to experiencing demoralization with HF was $M = 23.10$ ($SD = 17.03$) with scores ranging 0-

80. Although there is a wide range of demoralization scores the overall mean scores show mild demoralization although, criteria has yet to be established.

Depression (BDI-II)

Depression was measured with the BDI-II, $M = 11.86$ ($SD = 9.53$) ranging from 0-50. Considering the cut off points ≥ 10 for minimal depression and ranges of 14-19 for mild depression, 20-28 for moderate depression (Aben, et al. 2002; Segal, et al. 2008), this population's mean score shows mild depression with a wide variance up to moderate depression.

HRQoL (KCCQ)

Health related Quality of Life was measured by the KCCQ. The overall summary score for the KCCQ measuring HRQoL found scores ranging 9.64 -100 in this population. The mean HRQoL overall (clinical) summary score was 65.20 ($SD 25.72$).

Table 2

Descriptive Statistics of the Variables

Variable	Mean	SD	Cronbach's Alpha
Religious/Spiritual Coping (DUREL comp religious score reversed)	19.06	5.95	.85
DUREL 1r	3.42	1.76	
DUREL 2r	3.50	1.83	
DUREL intrinsic religiosity	12.14	3.45	.88
Spiritual Distress (RCOPE)	9.01	2.98	.75
Demoralization (DS)	23.10	17.03	.93
Depression (BDI-II)	11.85	9.53	.91
Health-related quality of life (KCCQ)	65.20	25.72	.97

Question 2:

What is the relationship of selected demographic variables age, gender, length of living with HF, ethnicity and religious/spiritual coping, spiritual distress, demoralization, and depression, with HRQoL?

One-way analysis of variance and t-tests were used to examine whether there are statistically significant differences between quality of life, spiritual/religious coping,

spiritual distress, demoralization, and depression mean scores by race/ethnicity, age, gender length of living with heart failure.

Levene's test was conducted for each ANOVA; where there was indication of violation of the homogeneity of variance assumption, Welch's F is reported. For the ANOVA for age and DS, Levene's test ($p = .010$) indicated a violation of the homogeneity of variance assumption. Therefore, Welch's test is reported for demoralization by age, $F(2, 57.39) = 3.09, p > .05$) and BDI by age, $F(2, 57.57) = .134, > .05$). One way ANOVA indicated there was no statistically significant difference on the positive or negative religious coping, demoralization, depression, and quality of life mean scores by age (see Table 3).

Table 3

ANOVA

AGE

Source	Mean	SD	F	Levene's test	df	<i>p</i>
DUREL						
25 – 54	19.18	5.50	.31	.737	2,112	.346
55 – 64	18.27	6.44				
65 – 85 and older	19.38	6.10				
RCOPE						
25 – 54	9.64	3.44	1.47	.234	2,112	.095
55 – 64	8.92	2.31				
65 – 85 and older	8.56	2.87				
DS						
25 – 54	25.28	18.16	3.02	.053	2,112	.010* \approx
55 – 64	27.96	19.43				
65 – 85 and older	18.88	13.84				

Table 3 ANOVA: Age (continued)

Source	Mean	SD	F	Levene's test	df	<i>p</i>
BDI						
25 – 54	12.72	9.49	2.17	.120	2,112	.003*≈
55 – 64	14.35	11.60				
65 – 85 and older	9.88	8.06				
KCCQ						
25 – 54	64.78	28.02	.053	.948	2,112	.403
55 – 64	64.16	26.35				
65 – 85 and older	66.06	23.98				

Note $p < .05$

Note ≈ Welch's post hoc test

Ethnicity

For positive religious/spiritual coping there was a significant difference among the means by ethnicity, $F(2,112) = 3.16, p < .05$. Tukey's HSD post hoc test showed no significant differences between the mean scores of ethnic groups (all $p > .05$). A trend is noted for Hispanic HF patients ($M = 21.26; SD = 5.04$) to use positive religious/spiritual coping more than Non-Hispanic White participants ($M = 17.96; SD = 6.42, p > .05$) (see Table 4). There were no significant differences on race/ethnicity for the other scales.

Table 4

*ANOVA**Ethnicity*

Source	Mean	SD	F	Levene's test	df	<i>p</i>
<i>DUREL</i>						
Caucasian	17.96	6.42	3.16	.046*	2,112	.054
Hispanic	21.26	5.04				
Other	20.00	4.73				
<i>RCOPE</i>						
Caucasian	8.87	2.91	.219	.804	2,112	.648
Hispanic	9.09	2.63				
Other	9.32	3.51				
<i>DS</i>						
Caucasian	24.54	18.30	.707	.495	2,112	.536
Hispanic	19.74	13.96				
Other	22.36	16.13				
<i>BDI-II</i>						
Caucasian	12.25	9.49	.419	.659	2,112	.559
Hispanic	10.22	8.63				
Other	12.28	10.58				

Table 4 ANOVA: Ethnicity (continued)

Source	Mean	SD	F	Levene's test	df	<i>p</i>
KCCQ						
Caucasian	62.99	25.77	.667	.515	2,112	.566
Hispanic	69.82	26.82				
Other	66.86	24.91				

Note $p < .05$ *

Length of Living with HF

There was no statistically significant difference on the positive or negative religious coping, demoralization, depression, and quality of life mean scores by length of time living with HF. Levene's test shows violation of the homogeneity of variance assumption for living with HF and the BDI – II ($p = .025$). Therefore, Welch's test was reported for the BDI by length of living with HF, $F(2, 63.37) = .80$, $p = .455$ (see Table 5).

Table 5

ANOVA
Length of Living with HF

Source	Mean	SD	F	Levene's test	df	<i>p</i>
DUREL						
3 yrs or less	18.94	5.82	.265	.768	2,112	.928
4-9 yrs	18.70	6.03				
10 or more years	19.66	6.08				
RCOPE						
3 yrs or less	9.27	3.43	.294	.746	2,112	.152
4-9 yrs	8.77	2.21				
10 or more years	9.09	3.45				
DS						
3 yrs or less	22.18	17.14	.179	.836	2,112	.067
4-9 yrs	22.70	15.41				
10 or more years	24.51	19.27				

Table 5 ANOVA: Length of Living with HF (continued)

Source	Mean	SD	F	Levene's test	df	<i>p</i>
BDI-II	12.03	11.00	.738	.481	2,112	.025
3 yrs or less						
4-9 yrs	10.68	7.44				
10 or more years	13.26	10.57				
KCCQ						
3 yrs or less	67.60	26.95	.694	.502		.199
4-9 yrs	66.67	23.44				
10 or more years	60.95	27.65				

Note * $p < .05$ *

Note \approx Welch's post hoc test

T- Test Gender

T-tests were conducted to examine potential gender differences on all scales. Levene's test was conducted for each t and where there was indication of violation of the homogeneity of variance assumption, the adjusted t was reported. Levene's test shows violation of the homogeneity of variance assumption for the DUREL and the BDI, the adjusted t is reported T-tests revealed statically significant differences for positive religious/spiritual coping $t(95.84) = -2.72, p = .008$ and differences approaching significance for HRQoL scores $t(113) = -1.95, p = .053$, demoralization $t(113) = -1.80, p = .075$, and depression $t(69.69) = 1.82, p = .073$ by gender. Women reported using significantly more positive religious coping 20.95 (SD 4.97) than men 18.05 (SD 6.20). Specifically, women use significantly more *private religious activity* $t(88.30) = -3.71, p = .000$ and more *intrinsic religiosity* $t(104.07) = -3.07, p = .003$. Women reported lower mean HRQoL scores 58.86 (SD 26.59) than men 68.57 (SD 24.77) and lower mean religious attendance score 3.33 (SD 1.94). Women score higher mean demoralization scores 26.98 (SD = 17.58) than men 21.04 (SD = 16.47) and higher mean depression scores 14.15 (SD 10.39) than men 10.63 (SD = 8.87) These differences were not statistically significant (see Table 6).

Table 6

T Test
Gender

N		Mean	SD	Levene's test	t	df	p
Male = 75							
Female = 40							
Variables							
DUREL	Male	18.05	6.20	.017*	-2.72	95.84	.008*
Overall	Female	20.05	4.97				
Total							
DUREL 1r	Male	3.47	1.67	.074	.409	113	.683
	Female	3.33	1.94				
DUREL 2r	Male	3.08	1.81	.015	-3.71	88.30	.000*
	Female	4.30	1.60				
DUREL	Male	11.51	3.68	.006	-3.07	104.07	.003*
Intrinsic	Female	13.33	2.01				
Religiosity							
RCOPE	Male	9.29	3.34	.108	1.41	113	.161
	Female	8.48	2.08				
KCCQ	Male	65.57	24.77	.170	1.95	113	.053
	Female	58.56	26.59				
DS	Male	21.04	16.47	.558	-1.80	113	.075
	Female	26.98	17.58				
BDI - II	Male	10.63	8.87	.046*	1.82	69.69	.073
	Female	14.15	10.39				

Note * $p < .05$

Correlational Analysis

Pearson correlations were conducted in order to quantify the relationships between the variables (see Table 7). Correlational analysis conducted using the DUREL 1r, religious attendance; DUREL 2r, private religious activity; and DUREL intrinsic religiosity reversed subscales, found no statistically significant relationships with any of the other scales. Total DUREL overall religiosity score is 27.

The RCOPE measuring negative spiritual/religious coping was positively significantly related to demoralization ($r(113) = 0.43; p < .01$), depression ($r(113) = 0.45, p < .01$) and a statistically significant inverse relationship to HRQoL ($r(113) = -0.22, p < .05$). High level of spiritual distress showed higher levels of demoralization and depression. Those who experience higher spiritual distress report lower HRQoL. Spearman's rho was also conducted because the RCOPE scores were positively skewed. The magnitude of the correlation coefficients were somewhat reduced for the most part but the pattern of significant findings was not changed. Results showed positive religious coping ($r(113) = 0.01, p > .05$), depression ($r(113) = 0.37, p < .01$), demoralization ($r(113) = .39, p < .01$), and HRQoL ($r(113) = -0.22, p < .05$).

The strongest correlation found is between the BDI-II and demoralization ($r(113) = .80, p < .01$). Respondents who scored high in demoralization also scored high in depression. Additionally, there is a significant negative relationship between depression

and health-related quality of life in this sample ($r(113) = -.65, p < .01$). The reliability coefficient for the HRQoL was 0.97 in this study (see Table 7).

Table 7 Correlation Analysis

Variable	1	2	3	4	5	6	7
1. KCCQ	1.0						
2. RCOPE	-.218*	1.0					
3. DS	-.507**	.425**	1.0				
4. BDI	-.645**	.448**	.801**	1.0			
5. DUREL 1r	.943	.081	-.017	.138	1.0		
6. DUREL 2r	-.056	-.052	-.058	.067	.816**	1.0	
7. DUREL Intrinsic Religiosity	.019	-.106	-.137	-.063	.918**	.492**	1.0

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

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

Multiple Regression Analysis

Multiple regression analysis was conducted to examine which predictors influence the quality of life of heart failure patients. A simultaneous multiple regression was generated to examine the contribution of: religious/spiritual coping, spiritual distress, demoralization, depression, and gender in predicting HRQoL in heart failure patients. Collinearity statistics were acceptable for all predictors (all tolerance values were $>.2$). Regression results indicate the overall model significantly predicted quality of life, $R^2 = .425$, $R^2_{\text{adj}} = .399$, $F(5, 109) = 16.12$, $p < .001$. This model accounts for 42 percent of the variance in heart failure patient's quality of life. A summary of the regression coefficients is presented in Table 8 and indicates one (depression) of the five variables was significantly related to quality of life.

Regression Analysis of Heart Failure Patient's Health-related Quality of Life on
Five Predictor Variables

Independent Variable	B	Std. Error	β	<i>p</i> -value
Gender	-3.27	4.22	0.6	.441
RCOPE	.63	.73	.07	.39
DS	.04	.19	.03	.824
BDI	-1.86*	.34	-.69	<.001
DUREL	.13	.33	.03	.694

Note: * $p < .05$

$R^2 = .425$ $R^2_{adj} = .399$ $F(5, 109) = 16.12, p < .001$

Chapter 5

Discussion of the Findings

This descriptive correlational study examined factors that predicted HRQoL in adults with HF. The variables of religious/spiritual coping, spiritual distress, demoralization, and depression were investigated in relation to the preliminary conceptual model. They are a combination of religious and psychological variables discovered from the state of the science research on the nature of distress in living with HF. The theoretical framework for this study was that of Daniel Sulmasy's Biopsychosocial-Spiritual Model for Health Care at End of Life.

Aim I Results

The purpose of Aim 1 was to describe the level of religious/spiritual coping, spiritual distress, demoralization, depression, and HRQoL among HF patients. The results of religious attendance were moderate. Considering that the majority of subjects declared to have a religious affiliation this would be expected. Many of them suffer with multiple comorbidities and undoubtedly have difficulty with religious

attendance and regular private religious activities. Moreover, some may claim to have religious affiliation but their belief does not include participation and is in name only. Sulmasy's philosophical foundation of a person's spiritual history making up the core of all individuals is informative here. Intrinsic religiosity was found to be quite high for this group with scores high experiencing presence of the Divine, their religious beliefs as the foundation for their whole life and carrying their religious beliefs into all parts of their life.

The seven items on the RCOPE scale describes negative spiritual coping methods: spiritual discontent, punishment God reappraisals, interpersonal religious discontentment, demonic reappraisal, and reappraisal of God's powers. Descriptive statistics found 51 respondents (44.3%) reported no spiritual distress, compared to 64 respondents out of 115 having experienced some level of spiritual distress within the last 2 weeks of the study. Thus, it can be said that the majority of HF subjects were experiencing some spiritual distress as well as positive religious/spiritual coping in dealing with the challenges of the disease. Spiritual distress is what happens when people's belief systems are challenged, or their picture of God comes into question resulting from life's difficulties and illness.

Within this study the concepts of religious coping were partially captured by the seven negative items of the RCOPE. In other words, those that were very religious/spiritual found transcendence over the trials of living with HF and reported no spiritual distress. Those who had no religious beliefs also had no spiritual distress because they do not have a religious frame of reference in which to respond positively. These two phenomena most likely account for the skewed distribution of scores.

There was a wide range of demoralization within this group of HF patients with some having very little, to some who are very demoralized by their situations. Subjects who scored higher on the DS felt dysphoria, loss of meaning and purpose, disheartenment, helplessness, sense of failure and suicidal thoughts that characterizes existential distress. The process of demoralization commonly begins when a situation is appraised as threatening, such as a serious illness. Descriptive statistics conducted showed a low to mild mean score of demoralization for these subjects overall. This corresponds with the minimal-mild mean level of depression as well. Few studies have been conducted using the DS, therefore level of demoralization with cutoff points delineating its severity have not been established yet. This is a weakness of the DS, showing a limitation of being able to interpret the scoring and generalize its results. Currently, one standard deviation from the mean is considered to be positive for demoralization, which varies among populations for each study (Kissane, personal communication, February 13, 2010).

The BDI-II mean of this group of respondents fell just between minimal and mild depression. According to Norra et al., (2008), HF patient's with depression have 2-3 more times medical visits, increased hospitalizations and mortality. A BDI-II of greater than the cut-off of 10 or higher signified poorer prognostic outcomes at 1year. Depression with HF has long been associated with impaired NYHC status and is cause for great concern.

The mean KCCQ score of 65.40 score is consistent with the initial validation studies comparing HRQoL scores on the KCCQ with NYHC II, exhibiting mild

symptoms of HF. The KCCQ is used as a screening tool to identify those who are at high risk out of the large population of HF outpatients. High risk patients are thought to respond the best to specialty programs that offer education, home monitoring and medication management. According to Green et al. (2000) in the initial development and evaluation of the KCCQ as a research tool, this would be comparative to a NYHA II classification on average. The NYHA classification data was not gathered on these participants for this study, but would be useful data for further study for determining the impact of treatments, survival and symptoms with HRQoL. Those with scores less than 25 were found to have a 4-fold greater mortality rate than those with a score of 75 and above. The concern has been that HRQoL is not included in the NYHC, yet low scores are shown to be predictive of mortality in certain cardiac populations. Its advantage over the NYHC is that it is the patient's perception and not the physician's assessment of a patient's health status. This is a fairly recently developed tool and stratification for valvular disease or systolic vs. diastolic function have yet to be conducted thus limiting the generalizability to other HF populations (Heidenreich et al., 2006),

AIM II Results

The purpose of AIM II was to examine the relationships of selected demographic variables age, gender, length of living with HF, ethnicity and religious/spiritual coping, spiritual distress, demoralization, depression, with HRQoL.

Spiritual Coping-Positive and Negative Methods

Despite the prevalence of religious affiliations in this population, there was no significant interaction of religious activity, non-organized religious activity and intrinsic

religiosity with HRQoL. However, many of these patients were fairly high functioning HF patients as indicated by the mean KCCQ scores. This researcher theorizes that people who are sicker and have lower KCCQ scores may also pray and participate in more religious/spiritual activity. HF patients are often home bound due to their low functional status, thus making religious service attendance difficult or impossible. One respondent wrote in between the lines of the DUREL that they watched church on the television instead. Religious/spiritual coping may have possibly shown some correlation with the outcome variable if more than one religious coping scale had been used, such as the FACIT-SpEX, and the 7 positive RCOPE scale for example, (Beckelman, et al, 2010; Pargament et al., 2002; Peterman, Fitchett, Brady, Hernandez & Cella, 2002;). State of the science research shows religion and spirituality positively affecting quality of life with health benefits; however, this study found only negative religious coping related to HRQoL.

Women Use Positive Religious Coping with HF

Findings revealed that women turn to their religious and spiritual beliefs significantly more so than men. In addition, trends show women have more demoralization, depression and rate their quality of life lower in living with HF, as evidenced by the mean scores. Fu and Parahoo (2008) strongly suggest that causes of depression in women are shown to be social and cultural in origin according to a study conducted with elderly women. Subsequently, research data finds women often seek comfort in social support for life stressors; therefore religious activity may evoke feelings of well-being through social contact and spiritual enrichment (Mirola, 1999).

Women in the general population have been found to have higher prevalence rates of depression. Studies have shown that for women, worsening depressive symptoms are associated with higher mortality rates resulting in increased risk for poorer health outcomes. Depression is a risk factor for women developing HF and mortality (Norra et al., 2007). Nature's changes along the lifespan of women present unique variables to the clinical picture of those at risk for HF bearing special consideration. Therefore regular screening for depressive symptoms in women is recommended along with appropriate pharmacological and nonpharmacological treatment. A broad age range of women represented in this study adds to the richness of the results and is strength of this study.

Hispanics Show Trends Towards Positive Religious/Spiritual Coping

Participants with Hispanic ethnicity show a trend towards more positive spiritual coping than Caucasians or those of other races. This result hints at how certain cultural groups use religious/spiritual activity to cope when experiencing the major stress of living with HF. The majority of research with HF is with Caucasian middle class white males; therefore studies of Hispanic culture with HF are few (Bean et al., 2009). Elucidating the unique risks and human responses of this culture presents rich opportunities for research that is greatly needed.

Higher Spiritual Distress is Associated with Lower HRQoL

Spiritual distress measured by the negative RCOPE scale although positively skewed, showed a significant negative effect on HRQoL. A chronic illness often strips one's meaning to life and leaves people asking ultimate questions about God/Ultimate Being and feeling disoriented at the core of their being. The result of this finding also

draws attention to the fact that for some people there is a spiritual component to suffering that causes inner turmoil affecting many aspects of life.

It is important to note that a score of zero on the RCOPE could have resulted from those who are neither religious by nature or had no religious beliefs; therefore the questions did not apply to them. There was no column for this choice, showing a weakness in measuring this concept with this scale. Consistent with the statistical results of this study, initial validation studies of the RCOPE found no relationship between positive religion/spiritual activity to illness or subjective health status. However, negative spiritual coping was associated with poorer functional status and subjective health status (Pargament et al., 1998) in the hospital cohort of the RCOPE study.

This study is one of the few of its kind to measure religious and secular dimensions of distress in living with heart failure; adding to the body of research on the negative effects one's struggles with God have when experiencing serious chronic illness. Its mixed results confirm the complexity of research on religion, spirituality and mental health. Considering whether religion adds something unique to the coping process focuses on the important dimensions of personal and social functioning that goes beyond the effects of general psychological dimensions such as anxiety or stress. There is exceptional diversity and complexity in religious and spiritual beliefs and the subjective religious attitudes of all individuals' lies in the personal search for significance related to the Sacred, Divine or an Ultimate Truth. What makes something holy refers to concepts of higher powers such as God or what is held divine in life. A search for significance in

one's life describes the pathways people follow in life and the destinations they seek, that is the core of their lives (Pargament et al., 2005).

Clearly, constructed meanings of religious involvement and spirituality have taken on pluristic trends (Cusveller, 1998). The multiplicities of these views are the multifaceted nature of religious life. For some individuals, religion is an end in itself, a primary motivating force that cannot be reduced by scientific methods. Within this context, the very definition of religion is unique as no other human process is organized around the Sacred or Divine (Pargament et al., 2005). Although positive religious/spiritual coping was found to have no correlation with depression, demoralization or HRQoL variables in this study, it does describe the religious nature of the HF population at this clinic. Perhaps the recognition that religion/spirituality matter to some people living with HF constitutes a type of clinical relevance worth further investigation.

Demoralization is Associated with Lower HRQoL

Demoralization is also common in patients with HF; therefore it is no surprise to find its negative interaction with HRQoL. The nature of HF can severely limit quality of life across functional, emotional, physical and spiritual domains. The strongest positive correlation of demoralization was with depression, showing a significant multicollinearity in this analysis and both means scoring mildly overall. These results are consistent with research data describing demoralization as a dimension of depression that is conceptually and experientially related. Those who are significantly demoralized are also depressed (Clarke, Kissane, Trauer, & Smith, 2005). Psychiatric literature states that those who are

demoralized are more distressed than those who are only depressed, and that it can range from mild to severe (Clarke et al., 2005). Demoralization adds to the experience of depression; helplessness, personal failure, disheartenment, loss of meaning to life that lead to existential distress and the desire to give up on life.

The concept of hopelessness is shared by both demoralization and depression. Thus, engendering hope should be a top priority in assessment in order to gain participation in self care. Unless people can be helped to recapture hope through a minister, counselor, a new situation or family member, they will get no relief from its downward spiral and all of its negative outcomes (Stone, 1998). Findings also show spiritual distress to be significantly related to demoralization. People use many coping behaviors when they are demoralized and depressed by illness. This is a unique finding that highlights the theological component of distress in living with HF that effects quality of life and may lead to suicidal ideation (Clarke et al., 2005).

A trend towards demoralization was found in the age group of 55-64. Erickson's stages of development show this group falling into the developmental stage of generativity vs. stagnation. This stage is characterized by feeling the need to be useful and having a sense of accomplishment. Living with the HF would certainly challenge those feelings, leaving one to feel demoralized (Kneisl, & Trigoboff, 2009).

Depression is an Independent Predictor of HRQoL

Although depression was mild in this population it was highly significant as the only variable predicting HRQoL. Although all three negatively correlated; HRQoL may depend largely on the presence of depression rather than religious/spirituality, and

demoralization. Risk for depression has been shown to increase with comorbidity and those with chronic illnesses are more vulnerable to depression, showing a cyclical relationship between illness and depression (Zauszniewski & Bekhet, 2008). In light of this result, future research is recommended to study whether depression may have more of an effect on HRQoL than severity of HF.

Recent research has found that depression often goes undiagnosed and only a minority of HF patients actually receives antidepressants (Jiang et al., 2004). It is unknown which if any of these subjects were receiving antidepressant pharmaceutical therapy and could be a factor in affecting level of depression in this population and its effects on HRQoL. HF and depression share similar symptoms; sleep disturbance, fatigue, lack of energy and weight changes. This may explain the reason for the BDI-II score being greater than 10 and why depression accounted for 42% of the variance in predicting HRQoL. This study of subjects did not find depression to be significantly associated with age, gender, marital status and length of living with HF.

It is interesting to note that none of the demographic variables measured with the KCCQ showed any significant relationships. In light of the large body of literature on the positive effects of religious/spirituality on health and improved quality of life, this scale was not sensitive to these variables and could be considered a weakness. The trend towards women's perception of HRQoL to be lower than men added the likelihood of gender being a pertinent issue in HF management.

Limitations of the Study

Patients were approached by clinic staff indiscriminate of NYHC status to participate in with a broad variance of comorbidities. Descriptive statistics showed that most HF patients suffer from a variety of chronic illnesses that was factorial in how they responded to the KCCQ. For example, several subjects suffered with arthritis, low vision and blindness and cannot dress themselves; others had concomitant pulmonary disease with and shortness of breath and 3 pillow orthopnea. These factors were not controlled for and could be considered a limitation in the generalizability of this study.

It is unclear why positive religious spiritual activity did not show an interaction with depression, demoralization or HRQoL. However, it is possible that HF patients who are sicker and have less functional abilities, people who are older, other religious denominations, or people who live in other geographical areas may have showed significant relationships with religious/spiritual activities. This study design had broad inclusionary criteria and may have unwittingly attracted those who had higher functional status. Those who were classified as NYHC association III and IV may have not felt well enough to participate in the study, naturally self-selecting those who had higher HRQoL scores, less depression, spiritual distress, and demoralization and did less spiritual coping. Controlling the effects of confounding variables such as age, sex, ethnicity, length of living with HF, level of education, and socioeconomic status could have possibly strengthened the role of association between religious variables and health outcomes. Although some studies show religion and spirituality positively affecting quality of life with health benefits; however, this study found only negative religious coping related to HRQoL.

Studying the HF population poses some challenges inherent to the disease. The disease is characterized by a widely varying trajectory from day to day making data collection challenging in studying certain characteristics, especially those who have the most profound symptoms (Corbin & Strauss, 1991). This could possibly be the reason why religious coping was not significant in this population, as demoralization and depression were on the mild to moderate side.

Methodological limitations of spirituality research in general are due to small sample sizes, sample biases and conceptual ambiguity. Therefore a larger sample size would make this study more generalizable and possibly represent HF patient's religious coping in a clearer way. Other concerns of this research design include how self report measures create method variance that could contribute to some associations between coping variables, psychosocial adjustments and health functioning. Unfortunately, the sampled population of women was only 36% showing an underrepresentation of females.

Research Implications and Recommendations

Clearly, the overwhelming effect of living with heart failure resulting in depression deserves additional scholarly inquiry. The World Health Organization states that cardiovascular disease is the leading cause of death in women globally and its incidence is expected to increase. (World Health Organization, 2009). Women are more at risk for HF along with differences in causes, symptoms and treatment of heart disease than men. According to an American Heart Association 2007 update of evidence-based guidelines for cardiovascular disease prevention in women, the key to prevention of cardiovascular disease is paramount to the health and well-being of all women.

Ironically, women have been consistently underrepresented in clinical trials relating to cardiovascular disease. Research in general of women with heart failure are also few. The development, prevention and treatment of cardiovascular disease in women leave key questions unanswered. In order to develop appropriate guidelines for treating women with cardiovascular disease there needs to be adequate representation in clinical trials and all research studies. Genetic research questioning how the role of gender and sex hormones affects outcomes after interventions and the prognostic value of biomarkers are on the horizon (Petrie et al., 1999).

During the study, it seemed as though the sensitive nature of the questionnaire's contents were stimulus for subjects to open their hearts and talk about themselves. Recurring conversations with subjects took place that would be fertile background for future qualitative research. The following themes are worth noting: 1. Subjects current medical conditions. 2. The successes and accomplishments before HF, the limitations that they live with now and how they feel about this. 3. How they have adapted to their limitations in living with HF. 4. Caregivers of the subjects wanted to talk about the stress they have in caring for them. 5. How HF has made them appreciate their life and families more. 6. The difficulty in answering the KCCQ due to other comorbidities and the limitations they suffer from. 7. Several subjects said that they did not have HF even though they had been treated in the clinic for years, they were not aware they had HF; suggesting that they possibly experienced denial relating to their diagnosis.

Additionally, many subjects discussed their faith and how it helped them cope with the difficulties of living with HF. It was apparent that many people do use

religious/spiritual coping to give them strength during difficult times, but the phenomenon was not captured by the scale chosen in this research design. A mixed methods design would most likely have captured the nature of that meaning more explicitly, by giving voice to the feelings, thoughts, beliefs, cultural, and spiritual practices that define he/she's own quality of life. Qualitative research, specifically, grounded theory methods will help build the theoretical foundation needed to guide future research, focusing on the unique characteristics of HF patients. Other research tools such as the FACTI-SP (Peterman et al., 2002;) and the Brief RCOPE (Pargament et al., 2000) containing the seven positive items of spiritual coping, may have more accurately captured how people use their faith to help them cope in living with their illness.

Thus, continued theoretical development is essential for clarity and practice guidance that is knowledge building within the biopsychosocial-spiritual domains. Religion is a multidimensional construct that is currently being studied as a separate construct from psychological concepts of well-being and should continue as part of research for consistency purposes and enlightenment of understanding. Concepts that are secular, humanistic and psychological in nature should not be used to describe one's relationship with the Sacred/Ultimate Being (Koenig, 2009). Having said this, existing research on concepts that clarify the relationships of anxiety, distress and depression are few.

Quantitative research should include longitudinal design to possibly capture the secular and religious nature of distress in living with HF over the course of the HF

disease trajectory; showing how transitions and challenges over time influence its health outcomes (Murray et al., 2007). It also might possibly uncover the nature of spiritual distress, demoralization and depression approaching the end of life. Coping is a situational process that should be measured over time because coping styles can change as illness progresses (Doering et al., 2004). Building evidence-based knowledge will help benefit the patients by ensuring that advance practice nurses don't miss the opportunity to provide comfort, aid and healing to those who are experiencing spiritual pain.

This study further validates that although depression and demoralization were found to be highly correlated, they add distinct dimensions to suffering to living with HF. Demoralization has been studied as a possible precursor to major depression and may be an early warning sign of a patient's risk for depression with HF, warranting further investigation. Depression is both preventable and treatable, subsequently a person who is demoralized will likely benefit from early intervention as prevention to major depression. The discussion of demoralization as a distinct concept would benefit from future conceptual analysis in order to help clarify its meaning and contribution to the depression experience. Finally, additional study recommendations are to explore the relationship between depression and symptom burden and how spirituality moderates depressive symptoms with HF. Studies should be replicated within and varied, along with more systematic and meta-analysis in order to solidify a body of evidence-based knowledge that can appropriately be integrated into advanced nursing practice.

Implications for Nursing Practice

Changing treatment paradigms from pharmacological interventions to a more holistic approach may result in reducing numbers of hospitalizations, improved patient satisfaction and outcomes. Current research literature on HF management consists mainly of symptomology and little on the everyday work of maintaining spiritual well-being. As of 2005, the American Heart Association and The American College of Cardiology has improved guidelines on heart failure emphasizing the importance of early diagnosis, treatment and patient education recommending a more holistic and client centered approach (ACC/AHA, 2005). A number of variables can affect NYHC status including a patient's understanding and compliance of patient's medical plan ordered by the healthcare practitioner. In clinical trials, functional status has been considered the end point in quality of life scales (Leidy et al., 1999). However, pharmacological and nonpharmacological variables can both affect HRQoL. The results of this study suggest a patient's religious/spirituality is another important domain to be added to this construct, as it is the core of an individual's identity. Development and refinement of quality of life scales that are more specific and sensitive to the demographic variables of those living with HF are needed.

Demographic factors such as age, sex and ethnicity, social factors such as social support, pet ownership, socioeconomic status and psychological factors, such as stress, anxiety and depression should all be recognized as important to patient's HRQoL. In this study 35 (30.4%) of the participants have had HF for 10 or more years – the largest of all of the length of living with HF categories. This is quite remarkable considering the

statistic that less than 25 % of HF patients are alive at 10 years after their initial diagnosis (hfsa.org, 2008).

As nurses seek to optimize quality of life for patients by improving hardiness and psychosocial adjustment through evidence-based research, the question of how to address spiritual needs of HF is coming into focus. A growing body of evidence is showing that healthcare practitioners recognize the importance of spirituality as integral to patient's well-being along with health benefits of positive spiritual coping (McSherry, Cash & Ross, 2003). A patient's spiritual history gives the health care practitioners valuable information into what gives their lives meaning in the face of health challenges. Spiritual assessment provides the opportunity for the nurse to learn what beliefs influence treatment decisions, compliance and other spiritual coping issues integral to the patient's well-being (Taylor, 2002). The emerging awareness of alternative therapies for illness management opens the dialogue for the discussion of medicine and spirituality in which spiritual distress and psychosis are difficult to distinguish. This paradigm encourages health-care providers to contextualize the patient's symptoms as a whole rather than a conglomeration of separate symptoms in need of pharmacological palliation.

Koenig (2009) states that 90% of the global population is involved in religious or spiritual practices and those beliefs are influential when it comes to decision making and people's health. In recognition of this, The Joint Commission calls for all nurses to perform spiritual inquiry with each patient. A recent revision of this recommendation actually lists examples of questions to ask in nurse's spiritual assessment (Joint Commission, 2004; Sumner, 1998). Additionally, the International Code of Nurses

(2006) states that individual's spiritual beliefs along with their human rights, values and customs deserve respect. Thus, it is important for the nursing profession to promote strategies supportive of HF patient's spiritual development (Berry et al., 2002).

Based on the body of literature including the results of this study, screening all HF patients for depression should be conducted. Heart failure specialists bear the responsibility of alleviating the multiplicity of symptoms such as pain, fatigue, dyspnea or weakness that cardiomyopathy patients often present with. In HF management increasing symptomology is associated with worsening pathology. An exacerbation of symptoms can lead to sudden decline, hospitalization and death. Understanding the meanings of these symptoms within the context of the client's perceptions is crucial to appropriate management for the individual client. When people verbalize their symptom experience they reveal their personally held beliefs about the current health episode. A client's self-efficacy is integral to their belief and perception of their illness. Exploration of the client's cultural, and spiritual beliefs, are essential to understanding their symptom experience. When it comes to symptom management the emphasis should be on the person, not on the symptom (Cassell, 2004). The significance that a client attaches to a symptom will strengthen the need for the advanced practice nurse to value in order to relieve or control the symptom (Haworth & Dluhy, 2001).

Despite its prevalence in nursing theory, concepts of spirituality are often confused with aspects of psychosocial well-being, making it a difficult topic to apply within nursing practice (Koenig, 2009). Many nurses claim to feel uncomfortable and untrained in addressing the spiritual needs of patients (Ross, 2006; Taylor & Mamier,

2005; Villagomez, L. R., 2005). Chaplain Dick Millsbaugh, (2005) states avoidance in engaging in important conversations denies patient's spiritual pain and is a handicap for healthcare professionals. Integrating the evidence-based body of research on religion and health into nursing education would help promote care that is both ethical and respectful to patients. Farley (2002) suggests that the integration of compassion and respect will bring conceptual clarity and moral discernment. Holistic care philosophy that addresses spiritual elements with compassion and presence, gives meaning to nurses' work that elevates care into the realm of art, by rebuilding trusting relationships (Ferrell & Coyle, 2008). Combining compassion with the duty to be merciful promotes justice in patient care.

Nursing professionals should embrace open-minded attitudes in order to communicate and support those of diverse beliefs and worldviews; with the goal of reducing the gap between institutional policies and the public's expectations. The ability to identify both the strengths and weaknesses of HF patients provide the clinician opportunities to intervene appropriately during times of greatest vulnerability. Careful evidence-based assessment, diagnosis, planning and evaluation will help create healing landscapes, facilitating hope for those suffering the devastating effects of HF.

References

- Aben, I., Verhey, F., Lousber, R., Lodder, J., & Honig, A. (2002). Validity of the beck depression inventory, hospital anxiety and depression scale, scl-90, and hamilton depression rating scale as screening instruments for depression in stroke patients. *Psychosomatics*, 43(5), 386-393.
- ACC/AHA, (2005). Guideline update for the diagnosis and management of chronic heart failure in the adult-summary article. Retrieved November 11, 2005 from <http://circ.ahajournals.org/cgi/content/full/112/12/1825>.
- American Heart Association, (2007). AHA Guidelines. Evidence-based guidelines for cardiovascular disease prevention in women: 2007 update. Retrieved February 17, 2010 from <http://circ.ahajournals.org/cgi/content/full/CIRCULATIONAHA.107.181546>.
- Almeida, O.P., & Almeida, S.A. (1999). Short Versions of the Geriatric Depression Scale: A study of their validity for the diagnosis of a major depressive episode according to ICD-10 and DSM-IV. *International Journal of Geriatric Psychiatry*, 14, 858-865.
- American Heart Association, (2007). Heart failure. Retrieved October 15, 2007 from <http://www.americanheart.org/presenter.jhtml?identifier=1486>

- American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR IV Edition (Text Revision)*. Washington: American Psychiatric Association.
- Armour, A.J. (2007). The little brain on the heart. *Cleveland, Clinic Journal of Medicine* 74(Supplement 1), S48-S51.
- Atkinson, M.J., Wishart, P.M., Wasil, B.I., & Robinson, J.W. (2004). The self-perceptions and relationships tool (P-SRT). A novel approach to the measurement of health-related quality of life. *Health and Quality Life Outcomes*, 2:36. Retrieved July 12, 2004 from <http://www.hqlo.com/content/pdf/1477-7525-2-36.pdf>
- Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S., & Small, N. (2006). Characteristics and views of family carers of older people with heart failure. International Code of Nurses (2006) states that individual's spiritual beliefs along with their human rights, values and customs deserve respect. *Journal of Palliative Nursing*, 12(8), 380-388.
- Bean, K.B., & Wagner, K. (2006). Self-transcendence, illness distress, and quality of life among liver transplant recipients. *The Journal of Theory Construction & Testing*, 10(2). 47-53.
- Bean, M.K., Gibson, D., Flattery, M., Duncan, A., & Hess, M. (2009). Psychosocial factors, quality of life, and psychological distress: ethnic differences in patients with heart failure. *Progress in Cardiovascular Nursing*, December 2009, 131-140.

- Beery, T., Bass, L., Fowler, C., & Allen, G. (2002). Spirituality in persons with heart failure. *Journal of Holistic Nursing, 20*, 5-25.
- Bekelman, D.B., Sydney, M., Becker, D.M., Wiottstein, I.S. Hendricks, D.E., Yamashita, T.E., & Gottlieb, S.H. (2006). Spiritual well-being and depression in patients with heart failure. *Journal of Internal Medicine, 22*(4), 470-477.
- Bennett, S. J., Sauve, M.J., & Shaw, R.M. (2005). A conceptual model of cognitive deficits in chronic heart failure. *Journal of Nursing Scholarship, 3rd Quarter*, 222-228.
- Boscaglia, N., & Clarke, D. (2007). Sense of coherence as a protective factor for demoralization in women with a recent diagnosis of gynaecological cancer. *Psycho-Oncology 16*, 189-195
- Bosworth, H.B., Stein Hauser, K.E., Orr, M.M., Lindquist, J.H., Grambow, S.C., & Oddone, E.Z. (2004). Congestive heart failure patients' perceptions of quality of life: the integration of physical and psychosocial factors. *Aging & Mental Health, 8*, 83-91.
- Buvat de Virginy, D.R. (2006). Novel and potential future biomarkers for assessment of the severity and prognosis of chronic heart failure. *Heart Failure Review 11*, 333-344.
- Carson V.B., & Koenig, H., (2004). *Spiritual caregiving: Healthcare as a ministry. Philadelphia: PA: Templeton Foundation Press.*

- Carson, V.B., & Koenig, H., (2008). *Spiritual dimensions of nursing practice*. West Conshohocken, PA: Templeton Foundation Press:
- Cassell, E.J. (1991). Recognizing suffering. *Hastings Center Report*, 21, 24-31.
- Cassell, E.J. (2004). *The nature of suffering and the goals of medicine*. New York: Oxford University Press Incorporated.
- Cavendish, R., Louise, B.K., Mitzeliotis, C., Bauer, M., Bajo, M.M., Calvino, C., et al. (2004). Spiritual perspectives of nurses in the united states relevant for education and practice. *Western Journal of Nursing Research*, 26(2). 196-212.
- Clarke, D. M., & Kissane, D. W. (2002). Demoralization: its phenomenology and importance. *Australian & New Zealand Journal of Psychiatry*, 36(6), 733-742.
- Clarke, D.M., Kissane, D.W., Trauer, T., & Smith, G.C. (2005). Demoralization, anhedonia and grief in patients with severe physical illness. *World Psychiatry*, 4(2). 96-104.
- Chaturvedi, S. K. (2007). Spiritual issues at the end of life. *Indian Journal of Palliative Care*. 13(2). 48-52.
- Chochinov, H.M. (2003). Thinking outside the box: depression, hope, and meaning at the end of life. *Journal of Palliative Medicine*, 6, 973-977.
- Coma-Canella, I., Macias, A., Varo. N., & Ibarrola, A.S. (2005). Neurohormones and cytokines in heart failure. correlation with coronary flow reserve. *Revista Española De Cardilogia*, 58(11), 1273-1277.

- Corbin, J., & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. *Scholarly Inquiry for Nursing Practice Journal*, 5, 155-174.
- Cotton, S., Puchalski, C.M., Sherman, S. N., Mrus, J.M., Peterman, A.H., Feinberg, J, Pargament, K.I., Justice, A.C., Leonard, A.C., & Tsevat, J. (2006). Spirituality and religion in patients with HIV/AIDS. *Journal of General Internal Medicine*, 21(Supplement 5), S5-S13.
- Courtney Devries, A., Craft, T, K.S., Glasper, E.R., Neigh, G.N., & Alexander J.K. (2007). Social influences on stress responses and health. *Psychoneuroendocrinology*, 32, 387-603.
- Coyle, J. (2002). Spirituality and Health: towards a framework for exploring the relationship between spirituality and health. *Journal of Advanced Nursing*, 37, 580-597.
- Crawford, G.B., & Robinson, J.A. (2008). The geriatric depression scale in palliative care. *Palliative and Supportive Care*, (6). 213-223.
- Cusvellar, B. (1998). Cut from the right wood: spiritual and ethical pluralism in professional and nursing practice. *Journal of Advanced Nursing* 28(2), 266-273.
- Daaleman, T., & Frey, B. (2004). The spirituality index of well-being: a new instrument for health-related quality-of-life research. *Annals of Family Medicine*, 2, 499-503.

- Deaton, C., & Grady, K., (2004). State of the science for cardiovascular nursing outcomes heart failure. *Journal of Cardiovascular Nursing, 19*, 329-338.
- Delgado, C. (2007). Sense of coherence, spirituality, stress and quality of life in chronic illness. *Journal of Nursing Scholarship, 39*(3), 229-234.
- Doering, L.V., Dracup, K., Caldwell, M.A., Moser, D. k., Erickson, V.S., Fonarow, G., & Hamilton, M. (2005). Is coping style linked to emotional states in heart failure patients? *Journal of Cardiac Failure, 10*(4), 334-349.
- Doris, S.F., Yu, Diana, T.F., & Lee, J.W. (2004). Health-related quality of life in chinese elderly patients with heart failure. *Research in Nursing and Health, 27*(5) 332-344.
- Duffy, J., Hoskins, L., & Dudley-Brown, S., (2005). Development and testing of a caring-based intervention for older adults with heart failure. *Journal of Cardiovascular Nursing, 20*, 325-333.
- Ellermann, C.R., & Reed, P.C. (2001). Self-transcendence and depression in middle-age adults. *Western Journal of Nursing Research 23*(7). 698-713.
- Emdin, M., Poletti, R., Passino, C., Ripoli, A. Khabirinejad, J., & Prontera, C. (2003). The clinical diagnosis of heart failure is predicted by neurohormonal and immune derangement. *Immuno-analyse & Biologie sp cilaiss  18*, 207-211.
- Esch, T., Stefano, G. B., Fricchione, G. L., & Benson, H. (2002). Stress in cardiovascular disease. *Medical Science Monitor, 8*, RA93- 101.

- Evaluation of Heart Failure; Clinical features. Part 1. *The American Journal of Cardiology*, 83, 2A.
- Faller, H, Störk, S., Schowalter, M., Steinbüchel, T., Wollner, V., Ertl, G., & Angermann, C.E. (2007). Depression and survival in chronic heart failure; does gender play a role? *European Journal of Heart Failure*, 9, 1018-1023.
- Farley, M. (2002). Compassionate respect: A feminist approach to medical ethics and other questions. *Madelvea Lecture I Spiritually*. Mahwa, New Jersey: Paullist Press.
- Ferrell, B. (2005). Ethical perspectives on pain and suffering. Retrieved November 19, 2005. *Pain Management Nursing*, 6, 83-90.
- Ferrell, B., & Coyle, N. (2006). *Textbook of palliative nursing..*: New York: Oxford University Press, Inc.
- Ferrell, B., & Coyle, N. (2008). *The nature of suffering and the goals of nursing*. *Oncology Nursing Forum*, 35(2), 241-247.
- Folkman, S., & Moskowitz, J.T. (2004). Coping: pitfalls and promise. *Annual Review of Psychology*, 55, 745-774.
- Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R.J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, 50, 992-1003.
- Frankl, V.E. (2006). *Man's search for meaning*. Boston: Beacon Press Hall,

- Fu, C., & Parahoo, K. (2008). Causes of depression: perceptions among people recovering from depression. *Journal of Advanced Nursing*, 65(1), 101-109.
- Gall, T., Charbonneau, C., Clarke, N., Grant, K., Joseph, A., & Shouldice, L. (2005). Understanding the nature and role of spirituality in relation to coping and health: a conceptual framework. *Canadian psychology/Psychologie canadienne*, 46, 88-104.
- Gary, R. (2006). Self-care practices in women with diastolic heart failure. *Heart & Lung*, 35(1), 9-19.
- Georges, J. (2002). Suffering: toward a contextual praxis. *Advances in Nursing Science*, 25(1), 79-86.
- Green, C.P., Porter, C.B., Bresnahan, D.R., & Spertus, J.A. (2000). Development and evaluation of the kansas city cardiomyopathy questionnaire: a new health status measure for heart failure. *Journal of the American College of Cardiology*, 35, 1245-1255.
- Gusick, G.M. (2008). The contribution of depression and spirituality to symptom burden in chronic heart failure. *Archives of Psychiatric Nursing*, 22(1), 53-55.
- Hall, D.E., Koenig, H.G., & Meador, K.G. (2004). Conceptualizing "Religion". *Perspectives in Biology and Medicine*, (47), 386-401.

- Halldorsdottir, S. (2007). A psychoneuroimmunological view of the healing potential of professional caring in the face of human suffering. *International Journal for Human Caring, 11*, 32-39.
- Hardin, S., & Hussey, L. (2003). AACN synergy model for patient care: Case study of a chf patient. *Critical Care Nurse, 23*(1), 73-76.
- Harper, D., (2001) Online etymology dictionary Retrieve May 13, 2007 from <http://www.etymonline.com/index.php?search=spirituality&searchmode=none>
- Haworth, S.K., & Dluhy, N.M. (2001). Holistic symptom management: modeling the interaction phase. *Journal of Advance Nursing 36*(2), 302-310.
- Heart Failure Society of America (2006). Pocket guide. HFSA 2006 comprehensive heart failure practice guideline. *Heart Failure Society of America*. St. Paul: Minnesota.
- Heart Failure Society of America (2006). Quick facts and questions about heart failure. Retrieved June 14, 2008 from http://www.hfsa.org/heart_failure_facts.asp.
- Heidenreich, P.A., Spertus, J.A., Jones, P. G., Weintraub, W.S., Rumsfeld, J.S., Rathore, S.S., Peterson, E.D., Masoudi, F.A., Krumholz, H.M., Havranek, E.P., Conard, M.W., & Williams, R.E., (2006). Health Status Identifies Heart Failure Outpatients at Risk for Hospitalization or Death. *Journal of the American College of Cardiology, 47*(4), 752-756.

Heywood, J., Elatre, W., Ramdas, Pai, R.G., Fabbri, S., & Huiskes, B. (2005). Simple clinical criteria to determine the prognosis of heart failure. *Journal of Cardiovascular Pharmacology Therapeutics*, 10(3), 173-180.

Hills, J., Paice, J a., Cameron, J.R., & Shott, S. (2005). Spirituality and distress in palliative care. *Journal of Palliative Medicine*, 8(4), 782-788.

Idler, E.L., Music, M.A., Ellison, C.G., George, L.K., Krause, N., Ory, M.G., Pargament, K.I., Powell, L. H., Underwood, L. G., & Williams, D. R. (2003). Measuring multiple dimensions of religion and spirituality for health research. *Research on Aging*, 25(4). 327-365.

International Code of Nurses. The ICN code of ethics for nurses. Retrieved October 6, 2006 from <http://www.icn.ch/icncode.pdf>

Institute of Medicine, Field M.J., & Cassel, D.K. (1997). *Approaching Death; Care at the End of Life*. Washington, DC: National Academy Press.

Jaffe, D. H., Eisenbach, Z., Neumark, Y.D. & Manor, (2005). Does living in a religiously affiliated neighborhood lower mortality? *Annals of Epidemiology* 15(10), 804-10.

Jekell, A., Hossain, A., Alehagen, U., Dahstrom, U., Rosen, A. (2004). Elevated circulating levels of thioredoxin and stress in chronic heart failure. *The European Journal of Heart Failure*, 6, 883-890.

- Jiang, W., Alexander, J., Christopher, E., Kuchibhatla, M., Gauden, L.H., Cuffe, M.S., Blazing, M.A., Davenport, C., Califf, R.M., Krishnan, R.R., O'Connor, C.M. (2001). Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Archives of Internal Medicine*, 94(12), 1577-80.
- Jiang, W., Kuchibhatla, M., Cuffe, M.S., Christopher, E.J., Alexander, J.D., Clary, G.L., Clary, G. L., Blazing, M.A., Gauden, L. H., Califf R., Krishnan, R. R., O'Connor, C. M. (2004). Prognostic value of anxiety and depression in patients with chronic heart failure. *Circulation*, 110, 3452-3456.
- John E. Fetzer Institute (2003). Multidimensional measurement of religiousness/spirituality for use in health research, *A Report of the Fetzer Institute/National Institute on Aging Working Group*.
- Joint Commission on Accreditation of Healthcare Organizations. Retrieved from October 6, 2006 from http://www.jointcommission.org/AccreditationPrograms/HomeCare/Standards/FAQs/Provision+of+Care/Assessment/Spiritual_Assessment.htmconsultation.
- Kennedy, C., & Cheston, S.E. (2003). Spiritual distress at life's end: finding meaning in the maelstrom. *The Journal of Pastoral Care & Counseling*, 57(2), 131-141.
- Kissane, D. (2004a). The contribution of demoralization to end of life decision making. *Hastings Report Center* 34(4). 21-31.

- Kissane, D. (2004b). The demoralization scale: a report of its development and preliminary validation. *Journal of Palliative Care*, 20(4), 269-276.
- Kneisl, C.R., & Trigoboff, D. (2009). *Contemporary Psychiatric-Mental Health Nursing* (2nd ed.). New Jersey: Prentice Hall.
- Koenig, H.G. (1998). Depression in hospitalized older patients with congestive heart failure. *General Hospital Psychiatry*, 20, 29-43.
- Koenig, H.G. (2001). *The Handbook of Religion and Health*. New York: Oxford University Press.
- Koenig, H.G. (2002). Religion, congestive heart failure, chronic pulmonary disease. *Journal of Religions and Health*, 41(3), 263-278.
- Koenig, H.G. (2006). Depression outcome in inpatients with congestive heart failure. *Archives of Internal Medicine*, 166, 991-996.
- Koenig, H.G. (2007). *Spirituality in patient care*. Philadelphia: Templeton Foundation Press.
- Koenig, H.G. (2008a). Concerns about measurements of spirituality. *Journal of Nervous and Mental Disease*. 196(5). 349-355.
- Koenig, H.G. (2008b). *Medicine, religion and health*. Philadelphia.: Templeton Foundation Press:

- Koenig, H.G. (2009). Research on Religion, Spirituality, and Mental Health: A Review. *The Canadian Journal of Psychiatry*, 54(5), 283-291.
- Koenig, H.G., Cohen, H.J., George, L.K., Hays, J.C., Larson, D.B., & Blazer, D.G. (1997). Attendance at religious services, interleukin-6, and other biological parameters of immune function in older adults. *International Journal of Psychiatry in Medicine*, 27(3), 233-250.
- Koenig, H.G. Johnson, J.L., & Peterson, B.L. (2006). Major depression and physical illness trajectories in heart failure and pulmonary disease. *The Journal of Nervous and Mental Disease*, 194(12), 909-916.
- Koenig, H.G., & Meador, K.G. (2004). Conceptualizing "Religion". *Perspectives in Biology and Medicine*, (47), 386-401.
- Koenig, H. G., & Meador, K.G. (2007). Coping with chronic illness. *Crossroads... exploring the intersection of health, spirituality and faith*, 1(2), 1-4.
- Koenig, H.G., Meador, K.G., & Parkerson, G. (1997). Religion index for psychiatric research: A 5-item measure for use in health outcome studies. *American Journal of Psychiatry*, 154, 885-886.
- Koenig, H.G., Pargament, K.I., & Nielsen, J. (1998). Religious coping and health status in medically ill hospitalized older adults. *The Journal of Nervous and Mental Disease*, 186(9), 513-521.

- Koenig, H. G., Vandermeer, J., Chambers, A., Burr-Crutchfield, L., & Johnson, J. L. (2006). Comparison of major and minor depression in older medical inpatients with chronic heart and pulmonary disease. *Psychosomatics: Journal of Consultation Liaison Psychiatry*, 47(4), 296-303.
- Kristeller J.L., Rhodes, M., Cripe, L.D., & Sheets, V. (2005). Oncologist assisted spiritual intervention study (OASIS): patient acceptability and initial evidence of effects. *International Journal of Psychiatry in Medicine*, 35(4). 329-347.
- Kubzansky, L.D. (2007). Sick at heart: The pathophysiology of negative emotions. *Cleveland Clinic Journal*, 74, Supplement 1, S67-S72.
- Leidy, N.K., Rentz, A.M., & Zyczynski, T.M. (1999). Evaluating health-related quality-of-life outcomes in patients with congestive heart failure. A review of recent randomized controlled trials. *Pharmacoeconomics*, 15(1). 19-46.
- Leininger, M.M. (1988). Leininger's theory of nursing: cultural care diversity and universality. *Nursing Science Quarterly*. 152-160.
- Logstrup, K. E. (1997). *The ethical demand*. Notre Dame: University of Notre Dame Press.
- Mako, C., Galek, K., & Poppito, S. R. (2006). Spiritual pain among patients with advanced cancer in palliative care. *Journal of Palliative Medicine*, 9(5). 1106-1113.

- Manning, L. (2006). Defining spirituality from a student's perspective. *American Association of Integrative Medicine* Retrieved April 29, 2006 from http://www.aaimedicine.com/continuing_education_article-DSSP.php
- Martsof, D.S., & Mickley, J.R. (1998). The concept of spirituality in nursing theories: differing world-views and extent of focus. *Journal of Advanced Nursing*, 27(2), 294-303.
- Marshall, D., Walizer, E., & Vernalis, M. (2004). Optimal healing environments for chronic cardiovascular disease. *Journal of Alternative and Complementary Medicine*, 10, 147-155.
- McConnell, K.M., Pargament, K.I., Ellison, C.G., & Flannelly, K.J. (2006). Examining the links between spiritual struggles and symptoms of psychopathology in a national sample. *Journal of clinical psychology*, 62(12), 1469-1284.
- McMahon, K. M., & Gregory, Y.H. (2002). Psychological factors in heart failure. *Archives of Internal Medicine* 162, 509-516.
- McSherry, W., Cash, K., & Ross, L. (2003). Meaning of spirituality: implications for nursing practice. *Journal of Clinical Nursing*, 13, 934-941.
- Meleis, A. I. (2007). *Theoretical Nursing*.: (4th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Meyerstein, I. (2005). Sustaining our spirits: spiritual study/discussion groups for coping with medical illness. *Journal of Religion and Health* 44(2), 207-225.

Millsbaugh, D. (2005). Assessment and response to spiritual pain: Part 1. *Journal of Palliative Medicine*, 8(5), 919-923.

Miner-Williams, D. (2006). Putting a puzzle together: making spirituality meaningful for nursing using an evolving theoretical framework. *Journal of Clinical Nursing*, 15, 811-821.

Mirola, W.A. (1999). A refuge for some: gender differences in the relationship between religious involvement and depression. *Sociology of Religion* 60(4), 419-437.

Murberg, T., & Bru, E. (2001). Coping and mortality among patients with congestive heart failure. *Journal of Behavioral Medicine*, 8, 66-79.

Murray, S.A., Kendall, M., Worth, A., & Benton, T.F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18, 39-45.

Murray, S.A., Kendall, M., Grant, E., Boyd, K., Barclay, S., & Sheikh, A. (2007). Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *Journal of Pain and Symptom Management*, 34(4), 393-402.

NANDA (2000). *Nursing diagnosis definitions and classification*. Philadelphia, PA: North American Nursing Diagnosis Association.

- Norra, C., Skolbel, E.C., Arndt, M., & Schauerte, P. (2008). High impact of depression in heart failure: Early diagnosis and treatment options. *International Journal of Cardiology, 125*, 220-231.
- Oates, L. (2004). Providing spiritual care in end-stage cardiac failure. *Journal of Palliative Nursing, 10*(10), 485-490.
- O'Brien, M.E. (2003). *Spirituality in nursing; standing on holy ground* (2nd Ed). Sudbury, Massachusetts: Jones and Bartlett.
- Onwuanyi, A., & Taylor, M. (2007). Acute decompensated heart failure: pathophysiology and Treatment. Retrieved July 20, 2008 from [www. AJConline.org](http://www.AJConline.org). *American Journal of Cardiology 99*(6B).
- Pargament, K.I. (1997). *The psychology of religion and coping*. New York: The Guilford Press.
- Pargament, K.I., Koenig, H.G., Tarakeshwar, N., & Hahn, J. (2001). Religious struggle as a predictor of mortality among medically ill elderly patients. Retrieved August 16, 2008 from www.archintermed.com. *Archives of Internal Medicine, 16*, 1881-1885.
- Pargament, K.I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: a two-year longitudinal study. *Journal of Health Psychology, 9*(6), 713-730.

- Pargament, K.I., Tarakeshwar, N. Ellison, C.G., & Wulff, K.M. (1998). Religious coping among the religious: the relationships between religious coping and well-being in a national sample of presbyterian clergy, elders and members. *Paper presented at the Society for the Scientific Study of Religion*. Montreal, Canada.
- Pargament, K.I., Smith, B.W., Koenig, H.G., & Perez, L. (1999). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion*, 37(4), 710-724.
- Pargament, K.I., Koenig, H.G., & Perez, (2000). The many methods of religious coping: development and initial validation of the RCOPE. *Journal of Clinical Psychology*, 58(4), 519-543.
- Pargament, K.I., Magyar-Russell, G.M., & Murray-Swank, N.A. (2005). The sacred and the search for significance: religion as a unique process. *Journal of Social Issues*, 61(4), 665-687.
- Pargament K.I., & Ano, G.G. (2006). Spiritual resources and struggles in coping with medical illness. *Southern Medical Journal*, 99(10), 1161.
- Park, C.L., Fenster, J.R., Suresh, D.P., & Bliss, D.E. (2006). Social support, appraisals, and coping as predictors of depression in congestive heart failure patients. *Psychology and Health*, 21(6). 773-789.
- Park, C., L. (2005). Religion as meaning-making framework in coping with life stress. *Journal of Social Issues*, 61(4), 707-729.

- Pearsall, P. (1998). *The heart's code*. New York: Random House.
- Pelle, A.J.M., Gidron, Y.Y., Szabó, M.B., & Denollet, J. (2008). Psychological predictors of prognosis in chronic heart failure. *Journal of Cardiac Failure, 14*(4), 341-350.
- Peterman, A.H., Fitchett, G., Brady, M.J., Hernandez, L., & Cella, D. (2002). Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy-spiritual well-being scale (FACIT-SP). *Annals of Behavioral Medicine 24*, 49-58.
- Petrie, M.C., Dawson, N. F., Murdoch, D. R., Davie, A.P., & McMurray, J.J.V. (1999). Failure of Women's Hearts. *Circulation, 99*, 2334-2341.
- Philip Greenway, A., Phelan, M., Turnbull, S., & Milne, L.C. (2007). Religious coping strategies and spiritual transcendence. *Mental Health, Religion & Culture, 10*(4), 325-333.
- Polit, D.E, (1996). *Data analysis and statistics for nursing research*. London: Prentice Hall.
- Polit, D., & Beck, C. (2004). *Nursing Research: Principles and Methods* (7th Ed.). New York: J.B. Lippincott.
- Posey, A. D. (2006). Symptom perception: a concept exploration. *Nursing Forum, 41*(3) 113-124.
- Puchalski, C.M. (2006). *A time for listening and caring*. New York: Oxford University Press.

- Puchalski, C.M., Lunsford, B., Harris, M.H., & Miller, T. R. (2006). Interdisciplinary spiritual care for seriously ill and dying patients: a collaborative model. *Cancer Journal, 12*, 398-416.
- Rajagopal, D., Mackenzie, E., Bailey, C., & Lavizzo-Mourey, R. (2002). The effectiveness of a spiritually-based intervention to alleviate subsyndromal anxiety and minor depression among older adults. *Journal of Religion and Health, 41*(2), 153-166.
- Rafael, A. (2000). Watson's philosophy, science, and theory of human caring as a conceptual framework for guiding community health nursing practice. *Advances in Nursing Science, 23*(2), 34-49.
- Rafael, M. (2003). *The female face of god in auschwitz: a jewish theology of the holocaust (religion and gender)*. London: Routledge.
- Rickelman, B.L. (2002). Demoralization as a precursor to serious depression. *Journal of the American Psychiatric Nurses Association, 8*(1), 9-19.
- Ridner, S.H. (2004). Psychological distress: concept analysis. *Journal of Advanced Nursing 45*(5), 536-545.
- Rowe, M., & Allen, R. (2004). Spirituality as a means of coping with chronic illness. *American Journal for Health Studies, 19*. 62-67.
- Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *University of Glamorgan, 852-862*.

- Roy, M. P., Kirschbaum, C., & Steptoe, A. (2000). Psychological, cardiovascular, and metabolic correlates of individual differences in cortisol stress recovery in young men. *Psychoneuroendocrinology*, *26*, 375-391.
- Rumsfeld, J.S., Havranek, E., Masoudi, F.A., Peterson, E.D., Jones, P., Tooley, J.F., Krumholz, H.M., & Spertus, J.A. (2003). Depressive symptoms are the strongest predictors of short-term declines, in health status in patients with heart failure. *Journal of the American College of Cardiology*, *42*(10), 0735-1097.
- Rutledge, T., Reis, V.A., Linke, S.E., Greenberg, B.H., & Mills, P.J. (2006). Depression in heart failure. *Journal of the American College of Cardiology*, *48*(8), 1527-1537.
- Sawatsky, R., & Pesut, B. (2005). Attributes of Spiritual care in nursing practice. *Journal of holistic nursing* *23*(1) 19-33.
- Sayers, S.L., Hanrahan, N., Kutney, A., Clarke, S.P., Reis, B.F., & Riegel, B. (2007). Psychiatric comorbidity and greater hospitalization risk, longer length of stay and higher hospitalization costs in older adults with heart failure. *Journal of American Geriatrics Society*, *55*(10), 1585-1591.
- Schanowitz, J.Y., & Nicassio, P. M. (2006). Predictors of positive psychosocial functioning of older adults in residential care facilities. *Journal of Behavioral Medicine*, *29*(2). 191-201.

- Seeman, T.E., & McEwen, B.S. (1996). Impact of social environment characteristics on neuroendocrine regulation. *Psychosomatic Medicine*, 58, 459-471.
- Segal, D.L., Coolidge, F.L., Cahill, B.S., & O'Riley, A.A. (2008). Psychometric properties of the beck depression inventory II (BDI-II) among community-dwelling older adults. *Behavior Modification*, 32(1) 3-20.
- Seskevich, J., Gabert, H., Charles. A., & Cuffe, M. (2005). Helping patients with heart failure manage stress. *Nursing 2005*, 223.
- Shuman, J.J., & Meador, K. (2003). *Heal thyself*. New York: Oxford University Press.
- Sloan, R.P. Bagiella, E., & Powell, T. (1999). Religion, spirituality, and medicine. *THE LANCET*, 353, 664-667.
- Steer, R.A., Ball, R., & Beck A.T. (1999). Dimensions of the beck depression inventory-II in clinically depressed patients. *Journal of Clinical Psychology*. 55(1), 171-128.
- Soufer, R., & Burg, M.M. (2007). The heart-brain interaction during emotionally provoked myocardial ischemia: implications of cortical hyperactivation in CAD and gender interactions. *Cleveland Clinic Journal of Medicine*, 74(Supplement 1), S59-S62.
- Stone, H. W. (1998). Summoning hope in those who are depressed. *Pastoral Psychology*, 46(6), 431-445.

- Storch, R.A., Roberti, J.W., Heidgerken, A.D., Storch, J.B., Lewen, A.B., Killiany, E.M. (2004). The duke religion index: A psychometric investigation. *Pastoral Psychology, 53*(2), 175-182.
- Sullivan, M.D., Newton, K., Hecht, J., Russo, J.E., & Spertus, J.A. (2004). Depression and health status in elderly patients with heart failure: a 6-month prospective study in primary care. *The American Journal of Geriatric Cardiology, 13*(5), 252-260.
- Sulmasy, D. P. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist, 42*(III), 24-33.
- Sumner, C. (1998). Recognizing and responding. *American Journal of Nursing, 98*, 26-31.
- Swinton, J. (2006). Identity and resistance: why spiritual care needs 'enemies'. *Journal of Clinical Nursing, 15*(7), 908-928.
- Tarakeshwar, N., Vanderwerker, L.C., Paulk, E., Pearce, M.J., Stanislav, V.K., & Prigerson, H.G. (2006). Religious coping is associated with the quality of life of patients with advanced cancer. *Journal of Palliative Medicine, 9*(3), 646-657.
- Taylor, E.J. (2002). *Spiritual Care*. New Jersey: Prentice Hall.
- Taylor, E.J., & Mamier, I. (2005). Spiritual care nursing: what cancer patients and family caregivers want. *Journal of Advanced Nursing, 49*(3), 260-267.

- Thomas, S., Wince Chapa, D., Friedmann, E., Durden, C., Ross, A., Lee, M.Y., & Lee, H. (2008). Depression in patients with heart failure: prevalence, pathophysiological mechanisms, and treatment. *CriticalCareNurse* 28(2), 40-55.
- Townsend, M., Kladder, V., & Mulligan, T. (2002). Systematic review of clinical trials examining the effects of religion on health. *Southern Medical Journal*, 95 pp. 1429-1434.
- Tu, M. (2006). Illness: An opportunity for spiritual growth. *The Journal of Alternative and Complementary Medicine*, 12(10), 1029-1033.
- VandeCreek, L., Pargament, K., Belavich, T., Cowell, B., & Friedel, L. (1999). The unique benefits of religious support during cardiac bypass surgery. *Journal of Pastoral Care*, 53, 19-29.
- Veith, R.C., Lewix, N., Linares, O.A., Barnes, R.F., Raskind, M.A., & Villacres, E.C. (1993). Sympathetic nervous system activity in major depression-basal and desipramine-induced alterations in plasma norepinephrine kinetics. *Archives of General Psychiatry*, 50, 1-12.
- Venes, D., Thomas, C.L., Egan, E.J., Morelli, N.A., & Houska, A. (2001). *Taber's Cyclopedic Medical Dictionary*. Philadelphia: F.A. Davis.
- Watson, (2005). *Caring science as sacred science*. Philadelphia: F.A. Davis
- Websters-online Dictionary, (2007). Distress. Retrieved May 13, 2007 from <http://www.websters-online-dictionary.org/definition/distress>.

- Westlake, C., & Dracup, K. (2000). Role of spirituality in adjustment of patients with advanced heart failure. *Progress in Cardiovascular Nursing* 16, 119-125.
- Wright, L.M. (2005). *Suffering, spirituality and illness: Ideas for healing*. Philadelphia: F.A. Davis.
- Whipple, M.O, Lewis, T.T., Sutton-Tyrell, K., Matthews, K.A., Barinas-Mitchell, E., Powell, & L.H. (2009). Hopelessness, Depressive Symptoms and Atherosclerosis in Women. *Stroke* 40, 3166-3172.
- World Health Organization (2009). Cardiovascular diseases (CVD). Retrieved March 14, 2010 from <http://www.who.int/mediacentre/factsheets/fs317/en/index.html>.
- Villagomez, L.R. (2005). Spiritual distress in adult cancer patients. Toward conceptual clarity. *Holistic Nursing Practice*, 19(6), 285-294.
- Zauszniewski, J.A., & Bekhet, A. K. (2008). Depressive symptoms in elderly women with chronic conditions: measurement issues. *Aging & Mental Health*, 13(1), 64-72.

Appendix A

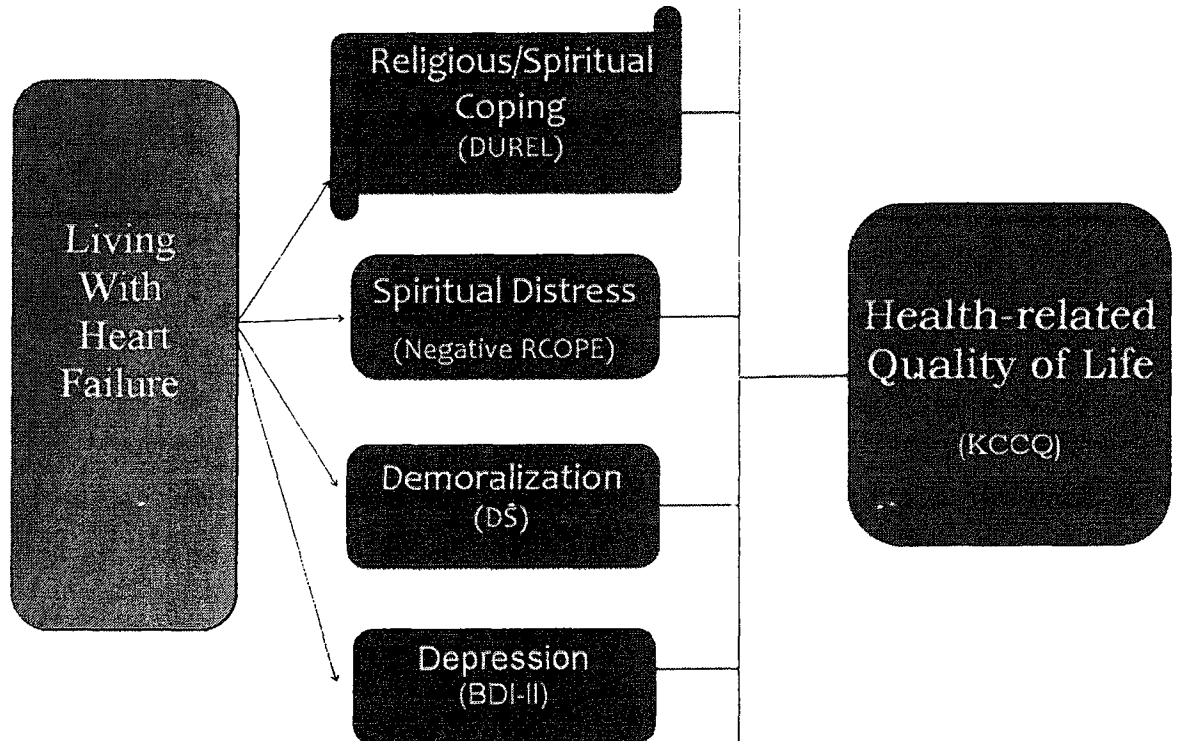
The Stages of Heart Failure – NYHA Classification

In order to determine the best course of therapy, physicians often assess the stage of heart failure according to the New York Heart Association (NYHA) functional classification system. This system relates symptoms to everyday activities and the patient's quality of life.

NYHA Class	Symptoms
I (Mild)	No symptoms and no limitation in ordinary physical activity, e.g. shortness of breath when walking, climbing stairs etc.
II (Mild)	Mild symptoms (mild shortness of breath and/or angina) and slight limitation during ordinary activity.
III (Moderate)	Marked limitation in activity due to symptoms, even during less-than-ordinary activity, e.g. walking short distances (20-100 m). Comfortable only at rest.
IV (Severe)	Severe limitations. Experiences symptoms even while at rest. Mostly bedbound patients.

Appendix B

CONCEPTUAL MODEL



Appendix C

DUREL: Duke University Religion Index

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.

Directions: Please answer the following questions about your religious beliefs and/or involvement. Please indicate your answer with a checkmark.

(1) How often do you attend church or other religious meetings?

1. More than once/wk
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 more times/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 *not* to 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 *not* to 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 *not* to be true
5. Definitely *not* true

Appendix D

Brief RCOPE (Negative Religious/Spiritual Coping)

The following items deal with ways you coped with the negative event in your life. There are many ways to try to deal with problems. These items ask what you did to cope with this negative event. Obviously different people deal with things in different ways, but we are interested in how you tried to deal with it. Each item says something about a particular way of coping. We want to know to what extent you did what the item says. *How much or how frequently.* Don't answer on the basis of what worked or not – just whether or not you did it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can. Circle the answer that best applies to you.

1 – not at all

2 – somewhat

3 – quite a bit

4 – a great deal

8. Wondered whether God had abandoned me.	1	2	3	4
9. Felt punished by God for my lack of devotion.	1	2	3	4
10. Wondered what I did for God to punish me.	1	2	3	4
11. Questioned God's love for me.	1	2	3	4
12. Wondered whether my church had abandoned me.	1	2	3	4
13. Decided the devil made this happen.	1	2	3	4
14. Questioned the power of God.	1	2	3	4

Appendix E

Demoralization Scale

For each statement below. Please indicate how strongly you have felt this way *over the last two weeks* by circling the corresponding number.

	Never	Seldom	Sometimes	Often	All the Time
1. There is a lot of value in what I can offer others.	0	1	2	3	4
2. My life seems to be pointless.	0	1	2	3	4
3. There is not purpose to the activities in my life.	0	1	2	3	4
4. My role in life has been lost.	0	1	2	3	4
5. I no longer feel emotionally in control.	0	1	2	3	4
6. I am in good spirits.	0	1	2	3	4
7. No one can help me.	0	1	2	3	4
8. I feel that I cannot help myself.	0	1	2	3	4
9. I feel hopeless.	0	1	2	3	4
10. I feel guilty.	0	1	2	3	4
11. I feel irritable.	0	1	2	3	4
12. I cope fairly well with life.	0	1	2	3	4
13. I have a lot of regret about my life.	0	1	2	3	4
14. Life is no longer worth living.	0	1	2	3	4
15. I tend to feel hurt easily.	0	1	2	3	4

16. I am angry about a lot of things.	0	1	2	3	4
17. I am proud of my accomplishments.	0	1	2	3	4
18. I feel distressed about what is happening to me.	0	1	2	3	4
19. I am a worthwhile person.	0	1	2	3	4
20. I would rather not be alive.	0	1	2	3	4
21. I feel sad and miserable.	0	1	2	3	4
22. I feel discouraged about life.	0	1	2	3	4
23. I feel quite isolated or alone.	0	1	2	3	4
24. I feel trapped by what is happening to me.	0	1	2	3	4

Appendix F

Beck Depression Scale (BDI-II)

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the groups seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

<p>1. Sadness</p> <p>0 I do not feel sad.</p> <p>1 I feel sad much of the time.</p> <p>2 I am sad all the time.</p> <p>3 I am so sad or unhappy that I can't stand it.</p>	<p>4. Loss of Pleasure</p> <p>0. I get as much pleasure as I ever did from the things I enjoy.</p> <p>1 I don't enjoy things as much as I used to.</p> <p>2 I get very little pleasure from the things I used to enjoy.</p> <p>3 I can't get any pleasure from the things I used to enjoy.</p>
<p>2. Pessimism</p> <p>0 I am not discouraged about my future.</p> <p>1 I feel more discouraged about my future than I used to be.</p> <p>2 I do not expect things to work out for me.</p> <p>3 I feel my future is hopeless and will only get worse.</p>	<p>5. Guilty Feelings</p> <p>0 I don't feel particularly guilty</p> <p>1 I feel guilty over many things I have done or should have done</p> <p>2 I feel quite guilty most of the time.</p> <p>3 I feel guilty all of the time.</p>
<p>3. Past Failure</p> <p>0 I do not feel like a failure.</p> <p>1 I have failed more than I should have.</p> <p>2 As I look back, I see a lot of failures.</p> <p>3 I feel I am a total failure as a person.</p>	<p>6. Punishment Feelings</p> <p>0 I don't feel I am being punished.</p> <p>1 I feel I may be punished.</p> <p>2 I expect to be punished.</p> <p>3 I feel I am being punished</p>

7. Self Dislike	10. Crying
0 I feel the same about myself as ever.	0 I don't cry anymore than I used to.
1 I have lost confidence in myself.	1 I cry more than I used to.
2 I am disappointed in myself.	2 I cry over every little thing.
3 I dislike myself.	3 I feel like crying but I can't.
8. Self-Criticalness	11. Agitation
0 I don't criticize or blame myself more than usual.	0 I am no more restless or wound up than usual.
1 I am more critical of myself than I used to be.	1 I feel more restless or wound up than usual.
2 I criticize myself for all of my faults.	2 I am so restless and agitated tha7 it's hard to stay still.
3 I blame myself for everything that happens.	3 I am so restless or agitated that I have to keep moving or doing something.
9. Suicidal Thoughts or Wishes	12. Loss of Interest
0 I don't have any thoughts of killing myself.	0 I have not lost interest in other people or activities.
1 I have thoughts of killing myself, but I would not carry them out.	1 I am less interested in other people or activities.
2 I would like to kill myself.	2 I have lost most of my interest in other people or things.
3 I would kill myself if I had the chance.	3 It's hard to get interested in anything.

13. Indecisiveness	16. Changes in Sleep Pattern
<p>0 I make decisions about as well as ever.</p> <p>1 I find it more difficult to make decisions than usual.</p> <p>2 I have much greater difficulty in making decisions than I used to.</p> <p>3 I have trouble making any decisions.</p>	<p>0 I sleep somewhat more than usual.</p> <p>1a I sleep somewhat less than usual.</p> <p>1b I sleep a lot more than usual.</p> <p>2 I sleep a lot less than usual.</p> <p>3a I sleep most of the day.</p> <p>3b I wake up 1-2 hours early and can't get back to sleep.</p>
14. Worthlessness	17. Irritability
<p>0 I do not feel I am worthless.</p> <p>1 I don't consider myself worthwhile and useful as I used to.</p> <p>2 I feel more worthless as compared to other people.</p> <p>3 I feel utterly worthless.</p>	<p>0 I am no more irritable than usual.</p> <p>1 I am more irritable than usual.</p> <p>2 I am much more irritable than usual.</p> <p>3 I am irritable all the time.</p>
15. Loss of Energy	18. Changes in Appetite
<p>0 I have as much energy as ever.</p> <p>1 I have less energy than I used to have.</p> <p>2 I don't have enough energy to do very much.</p> <p>3 I don't have enough energy to do anything.</p>	<p>0 I have not experienced any change in my appetite.</p> <p>1a My appetite is somewhat less than usual.</p> <p>1b My appetite is somewhat greater than usual.</p> <p>2a My appetite is much less than before.</p> <p>2b My appetite is much greater than usual.</p> <p>3a I have no appetite at all.</p> <p>3b I crave food all the time.</p>

19. Concentration Difficulty	
0	I can concentrate as well as ever.
1	I can't concentrate as well as usual.
2	It's hard to keep my mind on anything for very long.
3	I find I can't concentrate on anything.
20. Tiredness or Fatigue	
0	I am no more tired or fatigued than usual.
1	I get more tired or fatigued more easily than usual.
2	I am too tired or fatigued to do a lot of the things I used to do.
3	I am too tired or fatigued to do most of the things I used to do.
21. Loss of Interest in Sex	
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 G



LICENSE AGREEMENT

THIS LICENSE AGREEMENT is made as of this 16 October 2009, by and between CV Outcomes, Inc., a not-for-profit organization in Missouri, whose address is 18 W. 52nd Street, Kansas City, Missouri, 64112, United States ("Licensor") and University of San Diego, a not-for-profit organization in California, whose address is 41950 Green Tree Rd, Temecula, California, 92592, United States ("Licensee").

RECITALS

A. Licensor has rights in certain research methodologies, technical developments, know-how, discoveries, works of authorship, questionnaires, registries, study protocols, processes, datasets and other useful art, whether or not protected by patents, copyrights, trademarks, trade secrets or other laws protecting intellectual property rights, as more particularly described on Schedule A attached hereto and incorporated herein by this reference (the "Licensed Properties").

B. Licensee is engaged in that certain study more particularly described on Schedule B attached hereto and incorporated herein by this reference (the "Subject Study").

C. Licensor desires to grant Licensee the right to use the Licensed Properties solely in connection with the Subject Study, and Licensee desires to use the Licensed Properties in connection therewith, subject to all of the terms and conditions hereof.

NOW, THEREFORE, in consideration of the premises and the mutual promises and undertakings contained herein, the parties hereto agree as follows:

1. Grant of Limited License. Subject to the terms and conditions hereof, Licensor grants to Licensee a non-exclusive, non-transferable, non-assignable limited license to use the Licensed Properties solely in connection with the conduct of the Subject Study.
2. Ownership of Licensed Properties. As between Licensor and Licensee, Licensee acknowledges that Licensor retains all ownership rights in and to the Licensed Properties, and any improvements, modifications and derivatives thereof (whether prepared by Licensor or Licensee or otherwise), and that except for the rights granted hereunder, Licensee has no right, title or interest in and to the Licensed Properties. Licensee agrees to reproduce the appropriate copyright legends and/or trademark symbols on all written or displayed versions of the Licensed Properties and/or the results attributed to the use thereof. Licensee further acknowledges and understands that Licensor reserves the right to (i) grant others the license to use the Licensed Properties and (ii) use the Licensed Properties in its own research and investigations, without the need to account to Licensee in connection with such activities.

3. Fees. In consideration for the license granted hereunder, Licensee shall pay Licensor the license fees set forth on Schedule C attached hereto and incorporated herein by this reference, at the times, and in the manner, set forth on such Schedule.
4. Licensor's Representations and Covenants. Licensor represents and warrants to Licensee that Licensor has the full power and authority to execute and deliver this Agreement and to perform its obligations hereunder without need to obtain the consent of any third party.
5. Site Visits. Licensor shall have the right to inspect and observe from time to time through such agents or representatives as Licensor may designate, on Licensee's site, the activities conducted by or for Licensee with respect to the Licensed Properties to determine whether Licensee is using the Licensed Properties in a proper fashion as provided hereunder. To the extent Licensor is granted access to a patient's "protected health information" ("PHI"), as such term is defined in the Health Insurance Portability and Accountability Act of 1996 and the regulations promulgated thereunder, the parties agree to negotiate and execute a Business Associates Agreement containing customary covenants regarding the confidentiality and limited use of such PHI.
6. Reports. Licensee shall keep and maintain comprehensive and accurate records pertaining to its use of the Licensed Properties, and the status and progress of the Subject Study. Such reports shall be available for examination by Licensor and its agents or representatives at any time upon reasonable advance notice.
7. Licensee's Conduct. Licensee agrees that it shall use the Licensed Properties only as permitted hereunder and further agrees to refrain from modifying, altering or amending the Licensed Properties or taking any action which could adversely affect the validity, goodwill and reputation thereof. Upon the termination or expiration of this Agreement, Licensee shall immediately discontinue all use of the Licensed Properties.
8. Litigation. As between Licensor and Licensee, only the Licensor shall have the right to commence or prosecute any claims or litigation to protect or enforce its rights in and to the Licensed Properties. Licensee agrees that it will immediately provide notice to Licensor upon learning of any litigation, whether actual or threatened, against Licensee in connection with Licensee's use of the Licensed Properties. Licensee further agrees that it will cooperate fully with Licensor by providing any information requested by Licensor in any litigation arising in connection with Licensee's use of the Licensed Properties.
9. Disclaimers; Limitations of Liability. LICENSEE ACKNOWLEDGES THAT THE LICENSED PROPERTIES ARE LICENSED "AS IS", WITH ALL FAULTS. LICENSOR HAS MADE NO REPRESENTATION OR WARRANTY THAT THE LICENSED PROPERTIES ARE SUITABLE FOR LICENSEE'S USE IN CONNECTION WITH THE SUBJECT STUDY. LICENSEE SHALL RELY ON ITS OWN JUDGMENT IN EVALUATING ITS USE OF THE LICENSED PROPERTIES AND ANY OUTCOMES ATTRIBUTABLE THERETO, WITHOUT RELYING ON ANY MATERIAL OR INFORMATION PROVIDED BY LICENSOR. LICENSOR DISCLAIMS ANY REPRESENTATIONS OR WARRANTIES, EXPRESS OR IMPLIED, INCLUDING WITHOUT LIMITATION ANY REPRESENTATIONS OR WARRANTIES AS TO THE LICENSED PROPERTIES' MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE. IN NO EVENT SHALL LICENSOR BE LIABLE FOR SPECIAL, CONSEQUENTIAL, EXEMPLARY OR PUNITIVE DAMAGES. LICENSOR'S LIABILITY HEREUNDER SHALL BE LIMITED TO LICENSEE'S DIRECT DAMAGES RESULTING FROM LICENSOR'S BREACH OF ANY OF ITS OBLIGATIONS HEREUNDER WHICH CONTINUES UNREMEDIED FOR THIRTY DAYS AFTER WRITTEN NOTICE BUT SHALL IN NO EVENT

EXCEED THE AMOUNT OF THE FEES ACTUALLY PAID BY LICENSEE TO LICENSOR HEREUNDER.

10. Indemnification of Licensor. Licensee hereby agrees to hold Licensor harmless of and from and indemnifies it against any and all losses, liabilities, claims, damages and expenses (including attorneys' fees and expenses) which Licensor may incur or be obligated to pay, or for which it may become liable or be compelled to pay in any action, claim or proceeding for or by reason of any acts, whether of omission or commission, that may be claimed to be or are actually committed or suffered by Licensee arising out of Licensee's use of the Licensed Properties. The provisions of this paragraph and Licensee's obligations hereunder shall survive the expiration or termination of this Agreement.
11. Indemnification of Licensee. Subject to Section 9 hereof, Licensor hereby agrees to hold Licensee harmless of and from and indemnifies it against any and all losses, liabilities, claims, damages and expenses (including attorneys' fees and expenses) which Licensee may incur or be obligated to pay, or for which it may become liable or compelled to pay in any action, claim or proceeding for or by reason of any breach of any representation, warranty or agreement on the part of Licensor under this Agreement.
12. Nondisclosure. During the term of this Agreement, the parties may have access to trade secrets, proprietary information, or other sensitive materials belonging to the other which are not generally known to the public ("Confidential Information"). During the term of this Agreement and for a period of five (5) years after termination or expiration hereof, the receiving party ("Recipient") agrees to maintain in trust and confidence all Confidential Information of the other party (the "Disclosing Party"). The Recipient agrees to safeguard the Confidential Information using the same standard of care it uses to protect its own Confidential Information. The Recipient will not disclose any Confidential Information to any third party, or make any use thereof other than as expressly permitted hereby, without the prior written consent of the Disclosing Party. As used herein, Confidential Information does not include any information which the Recipient can demonstrate (i) was known to the Recipient or to the general public at the time of disclosure; (ii) was independently developed by the Recipient without the use of any of the Confidential Information; or (iii) was disclosed by a third party without violating any restriction or duty to the Disclosing Party.
13. Publications. Notwithstanding the general restrictions set forth in Section 12 above, the parties agree that publication of the results of research activities serves their mutual interests in improving the quality of health care. Accordingly, Licensee shall be free to publish the results of its research and development activities carried out with respect to the Licensed Properties and the Subject Study. Licensee agrees to refer to Licensor and the Licensed Properties in the bibliography section of the publication.
14. Term. Subject to the provisions of Section 15 hereof, this Agreement shall remain in effect from 10/15/2009 to 10/15/2010. Subsequent renewal of this Agreement shall be optionally available through application through the web site.
15. Licensor's Right to Terminate. Licensor shall have the right to immediately terminate this Agreement by giving written notice to Licensee in the event Licensee: (i) fails to perform any of its duties and obligations set forth herein, and the continuation thereof for thirty (30) days after notice; (ii) files a petition in bankruptcy or is adjudicated a bankrupt or insolvent, or makes an assignment for the benefit of creditors; (iii) makes any use of the Licensed Properties not otherwise expressly permitted herein or (iv) the Subject Study is cancelled, abandoned, withdrawn or suspended. In such event, Licensee shall immediately cease and terminate its use of any of the rights granted hereby and shall,

upon the request of Licensor, return to Licensor all records, copies, documents, media and files making use of the Licensed Properties, or furnish evidence, satisfactory to Licensor, of the destruction thereof.

16. Equitable Remedies. The parties further acknowledge that the breach, whether threatened or actual, of any of the terms hereof by Licensee shall result in immediate, irreparable injury to Licensor and its goodwill and that accordingly, Licensor shall be entitled to apply for a preliminary and/or permanent injunction to restrain the threatened or actual violation of the terms hereof by the Licensee or to compel specific performance of the terms and conditions of this License Agreement. Nothing set forth herein shall be construed as prohibiting the Licensor from pursuing any other remedies available for such breach or threatened breach, including the recovery of damages and costs incurred, together with attorneys' fees.

17. Miscellaneous.

a. This Agreement together with the exhibits hereto constitutes the entire understanding between the parties with respect to this Agreement. No change or modification of any of the provisions of this Agreement shall be effective unless memorialized by an instrument in writing signed by the parties hereto. All notices required or permitted to be given hereunder shall be given in writing, to the parties at their addresses set forth herein, or to such other address with respect to which notice has been given in accordance herewith. Whenever possible, each provision of this License Agreement shall be interpreted in such a manner as to be effective and valid under applicable law. If any covenant or other provision of this Agreement, or portion thereof, under circumstances not now contemplated by the parties, is invalid, illegal or incapable of being enforced, by reason of any rule of law, administrative order, judicial decision or public policy, all other conditions and provisions of this Agreement shall, nevertheless, remain in full force and effect, and no covenant or provision shall be deemed dependent upon any other covenant or provision unless so expressed herein. The parties desire and consent that the court or other body making such determination shall, to the extent necessary to avoid any unenforceability, so reform such covenant, term, condition or other provision or portion of this Agreement to the minimum extent necessary so as to render the same enforceable in accordance with the intent herein expressed.

b. This Agreement shall inure to the benefit of Licensor, its successors and assigns. Licensee shall not have the right to assign this Agreement, or delegate its duties, by operation of law or otherwise, without first obtaining the written consent of Licensor.

c. This Agreement shall be governed by and construed in accordance with the laws of the State of Missouri.

IN WITNESS WHEREOF, the parties hereto have caused this Agreement to be duly executed as of the day and year first above mentioned.

CV Outcomes, Inc.

Univeristy of San Diego

By: John Spertus

By:

Title: President

Title:

"Licensor"

"Licensee"

Th.D. RN

SCHEDULE A: LICENSED PROPERTIES**KCCQ – English (US)**

This version of the KCCQ has been validated among English-speaking residents of the US. This zip file includes two PDF files: the KCCQ itself and scoring instructions.

SCHEDULE B: DESCRIPTION OF STUDY**Project Name**

The Unique Contribution to Spiritual Coping with Health Failure

Project Type

Other

Project Dates

Start: 10/15/2009

End: 10/15/2010

Duration: 365 days

Enrollment

Sites: 1

Average subjects per site: 115

Total enrollment: 115

Schedule of Use

Administer to subjects thus: every 90 days

Total uses per subject: 4

Total uses: 460

Sponsor Name

University of San Diego

Sponsor Type

Other

SCHEDULE C: LICENSE FEES & PAYMENT TERMS**Payment Terms**

Payable on Receipt

Total Instrument Fees

\$ 57.50

Total License Fee

\$ 57.50

Appendix H

Clinical Research Orientation Presentation for:

THE UNIQUE CONTRIBUTION OF SPIRITUAL COPING TO HEALTH-RELATED QUALITY OF LIFE WITH HEART FAILURE

Consent

- Describe the study and what would be requested of each participant
- Answer any questions
- Give them the consent forms to read, answer any questions, and inform that they will be given a copy to take home
- Witness signature of all forms

Consent

- Review all forms to ensure they were all signed and accurately dated
- Sign as the investigator on the last page
- Copy the original consent 3 times
- Give one of the copies to the participant while keeping the original

Survey

- After consent is signed give the participant the survey
- Describe each of the 5 surveys to be completed *noting the different directions and scoring styles of each survey*
- Answer any questions
- Encourage the Participant to answer all questions to the best of their ability

Completed Survey

- Once the survey is completed and before the participant leaves, review all surveys for:
 - Unanswered Questions
 - Offer clarification of the question and encourage the participant to answer to the best of their ability
 - Signs of Suicide
 - If a participant has answered one of the questions showing signs of suicide notify their PCP at the clinic, before the participant leaves, and give the participant the suicide hotline phone number

Completed Survey

- After reviewing the survey give the participant the "Thank You" card with the \$10 enclosed in the card
- Have them initial and date the cash log to show that they have received the \$10
- Answer any final questions
- The participant is now free to leave

Paper Work to Keep with Research

Original consent

- On the original consent form place the participants designated number in the top right corner then file the original consent form
- Place the participants name and designated number in the master log

Completed Survey

- Return survey to the numbered envelope and file in numerical order

Place original consent, master log and survey in locked cabinet

Paper Work for LLUMC

First Copy of Consent

- Place participants medical record number and name at the bottom of each page
- Stamp front page on the top with "Scan as Original"
- Staple together and send to Medical Records

Second Copy of Consent

- Place participants medical record number and name at the bottom of the front page
- Place in participant's chart under "miscellaneous"

Paper Work for LLUMC

Nurse Notes

- Write a note for the participants chart saying that they participated, what PCP referred them, were informed, signed a consent and that you answered any questions
- Sign and date
- Place in participant's chart under "Nurse Notes"

Appendix K

You are invited to participate in a research study of patients living with heart failure-



Your participation will involve completing questionnaires about your experience of living with heart failure that will take approximately 30-60 minutes. This can be completed here in the LLUMC Cardiomyopathy Clinic.

A PhD Nursing Student from the University of San Diego is conducting this study with the approval of LLUMC.

Please contact me M-F, 9am-5pm

Terry Larsen PhDc RN

951-551-9421

tlarsen@gmail.com

Appendix L



LOMA LINDA UNIVERSITY MEDICAL CENTER

LOMA LINDA INTERNATIONAL HEART INSTITUTE

Cardiomyopathy Program

11234 Anderson Street
Post Office Box 2000
Loma Linda, California 92354-0200
(909) 558-7249
(800) INTL-HEART
FAX: (909) 558-0193

The Unique Contribution of Spiritual Coping to Health-related Quality of Life with Heart Failure

You are being invited to participate in this research study conducted by Sharon Fabbri, NP and Terry Larsen, RN who is a Nursing Doctoral Student at San Diego University School of Nursing. This study is conducted as part of a student research project. You are invited to participate in this research because you have been diagnosed with heart failure and are a patient in the Cardiology Heart Failure Clinic at Loma Linda University Medical Center.

The purpose of this study is to increase the researcher's understanding of how persons living with heart failure cope with their concerns and how to explore their quality of life.

Procedure: If you agree to participate, during your clinic visit to the heart institute, you will be asked to answer questions about yourself. There are 5 questionnaires that will ask you information about how you are coping with your disease and what you think about your quality of life. Your name will not be used on any of these documents. The researcher will use a study number to identify you. A log with your name and study number will be kept locked in a drawer in Sharon Fabbri's office at the Heart Clinic. The research will involve one meeting and will take about one hour.

5/13/09 5/12/2010
59035

Initials _____
Date _____

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The Unique Contribution of Spiritual Coping to Health-related Quality of Life with Heart Failure

The Right to Withdraw: Joining this study is voluntary which means you can choose whether or not you want to participate. You may withdraw any time without penalty. Whether or not you choose to participate will not affect your current or future medical care.

Possible Risks & Benefits: Taking part in this study should pose no more than minimal risk of a breach of confidentiality or discomfort.

There may be a risk that you will feel tired or fatigued while filling out the questionnaires. You can stop at any time to rest, decide not to fill out all the forms, or withdraw from the study at any time.

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free 24 hours a day the Riverside County's Crises & Suicide Number (951) 686-HELP (4357).

Benefits: There is no direct benefit to you by participating in this study. The potential benefit to society is that nurses and health care providers may increase their understanding of the issues and concerns of patients with heart failure.

Costs/Reimbursement: There is no cost to you for participating in this study; you will be paid ten dollars upon completion of the surveys for helping with this study.

Confidentiality & Consent: Confidentiality of your information cannot be absolutely guaranteed, however, measures will be taken to ensure that data collected about you will be kept as secure as possible. Your identity will be kept strictly confidential by using a code number on a questionnaire rather than your name when gathering answers to questions. Also, all identifying information and answers will be seen only by the researchers and will be kept in a locked cabinet in the principal investigator office. Any publications of the results of this study will refer to the group results and not to you personally.

Initials _____
Date _____

Riverside County Health Center
Community Health Center
159035 Chair
5/13/09 Valid after 5/12/2010

The Unique Contribution of Spiritual Coping to Health-related Quality of Life with Heart Failure

Questions: This document explains your rights as a research subject. If you have questions regarding your participation in this research study or have any questions about your rights as a research subject, please contact Sharon Fabbri at (909) 558-4000 ext. 82114 or Terry Larsen at (951) 551-9421 between 8 am and 5 pm.

If you wish to contact an impartial third party not associated with this study regarding any question or complaint you may have about the study, you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda CA 92354, phone (909) 558-4647 for information and assistance.

Consent: I have read the contents of the consent form and have listened to the verbal explanation given by the investigator. My questions concerning this study have been answered to my satisfaction. I hereby give voluntary consent to participate in this study. Signing this consent document does not waive my rights nor does it release the investigators or institution from their responsibilities. I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time without penalty. I have received a copy of this consent form for my records. I consent to participate in the study.

Participant Name Printed:

Participant Name Signed:

Date:

I have reviewed the contents of this consent form with the person signing above. I have explained potential risks and benefits of the study.

Signature of Investigator

Date:

Initials _____
Date _____

5/13/09 5/12/2010
59035

California Experimental Subject's Bill of Rights

You have been asked to participate as a subject in an experimental clinical procedure. Before you decide whether you want to participate in the experimental procedure, you have a right to:

1. Be informed of the nature and purpose of the experiment.
2. Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
3. Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.
4. Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.
5. Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.
6. Be informed of the avenues of medical treatment, if any available to the subject after the experiment, if complications should arise.
7. Be given an opportunity to ask any questions concerning the experiment or the procedure involved.
8. Be instructed that consent to participate in the medical experiment may be withdrawn at any time, and the subject may discontinue participation in the medical experiment without prejudice.
9. Be given a copy of any signed and dated written consent form used in relation to the experiment.
10. Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

I have carefully read the information contained above in the "California Experimental Subject's Bill of Rights" and I understand fully my rights as a potential subject in a medical experiment involving people as subjects.

Date

Subject

Time

Parent/Legal Guardian

If signed by other than the subject, indicate relationship:

Relationship

Witness

Appendix M

Demographic Profile Questionnaire

ID Code # _____

In order to better understand you and the impact your life experiences and health history may have on this research, please respond to the following questions.

Today's Date _____

Circle the correct response

1. Gender: Male Female

2. Age: 25-34 35-44 45-54 55-64 65-74 75-84 older than 85 yrs

3. Marital status: Married Separated Widowed Divorced Single

4. Are you currently employed? (Circle one response) Yes No

5. What is your highest level of education? (Circle one response) 8th grade 12th grade
Some College College Degree Graduate School Doctoral Degree

6. How long have you had heart failure?

Less than 1 year 1-3 yrs 4-6 yrs 7--9 yrs 10 or more years

7. How many times have you been hospitalized for your heart failure within the last year? (Circle one response) 1 2 3 or more

8. What type of treatment are you receiving? _____

9. Have you used alternative treatments such as herbs, yoga, meditation, etc? (Circle one response) Yes No

If so what are you using?
_____10. What is your ethnic background?
_____11. Do you have a religious affiliation? If so, please state:

12. Do you feel you have adequate financial resources to manage your healthcare concerns? (Circle one response) Yes No

13. What is/was your occupation? _____