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

QUALITY OF LIFE, HOPE, SOCIAL SUPPORT, AND SELF-CARE
IN HEART FAILURE PATIENTS

by

Karen A. McGurk RN, MN

A dissertation presented to the
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SCIENCE

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requirements for the degree
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Dissertation Committee

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Abstract

Quality of Life, Hope, Social Support, and Self-Care
in Heart Failure Patients

Heart failure is a significant, chronic health problem. Much is known about physiological factors related to this condition. Less is known about the psychosocial aspects that influence disease risk, progression, and treatment. The purpose of this study was to describe the relationships between quality of life, hope, social support, and self-care.

A descriptive, correlational study was conducted. The participants were 65 heart failure patients who attended 2 military-based heart failure clinics. Quality of Life was measured using the Left Ventricular Dysfunction Questionnaire (LVD-36), Hope was measured using the Herth Hope Index (HHI), Social Support was measured using the Medical Outcomes Study – Social Support Survey (MOS – SSS), and Self-Care was measured using the Self-Care of Heart Failure Index (SCHFI). A researcher developed form was utilized to capture demographic information.

Higher levels of hope were found to be significantly related to quality of life. Social support and self-care were not found to be significantly related to quality of life.

Findings revealed those patients who were diagnosed with heart failure for one year had improved quality of life compared to patients who were diagnosed with heart failure for eleven years. Patients who had no physical impairments

(functional status Class I) had a better quality of life than patients who had slight to debilitating physical impairments (functional status Classes II, III, IV). Age, gender, race/ethnicity, marital status, and co-morbidity were not significantly related to quality of life.

Quality of Life has been established as an important patient outcome. This study supports inclusion of hope fostering interventions in heart failure care and further examination of functional status and length of time of heart failure diagnosis in efforts to support heart failure patients' quality of life over time. Increased understanding of the significant relationship between psychosocial factors and patient outcomes necessitates their inclusion in heart failure care. Funding must be allocated to support education and research that supports development of new, cost effective models of care. Nursing is the ideal health care profession to move these treatment models forward.

DEDICATION

I dedicate this dissertation to my sweet Lochinvar, Bill McGurk. Your steadfast love, incredible patience, and never failing encouragement gave me hope and strength.

To my awesome children Joshua Glenn, Kindra Hart, and Julia Immen; their wonderful spouses Katherine, Jonathan, and Brandon; and sweet Will – I am truly humbled by your accomplishments and grateful for your love and support.

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My sincere appreciation and thanks to the many individuals who supported me through this endeavor.

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My sincere thanks are expressed for the assistance and cooperation I received from the officers, physicians, administrators, and staff at the Naval Medical Center San Diego and Naval Hospital Camp Pendleton. Special thanks are extended to the patients and families at the heart failure clinics who so willingly gave of their time in support of this study.

Sincere appreciation is extended to the many individuals at Palomar College who facilitated completion of my doctoral studies including administrators, faculty, staff, and the sabbatical leave committee. I am especially grateful to Judy Eckhart, friend and colleague, for her unfailing support.

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Chapter 1

The Problem

Background of the Problem

Heart failure is a chronic, progressive, terminal condition estimated to be prevalent in 5.2 million adults living in the United States of America. By the age of 40 years, life time risk of developing HF is estimated to be one in five for both men and women (American Heart Association [AHA], 2009). Mortality related to HF is increasing while the national death rate is decreasing. Heart failure is the most frequent diagnosis for hospital admissions and readmissions. More than 80% of heart failure hospital admissions are covered by Medicare or Medicaid (Fang, Mensah, Croft, & Keenan, 2008). The economic burden is significant with direct and indirect costs estimated at \$33.2 billion for 2007 (AHA).

Best practice guidelines for heart failure treatment have been designed by nationally recognized leaders in heart disease (Hunt et al., 2005; National Institutes of Health [NIH], 2007). The American Heart Association and the American College of Cardiology (ACC) developed a national initiative “Get with the Guidelines-Heart Failure” (GWTG-HF) to standardize interventions based on the results of multiple clinical trials. Treatment focuses on medication administration and lifestyle changes that include smoking cessation, weight management, and physical activity (Fonarow, 2007). However, despite best-practice treatment interventions, heart failure remains a pervasive problem.

The focus on medical and lifestyle management fails to include assessment and treatment of psychosocial factors that have significance related to the etiology and progression of heart failure. Quality of life is one factor that has been identified as a relevant patient outcome in both clinical practice and research (George & Clipp, 2000). The significance of quality of life has been recognized by international, the World Health Organization (World Health Organization [WHO], 2004), and national programs. One of the two primary goals of Healthy People 2010 is to improve individuals' quality of life (Healthy People 2010, 2008).

Quality of life studies emphasize the importance of a holistic perspective when examining patient outcomes. Multiple studies have been conducted examining heart failure patients' quality of life and demographic and physiologic factors. Demographic factors including age ((Fang, Mensah, Croft, & Keenan, 2008; Hou et al., 2004), gender (Heo, Moser, & Widener, 2007; Hou et al., 2004; Riedinger et al., 2001), socioeconomic status, race (Singh, Gordon, & Deswal, 2005), destination following hospitalization (Hoskins, Walton-Moss, Clark, Schroeder, & Thiel, 1999), living alone, marital status (Hamner), and receiving Medicare (Hamner) have been associated with patient outcomes

Frequently studied physiologic variables including ejection fraction (Konstam et al., 1996), hemoglobin (Felker et al., 2004), Brain Natriuretic Protein (Bettencourt; Laederach-Hoffman, Rohrer-Gubeli, Messerli, & Meyer, 2007; Laederach-Hoffman et al.), Blood Urea Nitrogen (Felker et al., 2004), hemoglobin level (Go et al., 2006), disease severity and functional status (Reiley

& Howard, 1995; Westlake et al., 2002), comorbidities (Aranda & Johnson, 2009; Hamner & Ellison, 2005; Schwarz & Elman, 2003), memory loss and confusion (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004), and sleep difficulties (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004; Redecker, 2008) have been found to influence quality of life and disease progression. These findings improve understanding of the relationship between physiologic factors and heart failure and guide development of interventions to improve patient outcomes. However, despite increased understanding of the role of physiologic factors, hospital readmission rates show minimal improvement with rates ranging from 27% - 60% (Aranda & Johnson; Deaton et al., 2004; Felker et al., 2004; Hamner & Ellison, 2005; Lagoe, Noetscher, & Murphy, 2001; Proctor, Morrow-Howell, Li, & Dore, 2000; Reiley & Howard, 1995).

The chronic, progressive nature of heart failure despite understanding of the role of physiologic variables and optimal treatment interventions necessitates identification of other factors that influence patient outcomes. Studies have examined the relationship between quality of life and psychosocial factors such as self care/self efficacy (Chriss, Sheposh, Carlson, & Riegel, 2004; Gary, 2006; Schnell-Hoehn, Naimark, & Tate, 2009), coping (Ekman, Fagerberg, & Lundman, 2002; Gustavsson & Branholm, 2003), sense of coherence (Ekman, Fagerberg, & Lundman, 2002; Gustavsson & Branholm, 2003), and depression (Friedman & Griffin, 2001; Fulop, Strain, & Stettin, 2003; Havranek, Spertus, Masoudi, Jones, & Rumsfeld, 2004; Johansson, Dahlstrom, & Brostrom, 2006; Klein, Turvey, & Pies, 2007). Most studies regarding psychosocial factors reveal a positive

significant relationship with quality of life. The exception is depression which is inversely related to quality of life.

However, there is a gap in the literature regarding the relationship between Hope, Social Support, and Self-Care in heart failure patient quality of life outcomes. Hope has been studied in relation to chronic illnesses such as cancer, drug dependency, homelessness (Herth, 1996), myocardial infarction (Johnson & Roberts, 1996) and HIV infection (Rabkin, Neugebauer, & Remien, 1990). However, Hope is a little studied trait in heart failure patients (Davidson, Dracup, Phillips, Daly, & Padilla, 2007). It is important to understand Hope in the heart failure patient in order to foster and support a trait that has been demonstrated to improve quality of life in other populations.

In addition to Hope, Social Support has been found to be positively correlated to physical and mental health (Farran, 1985) and changes in Social Support have been found to predict changes in quality of life in heart failure patients (Bennett et al., 2001; Meagher-Stewart & Hart, 2002; Murberg, 2004; Park, Fenster, Suresh, & Bliss, 2006; Westlake et al., 2002).

Social Support has been included in the conceptual definition of hope. Farran, Herth, and Popovich define hope to include “four central attributes: (a) an experiential process, (b) a spiritual or transcendent process, (c) a rational thought process, and (d) a relational process” (1995, p. 6). The relational process is defined as the social relationship between persons. Yet, the relationship between social support and hope as related to quality of life in heart failure patients has not been studied.

Self care is a critical component in heart failure disease management. In order to halt or minimize disease progression, patients must be able to manage a complex lifestyle regimen. Medication and diet adherence, appropriate physical activity, and daily symptom monitoring are cornerstones for heart health in this population. Studies demonstrate a significant relationship between Self-Care and positive outcomes (Chriss, Sheposh, Carlson, & Riegel, 2004).

Statement of the Problem

Heart Failure is a disease that results in significant personal and economic burdens. Much is understood regarding the relationship between demographic and physiologic factors and heart failure. Best practice guidelines have been developed in an effort to halt or slow this progressive condition. Yet, despite these interventions, heart failure remains the primary reason for hospital admissions and readmissions.

Quality of life has been identified as important patient outcome. Existing studies have examined the relationship between quality of life and many psychosocial variables. Lacking are studies that examine the relationship between quality of life and hope, social support, and self-care.

Purpose of the Study

The purpose of this study is twofold. First, it will fill a gap in the heart failure and nursing literature by describing Quality of Life and the psychosocial variables of Hope, Social Support, and Self-Care in heart failure patients. Second,

it will examine the conceptual relationships between Quality of Life, Hope, Social Support, and Self-Care in this population.

Specific Aims

Aim # 1: Characterize hope, social support, self-care and quality of life in heart failure patients.

Aim #2: Examine the relationship between demographic and physiologic variables and quality of life.

Aim #3: Examine the relationship among the psychosocial variables of hope, social support, self-care, and quality of life in heart failure patients.

Research Questions

Question #1: What is the level of hope, social support, self care, and quality of life among heart failure patients?

Question #2: Is there a statistically significant difference among quality of life mean scores by race/ethnicity, marital status, age, gender, length of time diagnosed with heart failure, functional status, and comorbidities?

Question #3: What is the relationship of hope, social support, and self-care to quality of life in heart failure patients?

Conceptual Framework

The conceptual framework underlying this study is derived from the literature and based on the concepts of quality of life, hope, social support, and

self-care. In effort to address the holistic needs of individuals, quality of life has been identified as an important outcome in patients with heart failure.

Quality of life is a multidimensional concept that includes physical and social function, mental health, and role limitations, as well as physical health aspects. In the heart failure population, quality of life is used in both correlational and intervention studies. It is very important to measure quality of life in order to truly understand the impact of heart failure which in the end is a terminal illness. As patients become less responsive to therapeutic modalities, satisfactory patient outcomes must be re-defined. Rather than using physiologic variables only to define successful patient outcomes, it will be meaningful to focus on psychosocial variables to measure success.

A psychosocial variable of particular interest and importance is hope. Hope has been identified as an important coping strategy during critical life experiences. Hope is comprised of four central attributes according to Farran et al. (1995). Of particular relevance to this study is the relational process. Hope is the result of a caring interaction between people. It is facilitated by presence of another and by communication of positive expectations. Hope is reliant in part on social relationships.

Social support is also a concept that is relationship based. Clinical observation of heart failure patients reveals that individuals who have similar physical disease indicators often have very different outcomes. The role of spouses, family members, and friends appears to influence patient health-related

quality of life. Multiple studies support this observation. The question must be asked: Is there a relationship between hope and social support?

In addition to hope and social support, self-care is a concept that will be examined in relation to quality of life. Self-care is defined as activities that are either controlled by the individual with little input from health care providers, or managed by a health care professional who teaches individuals the necessary skills and is responsible for their care (Frank-Stromborg & Olsen, 2004). Lifestyle changes are imperative in the heart failure population to ameliorate disease progression. Self-care management of daily activities is required to maintain health.

All four concepts: quality of life, hope, social support, and self-care have been studied to varying degrees. Quality of life has been widely examined especially in relation to demographic and physiologic variables. There has been much less study of the psychosocial variables hope, social support, and self-care. However, these variables are very important in the context of heart failure which is a progressive, terminal condition. This study will examine the concepts of quality of life, hope, social support, and self-care in an effort to identify the relationships between them.

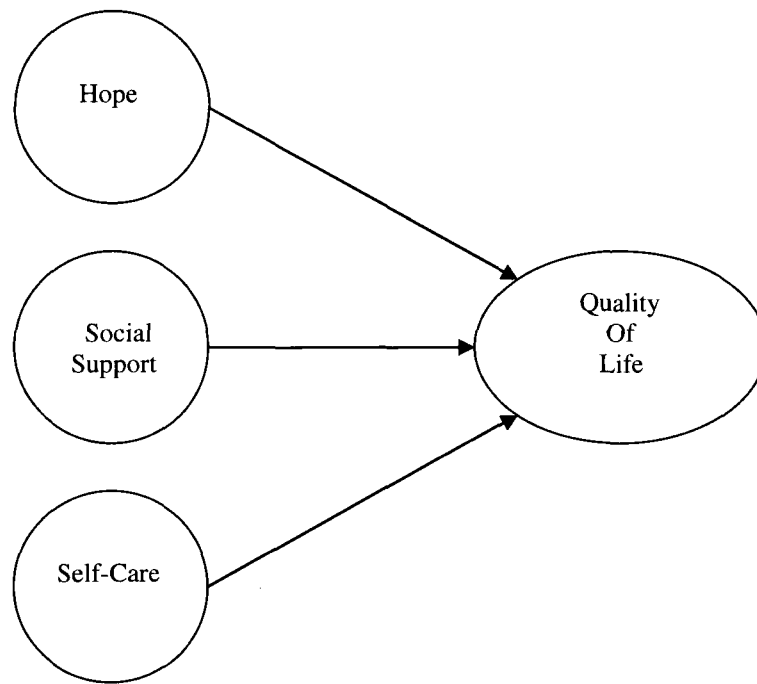


Figure 1: Proposed Conceptual Model: Variables affecting Quality of Life in Heart Failure Patients.

Definition of Terms

For the purposes of this study, variables are operationally defined as follows:

Quality of Life

Quality of Life is a multidimensional concept that has been defined across a continuum ranging from a general or global perspective to a narrow, disease-specific perspective. Identifying the spheres of life experience within these definitions is crucial for clarity of study intent. This study will operationalize the definition of quality of life utilizing the scores from the Left Ventricular Dysfunction Questionnaire (LVD-36). The LVD-36 examines daily life and well-

being from the perspective of the heart failure patient. It is a 36 item, dichotomous questionnaire with scores that range from 0 (best possible score) to 100 (worst possible score) (O’Leary & Jones, 2000).

Hope

Hope is a basic, human trait that is necessary to overcome life’s difficulties and maintain a sense of joy. For the purposes of this study, hope will be defined using the scores from the Herth Hope Index (HHI). The HHI contains three subscales of hope: the first measuring future-orientation, the second measuring positive expectancy, and the third measuring interconnectedness with others. It is a 12 item, Likert-scale tool with scores ranging from 12 (lowest level of hope) to 48 (highest level of hope) (Herth, 1992).

Social Support

Social Support is a multidimensional, relationship-based concept. It is defined in this study based on the scores from the Medical Outcomes Study – Social Support Survey (MOS-SSS). The MOS-SSS is a 19-item tool comprised of four subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. The Likert scale instrument measures types of support, not the source of support. A higher score indicates more support (Sherbourne & Stewart, 1991).

Self-Care

Self-Care is a multifaceted concept that includes knowledge and adherence to treatment regimens and appropriate decision making related to symptom management. For the purposes of this study, self-care will be defined

using the Self-Care of Heart Failure Index (SCHFI). The SCHFI is a 15 item, Likert scale tool that measures self-care maintenance, self-care management, and self confidence in the heart failure patient (Riegel, et al., 2004).

Significance of the Study to Nursing

This study is important for several reasons. First, it will fill a gap in the literature by describing the relationship between the psychosocial variables of Hope, Social Support, and Self-Care and Quality of Life. Second, it will test the conceptual linkage between Hope, Social Support, and Self-Care.

Nursing is a science that addresses the holistic nature of human beings. Influences on health and illness are of particular interest to nursing (Meleis, 2005). The health/illness continuum experienced by heart failure patients is influenced by environmental, cultural, economic, physical, psychological, and social factors. In order to best address the needs of this patient population, nursing requires knowledge of these factors.

The domain of nursing knowledge is based in theory and practice (Meleis, 2005). Theoretical or conceptual models expand the nursing purview and help guide nursing vision and philosophy. The identification of a conceptual model will clarify quality of life and psychosocial relationships and provide a foundation for research and practice.

Research questions arise from clinical observations and research findings guide nursing interventions. Limited studies exist that examine the role of psychosocial factors and outcomes in heart failure patients. Understanding how

Quality of Life is influenced by Hope, Social Support, and Self-Care will provide guidance for nursing practice. The findings can be used to develop clinical interventions in the outpatient setting that optimize patient outcomes including individualizing plans of care and discharge. The findings may assist in the development of a risk measure for patients accessing health care services.

Chapter II

Review of the Literature

Significance of chronic illness

Chronic illness is the leading cause of death and disability internationally. Chronic diseases are more prevalent than infectious diseases resulting in the death of over 35 million people in 2005. Mortality rates are greatest in low and middle income countries and in women. It is predicted that without intervention, chronic diseases will increase 17% by 2015 (World Health Organization [WHO], 2007).

In the United States, chronic diseases are the leading cause of death, illness, and disability. More than 125 million Americans live with chronic conditions. They are costly in terms of economic expenditures accounting for more than 75% of the \$1.4 trillion spent on health care (Healthy People 2010, 2008), in addition to societal and individual burdens. Ironically, they are often preventable. Of the multiple existing chronic diseases, heart disease has been identified as the leading cause of death across all racial and ethnic lines (Centers for Disease Control and Prevention [CDC], 2007a).

Heart disease is prevalent in more than 79 million Americans. The projected cost of heart disease and stroke in 2007 is \$431.8 billion. It is expected that the personal and financial impact of heart disease will continue to grow as the population ages (Center for Disease Control and Prevention [CDC], 2007b).

Significantly, a population-based, cross-sectional prevalence study found that 56% of adults over the age of 45 years were identified as having risk factors or asymptomatic dysfunction related to heart failure (Ammar et al., 2007)!

Heart failure (HF) is estimated to be prevalent in 5.2 million Americans. People aged 65 years and older have the highest incidence of HF. The lifetime risk of developing HF is 1 in 5 for men and women at age 40 years (American Heart Association [AHA], 2009). Mortality related to HF is increasing while the overall death rate is decreasing. Individuals with heart failure face increased physical and psychological disabilities. Heart Failure is the number 1 diagnosis responsible for admission/readmission to the hospital (Hammill, Curtis, & Bennett-Guerrero, 2008; Hunt et al., 2005) with rates tripling between 1979 and 2004 (Fang, Mensah, Croft, & Keenan, 2008).

Heart Failure

Heart Failure is defined as a clinical syndrome that results from inability of the heart to function effectively as a pump. Shortness of breath, fatigue, and fluid retention are primary signs of heart failure and are thought to result from complex molecular, neuroendocrine, and neurohormonal interactions (Hunt et al., 2005, p. 1828). The majority of people with HF have impairment of the left ventricle. Heart Failure may result from a number of conditions including disorders of the heart and major vessels; however, hypertension and coronary artery disease are considered to be the most common risk factors (American Heart Association [AHA], 2007,

p. 21). Risk factors for the development of heart failure include obesity, excessive alcohol intake, cigarette smoking, dyslipidemia, renal insufficiency, toxic risk precipitants such as chemotherapy, and genetic polymorphisms (property of crystallizing into two or more different forms) such as those involved in gene coding of alpha and beta adrenergic receptors have been identified (Schocken et al., 2008).

There is no simple test for heart failure; rather, careful history and physical assessment identify clinical manifestations and changes in functional status. Limitations in functional status were used by the New York Heart Association (NYHA) to develop a heart failure classification system. Individuals were assigned to one-of-four functional classes that measured degree of physical effort. The classes ranged from class I where individuals have no physical activity limitations through Class IV where individuals have symptoms of heart failure at rest (Heart Failure Society of America, 2002). The AHA developed - Stages of Heart Failure – utilizing structural changes to define the level of heart failure. Stages range from Stage A where individuals have no structural heart changes but are at risk for HF through Stage D where individuals have end-stage disease and require specialized treatments (Hunt et al., 2005).

Echocardiography is the single most diagnostic test used to quantify heart failure. It is used to measure left ventricular ejection fraction and assess dimensions and thickness of left and right ventricular walls. Other tests such as radionuclide ventriculography, magnetic resource imaging, and computed tomography are used to measure the severity of the heart problem. Chest X-rays

indicate heart enlargement as well as pulmonary congestion (Hunt et al., 2001). Brain Natriuretic Peptide (BNP), a protein found in the blood, is excreted when the left ventricle fails. It is used as a diagnostic marker of heart failure; increased levels correspond to increased heart failure (Deaton, Bennett, & Riegel, 2004).

Heart Failure is a progressive disease resulting in cardiac remodeling, a change in the size, shape, and structure of the left ventricle. The chamber dilates and the walls thicken resulting in less effective performance and frequently leading to regurgitation of blood flow through the valves. Remodeling usually occurs before symptoms appear and continues throughout the course of the disease contributing to worsening of symptoms despite treatment (Hunt et al., 2005).

The AHA and the American College of Cardiology (ACC) have developed guidelines for the assessment and treatment of heart failure. Assessment begins with identification of structural and functional abnormalities. A careful history, physical assessment, and diagnostic tests identify individual classification. Treatment protocols are based on the classification of the patient's symptoms. A patient who is at High Risk for developing heart failure (Stage A) should be instructed to avoid risk increasing behaviors such as smoking, large amounts of alcohol consumption, and high-fat diets. Patients who have structural abnormalities of the heart but who have not developed symptoms (Stage B) should be counseled to follow all the recommendations of Stage A with the addition of medication interventions. Patients with symptoms of heart failure (Stage C) should follow all the Stage A and B guidelines with additional

medication interventions and dietary restrictions. Treatment for patients with Refractory End-Stage (Stage D) should include all previously utilized therapies with the addition of mechanical and surgical interventions (Hunt et al., 2005). Hospice and palliative care should also be considered at this stage.

Despite recognized treatment interventions, heart failure remains a progressive, terminal disease. As treatment options become less effective, focus shifts to quality of life as an important patient outcome. A descriptive study of over 5000 heart failure patients demonstrated the predictive value of quality of life when related to mortality and hospitalization. “Quality of life independently predicted mortality and CHF-related hospitalizations after adjustment for ejection fraction, age, treatment, and New York Heart Association classification in patients with an ejection fraction of <0.35 ...” (Konstam et al., 1996, p. 890).

Conceptual Framework

The conceptual framework underlying this study is derived from the literature and based on the concepts of quality of life, hope, social support, and self-care. The relationship between hope, social support, and self-care had been little studied in heart failure. Examining these variables in the context of a widely-accepted outcome – quality of life – will help inform nursing practice. Discussion of these concepts will be organized topically: Quality of Life, Hope, Social Support, and Self-Care with the heart failure patient as the central concern.

Quality of Life

Patient outcomes related to heart failure have been measured in terms of physiological markers primarily focusing on disease progression and mortality. More recent studies have recognized the importance of psychosocial concepts and studies have included their influence on the same outcomes. It is only recently that quality of life has been recognized as an acceptable patient outcome (Lancet, 1995) and there are limited studies that examine the relationship between quality of life and psychosocial factors.

The broad concept of quality of life has been examined by prominent national and international groups. The World Health Organization developed an international quality of life measurement tool that was focused on well being rather than just absence of disease. Quality of life was defined as a subjective experience that is influenced by social, cultural, and environmental factors (World Health Organization [WHO], 2004).

At the national level, the National Institutes of Health worked with several federal health care agencies to coordinate efforts to define quality of life in chronic illnesses. The resulting definition addressed the need for specific and objective methods of assessment (National Institutes of Health [NIH], 2003). In addition, one of the two primary goals of Healthy People 2010 (Healthy People 2010, 2008) is to improve individuals' quality of life.

Quality of life (QOL) is a broad concept that encompasses many different aspects of an individual's life experience. It has been argued that quality of life be considered as a mediating variable rather than an endpoint. However, it has been

identified and accepted as an outcome measure in both clinical trials and multidisciplinary health care research (George & Clipp, 2000; Hofer, Benzer, Kopp, Schussler, & Doering, 2005; Lancet, 1995).

Wilson and Cleary developed a conceptual model of quality of life that suggested a causal relationship between health concepts and quality of life (1995). Hofer, Benzer, Kopp, Schussler, and Doering identified measures and then tested the five variables in the Wilson & Cleary model. Patients who had coronary artery disease were surveyed prior to a planned diagnostic treatment, at one month, and at 3 months. Structural equation modeling (a combination of factor and path analyses) was used to compare the model's hypothesized relationships with actual data obtained from the study. The five hypothesized variables were found to be significantly linked. More importantly, the five variables were found to be separate from quality of life. They influenced QOL, but QOL was demonstrated to be a distinct concept (2005).

In order to clearly define QOL, it is necessary to first delineate the domains that are to be studied and measured. Quality of Life has been characterized as global, health-related, or disease-specific. Global assessment measures quality of life across all important domains in an individual's life. The goal of global measures is to view the individual's overall quality of life. Social and behavioral scientists utilize global QOL measures primarily to measure the ability of societal resources to meet the needs of the individual. These tools have been used in health care research, but are not sensitive to the effects of healthcare interventions on patients' quality of life (George & Clipp, 2000).

Global quality of life measures tend to be short and produce a single score. Examples include the General-Well Being Scale and the Perceived Quality of Life Scale. Global scales that measure multiple quality of life domains also exist. These scales typically yield separate scores for separate domains that do not result in a single overall quality of life score. The OARS Multidimensional Functional Assessment Questionnaire is such a tool (George & Clipp, 2000).

A second operationally defined categorization involves health-related quality of life (HQOL). It is necessary to note that quality of life and health-related quality of life are terms that are used interchangeably in the literature even though the outcomes may be very different (Frank-Stromberg & Olsen, 2004). The concept of health-related quality of life has been continually refined since the 1970s. Early definitions were based on physiologic variables and clinical observations (Bosworth et al., 2004). Over time, emotional health and/or psychosocial variables were added. The Medical Outcomes Study 36-item short form health survey (SF-36) is an example of a health related quality of life measure that evaluates both physical and psychosocial dimensions of health and can be used to assess both disease progression and the result of health care interventions (George & Clipp, 2000).

The third quality of life category is disease specific and utilizes measurement tools, such as the Yale Scale and Minnesota Living with Heart Failure Questionnaire, that display a narrow focus. These tools are disease-specific and multidimensional but still limited to examination of physical symptoms. Certainly, physical wellness is of importance to patients with heart

failure but this singular focus fails to address mental wellness or other psychosocial factors (Bosworth et al., 2004).

Use of a HQOL tool may be useful to measure both physical and psychosocial factors related to perceived health. However, it does not measure those concepts specifically in relation to heart failure. The Left Ventricular Dysfunction Questionnaire (LVD-36) includes both physical and psychosocial factors that are related exclusively to patients with heart failure. It provides a framework for defining aspects of life satisfaction, physical function, emotional fulfillment, social interaction, and perceived health (O'Leary & Jones, 2000); therefore, its use is appropriate for this study.

Quality of Life Studies in Heart Failure Patients

Many demographic variables have been related to quality of life in the heart failure patient. A review of the literature identified multiple demographic variables that are related to heart failure. For the purposes of this study, gender, age, comorbidities, and functional status were selected for examination. Gender considerations have particular significance in the heart failure patient. Women demonstrate different symptomology, have different risk factors, and develop heart failure later in life than men. The percentage of women with a first myocardial infarction who develop heart failure within five years is higher than the percentage of men. After heart failure develops, less than 15% of women will live longer than 12 years (AHA, 2007).

Women demonstrate many of the same symptoms but experience more shortness of breath, difficulty exercising, and ankle edema than men. Women are more likely to develop diastolic heart failure while men are more likely to develop systolic heart failure. Although unusual, women may develop heart failure within the last month of pregnancy or the following five months after birth (Cleveland Clinic, 2007a).

Health related quality of life and sense of coherence were examined in a group of moderate to severe heart failure patients and compared to a healthy control group matched for gender and age. The patient results were significantly lower than the control group in all aspects of quality of life. Within the patient group, it was also discovered that women with heart failure had significantly lower physical function than men (Ekman, Fagerberg, & Lundman, 2002; Rideout & Montemuro, 1986).

A worse quality of life was found to be associated with increased mortality in male participants in the Optimizing Congestive Heart Failure Outpatient Clinic Project (OPTIMAL). Women were found to develop heart failure later in life and have an overall lower mortality rate than men. A higher Left Ventricular Mass Index was found to be a prognosticator of mortality in women, but not men (Mejhert, Kahan, Edner, & Persson, 2008).

A study of 3580 European patients found multiple gender-related differences in patients hospitalized for acute heart failure. Hospitalized women were older, more often retired, and living alone than their male counterparts. Women were found to have different underlying pathologies and comorbidities

than men (Nieminen et al., 2008). Women were found to have more co-morbid psychiatric illness than men with depression and anxiety being most common (Sayers et al., 2007).

Women have not been routinely included in heart failure studies despite the fact that women are responsible for 50% of heart failure hospital admissions (Cleveland Clinic, 2007a). An examination of eighteen heart failure clinical trials was conducted by the Cleveland Clinic. The percentage of women included in the trials ranged from 0-40% (Cleveland Clinic, 2007b).

An analysis of the National Hospital Discharge Survey data from 1979 through 2004 contradicts the Cleveland Clinic findings. Although hospitalization rates increased for both genders, men had higher rates than women when heart failure was the primary reason for admission. When heart failure was a secondary diagnosis, women had a greater percent of change in hospitalization rates than men during the 24 years included in the study (Fang et al., 2008).

Women were included in a German study that investigated gender-related differences in prevalence, cost of hospitalization, and medication prescribing practices. Women were found to have a higher prevalence of heart failure than men. The cost of hospitalization was 17% less for women. Women received more prescriptions than men; yet, average medication costs were 14-26% higher for men and men were treated with different medications (Stock, Stollenwerk, Redaelli, Civello, & Lauterbach, 2008). In contrast to these findings,

a previous study found no differences in medication prescriptions between men and women (Nieminen et al., 2008).

Women have different life and general health perceptions, and different physical and emotional symptoms than men. Hospitalized women reported high levels of symptom impact, poor health status, and diminished quality of life (Bennett, Baker, & Hunter, 1998). Women were found to be more expert than men in heart failure self-care, but they reported their overall quality of life as poor (Riegel, Dickson, Goldberg, & Deatruck, 2007). Fear was found to be a more frequent concern of living with heart failure in women than in men (Costello & Boblin, 2004).

A qualitative study of women living with heart failure found participants to be more concerned about the quality of their daily lives than concerns about the future. Heart failure was found to place limitations on physical and social interactions. Anxiety related to ability to self-care and concern about being a burden on others led to feelings of powerlessness and worthlessness (Martensson, Karlsson, & Fridlund, 1998).

No gender differences were revealed when physical and emotional status, NYHA functional classification, and HQOL were examined as part of a randomized, controlled trial. However, when examined individually, physical symptoms and depression were found to have significance. Women who had more severe physical symptoms and men who were more depressed experienced poorer quality of life (Heo, Moser, & Widener, 2007).

A study examining patients experiencing advanced heart failure revealed gender differences in quality of life across two dimensions: psychosocial perceptions and functional capabilities. Women reported significantly lower (better) vocational adjustment than did men and walked less distance in the 6-minute Walk than did men (Dracup, Walden, Stevenson, & Brecht, 1992).

Hou et al. examined the differences in gender and age with quality of life. Two different scales, the Chronic Heart Failure Questionnaire (CHQ) and the Minnesota Living with Heart Failure Questionnaire (LHFQ) were used. At baseline, women had significantly poorer scores on the dyspnea and emotional subscales, and the total score on the CHQ than men. Women scored significantly worse on the total LHFQ score than men. Women who were less than 65 years of age had the poorest quality of life of all participants. However, these women demonstrated the greatest improvement in QOL over time (2004).

A convenience sample of 103 community dwelling patients with New York Heart Association Class III/IV was studied to determine the impact of symptoms and other factors on quality of life. Decreased quality of life was associated with female gender (Binderman, Homel, Billings, Portenoy, & Tennstedt, 2008).

Gender differences were examined as a secondary analysis of data from the Studies of Left Ventricular Dysfunction (SOLVD) trials. It was found that women had a decreased quality of life overall. Many significant differences in QOL were found between men and women. However, men were found to have a significantly higher illness severity. Because severity of illness can impact QOL,

additional statistical analyses were performed to control for this variable. It was then discovered that only intermediate Activities of Daily Living and social activity demonstrated poorer quality of life scores in women (Riedinger et al., 2001).

A cross-sectional, correlational study of 122 patients attending heart failure clinics was conducted to identify if gender influenced other correlates of self-care. It was discovered that the majority of both men and women did not engage in self-care on a regular basis. Men were found to have greater functional ability than women. Improved self-care in men was related to greater perceived control and heart failure management knowledge and in women was found to be related to higher self-care confidence and poorer functional ability (Heo et al.).

A pilot study examining the role of gender in 90-day rehospitalization rates of HF patients demonstrated that female gender was significantly related to hospital readmissions. Women were readmitted at a rate 2.5 times greater than men. It was also discovered that women were more anemic on admission and demonstrated less physical function (as measured by the 6 Minute Walk Test) than men (Howie-Esquivel & Dracup, 2008).

Some studies examining heart failure failed to reveal gender differences. A longitudinal study of HF patients found that quality of life was significantly impaired during hospitalization, but improved significantly after discharge. There no differences were found between men and women (De Jong, Riegel, Armola, & Moser, 2006). Sleep habits, sleep difficulties, daytime sleepiness, and quality of life were not found to be significantly different between men and women

(Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004). In comparison with women, men were found to have significant impairment in quality of life related to emotional problems, lack of energy, and pain (Hobbs et al., 2002; Yu, Lee, Kwong, Thompson, & Woo, 2008).

In summary, a majority of studies identified gender as a significant variable related to heart failure. Compared to men; women develop heart failure later in life, have different underlying pathological conditions and demonstrate different symptomology. Women exhibit more co-morbid psychiatric illnesses with depression and anxiety being the most common. Socially, women with heart failure are more likely to be retired and live alone. Although hospitalization rates have increased significantly in both men and women, resource utilization is unequal. Once hospitalized; overall cost is less, prescription usage is greater but at less cost, and readmission rates are greater. Although recent attempts have increased inclusion of women in heart failure studies, gender remains an unequally addressed variable with potential findings that influence diagnosis, treatment, and outcomes.

Unlike the findings related to heart failure and gender, studies related to age are less conclusive. Heart failure is a condition found primarily in the elderly. As treatment options improve and the baby boomer generation approaches old age, more people will live long enough to develop heart failure. Understanding the role of age in heart failure quality of life will become increasingly important.

A search of qualitative studies utilizing four databases was initiated to gain insight into older adults' experience living with heart failure. The disease

was found to be distressing and debilitating resulting in impaired physical and psychosocial functioning. Multiple self-care strategies that were required to stabilize disease progression often taxed ability and resulted in feelings of powerless and hopelessness (Yu, Lee, Kwong, Thompson, & Woo, 2008).

Heart failure in older adults has been related to increased number of co-morbid conditions (Deaton et al., 2004). A study of 140 hospitalized patients over the age of 70 years revealed that the presence of cardiac and non-cardiac comorbidities was related to increased incidence of hospital readmissions. An interesting finding in this study was that 53% of first readmissions were identified as possibly or probably preventable (Vinson, Rich, Sperry, Shah, & McNamara, 1990).

A longitudinal study of 5888 older adults found that the risk of heart failure increased by 9% per year for each year following age 65 years. Heart failure was found to be more common in both men and women over the age of 75 years. It was also observed that African-American participants were significantly younger than white participants at initial diagnosis of heart failure (Arnold et al., 2005).

Individuals with poorer self-rated quality of life were significantly more likely to be hospitalized for heart failure in the Studies of Left Ventricular Dysfunction (SOLVD). Interestingly, quality of life in younger individuals (21-44 years) was more predictive of hospitalization than in older adults (45-54 years). However; in participants aged 55 years and older, quality of life was not predictive of hospital admission (Stull, Clough, & Van Dussen, 2001).

Older patients, especially those who have had heart failure for any length of time, experienced higher levels of functional impairment (Moser, Doering, & Chung, 2005). Younger women who received heart transplants (a treatment for heart failure when standard medical interventions no longer work) reported a higher quality of life than older women (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003). Conversely, a study of male veterans with heart failure found that older men reported higher quality of life than younger men. It was also discovered that age was a better indicator of quality of life than physical functioning (Corvera-Tindel, Doering, Roper, & Dracup, 2009).

Plach hypothesized that social role quality and age influenced physical and psychological well-being in women who had heart failure. Regardless of physical health or age, women who had higher social role perceptions exhibited a higher level of psychological health. However, older women reported better health and were less bothered by symptoms of heart failure and other co-morbidities than younger women. Older women had better social relations, higher levels of self-acceptance, and less anxiety and depression than younger women. (2008).

In a study of more than 21,000 hospitalized heart failure elders, a significant minority were found to have at least one co-morbid psychiatric diagnosis. Patients with any psychiatric diagnosis, after adjusting for medical diagnoses, were found to be at significantly greater risk for re-hospitalization (Sayers et al., 2007).

A qualitative study examined the experience of heart failure patients attending a clinic. Thirteen themes were identified. Cross case analysis by age

revealed that the majority of expressed themes applied to all participants. The oldest and youngest participants conveyed a strong need to maintain independence. Adults over the age of 50 years stated most concern about feelings of isolation related to their disease (Costello & Boblin, 2004).

Perceived social support was found to be significantly related to increased age in a population of heart failure clinic patients. The authors postulated that this finding may be related to the caregiver's response to aging patient's increased needs (Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008). Heo et al. found that older age was related to better self-care behaviors in men, but not in women (2008).

In summary; increased age is clearly related to increased risk of heart failure, number of co-morbidities, and functional impairment. However, aging does not always relate to poorer outcomes in heart failure patients especially when psychosocial variables are considered. Interestingly, when age and gender are examined in relation to psychosocial variables, differences are notable.

Differences are also notable when the influence of race and ethnicity is considered. It should be noted that the majority of heart failure studies have been conducted on Caucasian individuals (Yu, Lee, Kwong, Thompson, & Woo, 2007). Heart failure incidence differs for African-American men and women when compared to other ethnic groups. According to Schocken et al., the high incidence of hypertension in non-Hispanic black women represents a unique risk related to the development of heart failure (2008). African American women have higher rates of hospital readmission than Caucasian women and African American men

have higher rates of hospital readmission than any ethnic group (American Heart Association, 2007). A study by Singh, Gordon, and Deswal found that African-American hospitalized patients had less severity of illness and less comorbidity than white patients (2005).

A study of more than 200,000 patients admitted to hospitals for acute decompensated heart failure (ADHF) found that African-American patients were younger than white patients. African-American prevalence rates were higher for hypertension, diabetes mellitus, and obesity compared to white patients. More African American patients were hospitalized than white patients, yet their in-hospital mortality rates were lower (Kamath, Drazner, Wynne, Fonarow, & Yancy, 2008).

Use of Implantable Cardioverter-Defibrillator (ICD) therapy, which reduces mortality in heart failure patients, was examined in a study conducted by the Get-With-the-Guidelines Program. Approximately 13,000 heart failure patients from 217 hospitals were found to be eligible for ICD therapy. Findings revealed that gender (female) and race (African-American) were significantly related to decreased use of ICD therapy (Hernandez et al., 2007).

An eight-year (1991-1998) analysis of discharge data from California hospitals examined rates of hospitalization in four groups – African-American, Asian, Hispanic, and White adults ranging in age from 18 – 64 years. For each of the four chronic and potentially preventable diseases studied, African-American men had higher rates of admission than the other groups. African-American men had disproportionately (19.7 per 10,000) higher rates of admission than Asian

men (3.5 per 10,000), Hispanic men (3.5 per 10,000), and White men (4.8 per 10,000) for heart failure. The same inconsistency was found to be true for African-American women highlighting the disparity between the groups (Davis, Liu, & Gibbons, 2003).

A very large (> 1.7 million participants), geographically diverse (22 states representing all national regions in the United States) population was examined to estimate prevalence rates of six chronic conditions including heart failure. Preventable hospital rates were also studied in relation race (African American, Hispanic, and White) and age (19-64 and 65 and over years). Preventable hospital admission rates were significantly higher in Hispanic men and women of any age and in African American women than White men and women (Laditka & Laditka, 2006).

A secondary analysis of the Comprehensive Discharge Planning Studies for Hospitalized Elders data investigated the role of sociodemographic variables as predictors of post-discharge outcomes. It was discovered that African-American and Asian races were significantly associated with greater use of health care services following discharge to home (Roe-Prior, 2007). In a separate study concerning psychological well-being and social roles, African-American women were found to require emergency care and hospitalization significantly more often than White women (Plach, 2008).

A study of 74 heart failure clinic patients examining the role of social support in self-care found that African-American participants had significantly higher levels of emotional support than white participants. White patients who

were not married but lived with other people had the lowest levels of perceived emotional support even when they lived with significant others (Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008).

A prevalence study found that 10% of the 100 African-American heart failure patients were cognitively impaired. When compared to age adjusted rates of a Caucasian population, cognitive impairment was lower in the African-American population. Age, gender, feelings of depression, and functional class were not significantly related to cognitive impairment. Only increased level of education was found to be significantly related to cognitive impairment (Akomolafe et al., 2005).

Limited studies exist that examine the burden of heart failure in the Asian-American population. A notable problem is the tendency for studies to categorize multiple ethnic groups as Asian. This is particularly true regarding the Pacific Islander populations. Even the prevalence of heart failure in this population is unclear, although studies have identified the high incidence of risk factors that lead to this condition (Kaholokula, Saito, Mau, Latimer, & Seto, 2008).

A qualitative study of 11 patients and 25 caregivers examined the health beliefs, attitudes, and practices; social support; and barriers to heart failure management in Native Hawaiians and Samoans. Negative coping styles, denial and avoidance, as well as positive reliance on spirituality and religion were found to be typical behaviors utilized by this population when dealing heart failure. Emotional distress in the form of hopelessness and despair, distrust of medical practitioners (in the case of Native Hawaiians), and lack of disease-related

information were identified as barriers to heart failure management. Family members provided critical informational and tangible support, but the study revealed that respite care was a significant concern for the caregivers (Kaholokula et al., 2008).

A prospective cohort study of 2,611 community-dwelling Chinese elders aimed to determine if depression found in chronic illness was related to variables including subjective health and functional status. Depression was identified in 22.3% of the heart failure patients and remained independently associated with heart failure after adjustment for co-morbidities, functional capability, subjective health, cognitive function, and other identified variables. The authors postulate that heart failure may have a direct psychobiological relationship to depression that is not related to other confounding variables (Niti, Ng, Kua, Ho, & Tan, 2007).

In summary, research examining the role of race and ethnicity in heart failure is limited. African Americans have been found to have increased risk of heart failure, rates of hospitalization and readmissions, in addition to increased utilization of resources. Even fewer studies have been initiated to examine the unique needs of Asian American and Hispanic American populations.

Certain physiologic variables have been identified in relation to heart failure. Co-morbid conditions, both cardiac and non-cardiac in origin and ranging in number from 1 to > 5, are prevalent in heart failure patients (Akosah, Schaper, Havlick, Barnhart, & Devine, 2002; Deaton et al., 2004; Felker et al., 2004; Rockwell & Riegel, 2001; Schnell-Hoehn, Naimark, & Tate, 2009). The presence

of comorbidities has been linked with disease progression and effective response to treatment (Lang & Mancini, 2007). Increased comorbidities have been correlated with increased hospital readmission rates (Lagoe, Noetscher, & Murphy, 2001; Singh et al., 2005; Vinson et al., 1990). The most commonly found comorbidities in a community population of heart failure patients were diabetes, myocardial infarction, and chronic obstructive pulmonary disease (Walke et al., 2007).

Analysis of the National Hospital Discharge Survey data revealed that although hospitalization rates for heart failure have increased, the greatest percent of increase occurred when heart failure was a secondary rather than primary reason for admission. The findings also suggested that non-cardiac chronic conditions were becoming more common than cardiac conditions in heart failure related hospital admissions (Fang et al., 2008).

The influence of comorbidities in heart failure patients has been linked with increased cognitive deficiencies (Bennett, Sauve, & Shaw, 2005). Patients who have multiple conditions confuse symptoms. They may think shortness of breath is related to aging or a pulmonary condition, rather than to an exacerbation of their heart failure (Moser & Watkins, 2008).

Comorbidities influence patients' ability to maintain and manage self-care. Multiple conditions require multiple treatment plans. Patients are often prescribed numerous medications. Multiple conditions increase problems with polypharmacy (Deaton et al., 2004). In addition, patients are frequently instructed to follow

numerous diet plans with nonadherence often a result (Carlson, Riegel, & Moser, 2001).

Other physiologic variables have been found to be predictive of QOL in HF patients. Physical symptoms such as fatigue, dyspnea, and fluid retention have been identified as negatively related to quality of life (Bosworth et al., 2004; Evangelista et al., 2008; Heo, Moser, & Widener, 2007). Sleep difficulties were significantly related to a negative perception of QOL (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004). Cognitive difficulties have been found to negatively impact quality of life (Bosworth et al., 2004).

Functional status has been found to decrease following the diagnosis of heart failure (Kempen, Sanderman, Miedema, Meyboom-de Jong, & Ormel, 2000). It has been identified as a covariant that influences quality of life. Higher levels of function have been positively related to mental health (Westlake et al., 2002). Worsening function has been correlated with decreased quality of life (Hobbs et al., 2002), depression (Park, Fenster, Suresh, & Bliss, 2006), and decreased social role abilities (Plach, 2008). Decreased functional status was found to be predictive of hospitalization in middle- and older-aged adults (Stull et al., 2001).

Patients with heart failure who had less functional ability were found to perceive their quality of life as poor. Ekman et al. found significantly lower functional ability (measured using the 36-Item Short Form Health Survey) in hospitalized heart failure patients when compared to matched controls (2002).

Eighty patients attending a heart failure clinic were studied to examine the relationship between coping styles and quality of life and depression. The NYHA class system was utilized to measure functional impairment and the Kansas City Cardiomyopathy Questionnaire (KCCQ) to measure quality of life. All quality of life components of the KCCQ were significantly and negatively related to functional status (Klein, Turvey, & Pies, 2007). In addition, reduced physical function limits patients' ability to engage in self-care activities (Moser & Watkins, 2008).

A study of 134 heart failure patients examined the relationships between physical function, symptom status, and psychosocial adjustment as components of quality of life. Functional status as measured by the Heart Failure Functional Status Inventory and Six-minute walk was significantly correlated with the New York Heart Association (NYHA) class; better function was related to lower NYHA classes. In addition, functional status was significantly correlated with psychosocial function (Dracup, Walden, Stevenson, & Brecht, 1992).

Fourteen outpatient centers collected information regarding the relationship between quality of life and functional status in younger and older heart failure patients. Despite worse functional status, older patients had significantly better quality of life than younger patients. It was discovered that as older patients' functional status declined quality of life declined. In contrast, younger adults who experienced functional decline had no deterioration in their quality of life (Masoudi et al., 2004).

A European study compared 205 heart failure patients with the general population to examine the extent of functional impairment using the NYHA functional class definitions. Not surprisingly, heart failure patients had an overall reduction in quality of life. However, it was discovered that patients classified as NYHA Class I (who were asymptomatic but had left ventricular dysfunction) had significant decreases in physical function and fatigue. It was also revealed that patients characterized as NYHA Class III had a quality of life that was comparable to patients with major depression (Juenger et al., 2002).

Physical symptoms are burdensomely present in the daily lives of heart failure patients. Heo, Doering, Widener, & Moser implemented a longitudinal study to determine the effect of physical symptom status on quality of life. Improved quality of life was demonstrated in patients who were older, worked, were less anxious, and had fewer physical symptoms (2008).

Greater symptom impact levels were found to be inversely correlated with quality of life (Bennett, Baker, & Hunter, 1998). Perception of poor general health and decreased ability to perform activities of daily living were related to more frequent hospitalizations (Konstam et al., 1996). Quality of life was found to decrease as severity of heart failure increased (Hobbs et al., 2002). A longitudinal study examining symptoms prevalence revealed that shortness of breath, fatigue, pain, and feelings of depression increased significantly over time. Interestingly, the remaining symptom burden was as high at the beginning of the study as it was found to be two years later (Walke et al., 2007).

More recent inclusion of psychosocial variables in heart failure research has identified the influence of these variables on QOL. A cross sectional qualitative study identified role loss, both work-related and social; affective factors; and coping mechanisms as essential characteristics in relation to quality of life (Bosworth et al., 2004).

A secondary data analysis of the Studies of Left Ventricular Dysfunction (SOLVD) examined predictors of hospitalizations for 3, 884 patients with heart failure. Individuals who had poorer health-related and psychosocial quality of life were found to have significantly greater risk of hospitalization during the clinical trial and the three years following completion of the study (Stull, Clough, & Van Dussen, 2001).

Ability to cope with the unpleasantness of heart failure was examined in a population of 60 patients attending a heart failure clinic. Coping ability was positively related to quality of life while social identification with other heart failure patients who were doing worse was negatively related to quality of life. In addition, lack of health-related information was found to be negatively related to coping ability (Jansen et al., 2003).

Klein et al. also examined the influence of coping mechanisms on depression and quality of life. It was discovered that maladaptive coping methods were related to lower quality of life and increased symptoms of depression. However, it was also discovered that patients were more likely to utilize adaptive coping strategies when dealing with heart failure (2007).

Sense of Coherence (SOC), which is defined as a response to stressful situations, is based on the individual's historical, social, and cultural experiences. Ability to manage or cope with the stressful situation will determine process and outcomes. The relationship between sense of coherence and quality of life was tested with 94 HF patient and control groups. The patient group had a significantly lower QOL than the control group. A significant positive correlation was noted between the sense of coherence and quality of life (Ekman et al., 2002).

A study by Gustavsson and Branholm noted that participants who reported higher life satisfaction also reported a stronger sense of coherence, more coping resources, and less symptoms of heart failure (2003). However, this article relied primarily on narrative description of the results with minimal statistical information to support the findings. The results should be interpreted with caution.

Depressive symptoms have been related to heart failure patients' QOL in many studies. A meta-analysis of the relationship between depression and heart failure found that clinically significant depression was present in 21% of the aggregated populations and more common in women, Caucasians, and individuals with less functional ability. Depressed patients utilized more health care resources and were found to have higher mortality rates than non-depressed patients (Rutledge, Reis, Linke, Greenberg, & Mills, 2006).

Depression was the most significant variable related to poor quality of life in a study of 134 advanced heart failure patients (Dracup et al., 1992). Fifty-eight participants in a heart failure clinic completed a quality of life diary for two weeks

in addition to Beck's Depression Inventory. Diminished emotional quality of life and increased incidence of daily negative mood were significantly associated with depression (Carels, 2003). Emotional functioning (especially the presence of depression) was found to be more significantly related to quality of life than physical functioning in a study of 76 men with heart failure (Corvera-Tindel et al., 2009).

Identifying predictors of depression in patients with heart failure was the goal of a study by Havranek et al. (2007). Study participants were enrolled in the Kansas City Cardiomyopathy Questionnaire (KCCQ) Interpretability Study. 245 patients who were free of depressive symptoms at baseline were contacted one year later. At follow up, 21.2% had developed significant depressive symptoms that were related to living alone, medical care providing a financial burden, and history of alcohol abuse. Overall QOL was found to be significantly worse in patients who developed depression. The incidence of depression "approximately doubled with each additional risk factor" (Havranek et al., p. 2335).

A descriptive, correlational study design was used to examine depression and coping strategies in 75 heart failure patients who attended a heart failure program. Participants in the study experienced mild to moderate depression (53%) and 43% of the participants were taking antidepressant medications. Patients who used problem-solving and social support-seeking coping strategies were significantly less depressed (Vollman, LaMontagne, & Hepworth, 2007).

An experimental study was undertaken to evaluate exercise self-efficacy in older women with heart failure. Women were randomly assigned to either a

walking program intervention or to an education-only control group. Women in the intervention group demonstrated significant improvement in self-efficacy, depression levels, and quality of life. There were no significant changes in the control group (Gary, 2006).

In contrast to most findings, a descriptive pilot study involving 30 women diagnosed with heart failure found that emotional symptoms (worry, depression, believing one self to be a burden) were not related to quality of life. The authors postulated that recent discharge from an acute care setting may have improved the participants' health and therefore improved their emotional health (Bennett et al., 1998). It may be that the sample size (small) and diversity (primarily white) influenced the results. Other factors such as co-morbidities, age, and socioeconomic status were not controlled and may have influenced the results.

In summary, quality of life has been accepted as an outcome measure for patients with heart failure. Many existing studies examine the relationship between demographic and physiologic variable and QOL. A gap exists in the literature involving the etiology, symptomology, and risk factors related to women with heart failure. Studies analyzing the role of age are inconclusive as are studies related to race and ethnicity. Multiple physiologic variables have been studied and found to be predictive of quality of life. Recent inclusion of psychosocial variables in heart failure studies has improved particularly related to the role of depression. However, the psychosocial variables of hope, social support, and self-care have only limited attention in heart failure studies.

Hope

Heart failure is an increasingly prevalent, chronic condition. Of particular concern is the fact that heart failure is the most frequent diagnosis responsible for hospital admission and readmission. Research exists focusing on physiological variables related to heart failure. Psychosocial factors have been less delineated in this regard. A significant gap has been identified in the literature concerning the role of hope in heart failure patients (Davidson, Dracup, Phillips, Daley, & Padilla, 2007).

Although the chronic illness trajectory can be slowed, it cannot be halted. This downward course results in on-going patient adaptation to physical and psychosocial changes. Once patients have assessed their situations, they identify adaptive tasks that may be biological, psychological, or sociocultural that will help them adjust to changes in their health status. Hope has been identified as a critical adaptive task for dealing with an uncertain future. The individual hopes for restoration of health, but if that is not possible, at least hopes for acceptance of limitations. In the face of impending death, the individual hopes for comfort and peace (Craig & Edwards, 1983).

According to Farran, Herth, and Popovich, hope has been identified to be comprised of 4 central attributes. Hope is an Experiential Process (pain) that results when individuals are faced with situations that are extremely challenging and life altering. A Spiritual or Transcendent Process (soul) explains the second attribute. Many philosophers believe that faith and hope are based on spirituality. The individuals who have hope believe in themselves and others and are able to

transcend difficult situations. As a Rational Thought Process (mind), hope facilitates realistic goal setting, identification of internal and external resources, a sense of control over the outcome, and a sense of time – past, present, and future. Hope is influenced by the presence of others: a Relational Process (heart) that provides support during difficult times (1995).

A meta-analysis of the nursing literature examined the ontologic (the nature of reality) and epistemologic (relationship between the researcher and the participants) nature of hope. Hope was defined in positive terms, yet often lacked clarity of meaning. Many studies defined hope as future-oriented, realistic, and necessary for life. Hope was perceived to be a dynamic process that involves emotional, physical, cognitive, social, and spiritual activities. The majority of studies was descriptive, cross-sectional, and included individuals who were sick (Kylma & Vehvilainen-Julkunen, 1997).

Data obtained from a qualitative study including patients awaiting a heart transplant, spinal cord injured patients, breast cancer survivors, and breast feeding mothers who worked were used to conceptualize hope. Seven components were identified including: a realistic assessment of the situation, goal setting, recognition of negative outcomes, assessment of internal and external resources, existence of supportive relationships, signs that reinforce the goals, and a determination to endure. Although the experiences of the patients were different, the seven components were evidenced in their representation of hope (Morse & Doberneck, 1995).

Three concepts: enduring, suffering, and hope were analyzed by Morse and Penrod for the interrelatedness of their meanings. Hope was identified as the dominant concept, but due to the cyclical nature of the anticipated relationships was not examined in any greater depth than enduring or suffering. Each of the concepts was equated to a *level of knowing*. Enduring occurs when the level of knowing – *awareness* – permits the individual to begin to perceive the reality of a situation. Enduring allows the individual to focus on the present state and avoid the distress of the circumstances. Over time, the situation becomes more real and *recognition* occurs facilitating tentative goal setting (1999).

Suffering commences when the individual *acknowledges* the reality of the event and loses the ability to plan for the goal. This process results in overwhelming emotional pain and despair. When the individual is able to move beyond acknowledgement and enters the *acceptance* phase, it is possible to achieve hope. At this point, the individual is able to define realistic goals and consider all possibilities (Morse & Penrod, 1999).

Spirituality and anxiety were two mediating variables that were studied in relation to their influence on hope and well-being in a convenience sample of 130 well seniors. As expected, a statistically significant relationship was identified between hope and well-being and hope and spirituality. This finding supported theories that link hope, well-being, and spirituality. However, when anxiety was controlled for statistically, the relationship between hope and well-being remained significant; therefore, anxiety was not a mediator. Likewise, spirituality was not found to be a mediator between hope and well-being (Davis, 2005).

Hope and hopelessness are often examined together due to their dialectical (one idea generates the opposite idea) relationship. Hopelessness is a construct that is identified as approaching the opposite end of the hope/despair continuum. It has been recognized as a nursing diagnosis by the North American Nursing Diagnosis Association (NANDA List, 2008). According to Johnson, Dahlen, and Roberts; people who are hopeless feel that achievement of a goal is impossible. They are not future oriented, often feel abandoned and isolated, and are unable to act during a crisis (1997).

The National Health Examination Follow-up Study, a longitudinal study of adults in the United States, provided the data for a study that examined the role of depression and hopelessness on the incidence of ischemic heart disease. It was discovered that 13.7% of the participants reported moderate to severe hopelessness and black individuals reported the highest level of hopelessness. After adjusting for numerous demographic and physiological variables, the incidence of fatal and non-fatal ischemic heart disease was significantly higher in people who reported moderate or severe hopelessness (Anda et al., 1993).

A cross sectional, longitudinal study using triangulation methodology examined the meaning of hope in thirty terminally ill people. Hope was defined as an inner power that enables the individual to look past the present situation and see the future through new awareness. Hope fostering behaviors included: connection to others, sense of direction, spiritual beliefs and practices, positive personality traits, sense of humor, positive memories, and a sense of individual worth. Hope hindering strategies included: physical or emotional distance from

others, uncontrollable pain despite interventions, and decreased sense of personal worth (Herth, 1990).

Twenty five family caregivers of hospice patients were interviewed to investigate the meaning of hope. Hope fostering behaviors were similar to those found in Herth's study of terminally ill people. The ability to recognize and redefine achievable goals and assistance maintaining physical and psychological energy were unique hope fostering strategies for this group. Hope hindering strategies included physical, emotional, or spiritual isolation in addition to losses that occur simultaneously with caregiving and symptom mismanagement (Herth, 1993).

Herth again used triangulation methodology to increase understanding of hope in sixty older adults. The resulting definition of hope included inner purpose, ability to transcend the current problem, and strength to influence future direction. Participants described seven categories of hope fostering behaviors: interconnectedness with others, useful activities, positive memories, positive thinking, inanimate objects that have positive meaning, measuring time in terms of activities with others, sense of humor, and spiritual beliefs. Place of residence (long term care) and energy level (low) was significantly related to a lower level of hope (1993).

A study to investigate the meaning of hope in homeless adults by Herth resulted in findings that were similar to previous studies by the author. A hope fostering behavior not seen in previous studies included living in the moment as a method of sparking hope. Hope hindering strategies were similar to those found in

previous studies. An interesting finding was the significance of nurse-provided health care and level of hope (1996).

A quasi-experimental study randomly assigned 98 outpatients with recurrent cancer into three groups. The Hope Process Framework was used to design an 8 week hope intervention for the experimental group with the purpose of increasing quality of life. The second group was an attention control group attending informational sessions only and the third group (control group) received regular care and follow up. Data was collected before and after the intervention and then at 3, 6, and 9 months. Feelings of hope and quality of life were greater in the hope group following the intervention and remained greater over time (Herth, 2000).

Another quasi-experimental study randomly assigned 40 homeless veterans to either a 4 week hope intervention group or a control group where routine care was received. Hope was found to be significantly greater in the treatment group following the intervention. Within the experimental group, there were significant increases in hope, self-efficacy, self-esteem, and a significant decrease in depression (Tollett & Thomas, 1995).

In summary, the four central attributes of hope captured in the Hope Process Framework (Farran et al., 1995; Farran, Wilken, & Popovich, 1990) provide a foundation for descriptive and correlational hope studies. Hope as described by multiple authors is defined as an inner power to transcend obstacles based on internal characteristics and external support. Studies examining chronic illnesses, particularly cancer, dominate the literature.

Hope Studies in Heart Failure Patients

Limited quantitative and qualitative studies examine the role of hope in heart failure patients. Much of the heart failure research focused on hopelessness rather than hope. Yet, the authors of a qualitative study exploring the heart failure experience found that even dying patients still had hope (Costello & Boblin, 2004).

A recent review of the literature was performed to explore the role of hope in heart failure. Twenty four articles met the inclusion criteria. The majority of the studies were observational and descriptive; according to the authors no interventional studies were found. Hope and hopelessness were observed to be “underdeveloped yet important constructs” that need to be enriched (Davidson, Dracup, Phillips, Daley, & Padilla, 2007, p.159).

Heart transplantation is a possible option for heart failure patients when conventional medical treatments are no longer successful. A study of 50 female heart transplant recipients examined the role of hope in their quality of life. Depression, anxiety, and hostility were inversely related to hope. Quality of life was measured using the SF-12 which contained both physical and mental health components. The mental health component was found to be positively associated with hope, while the physical health component was not associated with hope (Evangelista et al., 2003).

In a descriptive study of 23 patients with chronic heart failure, hope was significantly correlated with morale and social function. It had been hypothesized that hope scores would be positively correlated with physical function. However,

it was discovered that neither hope, morale, nor social function were associated with physical function. It was felt that this finding supported the belief that the presence of hope is not dependent on impaired function (Rideout & Montemuro, 1986).

In an effort to describe hope in the hospitalized patient, a group of 93 patients with heart failure was compared with a group of 441 healthy control subjects. The study examined the effect of demographic, physiologic, and life satisfaction on hope. Hope was measured using the Herth Hope Index. A surprising finding was the difference in hope scores with heart failure patients reporting significantly higher global hope scores. Hope was also found to be significantly correlated with the number of co-morbid conditions, satisfaction with life, and self-assessed health (Rustoen, Howie, Eidsmo, & Moum, 2005). However; life satisfaction and self-assessed health were each evaluated using a single author designed question with no evidence of reliability or validity.

A sample of 87 patients attending outpatient heart failure clinics was interviewed regarding spirituality. Three processes were identified: regret for past lifestyle practices that led to heart failure, identification of a meaningful and purposeful life within the heart failure context, and a search for hope for the future. Patients identified spiritual beliefs as the primary mechanism for bolstering hope. In addition, faith in medical treatment and family and friends were important sources of hope (Westlake & Dracup, 2001).

In summary, Hope has been identified as an important coping strategy during critical life experiences. This concept had been studied in relation to

chronic illnesses such as cancer (Herth, 2000; Herth, 2001) and HIV infection (Herth, 1990), and other populations such as caregivers (Herth, 1993) and homeless families (Herth, 1996). Interventions that foster hope have been shown to improve disease management and patient outcomes (Herth, 2000; Tollett & Thomas, 1995). However, there exists very little information related to hope and quality of life in heart failure patients. This study will attempt to fill a gap in the heart failure and nursing literature by describing the relationship between hope and quality of life.

Social Support

Clinical observation of heart failure patients reveals that individuals who have similar physical disease indicators often have very different outcomes. Often, the role of spouses, family members, and friends appears to influence patient health-related quality of life. The role of social support in patient outcomes has been increasingly examined in the literature since the mid-1970s (Hupcey, 1998).

Different frameworks have been articulated to define the complex concept of social support. Early development in the 1970s provided a concrete, simplistic definition of social support that was comprised of interactions, persons, and relationships. More recent concepts are increasingly abstract and multidimensional (Frank-Stromberg & Olsen, 2004; Hupcey, 1998). However, the concept of social support has been critiqued as “fuzzy” and conceptually confusing (Hupcey, 1998, p. 1231) and persistently vague (Coyne & Bolger,

1990). A review of the literature that included prospective studies examining heart failure mortality related to depression, anxiety, and social support described the difficulty operationalizing social support (Pelle, Gidron, Szabo, & Denollet, 2008).

In an effort to explore the definitions, concepts, and models of social support; Hupcey reviewed theoretical and empirical literature from the mid-1970s through 1996. Social support could be divided into five major categories: type of support, recipient's perception of support, provider's behaviors, exchange of support between recipient and provider, and support networks (1998).

Cohen (1988) described three models that linked social support with illness. The Generic Model examines the influence of social support on behavioral practices (such as smoking) and biological processes (such as neuroendocrine response) on disease. The second model, Stress-Centered Model, is comprised of two components. The stress-buffering model suggests that social support influences well-being only when an individual is faced with a stressor. The main-effect model on the other hand, explains the positive effect of social support when the individual is not stressed. Finally, the Psychosocial Process Model is an examination of very specific psychological and biological factors that are hypothesized in the generic model.

Cohen notes that much of the work regarding the effect of social support has been interpolated from secondary data analysis of studies that were not designed to examine social support. It is recommended that future studies should select measures that are specific for testing the concept of social support (1988).

Based on Cohen's recommendations, Sherbourne and Stewart developed a tool, the Medical Outcomes Study – Social Support Survey, that focused on the measurement of perceived availability of functional support. After reviewing available support measurement tools, the authors felt the individual's perceptions of support were more important than other measurements of support. They believed that the absence of received support does not indicate lack of support; therefore, perception was a critical component of support (1991).

Hupcey found that the majority of studies related to social support remained simplistic and addressed type of support and network characteristics from the viewpoint of the recipient. Lacking were studies regarding the perceptions of the provider of support or the interaction between the two. How do the providers perceive the recipient's need? Are the two views congruent? What other variables influence how the provider assesses the recipient's needs? Do the individuals involved perceive and provide/receive support in the same manner? What motivates the provider of support? Although support is usually described as positive, there may be negative connotations that require examination (1998).

According to Lett et al. (2005), there was increasing consensus that social support falls within two broad domains: structure (network) and function (instrumental, financial, informational, appraisal, and emotional). Structural support refers to the organization of social relationships. It includes the type, whether peripheral or central to the individual, and frequency of interactions. Social characteristics such as marital status, membership in a religious organization, and geographic proximity are included. Functional support defines

the type of provided social support ranging from providing information, hands-on assistance, and helping assess a situation to emotional support and caring.

However, the author notes limitations to this construct. Merely describing relationships does not take into account the supportive nature of those relationships. It is possible to be in a marital relationship with a non-supportive partner for example. In addition, it is much more common to describe perceived social support than what is actually received. Instruments rarely measure actual received support; rather, they measure satisfaction with support received (Lett et al., 2005).

Cantor (1979) utilized a hierarchical model to describe how older adults select their social support. A survey of 1552 inner-city adults over the age of 60 years revealed that first children and then other kin were the preferred providers of support. After kin, close friends were most likely to be identified to provide support. Lastly, older adults turned to neighbors for assistance.

Harrison, Neufeld, and Kushner also found that women prefer to receive support from family members. The women described support as the availability of someone to talk to who would listen but allow them to make their own decisions. Barriers to use of support included belief that they were a burden on others, lack of ability to return the support, and reluctance to seek support (1995).

In summary, definitions of social support are varied addressing different forms of support. Despite the lack of consistent definitions, social support is related to physical and psychosocial well being. It is also one of the four dimensions identified in the Hope Process Framework.

Social Support in Heart Failure Patients

Physical limitations resulting from heart failure often necessitate requests for social support in order to meet patients' daily living needs. A complex regimen of multiple medications, dietary control, daily assessment of symptom status, and activity considerations makes independent health care management challenging at best. Additionally, most heart failure patients are elderly and often reliant on caregivers who are themselves elderly.

A review of the literature by Richardson noted that psychosocial issues including depression and social support fail to be addressed in the care of heart failure patients. Studies do suggest that these factors are interrelated; depression is correlated negatively with social support and lack of social support is related to increased depression. These findings have been linked to adverse outcomes and increased biologic responses that contribute to worsening disease (2003).

In a study conducted by Murberg, it was hypothesized that the patient's social network may be related to heart failure prognosis. Perceived social support was defined as intimate network support (spouse), primary network support (close family and friends), or secondary network support (relatives and neighbors). Social isolation was also assessed. None of the social support networks were related to mortality. Only social isolation was found to predict mortality (2004). However, findings should be interpreted with caution because the measurement tools were author-designed and lacked validity and reliability.

Physical limitations often reduce social activity for patients with heart failure. Murberg, Bru, Aarsland, & Svebak (1998) examined the effect of social

disability, personality factors such as neuroticism (negative, inward outlook on life) and extraversion (positive, outward outlook on life), and clinical variables on depression. A convenience sample of individuals from outpatient practices was utilized. The authors designed tools to assess social network support and social disability. Again, lack of validity and reliability data limits interpretation of this study. However, the authors found that neuroticism was positively associated with social disability and that extraversion was negatively associated with social disability. In addition, severity of disease and depression were significantly associated with social disability. No relationship was found between social support and social disability. The study also found that the primary social network, spouses and close family members, provided most social support for this population.

Bennett et al. (2001) described social support and examined it in relation to quality of life in a sample of heart failure patients during hospitalization and at twelve months. Overall, the patients reported moderate-to-high levels of perceived social support; however, patients perceived their quality of life to be low-to-moderate. In gender and age specific analyses, no significant relationships were found. It was discovered that baseline social support was not a predictor of health-related quality of life at 12 months. However, at 12 months it was discovered that increased social support did predict increased health-related quality of life.

Participants attending an outpatient general medicine clinic were recruited to collect data about perceptions of quality of life. Five major themes emerged:

symptoms, role loss, affective response, coping, and social support. Participants observed both positive and negative support related to their disease. Positive social support, including validation from other study participants, helped decrease the stress of illness. Family and friends who did not understand the multiple problems related to the disease often had unrealistic expectations and added stress (Bosworth et al., 2004).

A study of Thai heart failure patients found that social support was negatively correlated with quality of life. This finding is in conflict with most of the social support literature. The authors postulate that Thai patients' concern with becoming a burden may be a cultural factor that influenced the results (Krethong, Jirapaet, Jitpanya, & Sloan, 2008).

Park, Fenster, Suresh, and Bliss expanded on a previous study to determine if social support and coping were related to depression. A sample of 163 community-dwelling heart failure patients was included. Patients were surveyed at baseline and again in six months. It was identified that having less depressive symptomology at Time 1 and more social support at Time 2 were predictive of less depression at Time 2 (2006). Findings were limited by the fact that the sample was composed primarily of men.

Qualitative information was gathered from a clinical trial that examined the role of advanced practice nurses in transitional care of elderly heart failure patients. Findings included identification of three major factors for hospital readmissions: medication supply, dietary nonadherence, and poor health behaviors such as smoking. Preventive factors for rehospitalization included

social support (family and friends) and individual motivation (Happ, Naylor, & Roe-Prior, 1997).

Coyne et al. studied marital relationships (a form of social support) in heart failure patients over four years. The relationships among marital quality, functional class, and survival rates were examined. It was discovered that marital quality and functional class were statistically significant predictors of survival, especially in women (2001).

A cardiac rehabilitation program designed specifically for women revealed no statistically significant changes post-intervention. Quantitative data related to depression, anxiety, stress, and social support at baseline was the same at completion of the program. Qualitative data however revealed a different result. Women felt that participation in the cardiac rehabilitation program facilitated social support because the participants were able to understand them in a way that was not possible with spouses, families, or friends (Davidson et al., 2008).

A mixed methods study was conducted to examine the differences between heart failure patients and caregivers regarding perceived social support. Women in either patient or caregiver roles identified children, siblings, and friends as the preferred social support providers. Men chose their spouses for support. Caregivers perceived significantly higher levels of support than patients (Meagher-Stewart & Hart, 2002).

A study of 74 heart failure clinic patients examined the effect of social support on self-care. It was discovered that spouses were significantly more involved in providing medical care than other types of friends and relatives. In

contrast, self-confidence in ability to manage care was positively associated with friends, but negatively associated with spouses. Emotional support from any provider was found to be significantly associated with self-care (Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008).

In contrast to the majority of studies, Linden found no definite conclusion supporting relationships among depression, anxiety, coping style, and social support in heart failure patients. In a review of the literature from 1965-2000, only 12 studies could be identified to meet the inclusion criteria. The author felt that there was a lack of evidence-based research to support the role of social support in heart failure patient outcomes (2002). A constricted examination of the social support literature limits the findings in this review.

Bennett, Pressler, Hayes, Firestine, and Huster compared social support in two groups of patients with heart failure. Following baseline data collection, psychosocial variables were compared between patients who were and were not admitted to the hospital within a six month period of time. Social support and coping were not found to influence hospitalization (1997).

Data from the Studies of Left Ventricular Dysfunction (SOLVD) trials were used to examine the effects of social support on perceived health. Higher social support was associated with lower levels of perceived health. However, social support was found to be positively related to physical function, as measured by the 6-Minute Walk Test, and family income (Rosen, Contrada, Gorkin, & Kostis, 1997).

An experimental design was utilized to determine if peer support would decrease social isolation, improve self-care, and decrease rehospitalizations in adults with heart failure. Mentors who were diagnosed with heart failure received training related to the disease process, self-care techniques, and how to support patients with heart failure. Following a 3 month intervention, self-care was significantly improved. However, there were no significant differences in heart failure readmissions, length of stay, or cost. Surprisingly, the intervention group had a decrease in perceived social support reciprocity that was not found in the control group (Riegel & Carlson, 2004).

In summary, most studies support the relationship between social support and positive outcomes for heart failure patients. However, studies exist that fail to demonstrate a relationship between social support and other physical and emotional variables. Lack of a consistent definition and method of measuring social support presents a barrier to easy comparison among the studies.

In addition, social support involves a complex, fluid relationship between provider and recipient. It can be beneficial to one or both parties, or it may have negative outcomes. This is particularly important when considering heart failure, a chronic illness that will require major lifestyle changes. The nature of the provider-recipient relationship prior to illness would seem to be important to the availability of social support. In addition, the stress of long term illness places a heavy burden on the provider of social support. In the short term, meeting recipient needs without regard to the provider may benefit the recipient. But from a long term perspective, the provider may not have the emotional or physical

resources to continue meeting the recipient's needs. Ignoring the perceptions of the caregiver impacts both provider and recipient.

Self-Care

The prevalence of chronic illness, increased consumer awareness, and decreased resources has influenced health seeking behaviors. Since the 1960s, health care providers have been incorporating self-care concepts into patient care (Frank-Stromberg & Olsen, 2004) and consumers are assuming increasing responsibility for their health care. This is particularly true in the heart failure population.

In general terms, self-care can be described as the process individuals use to maintain health and manage illness. The definition of self-care depends on the viewpoint of the promoter. Within the health care arena, some practitioners advocate for minimal reliance on the system, while others support the opposite. Within these frameworks, similarities exist including the role of knowledgeable and skillful performance of behaviors that affect health. The major disagreement relates to the level of care performed without input from health care providers (Frank-Stromberg & Olsen, 2004).

Dorothea Orem developed a theory of nursing that was based on the concept of self-care. Self-care practices focused on the maintenance of life, health, and well-being and may be provided by self or others. Nursing focus was on providing support when individuals were unable to meet their own care needs (Meleis, 2005).

Orem defined three categories of self-care: universal, developmental, and health-deviation. Universal self-care included basic requirements for life and health including the need for air, water, food, safety, and social interaction. Developmental self-care was related to human growth and development. Health-deviation self-care focused on observation, interpretation, and action related to pathologic conditions (Meleis, 2005). The majority of nursing research related to self-care focuses on the health-deviation concept (Frank-Stromberg & Olsen, 2004).

Self-care is defined by Riegel et al. as a naturalistic decision making process (2004). Naturalistic decision making (NDM) was a framework introduced in 1989 to address decision making in real world contexts. The four essential characteristics of NDM include: focus on the cognitive processes of effective decision makers rather than outcomes, decisions are made by matching choices and informal reasoning, decisions are influenced by context and experience, and decisions are based on the information available at the time and not what is optimal but not available. Naturalistic decision makers utilize expertise to examine a situation and consider options when making decisions (Lipshitz, Klein, Orasanu, & Salas, 2001).

Riegel et al. designed a 5-stage self-care model utilizing NDM for heart failure patient decision making. Underlying assumptions of the model include self-maintenance, self-management, and self-confidence. Self-maintenance requires heart failure patients to monitor symptoms and adhere to treatment plans. Self-management necessitates rapid problem-solving abilities when changes in

condition occur. Self-confidence follows successful self-maintenance and management and is related to successful self-care (2004).

Self-Care Studies in Heart Failure Patients

Developing effective self-care skills is critical for the heart failure patient. Patients must be able to monitor the signs and symptoms related to the status of their heart failure on a daily basis. They must adhere to a complex medication, diet, and activity regimen. If symptoms occur, the patient must be able to quickly recognize the problem and implement appropriate interventions.

Psychosocial factors influence ability to execute self-care. An update on heart failure management identified health literacy, depression, social support, and caregiver burden as factors that decrease treatment adherence (Jurgens, Dumas, & Messina, 2007). A study of 65 ambulatory heart failure patients found that ethnicity (European versus aboriginal) and comorbidity (3 – 4 conditions) was correlated with higher self-care maintenance scores. Participants with high levels of anxiety and depression practiced significantly less health maintenance behaviors. Although not statistically significant, trends approaching significance were found in social support: participants with a spouse had higher self-care maintenance scores ($p = .056$) and participants with fewer social limitations had higher self-confidence scores ($p = .052$) (Schnell-Hoehn et al., 2009).

A population of 209 hospitalized heart failure patients participated in a correlational study to determine if severity of symptoms, comorbidity, social support, level of education, age, socioeconomic level, and gender are predictors of

self-care. Higher levels of education and severity of illness were significantly related to higher levels of self-care (Rockwell & Riegel, 2001). Social support was not found to be significant, but this finding is limited by the fact that social support was measured as a mathematical summation of 3 questions rather than utilizing a valid and reliable tool.

Education and support as well as barriers to self-care were examined in a population of 128 hospitalized patients who were randomly assigned to either a usual care or intervention group. The Heart Failure Self-Care Behavior Scale (developed for the purpose of the study) was administered at baseline, 1, 3, and 9 months following discharge. Patients who did not follow prescribed care guidelines were asked to explain why. At one month following discharge, both groups demonstrated significantly improved self-care scores. The patients in the intervention group displayed significantly more self-care behaviors. Although both groups decreased self-care behaviors at 3 and 9 months, patients in the intervention group demonstrated significantly more self-care behaviors at 3 months (Jaarsma, Abu-Saad, Dracup, & Halfens, 2000). Limitations of the study included low survey completion rate due to patient fatigue and lack of reliability and validity testing for the self-care measure.

Individuals with heart failure were trained to provide peer support to other heart failure patients in an experimental study by Riegel and Carlson (2004). The purpose of the study was to determine if peer support decreased hospital readmissions and social isolation, and improved self-care. At 3 months, the only

significant finding was that self-care was positively influenced in the intervention group.

A mixed methods design was used to examine evidence of self-care expertise in order to understand how expertise develops. A purposive sample identified patients who were considered by heart failure clinic staff to be outliers (very good or very poor) in self-care. Patients who were poor in self-care were found to have impaired memory, attention, and cognition; excessive daytime sleepiness; depression; and impaired family functioning. Good self-care providers were differentiated from experts by increased levels of daytime sleepiness and less family support (Riegel et al., 2007).

A convenience sample of 32 women with heart failure described self-care behaviors and the demographic and clinical characteristics that influenced self-care activities. A majority of the women did not regularly perform activities necessary for effective self-care. An exception was adherence with medication routines. Self-care decision making was related to daily plans and social activities rather than appropriate symptom monitoring or disease management. Lower socioeconomic status and older age were found to be related to poor self-care practices (Gary, 2006).

In summary, Self-care is described as activities undertaken to promote health and prevent illness. In regard to the heart failure patient, self-care refers to health maintenance (the ability to comply with treatment regimens and monitor symptoms) and health management (the ability to recognize changes in condition

and implement appropriate interventions). Studies have shown that poor self-care has been related to poor outcomes in heart failure patients.

Review of the literature reveals that heart failure patient outcomes have relied primarily on physiologic variables to measure success. Psychosocial variables have recently been identified as relevant for study. However, these variables are likely to be examined in relation to disease progression rather than quality of life. Although a growing interest in the role of psychosocial variables exists, there is a lack of empirical data in the examination of the roles of hope, social support, and self-care as they relate to quality of life. Preliminary studies support the relationship between quality of life and the identified variables. It is important to continue to examine these relationships so that meaningful treatment interventions for improved quality of life in heart failure patients can be designed.

Chapter III

Methods

Overview

Heart failure is a significant, chronic health problem. Much is known about physiological factors related to this condition. Less is known about the psychosocial aspects that influence disease risk, progression, and treatment. This is especially true when the relationships between hope, social support, self-care, and quality of life are examined. The purpose of this study was to examine the relationships between hope, social support, self-care, and quality of life in heart failure patients. In this chapter, the research design, sample and sample characteristics, procedures for data collection, measurement, as well as data analysis techniques are described. The protection of human subjects is also discussed.

Research Design

A descriptive, correlational design was used to examine the relationships between hope, social support, self-care, and quality of life in heart failure patients. A descriptive correlational design is a study conducted in a natural setting without any attempt to modify or control the environment (Kerlinger, 1986). Descriptive designs are employed when the researcher wishes to obtain information in areas in which little previous investigation has occurred. Limited studies exist that

examine the role of psychosocial factors and outcomes in heart failure patients; no studies were found that expressly looked at the relationships between hope, social support, self-care, and quality of life in heart failure patients.

Sample

A convenience sample of participants was recruited from a cohort of patients attending military-based heart failure clinics located in Southern California. Participants were members of the armed services or family members who qualified for health care at these centers. Inclusion criteria: Patients were clinically stable and able to speak and read English. The investigator relied on the Registered Nurse (RN) or Pharmacist to determine if the patient had the cognitive ability to participate. Exclusion criteria: Patients who were unstable (demonstrating acute heart failure symptoms), non-English speaking or reading, and unable to provide the necessary data.

Sample Size

Sample size was determined using the recommendations of Hinkle, Wiersma, & Jurs (2003) with $\alpha = 0.05$, power = .80, two tailed test, $d = 0.30$, resulting in a sample size of 70. Although the effect size could have been smaller, this study examined correlational relationships not causal relationships and use of 0.30 created a realistic sample size.

Data Collection

Approval was obtained from the University of San Diego's Institutional Review Board and the Naval Institutional Review Board prior to implementation of the study. Participants diagnosed with heart failure, which was defined using ICD – 9 428 and ICD-10 150 codes or physician diagnosis, were included. The investigator relied on a colleague, Dr. Denise Boren, for introduction to the staff and patients at the clinics.

Participants were recruited from a cohort of patients attending the Naval Medical Center San Diego's (NMCSD) Heart Failure Clinic and Naval Hospital Camp Pendleton's (NHCP) Heart Failure Clinic. The NMCSD clinic was offered weekly in a two-session format from either 0800-1000 or 1000-1200. The staff included a physician, advanced nurse practitioner, registered nurse, corpsman, pharmacist, and dietician. Individual assessment including: vital signs, weight, lung sounds, jugular vein distention, and peripheral edema were performed prior to an all-participant meeting. Each patient's condition and treatment regimen was reviewed and discussed in an informal manner. All participants – health care staff and patients - were encouraged to share information and helpful suggestions. A relevant health topic was presented by the staff at each meeting.

The NHCP clinic was offered weekly from 0800 – 1200. Each attendee was scheduled for 45 -60 minutes with a clinical pharmacist. Individual assessment included: vital signs and other heart failure signs and symptoms, such as peripheral edema, when a specific problem was identified. Occasionally the pharmacist would refer a patient to a cardiologist but there were no other health

care providers involved with patient care. Each patient's treatment regimen was reviewed and medications adjusted by the pharmacist.

At the NMCSD heart failure clinic, patients met in a large conference room. The investigator approached each patient with a flier that explained the study (see Appendix A). A brief verbal explanation was also provided and the patient was asked to contact the investigator if interested in enrolling in the study. A number of patients immediately requested packets and filled out the consent forms and surveys while they were waiting to be seen by the clinic staff. Others were provided a complete packet including a stamped, addressed envelope so that the surveys could be returned to the investigator at the patient's convenience. Only two patients refused to participate. Most requested packets that were later mailed to the investigator.

At the NHCP heart failure clinic, the pharmacist invited the investigator to attend each patient session. The pharmacist handed each patient a flier and explained the purpose of the study. The investigator answered any questions and handed the patient a packet if requested. Over a six week period, ten patients were contacted and six patients enrolled in the study. At that point in time, the pharmacist who conducted the clinic had a medical emergency and required emergency medical leave. Patients who attended the clinic were reassigned to their primary care physicians for follow-up. Repeated attempts to contact the head of the cardiology department via telephone calls and email messages to discuss continued enrollment of patients in the study were unsuccessful.

It had been identified by the clinic director that approximately 125 patients attended the NMCSO heart failure clinic. However, after 6 months of data collection, only 48 participants were enrolled in the study. When the low enrollment became evident, the use of mail-out packets was investigated. It was believed that some patients did not visit the clinic because they were effectively managing their disease or were being followed by either primary physicians or other cardiologists. Use of mailed packets would provide access to this NMCSO heart failure population.

University of San Diego and NMCSO Institutional Review Board approval for this amended data collection procedure was sought and obtained. Next, upon obtaining NMCSO Commanding Officer and Clinical Investigation Department approval, 52 survey packets were mailed to potential participants. Packets included: (1) a letter from the investigator explaining the study and inviting participation, (2) a letter of support from the clinic medical director, (3) a consent form and copy for each patient to keep, (4) a confidentiality document, (5) a survey including the four standardized measures questionnaires and demographic form, and (6) a stamped addressed envelope for return to the investigator. Of the fifty two mailed letters: eleven were returned completed, four were returned from patients whose addresses were no longer correct, and three were returned by family members of patients who were deceased. Sympathy letters were sent to each of the respondents who lost a family member. The remaining packets were not returned. The mail out response rate was 20%.

Measurement

The dependent variable – quality of life – was measured using the Left Ventricular Dysfunction Questionnaire (LVD-36). This 36 item questionnaire was designed to measure quality of life specifically in heart failure patients. Responses are either true or false. True responses are added as percentages with 100 per cent being the worst possible score and 0 per cent being the best possible score; scores range from 0 which is the best possible score to 100 which is the worst possible score. The survey takes approximately 5 minutes to complete.

For the instrument development, initially, a 179 item pool was obtained from literature reviews, existing questionnaires, and patient and clinician interviews. All items were associated with perceived global health and perceived level of functional impairment. Items were removed from the pool if “they were not associated with either of the global questions, if they were endorsed by the majority of the sample, if they were associated with sex, age, or disease duration, or if the endorsement rate was low and the association with global health was significant but weak” (O’Leary & Jones, 2000, p. 635). After testing and revisions, a 36-item questionnaire resulted.

The LVD-36 was validated using comparisons with established measures including the New York Heart Association (NYHA) scale for disease severity, the echocardiogram for heart function, the treadmill for level of impairment, and the Minnesota Living with Heart Failure Questionnaire (LHFE) for heart failure health status. Analysis revealed that age, gender, and cause of heart failure were

not associated with the LVD-36. The repeatability of the LVD-36 was high. After one week, the intraclass correlation was 0.95. Internal consistency between the LVD-36 and the LihFE was high with a resulting Kuder-Richardson coefficient of 0.95 (O'Leary & Jones, 2000).

The majority of patients felt that the LVD-36 contained items that were relevant to how heart failure impacted their daily lives. However, 35% felt that some issues regarding their heart failure had been omitted. Employer problems, sexual activity, and lack of concentration were identified. There were no significant differences between the group who felt the tool was relevant and the group who thought items were missing (O'Leary & Jones, 2000).

The LVD-36 (see Appendix B) was chosen for this study because it addressed the major issues related to heart failure and activities of daily living and has the specificity, reliability, and validity necessary for use as the quality of life measurement tool despite concerns related to disease-specific measurements' reliability and validity (George & Clipp, 2000). In addition, the LVD-36 was the quality of life tool already utilized by the heart failure clinic.

Independent Variables

Hope was measured using the Herth Hope Index (HHI, Herth, 1992), a twelve item Likert type scale. Scores range from 12 to 48 with 48 being the best possible score. The HHI (see Appendix C) was developed in response to the need for an instrument that did not place an unreasonable burden on respondents who were sick. The three factors identified in the Herth Hope Scale (Herth, 1991) were

adapted to fit the Index; despite the shortened format, the HHI remains a reliable and valid measure of hope (Herth, 1992).

The Herth Hope Scale (HHS) was developed in response to the need to identify a psychometrically reliable and valid measurement of hope. Previous hope measurement scales identified multiple dimensions including interpersonal factors, time orientation, future focus, and goal achievement. The HHS built on this framework but expanded measurement to include additional constructs including: hope despite lack of interpersonal relationships, hope as non-time oriented, hope as being rather than doing in relationships, and hope as controlling responses rather than events Herth (1991) argued this broader conceptual structure makes the Herth Hope Scale more applicable in the clinical setting.

The HHS is a 30 question, 4 point Likert scale for use with both well and ill individuals. The items are divided into 3 subscales: cognitive-temporal examining the likelihood of a positive outcome, affective-behavioral examining confidence in the ability to make plans affecting the outcome, and affiliative-contextual examining recognition of interconnectedness with self and others. Each item is scored using an ordinal scale ranging from 1 to 4 where 1 indicates strongly disagree and 4 indicates strongly agree. Total scores range from 12 to 48.

The scale was tested by Herth on cancer patients, homeless families, well adults, well elderly adults, and elderly widow(er)s. It is widely used in the United States and has been translated into Spanish and Thai (Farran, Herth, & Popovich, 1995).

The strength of the scale has been verified by alpha reliability coefficients

that range from 0.75 – 0.94 with a 3 week test-retest reliability of 0.89 – 0.91 and a significant negative correlation ($r = -0.69$) with the Beck Hopelessness Scale. Three factors were identified through factorial analysis procedures: temporality and future (cognitive-temporal dimension), positive readiness and expectancy (affective-behavioral dimension), and interconnectedness (affiliative-contextual dimension) (Herth, 1992). However, length of the scale limited utilization with ill populations. As stated above, the HHI was developed in response to the need for an instrument that did not place an unreasonable burden on respondents who were sick.

Twelve Likert scale items containing the three factors identified in the Herth Hope Scale were adapted. Despite the shortened format, the Herth Hope Index (HHI) remained a reliable and valid measure of hope (Herth, 1992).

Two review panels – one an expert research/measurement panel and one a client/nurse panel – addressed the face validity, language, clarity, and simplicity of the Herth Hope Index. Suggested changes were incorporated and the items were written at a sixth grade reading level (Herth, 1992, p. 1253).

The HHI was tested for concurrent criterion-related validity by administration of: the HHS, to determine if reducing the number of items changed the validity of the HHI in relation to the original tool; the Nowotny Hope Scale (NHS), for comparison with another hope tool; and the Existential Well Being Scale (EWS), because existential well being is linked theoretically with hope. In addition, the Beck Hopelessness Scale (HS) was used to assess divergent construct validity (Herth, 1992, p. 1255).

Results of a pilot test administered to 20 ill adults revealed internal reliability consistency (Cronbach's $\alpha = 0.94$) and no ceiling or floor effects. Completion time did not exceed four minutes. Findings also indicated that fatigue significantly ($p=0.05$) affected the HHI score. This anticipated result indicated that patients who were highly fatigued scored lower on the HHI than patients who were less fatigued (Herth, 1992, p. 1253).

The HHI and the instruments used previously to demonstrate construct validity were then administered to 172 adults who were acutely, chronically, or terminally ill. Attempts were made to make the sample as heterogeneous as possible using a mix of public and private health care agencies. Findings revealed high positive correlations: HHI to HHS ($r = 0.92$), HHI to EWS ($r = 0.84$), HHI to NHS ($r = 0.81$), and inverse relationships HHI to HS ($r = -0.73$) indicating construct validity. Internal consistency was found to be high (0.97 using Cronbach's α). Retest administration repeated after two weeks indicated stability over time (0.91) (Herth, 1992, p. 1256).

Stepwise multiple regression analysis revealed that marital status, length of illness, fatigue, and income were the best predictors of level of hope accounting for 27% of the variance (Herth, 1992, p. 1257). Subjects who were married had a higher hope score than those who were not. Participants with AIDS had lower hope scores than individuals with cardiovascular, gastrointestinal, respiratory, musculoskeletal, and neurological illnesses. Duration of illness exceeding 12 months correlated with lower hope scores. High levels of fatigue were correlated with lower hope scores.

The HHI has demonstrated statistical reliability and validity supporting use as a measurement tool for Hope. Selection of the HHI will provide additional information regarding reliability and validity of this measure in the heart failure population. It is believed that the findings will strengthen utilization of a nurse-designed tool.

Social support was measured by the Medical Outcomes Study – Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991), a nineteen item tool that measures five functional categories of social support: emotional support, informational support, tangible support, positive social interaction, and affectionate support. The developers of the MOS-SSS (see Appendix D) utilized Cohen's (1988) recommendation to examine recipients' perception of available social support (Sherbourne & Stewart, 1991). The authors combined the emotional and informational support items into one scale when multitrait correlational analysis revealed overlap between them. Scores range from 0 to 100 with 100 being the highest possible score.

A review of the social support instruments that emphasized perception of availability of functional support was utilized to develop a 50-item pool of questions. To test face validity, 6 behavioral scientists categorized each item. Items that were difficult to categorize were deleted. A Likert-type scale was used to measure responses ranging from 1 (none of the time) to 5 (all of the time) with a higher score indicating greater perceived support. In addition, two single-item indicators (number of close friends and marital status) were added to identify the structural nature of the support (Sherbourne & Stewart, 1991).

Analysis of the MOS-SSS found that internal consistency reliability (Cronbach's alpha) was above 0.91 for each subscale. The total index score (Cronbach's alpha > 0.91) was also found to be a reliable measure of overall social support. Validity testing with multitrait scaling (testing validity of items in a hypothesized scale) and factor analysis demonstrated strong convergent and discriminant validity (Frank-Stromborg & Olsen, 2004). Stability was tested at one year from baseline with resulting Cronbach's alpha > 0.91 for all scales.

A staged (first selecting sites, then settings within the sites, etc.) sampling design was used to select participants in the Medical Outcomes Study (MOS). It was discovered that patients who enrolled in the study were "younger, better educated, had a higher income, and were more likely to be married or employed than were patients who refused enrollment" (Sherbourne & Stewart, 1991, p. 706). This finding has the potential to limit utilization of the MOS-SSS.

However, the MOS participant population included heart failure patients thus strengthening its selection for use in this study. In addition, the MOS-SSS has been tested in heart failure populations and has been found to be reliable and valid (Bennett et al., 2001; Lee, Thompson, & Yu, 2005; Rosen, Contrada, Gorkin, & Kostis, 1997).

Self-Care was measured using the Self-Care for Heart Failure Index (SCHFI) (Riegel, et al., 2004), a fifteen item survey that measures ability of an individual to self-care. It evaluates a decision making process that involves self maintenance, self management, and self confidence in people with heart failure. Scores range from 0 to 300 with 300 being the best possible score. (see Appendix

E). The SCHFI is one of the few tools that measures both attributes of individual self-care and also includes a self confidence scale.

The SCHFI uses naturalistic decision making, or how individuals operate within their real-world context, as a theoretical framework. In order to be successful in the control of heart failure, patients must understand and implement healthy lifestyles (self-care maintenance) and recognize and respond to changes in condition (self-care management). The SCHFI is a self administered survey that takes approximately 5 minutes to complete and contains 17 items that measure self-care during the previous 3 months. Each response is measured using a 4 point scale. Scales and scores are standardized to 100 and range from 0 to 300 (Riegel et al., 2004; Riegel, Dickson, Goldberg, & Deatrck, 2007) with higher scores indicating better self-care.

A convenience sample of 760 heart failure patients was utilized to test the SCHFI. It was hypothesized that alpha coefficients for the SCHFI and its subscales would be ≥ 0.70 . Analysis revealed the following alpha coefficients: Self-care maintenance was 0.56, Self-care management was 0.70, Self-care confidence was 0.82, and the SCHFI was 0.76. The author postulated that the lower than expected internal consistency of the Self-care maintenance scale was related to the fact that the health behaviors are not dependent on each other and are controlled by different motivators (Riegel et al., 2004).

Factor analysis found the SCHFI model (self-care maintenance, management, and confidence) fit was adequate. Within the self-maintenance scale, one question regarding a yearly flu shot was problematic but included in the

final tool because it contributed to the construct validity of the index. Additional construct validity support was identified by the significant subscale correlation (Riegel et al., 2004).

The SCHFI has been acknowledged to be a tool that shows significant progress for use in research (Frank-Stromborg & Olsen, 2004). Riegel noted that the tool is limited by the lower alpha coefficient for the self-maintenance scales. In addition, the tool assesses only two symptoms – shortness of breath and ankle swelling (2004) and three symptoms - dyspnea, fatigue and fluid overload have been identified as cardinal manifestations of heart failure (Hunt et al., 2001). However; the instrument addresses disease-specific problems and demonstrates reasonable reliability and validity, and is therefore appropriate for inclusion in this study. In addition, the SCHFI is utilized by the Naval Medical Center San Diego heart failure clinic to collect baseline assessment information.

A new version (SCHFI v.6) has just become available and was not used in this study. In the new version, a major revision was made to the self-care maintenance scale. Five additional items were added to the scale to address the low reliability coefficient (.56) in the 2004 version. It is now recommended that the three scales be used independently rather than calculating a total score. However; after additional testing, the reliability coefficient was not significantly different from the 2004 alpha coefficients (Riegel, Lee, Dickson, & Carlson, 2009).

Other Factors: gender, age, race/ethnicity, co-morbidities, and functional status have been found to be significant in relation to heart disease in general and

heart failure in particular. A demographic sheet was utilized to capture this data and other socioeconomic information (See Appendix F).

Functional status, a physiologic variable was described using a slightly modified form of the New York Heart Association's (NYHA) Stages of Heart Failure (See Appendix G). This self-reported tool relates patient symptoms during activities of daily living and quality of life (Heart Failure Society of America, 2002).

Data Analysis

The *Statistical Package for Social Sciences (SPSS), Version 16* was used for statistical analysis. Descriptive statistics of the participant's demographic and physiologic variables are presented as frequencies and percentages of the group total. Correlational statistics were used to measure the relationships between quality of life, hope, social support, and self-care. Multiple regression statistics were used to measure the correlations between quality of life, hope, social support, self-care and the demographic and physiologic variables. All electronic data were stored in a computer file that was password protected.

Limitations

Quality of Life in heart failure patients has been examined in relation to other psychosocial variables such as role loss (Bosworth et al., 2004), depression (Carels, 2004; Heo, Moser, & Widener, 2007; Hofer et al., 2005; Johansson, Dahlstrom, & Brostrom, 2006; Klein, Turvey, & Pies, 2007), coping (Bosworth et

al., 2004; Klein et al., 2007) self efficacy (Kempen, Sanderman, Miedema, Meyboom-de Jong, & Ormel, 2000), and sense of coherence (Ekman, Fagerberg, & Lundman, 2002; Gustavsson & Branholm, 2003) that were not included in this study. In addition, the findings are limited to comparison with heart failure clinics of similar size, population, and function.

Human Subjects

Approval for the study was obtained from the University of San Diego's Institutional Review Board and the Naval Medical Center San Diego's Institutional Review Board, the Naval Medical Center San Diego's Commanding Officer, and Camp Pendleton Naval Hospital's Commanding Officer. In order to ensure protection of human subjects, the principal investigator completed an eight hour Collaborative Institutional Training Initiative course required by the Navy. Informed Consent and Patient Authorization to Use and/or Disclose Protected Health Information for Research (HIPAA) were obtained.

This study posed minimal risk to participants. It was possible that use of the psychosocial tools could cause anxiety or sadness. However, it was anticipated that participants would be more likely to experience a sense of hopefulness. If a participant became anxious, sad, fatigued, or began to demonstrate heart failure symptoms; the interview would have been terminated and rescheduled if possible. No participants described feelings of anxiety or sadness during administration of the tools. Of the participants who commented, all stated that they were happy to do something that would "help other heart

failure patients”.

To guarantee anonymity and confidentiality, each participant was informed that all data would be kept in strictest confidence. The findings would be reported as group findings; individuals would not be identifiable. Participants were also informed that refusal to participate or withdrawal from the study would not result in any changes in standard medical treatment.

The completed questionnaires were placed in an envelope marked with a code known only to this investigator. All identifying data was coded, kept confidential, and stored in the investigator's home in a locked cabinet.

Other than a bottle of Mrs. Dash (a salt substitute), there was no benefit for the individual participants. It was believed that the potential benefit of increased understanding of the role of Hope, Social Support, and Self-Care on Quality of Life outweighed the minimal risks to participants. Additionally, multiple participants told the investigator that they were happy to take part in any project that would help other individuals with heart failure.

Chapter IV

Results

The purpose of this study was to examine the relationships between hope, social support, self-care, and quality of life 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 hope, social support, self-care, and the dependent variable of quality of life is presented. The chapter concludes with the findings related to specific research questions.

Characteristics of the Sample

A purposive sample of 65 heart failure patients was recruited from military based heart failure clinics located in southern California between February and November 2009. Participants were members of the armed services or family members who qualified for health care at these centers. Fifty four subjects were recruited through use of fliers and investigator contact at the clinics; 11 responded to a targeted mailing to HF patients who did not attend the clinic on a regular basis or utilized the services of a primary care physician only. Participants returning the signed consent and confidentiality forms self-administered a survey containing demographic questions and four standardized measures: The Herth Hope Index (HHI) (Herth, 1992), The Medical Outcomes Study: Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991), The

Self-Care in Heart Failure Index (SCHFI) (Riegel et al., 2004), and the Left Ventricular Dysfunction Scale (LVD 36) (O'Leary & Jones, 2000).

Table 1 summarizes characteristics of the sample through frequency distributions.

Table 1

<u>Sample Characteristics</u>	Total (n = 65)	
	No.	%
Age		
30-39	2	3.1
40-50	1	1.5
51-60	6	9.2
61-70	16	24.6
71-80	23	35.4
81-90	16	24.6
91+	1	1.5
Gender		
Male	47	72.3
Female	18	27.7
Ethnicity		
Hispanic	2	7.1
Non-Hispanic	26	92.9
Race		
White/Caucasian	42	70.0
Black/African American	8	13.3
Pacific Islander	1	1.7
Asian	6	10.0
American Indian and Alaska Native	1	1.7
Other	2	3.1
Marital Status		
Single	1	1.5
Married	45	69.2
Divorced	4	6.2
Widowed	15	23.1
Length of time diagnosed with heart failure		
0 – 1 year	12	18.5
2 - 3 years	11	16.9
4 – 5 years	10	15.4
5 – 10 years	12	18.5
11 or more years	20	30.8

Table 1 Sample Characteristics (continued) Total (n = 65)

	No.	%
Co-morbidities		
Diabetes	24	41.4
High Blood Pressure	27	46.6
Lung Disease	1	1.7
Coronary Heart Disease/Previous Heart Attack	5	8.6
Kidney Disease	1	1.7
Number of hospitalizations for heart failure in the previous 12 months		
0	32	51.6
1	20	32.3
2	6	9.7
4	3	4.8
6	1	1.6
Length of time attending the Heart Failure Clinic		
0-12 months	22	37.9
13-24 months	17	29.4
25-36 months	10	17.4
37-48 months	6	10.3
49-60 months	1	1.7
61-72 months	1	1.7
73-84 months	1	1.7
Functional Status		
Class I	16	26.2
Class II	18	29.5
Class III	20	32.8
Class IV	7	11.5

The patients ranged in age from 30 to 91+ years with the majority (86.1%) between 61 – 90 years,, male (72.3%), and of Non-Hispanic ethnicity (92.9%). Nearly three quarters (70%) were Caucasian (70.0%) and married (69%).

Length of time diagnosed with heart failure varied. Twelve participants (18.5%) were diagnosed within one year, eleven (16.9%) diagnosed within 2 - 3 years, ten (15.4%) within 4 – 5 years, twelve (18.5%) within 5 – 10 years, and twenty (30.8%) for 11 or more years.

Comorbidities included: Diabetes (41.4%), High Blood Pressure (46.6%), Lung Disease (1.7%), Coronary Heart Disease/Previous Heart Attack (8.6%), and Kidney Disease (1.7%). Patients tended to have more than one comorbidity.

Number of hospitalizations for heart failure in the previous 12 months ranged from none to six. Thirty two (49.2%) participants had no hospitalizations, 20 (32.3%) had 1 hospitalization, 6 (9.7%) had 2 hospitalizations, three (4.8%) had 4 hospitalizations, and only one had 6 hospitalizations.

Participants were asked to fill in the blank when asked the question: Length of time attending the Heart Failure Clinic. Answers were grouped in 12 month increments in an effort to categorize the information. Answers ranged from 1 month to 7 years. Twenty two participants attended for 1 – 12 months (37.9%), seventeen participants attended for 13 – 24 months (29.4%), ten participants attended for 25 – 36 months (17.4%), six participants attended for 37 – 48 months (10.3%), one participant attended for 49 – 60 months (1.7%), one participant attended for 61 – 72 months (1.7%), and one participant attended for 73 – 84 months (1.7%).

A physiologic variable, functional status was also assessed. Sixteen (26.2%) self-rated themselves in Class I, 18 (29.5%) in Class II, 20 (32.8%) in Class III, and 7 (11.5%) in Class IV.

Findings Related to the Research Questions

- 1. What is the level of hope, social support, self care, and quality of life among heart failure patients receiving care from a military health clinic?*

Means, standard deviations, and reliability coefficients were computed for the overall and subscale scores of the study sample and are presented in Table 2.

Table 2

Means, Standard Deviations, Range, and Reliability Coefficients for the HHI, MOS-SSS, SCHFI, and LVD 36

Scale	<u>M</u>	<u>SD</u>	Range	Cronbach's Alpha
HHI	39.03	5.67	19.0 - 48	.874
C/T	12.52	2.30	5.0 - 16	.724
A/B	13.16	2.13	6.0 - 16	.802
A/C	13.30	1.965	5.0 - 16	.582
MOS-SSS	72.29	23.22	12.5 - 100	.968
E/I	69.90	25.13	0 - 100	.959
T	74.37	25.52	6.25 - 100	.882
A	80.24	28.92	0 - 100	.936
S	69.58	28.60	0 - 100	.967
SCHFI	226.33	34.83	156.29 – 295.91	.792
M	81.23	13.27	55.0 - 100	.614
Man.	77.56	14.73	41.7 – 100.08	.569
C	69.034	17.55	31.25 - 100	.907
LVD 36	15.74	9.15	0 - 33	.935

Note.

C/T = Cognitive/Temporal

A/B = Affective/Behavioral

A/C = Affiliative/Contextual

E/I = Emotional/Informational Support

T = Tangible Support

A = Affectionate Support

S = Positive Social Interaction

M = Self-Care Maintenance

Man. = Self-Care Management

C = Self-Care Confidence

One of the key independent variables, hope, was measured using the Herth Hope Index (HHI) (Herth, 1992), a twelve item Likert scale. Scores range from 12 to 48 with 48 being the best possible score. The reliability coefficient of the HHI in this study was .87 which is lower than the 0.97 reported by Herth (1992). Although the reliability coefficient is lower than the .97 reported in the original study (Herth, 1992), it is consistent with the .89 - .91 range of findings reported by others (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003; Herth, 1990; 1993a; 1993b; 1996; 2000). The mean HHI score in this study was 39.03 ($SD = 5.666$) compared to the mean HHI score of 32.39 ($SD = 9.61$) reported by Herth (1992). Reliability coefficients for each of the subscales ranged from .58 to .80 in this study which differed from the reliability coefficients for each of the subscales as reported by Herth (1992) which ranged from .78 to .86.

Social support was measured by the Medical Outcomes Study – Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991), a nineteen item tool that measures five functional categories of social support: emotional support, informational support, tangible support, positive social interaction, and affectionate support. The authors combined the emotional and informational support items into one scale when multitrait correlational analysis revealed overlap between them. Scores range from 0 to 100 with 100 being the highest possible score. The reliability coefficient of the MOS-SSS in this study was .97; subscale alphas ranged from .88 to .97 which is consistent with previous findings .97; .91-.97 respectively (Sherbourne & Stewart, 1991). The mean MOS-SSS

score in this study was 74.44 ($SD = 17.621$) compared to the mean MOS-SSS score of 70.1 ($SD = 24.2$) reported by Sherbourne and Stewart (1991).

Self-care, was measured using the Self Care in Heart Failure Index (SCHFI) (Riegel et al., 2004), a fifteen item survey that measures ability of an individual to self care. It evaluates a decision making process that involves self maintenance, self management, and self confidence of people with heart failure. Scores range from 0 to 300 with 300 being the best possible score. The reliability coefficient of the SCHFI in this study was .79 which is consistent with the .76 reported by Riegel et al. (2004). The mean score in this study was 226.33 ($SD = 34.83$) compared to the mean score 192 ($SD = 41.5$) reported by Riegel et al. (2004). The reliability coefficients for each of the subscales ranged from .57 to .91 in this study compared to the reliability coefficients for each of the subscales as reported by Riegel et al. (2004) which ranged from .56 to .82.

The dependent variable, quality of life, was measured by the Left Ventricular Dysfunction Questionnaire (LVD 36) (O'Leary & Jones, 2000). This 36 item questionnaire was designed to measure quality of life specifically in heart failure patients. Scores range from 0 which is the best possible score to 100 which is the worst possible score. The reliability coefficient of the LVD 36 was 0.94 for this sample which is consistent with the 0.95 reported by O'Leary and Jones (2000). The mean LVD 36 score in this study was 15.74 ($SD = 9.15$) compared to the mean LVD 36 score of 39.0 reported by O'Leary and Jones (2000).

Question 2. *Is there a statistically significant difference between quality of life mean scores by race/ethnicity, marital status, age, gender, length of time with heart disease, functional status, and comorbidities?*

One way ANOVA indicated there was a statistically significant difference on the quality of life mean scores and length of time diagnosed with heart failure, $F(4,60) = 3.54, p = .012$. Scheffe post hoc comparisons revealed that patients diagnosed with heart failure for 0 – 1 year ($M = 11.74, SD = 9.49$) have better quality of life than patients diagnosed with heart failure for 11 or more years ($M = 29.03, SD = 8.30$).

Statistically significant differences on quality of life mean scores by functional status, $F(3, 57) = 17.85, p = .000$ was found. Scheffe post hoc comparisons revealed patients who self-rated functional status as Class I (no physical limitations) have better quality of life than patients who self-rated functional status as Class II (slight physical limitations) ($M = 27.97, SD = 6.05$), Class III (marked physical limitations) ($M = 38.54, SD = 5.91$), or Class IV (unable to carry out physical activity) ($M = 45.19, SD = 7.98$). There were no significant differences between Classes II, III, and IV.

There were no statistically significant differences on quality of life mean scores by race/ethnicity, marital status, age, gender, and comorbidities.

Question 3. *What is the relationship of hope, social support, and self-care with quality of life among heart failure patients?*

A correlational matrix was first computed to identify the potential for multicollinearity among the continuous predictor variables. Multicollinearity exists when independent variables are highly correlated with each other (Huck, 2008); as argued by Munro (2001) problems are indicated when correlations are greater than .85. A review of the correlation matrix for the overall scale scores (Table 3) and subscales scores (Table 4) found no evidence of multicollinearity.

Table 3

Pearson Product-Moment Coefficients for Total Hope, Social Support (SS), and Self-Care (SC) Scores

	Hope	Social Support	Self-Care
Hope	1.00	.61**	.39**
SS	.61**	1.00	.19
SC	.39**	.19	1.00

Note. N = 65 ** $p = .01$

As can be seen in Table 3, Hope was statistically significantly positively related to Total Social Support ($r = .61, p = .000$) and Total Self-Care ($r = .39, p = .004$).

Table 4

Pearson Product-Moment Coefficients for Subscale Scores of Hope, Social Support, Self-Care

		Social Support				Self-Care		
		E/I	T	A	S	M	Man	C
Hope								
	C/T	.46**	.09	.39**	.55**	.23	.11	.29**
	A/B	.53**	.20	.43**	.56**	.29**	.22	.36**
	A/C	.54**	.28**	.45**	.51**	.27**	.18	.32**
SS								
	E/I					.07	.17	.27**
	T					-.14	.10	.21
	A					-.13	.00	.21
	S					.09	.11	.32**

Note. ** $p = .05$

* $p = .01$

Two Hope subscales were found to be statistically significantly positively related to the Social Support subscales: Emotional/Informational, Affectionate, and Social Interaction. The Hope Cognitive/ Temporal subscale and Emotional/Informational ($r = .46, p = .000$), Affectionate ($r = .39, p = .002$), and Social Interaction ($r = .55, p = .000$). The Hope Affective/Behavioral subscale and Emotional/Informational ($r = .53, p = .000$), Affectionate ($r = .43, p = .001$), and Social Interaction ($r = .56, p = .000$). The Hope Affiliative/Contextual subscale was statistically significantly positively related to Social Support Subscales: Emotional/Informational ($r = .54, p = .000$), Tangible ($r = .28, p = .027$), Affectionate ($r = .45, p = .000$), and Social Interaction ($r = .51, p = .000$).

Statistically significantly positive relationships were found between Hope Cognitive/ Temporal subscale and Self care subscale Confidence ($r = .29, p < .05$); Hope Affective/Behavioral subscale and Self care subscales of Maintenance ($r = .29, p < .05$); Confidence ($r = .36, p < .05$); and Hope Affiliative/Contextual subscale and Self care subscales of Maintenance ($r = .27, p < .05$); Confidence ($r = .32, p < .05$). Statistically significantly positive relationships were found between the Social Support subscales: (1) Emotional/Informational, (2) Social Interaction and Self care subscale Confidence ($r = .27, p < .05$); ($r = .32, p < .05$) respectively.

Next a correlation matrix was computed to examine the relationships between the three key continuous independent variables and quality of life. (Table 5)

Table 5

Pearson Product-Moment Correlations between Hope, Social Support, and Self-Care and Quality of Life

<u>Independent Variables</u>	<u>Quality of Life</u>	
	<u>r</u>	<u>p</u>
Hope	-.342	.008**
C/T	-.414	.001**
A/B	-.265	.037*
A/C	-.247	.049*
Social Support	-.172	.178
E/I	-.189	.133
T	-.020	.879
A	-.138	.068
Self-Care	-.099	.470
M	-.137	.308
Man	-.030	.820
C	-.068	.588

Note. N = 65

** $p < .05$ * $p = .01$

Note.

C/T = Cognitive/Temporal

A/B = Affective/Behavioral

A/C = Affiliative/Contextual

E/I = Emotional/Informational Support

T = Tangible Support

A = Affectionate Support

S = Positive Social Interaction

M = Self-Care Maintenance

Man. = Self-Care Management

C = Self-Care Confidence

Quality of Life was found to be statistically significantly inversely related to the Total Hope Scale ($r = -.342, p = .008$) and all subscales:

Cognitive/Temporal ($r = -.414, p = .001$), Affective/ Behavioral ($r = -.265, p = .037$), and Affiliative/Contextual ($r = -.247, p = .049$). It should be noted that scoring on the LVD36 is such that 0 is the best possible score and 100 is the worst possible score. Therefore, the inverse relationship between hope and quality of life actually supports the finding that higher levels of hope are correlated with better quality of life.

To examine which predictors influence the quality of life of heart failure patients several regression models were generated.

A simultaneous multiple regression was generated to determine the accuracy of the primary variables of interest: hope, self care, and social support in predicting heart failure patient's quality of life. Table 6.

Table 6

Regression Analysis of Heart Failure Patient's Quality of Life on Three Predictor Variables.

Independent Variable	B	β	Standard Error	<i>t</i>	<i>p-value</i>
Hope	-.52	-.32	-.29	-1.76	.08
Social Support	-.01	-.06	.06	-.19	.84
Self-Care	.01	.04	.03	.29	.77
Multiple R = .33		$R^2_{adj} = .05$			
$R^2 = .11$		$F(3, 46) = 1.92, p = .13$			

Regression results indicate the overall model does not statistically significantly predict quality of life, $R^2 = .11$, $R^2_{adj} = .05$, $F(3, 46) = 1.92$, $p = .13$.

A simultaneous multiple regression was generated to determine the accuracy of length of time diagnosed with heart failure and functional status to predict quality of life while controlling for hope, self care, and social support. Prior to the analysis variables were collapsed for length of time diagnosed with heart failure (0 = < 5 years, 1 = > 5 years) and functional status (0 = no limitations, 1 = limitations). Table 7.

Table 7

Regression Analysis of Heart Failure Patient's Quality of Life on Five Predictor Variables.

Independent Variable	B	β	Standard Error	<i>t</i>	<i>p</i>
Hope	-.43	-.29	.19	-2.20	.030
Social Support	-.05	-.13	.04	-1.08	.280
Self-Care	.01	.04	.02	.45	.650
Functional Status	10.59	.53	1.96	5.39	.000
Length of time with DX	5.47	.32	1.73	3.12	.003
Multiple R = .78 R ² = .61					
R ² _{adj} = .57 F(5, 42) = 13.55, <i>p</i> = .000					

Regression results indicate the overall model significantly predicts quality of life, $R^2 = .61$, $R^2_{adj} = .57$, $F(5, 42) = 13.55$, $p < .001$. This model accounts for 61 percent of the variance in heart failure patient's quality of life. A summary of the regression coefficients is presented in Table 7 and indicates three (hope, functional status, and length of time with diagnosis) of the five variables significantly contributed to the model.

To adhere to power conditions for multiple regression; an examination of the ANOVAs and correlations identified 3 predictive variables to include in the model: hope, functional status, and length of time with diagnosis. Table 8

Table 8

Regression Analysis of Heart Failure Patient's Quality of Life on Three Predictor Variables.

Independent Variable	B	β	Standard Error	<i>t</i>	<i>p</i>
Hope	-.47	-.30	.13	-3.62	.001
Functional Status	10.96	.56	1.70	6.40	.000
Length of time with DX	5.59	.32	1.53	3.64	.001
Multiple R = .798 $R^2_{adj} = .61$					
$R^2 = .63$ $F(3, 51) = 29.84, p = .000$					

Regression results indicate the overall model significantly predicts quality of life, $R^2 = .63$, $R^2_{adj} = .61$, $F(3, 51) = 29.84$, $p < .001$. This model accounts for 63 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 all three (hope, functional status, and length of time with diagnosis) of the variables significantly contributed to the model.

Significant relationships were found within the key independent variables of hope, social support, and self-care. All constructs of hope were significantly related to the social support total scale and all subscales with the exception of tangible support. All constructs of hope were significantly related to self-care confidence. The Hope subscales inner positive readiness and interconnectedness and the total Hope Scale were significantly related to the self-care maintenance scale. The Social Support total scale and emotional/informational and positive social interaction subscales were significantly related to self-care confidence.

Additional relationships were found among the continuous key independent variables. Non-significant findings related to Hope are as follows: a subscale of Hope - Cognitive/Temporal was not significantly related to one Social Support subscale: Tangible and two Self-Care subscales: Maintenance and Management; a subscale of Hope – Affective/ Behavioral was not significantly related to one Social Support subscale: Tangible and one Self-Care subscale: Management; and a subscale of Hope - Affiliative/Contextual was not significantly related to one Self-Care subscale: Management.

Additional non-significant findings were found in the relationship between Social Support and Self-Care. The Social Support subscale Emotional/Informational was not significantly related to two self-care subscales: Maintenance and Management. The Social Support subscale Tangible was not significantly related to three Self-Care subscales: Maintenance, Management, and Confidence. The Social Support Subscale Affectionate Support was not

significantly related to three Self-Care subscales: Maintenance, Management, and Confidence. The Social Support subscale Social Interaction was not significantly related to two Self-Care subscales: Maintenance and Management.

In conclusion, the principle findings in this study established that hope was significantly related to quality of life but social support and self-care were not significantly related to quality of life. Functional status and length of time diagnosed with heart failure were also significantly related to quality of life. Race/ethnicity, marital status, age, gender, or comorbidities were not found to be significantly related to quality of life. The findings in this study are represented in a predictive model. Figure 2.

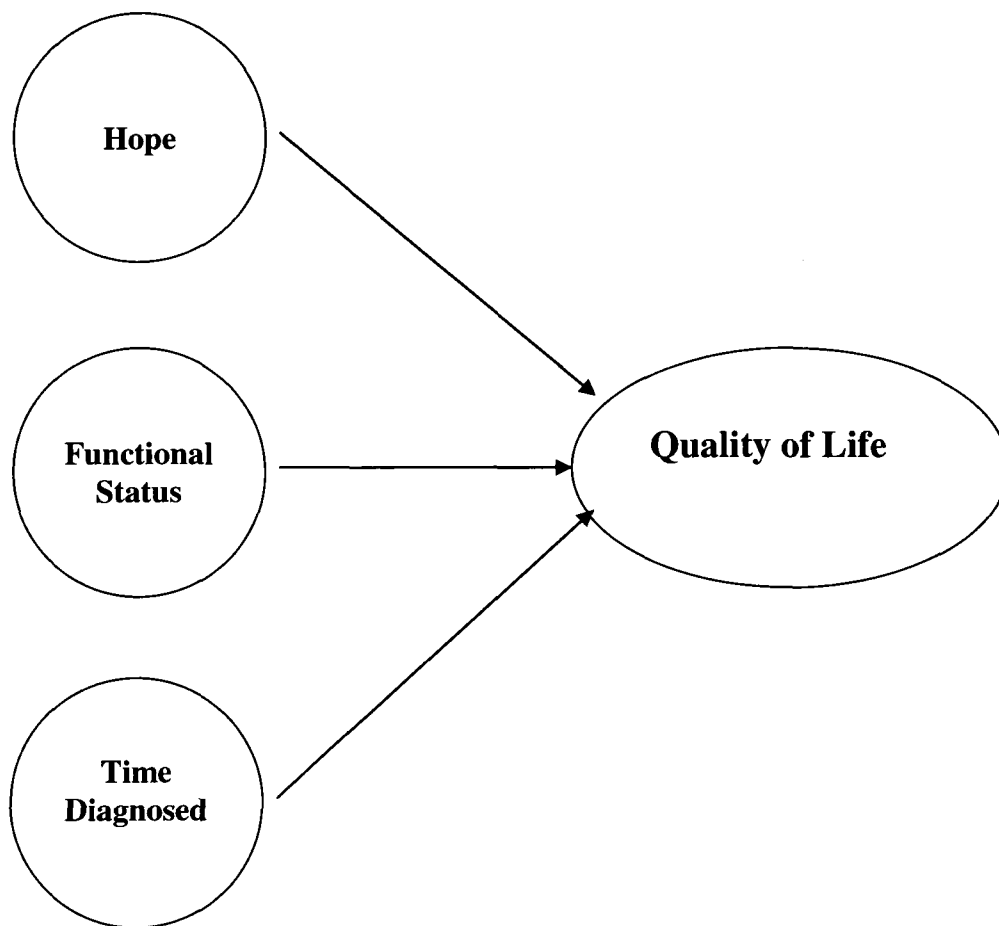


Figure 2: Revised Conceptual Model: Predictive Variables and Quality of Life in Heart Failure Patients

Chapter V

Conclusions, Implications, and Recommendations

Of existing chronic conditions, heart disease has been identified as the number one cause of death across all racial and ethnic lines. In particular, heart failure (HF) has been recognized as a progressive form of heart disease with increasing prevalence despite optimal treatment interventions. Best-practices patient care now includes focus on psychosocial needs of this population. Of particular significance is the recognition of quality of life as an essential patient outcome (Healthy People 2010, 2008; Lancet, 1995; World Health Organization, 2004). Limited work has been done examining the relationship between quality of life and psychosocial variables in Heart Failure patients. In particular, the relationship between hope, social support, self-care, and quality of life remains under examined.

Discussion of the Findings

The principle conclusions drawn from this study were:

1. Hope is related to quality of life.
2. Social support and self-care are not related to quality of life.
3. Functional status and length of time diagnosed with heart failure are related to quality of life.
4. Race/ethnicity, marital status, age, gender, and comorbidities are not related to quality of life.

Research Questions

Question #1: What is the level of hope, social support, self care, and quality of life among heart failure patients?

In this study, respondents reported high levels of hope $M = 39.03$ ($SD = 5.7$). Although there are limited studies examining hope, these findings are congruent with most of the literature. For example, high levels of hope were found to exist in older adults with heart failure (Davis, 2005), terminally ill adults (Herth, 1990), caregivers of terminally ill patients (Herth, 1993a), and older adults (Herth, 1993b). Levels of hope were found to be higher in hospitalized heart failure patients when compared to the general public (Rustoen, Howie, Eidsmo, & Moum, 2005).

Moderate levels of hope were found in heart transplant recipients (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003) and people with a first recurrence of cancer (Herth, 2000). In contrast, low levels of hope were found in homeless families (Herth, 1996).

Levels of social support in this study were found to be moderate to high ($M = 74.4$, $SD = 17.6$). Results of other heart failure studies reflected mixed levels of social support. For example, moderate to high levels of social support were found in Thai heart failure patients (Krethong, Jirapaet, Jitpanya, & Sloan, 2008), in heart failure patients (Park et. al., 2006), and in hospitalized heart failure patients calculated using an author-designed mathematical aggregate (Rockwell & Riegel, 2001). On the other hand, Bennett and colleagues (1997; 2001) found low

to moderate levels of social support in heart failure patients. Comparison of findings is problematic however due to the use of multiple measurement tools.

Above average levels of self care $M = 226.33$ ($SD = 34.83$) were identified in this study contrasted to Riegel & Carlson (2004) investigation indicating low levels of self-care were discovered following hospitalization for heart failure. The high levels of acuity resulting in hospitalization may be at least in part responsible for these findings. This same group did show significant improvement in self-care levels following mentor provided support (Riegel & Carlson, 2004). Low levels of self-care were also found in a study by Jaarsma et. al. (2000). However, the author-developed instrument utilized to measure self-care was not adequately tested for reliability or validity.

For quality of life, the overall mean score in this study $M = 15.74$ ($SD = 9.15$) indicated good to excellent quality. This finding is in contrast to the majority of the research which supports low to moderate levels of quality of life in heart failure patients.

Thai heart failure patients (Krethong, Jirapaet, Jitpanya, & Sloan, 2008), and women with heart failure (Heo et. al., 2007) were found to have moderate levels of quality of life. Low to moderate levels of quality of life were found in hospitalized patients (Bennet et. al, 1997; Bennet et. al, 2001) and outpatients (Bennett et al., 2002; Hou et. al., 2004). Other studies comparing heart failure patients with healthy adults reveal poorer quality of life experienced by heart failure patients (Brostrom et. al., 2004; Ekman, et. al., 2002; Heo et. al., 2008; Juenger et.al. 2002).

In general, patients with heart failure have poor to moderate quality of life. Based on the chronic, life style-altering nature of heart failure this is not surprising. What is surprising is the high level of self-care in this study population. It is possible that experience in the military influences individual conformity with authority. Current or ex-military individuals may be more likely to follow “commands” of the physician and heart failure clinic staff, thus increasing treatment plan compliance.

It is also possible that military personnel have different life experiences that influence their self-care practices. Further investigation into lifestyle practices, such as smoking, alcohol and drug consumption, and diet could help identify areas that are unique in this population. The role of post traumatic stress may influence health practices and has not been studied in relation to heart failure.

The majority of patients in this study were 61 years and older and had seen combat. Reliance on self during those times may establish a life-long pattern of behavior. Increased understanding of life style practices and self-care motivators could help direct future interventions.

Question #2: Is there a statistically significant difference among quality of life mean scores by race/ethnicity, marital status, age, gender, length of time with heart disease, functional status, and comorbidities?

In this study, Race/Ethnicity was not found to be significantly related to Quality of Life. The majority of heart failure studies have been conducted on Caucasian individuals. Of the studies that include other races/ethnicities, few

exam quality of life. Rather, results surround demographic and physiologic relationships.

Marital status was not found to be significant in relation to quality of life in this study. Although marital status is frequently included in study demographics (Brostrom et. al., 2004; Dracup et. al., 1992; Heo et. al., 2008; Hou et. al., 2004; Riegel et.al., 2003; Westlake et. al., 2002), it is rarely found to be related to quality of life

In this study, Age was not found to be significantly related to Quality of Life. Heart Failure occurs primarily in older adults. Results of studies examining the role of Age in Quality of Life are mixed. Older men (Corvera-Tindel, Doering, Roper, & Dracup, 2009; Heo et al., 2008) and older women (Plach, 2008) reported better Quality of Life than younger men and women. Conversely, younger women reported a better Quality of Life than older women (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003) and psychosocial quality of life was not found to be predictive of hospitalization in older adults when compared to younger adults (Stull, Clough, & Van Dussen, 2001). As in this study, the authors of the LVD 36 did not find an association between age and Quality of Life (O'Leary & Jones, 2000).

Gender was not found to be significantly related to Quality of Life in this study. Studies have shown that women demonstrate different symptomology, have different risk factors, and develop heart failure later in life than men. Differences have also been found in the relationship between gender and quality of life. Women with heart failure have significantly diminished quality of life

compared with men (Binderman, Homel, Billings, Portenoy, & Tennstedt, 2008; Ekman, Fagerberg, & Lundman, 2002; Hou et al., 2004; Rideout & Montemuro, 1986; Riedinger et al., 2001; Riegel, Dickson, Goldberg, & Deatrck, 2007).

Women were found to have more co-morbid psychiatric illness than men including depression and anxiety (Sayers et al., 2007) and fear (Costello & Boblin, 2004). Hospitalized women were older, more often retired, and living alone than their male counterparts (Nieminen et al., 2008) and reported high levels of symptom impact, poor health status, and diminished quality of life (Bennett, Baker, & Hunter, 1998). Men were found to have significant impairment in quality of life related to emotional problems, lack of energy, and pain (Hobbs et al., 2002; Yu, Lee, Kwong, Thompson, & Woo, 2008).

Similar to the findings in this study, gender has not always been found to be related to Quality of Life (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2004; De Jong, Riegel, Armola, & Moser, 2006; Heo, Moser, & Widener, 2007; O'Leary & Jones, 2000). The majority of the literature associates women with decreased Quality of Life when compared to men. The small sample size (28%) of women in this study may have influenced the results.

Length of time diagnosed with heart failure was found to be significantly related to quality of life in the study population. Patients with a recent diagnosis (within one year) were found to have better quality of life compared to patients living with heart failure for 11 years. It seems reasonable to assume, and this study reveals, that quality of life is better in more recently diagnosed individuals. The advent of a new condition often produces a crisis that stimulates health-

seeking behaviors. Patients receive immediate benefit from medical intervention and are more likely to maintain a therapeutic regimen. As time passes, perhaps the multiple, major life style changes required of living with heart failure become arduous and difficult to sustain resulting in diminished quality of life.

Identification of 11 years as the point of comparison between good and poor quality of life suggests the need for additional study to examine why the intervening years are not related to changes in quality of life. This is an area that has limited exploration in the literature. The majority of studies do not include length of time living with heart failure. Studies addressing this issue report means and ranges (Gustavsson & Branholm, 2003; Juenger et al., 2002) and do not look at this variable in relation to quality of life.

It should be noted that despite strict adherence to treatment plans, heart failure is ultimately a terminal condition. Despite a patient's best efforts, cardiac function diminishes over time. The relationships among quality of life, length of time living with heart failure, and cardiac function bear additional investigation. In particular, qualitative studies could help define quality of life in the population that lives with heart failure for many years. It is possible that the measure used to determine quality of life in this study is not sufficient to define that concept in this unique population.

In this study, Functional Status was significantly related to Quality of Life with patients who self-rated functional status as Class I (no physical limitations) having better quality of life than patients who self-rated functional status as Class II (slight physical limitations), Class III (marked physical limitations), or Class IV

(unable to carry out physical activity). This finding is congruent with the findings in the literature. Unimpaired functional status is significantly and positively related to mental health (Dracup, Walden, Stevenson, & Brecht, 1992; Westlake et al., 2002). Worsening function has been correlated with decreased quality of life (Ekman, 2002; Hobbs et al., 2002; Klein, Turvey, & Pies, 2007), depression (Park, Fenster, Suresh, & Bliss, 2006), decreased social role abilities (Plach, 2008), reduced ability to self-care (Moser & Watkins, 2008) and was found to be predictive of hospitalization in middle- and older-aged adults (Stull et al., 2001).

Masoudi et al. (2004) found that although baseline functional status was worse in older patients when compared to younger patients, their quality of life was significantly better. However; over time, as functional status declined quality of life decreased significantly in the older group but remained unchanged in the younger group. Additional studies are needed to test the relationships among age, functional status, and quality of life.

In this study, functional status was measured at one point in time and unimpaired functional status was found to be related to better quality of life. Longitudinal studies are needed to examine the effects of time and change in functional status on quality of life in this population.

Co-morbidity was not found to be significantly related to Quality of Life in this study. Similarly, the developers of the quality of life instrument used in this study did not find a relationship between comorbidity and Quality of Life (O'Leary & Jones, 2000).

Co-morbid conditions, both cardiac and non-cardiac, are prevalent in heart failure patients. Studies reveal that comorbidities are linked with disease progression and effective response to treatment (Lang & Mancini, 2007), increased hospital readmission rates (Lagoe, Noetscher, & Murphy, 2001; Singh et al., 2005; Vinson et al., 1990), and increased cognitive deficiencies (Bennett, Sauve, & Shaw, 2005). Comorbidities influence patients' ability to maintain and manage self-care resulting in negative consequences (Carlson, Riegel, & Moser, 2001; Deaton et al., 2004).

Although there is a plethora of research identifying the types and numbers of comorbidities experienced by heart failure patients, studies are limited that examine the relationship between quality of life and comorbidities.

Question #3: What is the relationship of hope, social support, and self-care with quality of life in heart failure patients?

In this study, hope was found to be related to quality of life. Much of the Hope literature examines the concept of hope in an effort to define its meaning (Herth, 2002; Holtslander, 2008; Johnson, Dahlen, & Roberts, 1997; Kylma & Vehvilainen-Julkunen, 1997; Morse, 1995; Morse & Penrod, 1999; Westlake & Dracup, 2001) rather than examining the relationship between hope and other psychosocial variables. Although limited studies examine the relationship between quality of life and hope in the heart failure patient, similar to the findings in this study, the majority support a positive relationship between these variables

Patients with heart failure were found to have significantly higher levels of hope than a sample from the general population (Rustoen, Howie, Eidsmo, & Torgjorm, 2005). Hope was related to well-being, a construct of quality of life, in community-based older women (Davis, 2005), positively associated with the psychosocial component of quality of life (Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003), and significantly correlated with morale and social function (Rideout & Montemuro, 1986). However, the number of studies examining these concepts in this population is limited (Davidson, Dracup, Phillips, Daly, & Padilla; 2007) and restricts generalization of hope concepts.

Notably, the data from this heart failure study produced lower subscale reliability coefficients than the Herth Hope Index (Herth, 1992). The author sampled a heterogeneous group of individuals who were acutely, chronically, and terminally ill and who were being treated in multiple health care settings. However, Herth's sample did not include individuals who were treated in a military clinic for heart failure. It is not unexpected that differences in group would produce differences in reliability (Frank-Stromberg & Olsen, 2004).

Social Support was not found to be significantly related to Quality of Life in this study. Social Support is a complex concept with multiple definitions that influence and limit broad interpretation of study findings (Hupcey, 1998). Social support has been identified as a network of friends and neighbors (Cantor, 1979), divided into structural and functional constructs (Cohen, 1988; Lett et al., 2005), and recognized as different between care givers and care receivers (Meagher-Stewart & Hart, 2002).

Presence of Social Support helps decrease stress of illness (Bosworth, 2004), decreases incidence of depression (Park et al., 2006) and anxiety (Davidson et al., 2008), is a preventive factor in rehospitalization (Happ, Naylor, & Roe-Prior, 1997), predicts survival (Coyne et al., 2001), and is significantly associated with self-care (Sayers et al., 2008). Lack of social support has been identified as a predictor of mortality (Murberg, 2004) and poor social function has been linked with depression (Murberg et al., 1998). Although not statistically significant in this study, Social Support was related to Quality of Life in a positive direction.

Not all studies are supportive of a relationship between social support and quality of life. Higher levels of social support were associated with lower levels of perceived health (Rosen, Contrada, Gorkin, & Kostis, 1997). Social Support was found to be a barrier during a life transition with women expressing concern about being a burden and reluctance to ask for help (Harrison, Neufeld, & Kushner, 1995). Bennett et al. (1997) found little difference in perceived social support between hospitalized and nonhospitalized patients. Higher levels of social support predicted hospital admissions (Bennett et al., 2001). Perceived social support decreased following an intervention to improve self-care in a group of heart failure patients when compared to a control group (Riegel & Carlson, 2004).

Self-Care was not found to be significantly related to Quality of Life in this study. Self-Care practices are critical to management and maintenance of health and well-being in heart failure patients. Yet there are limited studies examining this concept especially when related to quality of life.

Characteristics necessary to predict self-care ability have been identified. Patients were more likely to engage in self-care behaviors if they were better educated and had more severe symptoms (Rockwell & Riegel, 2001), were older, male, and had fewer comorbidities (Chriss, Sheposh, Carlson, & Riegel, 2004). Lower socioeconomic status and older age were found to decrease self-care behaviors (Gary, 2006a).

Although Self-Care was not found to be significantly related to Quality of Life in this study, the findings indicate a positive direction suggesting that higher Quality of Life is related to better self-care. It is possible that Self-Care as measured by the SCHFI did not capture all essential components of self-care. Although recognized as a measure with sufficient promise (Frank-Stromberg & Olsen, 2004), methodologic issues exist. The authors have revised the instrument: adding items, refining existing items, and refining the scoring procedure (Riegel, Lee, Dickson, & Carlson, 2010). It is possible that utilization of the revised measure would have resulted in different findings in the study population.

Additional findings:

Among the three key independent variables, significant differences were found between the hope subscale sense of temporality and ethnicity indicating that higher hope was associated with Hispanic ethnicity when compared to non-Hispanic ethnicity ($r = -.444, p = .018$). Self-care confidence and marital status demonstrated significant differences with divorced patients indicating higher levels of self-confidence when compared to married patients

($r = .304, p = .014$). It should be noted that in each of these findings the number of participants in the group demonstrating a relationship with the key independent variable was small. In the case of ethnicity, n equaled 2 for the Hispanic group while n equaled 26 for the Non-Hispanic group and n equaled 4 for the divorced group and n equaled 45 for the married group.

Ethnicity and self-care were found to be inversely related ($r = -.421; p = .032$) suggesting that Hispanic patients were less likely to perform self-care than Non-Hispanic patients. Again, the small number of participants must be considered when interpreting these findings.

However, the Hispanic community has been underrepresented in heart failure studies (Yu, Lee, Kwong, Thompson, & Woo, 2007). The significance of these findings despite the small number of participants indicates a need for further exploration of the relationship between race/ethnicity and quality of life.

In this study, better Quality of life in heart failure patients was found to be significantly related to functional status, length of time diagnosed with heart failure and hope. Although not statistically significant, higher levels of social support and self-care exhibited positive trends toward better quality of life as well. Based on these findings, implications for nursing practice, education, and research will be discussed.

Limitations

This descriptive, correlational study examined relationships and did not attempt to identify causes of the relationships. Only the variables of hope, social

support, and self-care were examined in relation to quality of life although there are numerous other psychosocial variables that were not selected for inclusion. The majority of the participants were Caucasian, male, married, and over the age of 61 years. The findings are limited to a specific population of heart failure patients who attended a military based outpatient clinic and cannot be generalized to other populations.

It should also be noted that the Self-Care in Heart Failure Index, although found to be a tool that shows significant progress for use in research (Frank-Stromborg & Olsen, 2004) continues to be limited by the lower alpha coefficient for the self-maintenance scales (Riegel, Lee, Dickson, & Carlson, 2009).

Implications for Nursing Research, Practice, and Education

Nursing is a science that addresses the holistic nature of human beings. Nursing practice focused on the health/illness experience of heart failure patients is influenced by environmental, cultural, economic, physical, psychological, and social factors. The significance of hope, functional status, and length of time diagnosed with heart failure related to quality of life revealed in this study provides a framework for nursing research, practice, and education recommendations.

Nursing Research

In this study, patients diagnosed with heart failure for less than one year, who had greatest functional status, and exhibited higher levels of hope experienced greater quality of life. It is believed that this is the first time that these three variables have been predictive of quality of life in heart failure patients. In an effort to substantiate the strength of this model, studies should be designed that replicate this study. In addition, studies should be designed to include other psychosocial variables, such as depression, to test their influence on the model.

Research has already demonstrated the relationship between depression and poor quality of life in this population. Findings in this study support the inclusion of hope as a component in the treatment plan for heart failure patients. Hope is often conceptualized as necessary to prevent or mitigate depression. Future studies should examine the relationship between hope and depression in the heart failure patient population. Findings will guide development of patient care interventions and strengthen utilization of a patient care model that incorporates psychosocial variables.

Based on the size and unique characteristics of the sample, additional research is needed to test the predictive value of this model in larger, diverse populations. Within the San Diego health care environment, there are other heart failure outpatient clinics that are not connected with the military services. It is recommended that this study be replicated in those settings to test the predictive value of the model.

Additional research is necessary to examine the influence of different heart failure clinic treatment models on quality of life. One of the clinics in this study utilized a team approach with nurses, pharmacists, dieticians, and physicians contributing to patient management. In the other clinic, treatment was provided employing a pharmacist-only model. A comparison study between the two models would help guide patient management decisions. It would also be helpful to factor cost analysis into the study to determine the most efficient model. Of course cost alone cannot be the single determinant of the most effective care, but it is a necessary component.

This study revealed that hope was significantly related to quality of life. However, hope and quality of life studies are limited in this patient population and additional research is needed. Qualitative studies would provide deeper understanding of patients' perceptions of hope and quality of life. Two facts support the use of this study population for additional research. First, the patients have already been introduced to and worked with the investigator. Second, the investigator's established relationship with the agency would facilitate initiation of a new study. Findings will provide insight into hope beliefs and practices that influence quality of life. These findings can then be used to replicate studies in other populations and provide the foundation for hope interventional studies.

Use of a military based sample is a unique feature of this study. Although there are studies that examine quality of life or hope in the outpatient setting, studies related to a military based population participating in an outpatient setting are essentially nonexistent. The study population received treatment from the

Department of the Navy. It is recommended that this study be replicated testing populations from other branches of the military services.

Levels of self-care were found to be above average in this study. This finding differs from other studies where participants are not associated with the military services. The majority (72.3%) of patients were men who were currently active or who had served in the military. The female patients were family members who qualified for health care provided by the Navy. In either case, life circumstances and provision of health care are influenced by the military experience that differs from that of the general population.

Qualitative studies could help identify self-care traits that are unique in this population. Additional studies would be necessary to identify self-care traits in non-military populations. Similarities may exist, or findings might reveal differences. In either case, identification of any characteristics that promote self-care would help shape supportive interventions.

Living environment was not an included variable in this study, yet hope levels have been found to be related to type of residence. It is probable that this outpatient sample lived in private homes. Exploration of the relationship of residence to hope and quality of life in this and other populations would support the ability to provide appropriate interventions for the distinct living circumstances of people with heart failure.

Additional research regarding the roles of social support and self-care in quality of life is also recommended. Most research findings demonstrate a positive relationship among these variables. Although social support and self-care

in this study were not found to be significantly related to quality of life, the positive direction of the findings should be noted. Nurses must continue to scrutinize the existing evidence and create new studies that include these variables in a variety of healthcare settings.

The predictive model included hope in addition to functional status. In this study, as in the majority of studies, optimal functional status was found to be related to better quality of life. It should be noted that there are two systems that grade functional status. The system used in this study utilized the NYHA Classification which relates patient symptoms to activities of daily living. The American College of Cardiology/American Heart Association's Stages of Heart Failure measures heart failure risk and severity based on structural changes in the heart. Further research should examine the relationship between these two classification systems to test if the levels in one tool correlate with the levels in the other tool. If a correlational relationship was identified, use of the NYHA Classification system would be a much less invasive and more cost effective method of determining functional status.

In this study, the relationship between quality of life, hope, social support, self-care and number of hospitalizations within the previous twelve months was examined. Although nonsignificant in this study, previous research has substantiated the high percentage of heart failure hospital admissions with the accompanying physical, social, and financial burdens to individuals and society. Additional studies are needed to identify which psychosocial variables are related to decreased (or increased) number of hospital admissions. Then specific

interventions can be designed and incorporated into treatment plans. Further research will be necessary to test the relationship between these new models of treatment and the rate of hospitalization.

Review of the literature revealed the majority of heart failure and quality of life studies focused on Caucasian participants. In this study, findings related to ethnicity indicate differences between Hispanic and non-Hispanic hope and self-care. Additional research is needed that explores the unique characteristics of quality of life in different races and in women. The same is true for understanding hope in different cultures. Data that is both measurable and specific can then be used to create and implement interventions that meet the needs of different populations.

Multiple studies have examined the types and numbers of comorbidities present in heart failure populations. Negative patient outcomes such as increased disease progression, number of hospital readmissions, and cognitive deficiencies have been demonstrated. In this study, comorbidity and quality of life were not found to be significantly related. However, few studies exist that examine the relationship between comorbidities and quality of life. This is an area requiring additional research especially when the number of negative outcomes associated with comorbidities is considered. Identifying how and which comorbidities are significantly related to quality of life will help target interventions.

Existing quantitative studies, including this study, have identified the significant relationship between hope and quality of life. Qualitative studies in patient populations have identified hope-fostering strategies. Interventional

studies that test the ability of hope promoting strategies to improve patient outcomes are the requisite next step. Few exist.

A possible interventional study based on the suggested heart failure treatment model (see Figure 2) is suggested. Individuals being treated for heart failure in an outpatient setting could be randomly assigned to intervention or usual-treatment groups. Both groups would receive the same medical and lifestyle management care but the intervention group would receive additional psychosocial support. Outcome variables would include quality of life and the number of health care interactions including hospital admissions and readmissions. Optimally, this would be a longitudinal study.

Nursing Practice

The findings in this study reveal the significance of the psychosocial variable hope, the physical characteristic functional status, and length of time diagnosed with heart failure in relation to patient outcomes. These variables significantly influenced patients' quality of life which underscores the importance of inclusion of psychosocial variables in the heart failure treatment model.

Hope is often described as ambiguous and difficult to define, yet it is universally recognized as a "powerful force" (Harvard Heart Letter, 2008, p2). The significance of hope in quality of life has been increasingly studied in multiple populations. The findings in this study provide additional support for the importance of hope in achieving quality of life. High levels of hope were found in this population of heart failure patients who attended a military based outpatient

clinic. Once hope levels were defined, the relationship between hope and quality of life was examined and found to be significant.

In this population, hope was measured using a multidimensional, reliable and valid, quantitative tool – the Herth Hope Index. The supporting hope framework that underpins this tool is based on three constructs: belief in a positive, achievable outcome; confidence necessary to initiate and implement a plan; and interconnectedness within self and among others (1992).

Heart failure is ultimately a terminal disease. Focus on this fact alone may result in patient feelings of hopelessness and despair resulting in lack of desire to participate in treatment. The balance between hope and hopelessness is easily disturbed. Changes in heart failure stability may result in patients' loss of hope. The first Hope construct promotes application of nursing actions that foster patients' belief in the possibility of a positive outcome. Nurses can help patients achieve balance and control in their health by honest, open dialogue about the course of heart failure and the role of the patient in preventing complications.

Nurses may be reluctant to share factual information with patients based on fear that knowledge regarding disease course will inhibit patient willingness to invest effort in a treatment plan. Patients must be encouraged to believe that a positive outcome is possible even if it is not related to a cure. Goals must be realistic however. Hope that is not grounded in reality leads to disappointment and lost opportunities. Empowering patients to develop realistic goals enables them to plan care that they perceive as important and achievable. Nurses are in a

unique position to help patients realistically identify health goals and support them in their belief that they can be successful.

Nurses can help patients look for alternative methods of goal achievement. Negative outcomes when treatment plans are not implemented cannot be ignored and may even be useful as a method to motivate treatment adherence. Incorporating cultural practices provide comfort and foster hope as well.

The second Hope construct involves confidence necessary to start and move a plan forward (Herth, 1992). Confidence requires an individual's certainty of their ability to achieve a goal. Again, nurses can help patients by emphasizing potentials rather than barriers to goal achievement. Yet, confidence cannot be sustained if not built on a realistic foundation. Nurses must recognize the potential for conflict between ideal treatment goals and the patient's treatment goals.

Nursing interventions must include focus on the patient's goals. An ability to provide supportive, nonjudgmental listening assists goal identification. Providing accurate information facilitates informed decision making. Nursing presence signals support and validates patients' efforts. These actions all send messages of confidence in patient's ability to achieve goals. Nurses must be willing to allow patient to express their fears, ask questions, and discuss failures within a caring environment.

In a study by Rustoen, Howie, Eidsmo, and Moum (2005) it was discovered that hospitalized heart failure patients had higher hope levels than the general public. The authors suggested that this finding "was counterintuitive because heart failure is associated with high morbidity and mortality" (p. 422) but

then proposed that response to a life threatening disease may result in a change in how quality of life is perceived. Morse and Doberneck also found that a realistic understanding of a threatening situation leads to a determination to endure that requires focused energy and hope (1995). These studies may help explain the finding in this study whereby improved quality of life was significantly related to newness of diagnosis. Recognizing this window of opportunity, nurses should direct intense teaching efforts to support patient management of disease.

Encouraging patients to recognize and utilize their inner strengths is another methodology for increasing confidence. Herth defined courage, determination, and serenity as values to be fostered (1990). Nurses can speak directly to these qualities by asking questions about how challenges were successfully met in the past. These identified methods can then be acknowledged by the nurse as a component of the care plan that will bolster the patient's ability to self-care effectively.

Humor provides a release from problems for many people. Herth noted the importance of "light heartedness" as a hope behavior (2002, p 1150) but nurses must be careful when using this approach. Not all people appreciate humor in the same manner so interventions must be patient specific.

Older adults are more likely to develop heart failure and have unique perceptions of hope. Hope fostering strategies that should be incorporated into patient care include: encouraging uplifting memories (Herth, 1993), focusing on the past rather than the present (Rustoen et al., 2005), and engaging in purposeful activities (Herth, 1993; Rideout & Montemuro, 1986). Depending on the patient's

functional status, these behaviors could range from active community involvement to the more physically passive providing prayer and phone calls for others.

According to Herth, use of hope objects was found to increase hope in older adults. Inanimate objects that have special significance for individuals were found to renew hope (1993). Nurses can ask patients and families to identify objects that provide them with a sense of comfort. Efforts should be made to make sure these objects are available for the patient.

The third Hope construct involves interconnectedness between inner resources and social resources (Herth, 1992). The nurse can promote inner resources development by way of caring relationships with patients and through support of spiritual beliefs.

Patients often identified spiritual beliefs as the primary mechanism for bolstering hope. In addition, faith in medical treatment and family and friends were important sources of hope (Hardin, Hussey, & Steele, 2003; Westlake & Dracup, 2001). Studies have established the important relationship between spiritual beliefs and hope (Davis, 2005; Herth, 1990; Herth, 1992; Herth, 1993; Rustoen et al., 2005). Nurses can foster hope by identifying patients' spiritual needs and preferences. Encouraging clergy visitation, providing uninterrupted time for prayer and meditation, and facilitating use of specific religious practices all support patient comfort and hope. Recognizing and promoting spiritual practices in any health care setting facilitates hope development.

Hope arises from within but is supported from without. Social relationships help bolster hope. Interconnectedness implies meaningful links with significant others such as family, friends, pets; or nature and the world (Herth, 1993). Supporting family participation in patient care and goal setting, allowing time for friend and family visitation, allowing patients as much control over social situations as possible all nurture hope. Nurses must support patient and family participation in health care decision making. Nurses recognize their patient advocacy role when they enlist other health care providers in support of patient/family control as a method of sustaining hope.

Nurses have a significant role as providers of connectedness that inspires hope. This was demonstrated in Herth's study of homeless families. Nurse-provided health care services were found to be significantly related to hope (1996). Caring gestures such as holding a hand or touching a shoulder, in addition to caring presence are indicative of the nurse's desire to connect with the patient.

Davidson, Dracup, Phillips, Padilla, and Daly identified a theoretical framework for hope in transition. Heart Failure diagnosis is recognized as a sentinel event necessitating patient and family transitions related to physical, social, psychological, and existential dimensions. The authors describe the interaction between hope and control as modifying perception of well-being and illness (2007).

Johnson, Dahlen, and Roberts also advocated for control over physiological illness as a method of restoring hope (1997). Nurses must apply interventions that ensure physiologic comfort and well-being. Meeting patient

needs for physical comfort has been identified as the most important nursing role in hope by caregivers of terminally ill individuals (Herth, 1993).

Of pragmatic concern is the ability of nurses to provide this level of personal interaction in an acute care setting. Heart failure clinics and outpatient services may lend themselves more readily to these practices. However, if the nurse is unable to implement particular hope measures due to time constraints, other resources should be identified and utilized. Family and friends are frequently available to help the patient but often don't know how to provide support. The nurse can make suggestions that will meet both patient and care provider needs. Other resources, such as social workers and clergy which are typically available in health care settings, can be enlisted. As the patient's advocate, the nurse has responsibility to coordinate all aspects of patient care utilizing all available resources.

In addition to hope enhancing practices, nurses must recognize hope hindering behaviors. Abandonment and isolation, uncontrollable pain, and loss of value as a human being have been identified as threats to hope (Herth, 1990; Herth, 1992). Davis found a negative relationship between anxiety and hope (2005). Recognition of hope destroying behaviors and situations can prevent inadvertent use in the clinical setting.

In this study, a heart failure diagnosis of less than one year was found to be significantly related to improved quality of life when compared to a diagnosis of 11 years. Statistical support for an intuitive assumption underlines the need for additional exploration of the relationship between time diagnosed with heart

failure and quality of life. Why does quality of life change at 11 years rather than at an earlier time? Is this relationship true in other heart failure populations?

If less than 50 percent of patients survive 5 years following an initial diagnosis (Heart Failure Society of America, 2008), is additional research necessary? Thirty one percent of the sample in this study was diagnosed with heart failure for 11 years. That number becomes important when two facts are considered. One, treatment options have greatly extended the life span of heart failure patients. Two, increasing numbers of adults – the baby boomer population – are of an age where development of heart failure substantially increases. Combined, these two facts increase the likelihood that large numbers of people will develop heart failure. Identifying the significance of disease-specific timeframes should facilitate development of interventions to foster improved quality of life.

In this study, quality of life was associated with functional status such that patients who were unimpaired by their disease had better quality of life than those who had physical function limitations. Nurses must consider the significance of early identification of risk factors in an effort to prevent or forestall progression of heart failure. The question must be asked: Should all individuals be screened for heart failure?

Asymptomatic (early stage) heart failure has been identified in well populations (Ammar et al., 2007). Progression to symptomatic heart failure would create an overwhelming social and economic burden. Creation and implementation of programs to screen for risk factors is clearly within the nursing

purview. Once risk is identified, individualized interventions could be designed to limit disease progression and therefore cost to individuals and society.

Nursing practice has historically focused on health promotion and disease prevention. The recognition of heart failure as a national (Rasmusson, Hall, & Renlund, 2006) and international (McMurray, Petrie, Murdoch, & Davie, 1998) epidemic requires immediate attention. Of all health care providers, nurses are best prepared to address the complexity of heart failure care practices that range from education regarding risk factors to end-of-life issues. In a health care environment that begs for redesign, nurses are in an ideal position to establish a cost effective, evidence-based health care model that is built on health promotion principles.

A new heart failure treatment model, with a framework based on the findings of this study is suggested. The new model (see Figure 3) should contain traditional components – medication, diet, and life style management – but would also include a quality of life component. The Quality of Life component would be based on patient-identified goals and include psychosocial variables that have been associated with positive patient outcomes.

Nursing Education

With a diagnosis of heart failure, life is forever altered for the individual. In an effort to improve patient outcomes, understanding and implications of the disease are of critical importance. Education of patients and families has shown

that nursing interventions improve heart failure patients' outcomes (McCauley, Bixby, & Naylor, 2006; Naylor et al., 2004; Sisk et al., 2006).

But nurses must also educate themselves regarding heart failure. In a study of 300 nurses, it was discovered that many were not adequately knowledgeable regarding heart failure management (Albert et al., 2002). Training modules should be designed to meet the needs of the student, novice, and experienced nurse. Based on the findings in this study, the importance of psychosocial variables in the management of heart failure must be included.

Of additional concern is the patient perception of Heart Failure as an acute rather than chronic illness. In a study by Horowitz, Rein, and Leventhal; patients believed that once symptoms were gone, they were cured and did not take responsibility to monitor their heart failure (2004). Nurses have a responsibility to inform patients of the true nature of their disease and the importance of health promotion in an effort to halt disease progression.

Awareness of high levels of morbidity and mortality (American Heart Association, 2009) related to heart failure compels nurses to examine their own beliefs surrounding end-of-life issues. Without an understanding of the value of hope in terminal stages of care, opportunities for patient and family support will be missed. The medical model as practiced in the acute care environment does not always lend itself to examination of these issues. Nurses are often placed in the position of intermediary for patients and other health care providers when treatment goals are not the same. Traditional pharmacological and lifestyle

management is important, but nursing practice encompasses options that may be more important to patients and families.

Hope is being increasingly addressed in the nursing literature. However, a gap between the body of hope knowledge and incorporation in nursing curriculum exists. Hope-focused teaching is “sporadic and inconsistent” according to Herth and Cutcliffe (2002). But hope could easily be incorporated into case scenarios that are often part of nursing education.

Herth and Cutcliffe further state that the current body of hope information has little presence outside the nursing literature (2002). Nurses must educate other health care providers regarding the growing body of hope-related research that demonstrates improvement in patient quality of life. Nurses must increase efforts to work as members of health care teams that guide practice and participate in policy making organizations in order to ensure that the need for hope-related education remains visible.

Health Care Policy

With the recent passage of health care overhaul legislation, provision of health care to millions of uninsured Americans is guaranteed. Focus on health insurance coverage is necessary; however, policy changes that address the need for illness prevention and health promotion services are limited.

Relevant to the search within the United States for an effective health care model is recognition of the power of psychosocial variables to influence patients' quality of life. It is imperative to develop new models of health care that not only

include, but place value on factors outside the medical model that improve quality of life and reduce cost. Nurses are in a key position to provide such services.

First, confusion about heart failure must be addressed. Public perception of heart failure is often inaccurate; heart failure is perceived as an end of life condition for which little can be done. The public is not adequately informed about the risks for development of heart failure and steps that can be taken to ameliorate disease progression. Although well aware of the dramatic symptoms of heart attack, people are unaware of the subtle symptoms of heart failure.

Misperceptions about heart failure exist even among health care providers despite best practice guidelines that have been designed by recognized leaders in heart failure care. Health care practitioners often focus on management of acute problems rather than focusing management of a chronic condition.

Education is critical for both citizens and health care providers. Public information campaigns designed by nurses and executed by public health agencies should be aggressively promoted.

Second, research and treatment biases must be recognized and addressed. Studies fail to include certain segments of the population. Gender and age discrimination result in failure to recognize unique symptoms and implement appropriate treatment. Research involving non-white participants is limited resulting in treatment disparities. The unique needs of different groups must be identified and treatment plans implemented in an effort to mitigate the course of heart failure. In addition to medication and lifestyle interventions, clinical trials

must include psychosocial variables which have been demonstrated to improve patients' quality of life.

Finally, responsibility for health requires both individual accountability and societal action. Individuals must be educated throughout their lifespan in order to make lifestyle choices that reduce risk of heart failure. The goal is twofold: preventing heart failure and improving the quality of life once heart failure is confirmed.

Social and legislative efforts must include environmental planning that makes it possible to achieve healthy lifestyles. Safe areas for exercise and physical activity must be created. Access to nutritious, reasonably priced foods must be ensured. Health insurance savings for health promotion activities can provide incentives for the maintenance of healthy lifestyles.

Nursing maintains a social contract with individuals and communities. As the largest health care profession, nurses can influence public perception of health. Rather than continued funding for the medical model's focus on disease and illness, nurses must advocate for new health care models that focus on prevention and health promotion. This is both fiscally and ethically prudent.

Nurse directed education and research can greatly influence health practices. Involvement in societal and legislative forums will ensure communication with a public who trust information from a nurse. A unique convergence of events has created a platform for nursing action that will improve quality of life not only for heart failure patients but for all Americans!

Summary

The purpose of this study was to examine the relationship between hope, social support, self-care, and quality of life in heart failure patients that has emerged from the literature. In order to accomplish this purpose, research questions were designed to test these relationships in a population of heart failure patients who attended military based heart failure clinics. Quality of Life was found to be significantly related to hope; patients with improved quality of life had higher hope levels. Social support and self-care were not found to be significantly related to quality of life.

Of the proposed Research Questions, findings revealed those patients who were diagnosed with heart failure for one year had improved quality of life compared to patients who were diagnosed with heart failure for eleven years. Functional status was also related to Quality of Life; patients who had no physical impairments (functional status Class I) had a better Quality of Life than patients who had slight to debilitating physical impairments (functional status Classes II, III, IV). Age, gender, race/ethnicity, marital status, and co-morbidity were not significantly related to Quality of Life.

Multiple regressions were generated to determine the accuracy of length of time diagnosed with heart failure and functional status as predictors of quality of life while controlling for hope, self care, and social support. Functional Status was found to be the major predictor of Quality of Life followed by Hope.

Quality of Life has been established as an important patient outcome. This study supports the inclusion of hope fostering interventions and further

examination of functional status and length of time of heart failure diagnosis in efforts to support heart failure patients' quality of life. The holistic philosophy of nursing makes it well suited to incorporate these findings into practice.

Traditional heart failure care models focus on pharmacologic and lifestyle management of disease. Certainly these interventions are important, but they are not enough. Increased understanding of the relationship between psychosocial factors and patient outcomes necessitates their inclusion in heart failure care. Funding must be allocated to support education and research that supports development of new, cost effective models of care. Nursing is the ideal health care profession to move this agenda forward.

Appendix A

Consent Forms for Research

Research Project Information Sheet

Location of Research - Naval Medical Center San Diego

Dear Subjects:

The Naval Medical Center in cooperation with the Cardiology Department and the Heart Failure Clinic Personnel, is conducting a research project titled "**Quality of Life and Psychosocial Variables in Heart Failure Patients**" to study: the relationship of quality of life and hope, social support, and self-care in heart failure patients.

Your Cooperation is greatly appreciated.

The purpose of this research is to help doctors, nurses, and other health care providers understand your feelings about living with heart failure. This information may be used in the future to provide you and other patients with treatment plans that are specially designed for people with heart failure.

Study Procedures - If you agree to participate, the following procedures will be performed: completion of four written surveys that will take approximately 45 - 60 minutes to complete.

No personal identifiers will be recorded to protect your privacy.

Risks - Participants may be at risk for: fatigue, and negative emotions such as anxiety and sadness.

Benefits - The findings will help us learn more about how you are feeling and functioning with your heart failure.

Your participation in this study is entirely voluntary and if you elect not to participate, there will be no penalty and you will receive standard of care medical treatment.

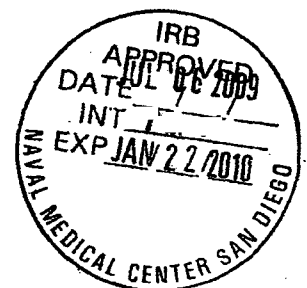
Confidentiality - In all publications and presentations resulting from this research study, information about you or your participation in this project will be kept in the strictest confidence and will not be released in any form identifiable to you personally.

If you have any questions regarding this research study, **you may contact (Karen McGurk) at (619) 981-6562.**

Subject's Initials: _____

IRB Approval Stamp/Seal Required

(Do not make any alterations to this documents w/out prior approval)



If you have any questions about your rights as an individual while participating in a research study at the Naval Medical Center, San Diego, you may contact **CDR D. A. Tanen, MC, USN, Chairman, Institutional Review Board at (619) 532-8125, or CAPT Peter Linz, MC, USN, Head, Clinical Investigation Department at (619) 532-6099.** If you believe that you have been injured as a result of your participation in this research study, you may contact **CDR Mary Ellen Moss, JAGC, USN, Naval Medical Center, San Diego, Legal Department, at (619) 532-6475.**

This form is yours to keep for your information. Thank you.

If you have any further Questions or Concerns, Please speak to one of the Physicians.

SIGNATURE

You are making a decision whether or not to participate in the research project above. Your signature indicates that you have had this information presented to you, have had the opportunity to ask questions about the research and your participation, and agree to participate in the study. Further, your signature indicates that you have been provided with a copy of this consent document, a Health Information Portability and Accountability Act (HIPAA) Patient Authorization form and a document entitled, "California Experimental Subject's Bill of Rights."

SIGNATURES AND DATE SIGNED: PRINTED OR TYPED IDENTIFICATION:

Patient / Subject (Date)

Name

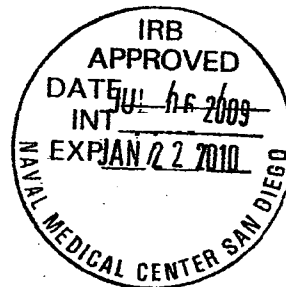
Investigator/ Researcher (Date)
(Person obtaining consent)

Name / Grade or Rank

Subject's Initials: _____

IRB Approval Stamp/Seal Required

(Do not make any alterations to this documents w/out prior approval)



Research Project Information Sheet

Location of Research - Naval Hospital Camp Pendleton

Dear Subjects:

The Naval Hospital Camp Pendleton, in cooperation with the Cardiology Department and the Heart Failure Clinic Personnel, is conducting a research project titled **"Quality of Life and Psychosocial Variables in Heart Failure Patients"** to study: the relationship of quality of life and hope, social support, and self-care in heart failure patients.

Your Cooperation is greatly appreciated.

The purpose of this research is to help doctors, nurses, and other health care providers understand your feelings about living with heart failure. This information may be used in the future to provide you and other patients with treatment plans that are specially designed for people with heart failure.

Study Procedures - If you agree to participate, the following procedures will be performed: completion of four written surveys that will take approximately 30 minutes to complete.

No personal identifiers will be recorded to protect your privacy.

Risks - Participants may be at risk for: fatigue, and negative emotions such as anxiety and sadness.

Benefits - The findings will help us learn more about how you are feeling and functioning with your heart failure.

Your participation in this study is entirely voluntary and if you elect not to participate, there will be no penalty and you will receive standard of care medical treatment.

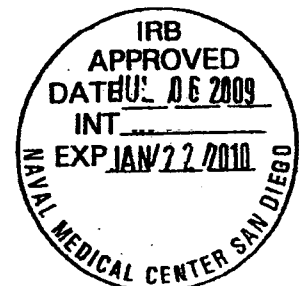
Confidentiality - In all publications and presentations resulting from this research study, information about you or your participation in this project will be kept in the strictest confidence and will not be released in any form identifiable to you personally.

If you have any questions regarding this research study, **you may contact Karen McGurk at (619) 981-6562 or CAPT Linnea Axman at (619) 532-7700.**

Subject's Initials: _____

IRB Approval Stamp/Seal Required

(Do not make any alterations to this documents w/out prior approval)



If you have any questions about your rights as an individual while participating in a research study at the Naval Medical Center, San Diego, you may contact **CDR D. A. Tanen, MC, USN, Chairman, Institutional Review Board at (619) 532-8125, or CAPT Peter Linz, MC, USN, Head, Clinical Investigation Department at (619) 532-6099.** If you believe that you have been injured as a result of your participation in this research study, you may contact **CDR Mary Ellen Moss, JAGC, USN, Naval Medical Center, San Diego, Legal Department, at (619) 532-6475.**

This form is yours to keep for your information. Thank you.

If you have any further Questions or Concerns, Please speak to one of the Physicians.

SIGNATURE

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SIGNATURES AND DATE SIGNED: PRINTED OR TYPED IDENTIFICATION:

Patient / Subject (Date)

Name

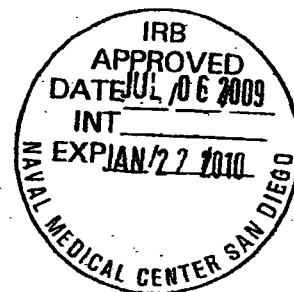
Investigator/ Researcher (Date)
(Person obtaining consent)

Name / Grade or Rank

Subject's Initials: _____

IRB Approval Stamp/Seal Required

(Do not make any alterations to this documents w/out prior approval)



PATIENT AUTHORIZATION TO USE AND/OR DISCLOSE PROTECTED HEALTH INFORMATION FOR RESEARCH (HIPAA)

(In Keeping with the Health Insurance Portability and Accountability Protection Act)

What is Confidentiality of records all about?

The Naval Medical Center San Diego makes every effort to maintain the confidentiality of protected health information we obtain about you. However, we cannot absolutely guarantee confidentiality because other people may need to see your information in the course of this research study. Most people and organizations will protect the privacy of your information, but may not be required to do so by the law. Also, if the results of this research study are presented at meetings or are published, your name will not be used.

What is HIPAA all about?

The Health Insurance Portability and Accountability Act (HIPAA) requires that we get your permission to use protected health information about you that is either created by or used in connection with this research study. This permission is called an Authorization. The information we use includes your entire research record and supporting information from your medical records, results of laboratory test, X-rays, MRIs, CT scans and observations made by a physician or nurse which are both clinical and research in nature.

[Principal Investigators: List any other specific information that you may use or disclose as you've indicated in your protocol.]

What will we do with this information?

Your protected health information will be collected and used during the course of the research study, to monitor your health status, to measure the effects of drugs or devices or procedures, to determine research results, and to possibly develop new tests, procedures, and commercial products.

Your research doctor will use this information to report the results of research to sponsors and federal agencies, like the Food and Drug Administration (FDA). The information may also be reviewed when the research study is audited for compliance. When the study is over, you have the right to see the information and copy it for your records.

Who will we share your information with?

Your information may be shared with any of the following:

- The sponsor of the study, or its agents, such as data repositories
- Other medical centers, institutions, or research investigators outside of the Naval Medical Center San Diego, participating in this research study
- State and Federal agencies which have authority over the research, the Naval Medical Center San Diego or patients. Good examples are: the Department of Health and Human Services (DHHS), the Food and Drug Administration (FDA), the National Institute of Health (NIH), the Office of Human Research Protections (OHRP), and the Department of Social Services (DSS) or other.
- This hospital or clinic.
- Accrediting agencies, such as JCAHO.
- A data safety monitoring board, if applicable
- Clinical staff who may not be involved directly in the research study, but who may become involved in your care, if it is possibly related to treatment

For this research study, the study investigator may share this authorization form and records which identify you to comply with regulatory requirements or for purposes related to this research to:

All documented Principal, Associate, and Sub-Investigators, and the Medical Monitor (if one is assigned). In addition,

[Principal Investigators: groups of persons, or organization, including data monitoring committee, government agencies, companies, coordination centers, data management centers, other research sites, etc., who might receive and/or use the information. If a person or organization is not included on the research authorization form, that person or organization may neither receive nor create nor use protected health information for research purposes.]

What if you want to revoke or cancel away your Authorization?

If you decide to participate in this research study, your Authorization for this study will not expire unless you revoke or cancel it in writing to the research doctor. If you revoke your Authorization, you will also be removed from the study, but standard medical care and any other benefit to which you are entitled will not be affected in any way.

Revoking your Authorization only affects the use and disclosure (sharing) of information after your written request has been received. Federal law requires sending study information to the FDA for studies it regulates, like studies of drugs and devices. In a case like this, your information may need to be reported to them and cannot be removed from the research records once it is collected.

Do you have to sign this form?

You have the right to refuse to sign this Authorization form and not be a part of this study. You can also tell your study doctor you want to withdraw from the study at any time without revoking the Authorization to use your health information. By signing this research Authorization form, you authorize the use and/or disclosure of your protected health information described above.

SIGNATURE AND DATE SIGNED:

PRINTED OR TYPED IDENTIFICATION:

Patient/Subject (Date)

Name/Status/Sponsor's SSN

Witness (Date)

Name/Grade or Rank

Researcher/investigator (Date)

Name/Grade or Rank

11 July 2009

From: Karen McGurk RN, MN, University of San Diego, Principal Investigator of NMCSO.2008.0142

To: Chair, Institutional Review Board, Naval Medical Center San Diego

Subj: NMCSO.2008.0142, "QUALITY OF LIFE AND PSYCHOSOCIAL VARIABLES IN HEART FAILURE PATIENTS"

Encl: (1) Letter of Introduction, Medical Director
(2) Cover Letter
(3) Participant Information Sheet for NMCSO.2008.0142
(4) Participant surveys for NMCSO.2008.0142

1. I have been collecting data for my study in the Heart Failure Clinic since February 27, 2009 with a resulting 40 participants. At least 80 participants are required for this descriptive study to have significance.
2. I respectfully request your consideration for the use of mailed questionnaires to heart failure patients who utilize the services of the cardiologists and the Heart Failure Clinics at the Naval Medical Center San Diego. Only heart failure patients will be included.
3. This method of participant enrollment would allow myself, as Principal Investigator (PI), to access patients who are doing well and do not come to the Heart Failure Clinic with any regularity. It would also provide access to patients who have been referred to, but have not yet attended the clinic.
4. Participants will be sent a packet that includes a cover letter explaining the study, research information sheet and confidentiality documents, the four questionnaires and demographic form, and a stamped envelope with the PI's home address. PI contact information will also be included.
5. Daniel Seidenstick, CDR, MC, USN, Medical Director, Heart Failure Clinic, NMCSO has given full support to this method of recruitment and has written a letter of introduction to be included in the participant packet.
6. Please contact me with any questions at 619-981-6562 or by email at kmcgurkn@sbcglobal.net, or you can contact the study's Administrative Principal Investigator, CAPT Linnea Axman, at 619-532-7803 or by email at linnea.axman@med.navy.mil.

Very respectfully,

K. MCGURK



NMCSO. 2008. 0142-AM02-A

July 10, 2009

Dear Patient,

Karen McGurk RN is conducting a study about heart failure patients. Please read the attached letter and consider participating in her study. Participating in the study is completely voluntary. It is your choice whether you want to participate or not. If you are interested, there are 5 questionnaires for you to complete. When the forms have been completed, you can place them in the stamped envelope and return them to Karen McGurk.

This study has the support of the Heart Failure Clinic staff and has been approved by the Institutional Review Board, Naval Medical Center San Diego. Your participation is appreciated.

Respectfully,

Daniel Seidensticker, CDR, MC, USN
Medical Director, Heart Failure Clinic

Appendix B

Left Ventricular Dysfunction Questionnaire (LVD-36)

*Please answer the following questions as you are feeling **these days**.
Tick either true or false for each question.*

Because of my heart condition:	True	False
I suffer with tired legs.		
I suffer with nausea (feeling sick).		
I suffer with swollen legs		
Because of my heart condition:		
I am afraid that if I go out I will be short of breath.		
I am frightened to do too much in case I become short of breath.		
I get out of breath with the least physical exercise.		
I am frightened to push myself too far.		
I take a long time to get washed or dressed.		

If you do not do these activities for any reason other than your heart condition, then please tick false

Because of my heart condition:	True	False
I have difficulty running, such as for a bus.		
I have difficulty either jogging, exercising or dancing.		
I have difficulty playing with children/grandchildren.		
I have difficulty either mowing the lawn or hovering/vacuum cleaning.		

Because of my heart condition:	True	False
I feel exhausted.		
I feel low in energy.		

I feel sleepy or drowsy.		
I need to rest more.		
Because of my heart condition:	True	False
I feel that everything is an effort.		
My muscles feel weak.		
I get cold easily.		
I wake up frequently during the night.		
I have become frail or an invalid.		

Because of my heart condition:	True	False
I feel frustrated.		
I feel nervous.		
I feel irritable.		
I feel restless.		
I feel out of control of my life.		
I feel that I cannot enjoy a full life.		
I've lost confidence in myself.		

Because of my heart condition:	True	False
I have difficulty having a regular social life.		
There are places I would like to go to but can't.		
I worry that going on holiday could make my heart condition worse.		
I have had to alter my lifestyle.		
I am restricted in fulfilling my family duties.		
I feel dependent on others.		

	True	False
I find it a real nuisance having to take tablets for my heart condition.		
My heart condition stops me doing things that I would like to do.		

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. THANK YOU FOR YOUR TIME!

Appendix C

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook on life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that give me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have a deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

Appendix D

Medical Outcomes Study: Social Support Survey

People sometimes look to other for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle the number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/Informational Support					
Someone you can count on to listen to you when you need to talk.	1	2	3	4	5
Someone to give you information to help you understand a situation.	1	2	3	4	5
Someone to give you good advice about a crisis.	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5
Someone whose advice you really want.	1	2	3	4	5
Someone to share your most private worries and fears with.	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support					

Someone to help you if you were confined to bed.	1	2	3	4	5
	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to take you to the doctor if you needed it.	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5
Someone to help with daily chores if you were sick.	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection.	1	2	3	4	5
Someone to love and make you feel wanted.	1	2	3	4	5
Someone who hugs you.	1	2	3	4	5
Positive Social Interaction					
Someone to have a good time with.	1	2	3	4	5
Someone to get together with for relaxation.	1	2	3	4	5
Someone to do something enjoyable with.	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things.	1	2	3	4	5

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. THANK YOU FOR YOUR TIME!

Appendix E

SELF-CARE OF HEART FAILURE INDEX

All answers are confidential.

SECTION A:

Listed below are common recommendations for persons with heart failure. How often do you do the following?

	Never or rarely	Sometimes	Frequently	Always
1. Weigh yourself daily?	1	2	3	4
2. Eat a low salt diet?	1	2	3	4
3. Take part in regular physical activity?	1	2	3	4
4. Keep your weight down?	1	2	3	4
5. Get a flu shot every year?	1	2	3	4

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past three months, have you had trouble breathing or ankle swelling? Circle one.

1) No

2) Yes

6. The LAST TIME you had trouble breathing or ankle swelling,

(circle one number)

	I did not recognize it	Not quickly	Somewhat quickly	Quickly	Very Quickly
how quickly did you recognize it as a symptom of heart failure?	0	1	2	3	4

Listed below are remedies that people with heart failure use. When you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

(circle one number for each remedy)

	Not Likely	Somewhat Likely	Likely	Very Likely
7. Reduce the salt in your diet.	1	2	3	4
8. Reduce your fluid intake.	1	2	3	4
9. Take an extra water pill.	1	2	3	4
10. Call your doctor or nurse for guidance.	1	2	3	4

11. If you tried any of these remedies the last time you had trouble breathing or ankle swelling,

(circle one number)

how <u>sure</u> were you that the remedy helped or not?	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
	N/A	1	2	3	4

SECTION C:**(circle one number)**

	Not confident	Somewhat confident	Very confident	Extremely confident
12. How confident are you that you can <u>evaluate the importance of your symptoms</u> ?	1	2	3	4
13. Generally, how confident are you that you can <u>recognize changes</u> in your health if they occur?	1	2	3	4
14. Generally, how confident are you that you can <u>do something</u> that will relieve your symptoms?	1	2	3	4
15. How confident are you that you can <u>evaluate the effectiveness</u> of whatever you do to relieve your symptoms?	1	2	3	4

Appendix F

Please complete each question by writing in your answer or checking the appropriate line.

1. Age: 1. 30 – 39 _____ 2. 40-50 _____ 3. 51-60 _____
 4. 61-70 _____ 5. 71-80 _____ 6. 81-90 _____ 7. 91+ _____

2. Gender: 1. Male _____ 2. Female _____

3. a. Ethnicity: 1. Hispanic _____ 2. Non-Hispanic _____
 b. Race: 1. White/Caucasian _____ 2. Black/African American _____
 3. Pacific Islander _____ 4. Asian _____
 5. American Indian and Alaska Native _____ 6. Other _____

4. Marital Status: 1. Single _____ 2. Married _____ 3. Divorced _____ 4. Widowed _____

5. Length of time diagnosed with heart failure: 1. 0 – 1 year _____ 2. 2 - 3 years _____
 3. 4 – 5 years _____ 4. 5 – 10 years _____ 5. 11 or more years _____

6. Other medical conditions: 1. Diabetes _____ 2. High Blood Pressure _____
 3. Lung Disease _____ 4. Coronary Heart Disease/Previous Heart Attack _____
 5. Kidney Disease _____

7. Number of hospitalizations for heart failure in the previous 12 months: _____

8. Length of time attending the Heart Failure Clinic: _____

Appendix G

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how your heart failure makes you feel most days.

[] No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations (rapid or irregular heart beats), or dyspnea (shortness of breath).

[] Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitations, or dyspnea.

[] Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitations, or dyspnea.

[] Unable to carry out any physical activity without discomfort. If any physical activity is undertaken, discomfort is increased.

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