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Exploring the Relationship Between Life Experiences and Quality of Life in Patients with Heart Failure

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**EXPLORING THE RELATIONSHIP BETWEEN LIFE EXPERIENCES AND
QUALITY OF LIFE IN PATIENTS WITH HEART FAILURE**

By

Sharon VanLeeuwen

A THESIS

**Submitted to
Grand Valley State University
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ABSTRACT

EXPLORING THE RELATIONSHIP BETWEEN LIFE EXPERIENCES AND QUALITY OF LIFE IN PATIENTS WITH HEART FAILURE

By

Sharon VanLeeuwen

This was a secondary analysis of data from 86 home care patients from a primary study by Kline (1999) of home care outcomes for persons with heart failure. Surveys were used to collect data on quality of life, energy/fatigue levels and functional abilities. In the secondary analysis, the relationships between functional abilities and energy/fatigue levels with quality of life in heart failure patients were examined using a Pearson's r correlation. Parse's theory of human becoming was used as the framework for this study.

The life experiences of persons with heart failure were examined in this study focusing specifically on functional abilities, energy/fatigue levels and quality of life. It was found that a significant relationship of moderate strength exists between functional abilities and quality of life as well as between energy/fatigue levels and quality of life in patients with heart failure. Based on the findings of this study, maximizing functional abilities and energy levels in persons with heart failure is important in improving their quality of life.

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CHAPTER 1

INTRODUCTION

General Statement of the Problem

Heart failure affects an estimated 4-5 million Americans (American Heart Association, 2000). As the population in the United States ages, the incidence and the prevalence of heart failure continue to increase. At the same time, medical advances in the management of heart failure allow persons to live longer lives.

Advances in the understanding of heart failure and an appreciation for defining both systolic and diastolic dysfunction have provided for advances in the treatment of heart failure over the past ten years. Patients are managed with therapies that lower heart rate, lower blood pressure and consequently blood supply to the brain. This decreases the workload of the heart, but may also increase feelings of fatigue or dizziness related to side effects of medical therapies. Perhaps more needs to be known about how living with heart failure relates to quality of life for the increasing number of older persons living with a decrease in their functional abilities as a result of medical therapies and the worsening of cardiac disease.

Many studies have reported on some of the changes in physical and functional capabilities of patients living with heart failure (Friedman & Griffen, 2001; Grady, Dracup, Kennedy, & Moser, 2000). These changes reflect the reduced vitality or energy that occurs as a natural change related to a decrease in myocardial contractility as the

myocardium changes in shape or cell structure. Currently, specific cardiac medications are aimed at reducing the workload of the heart by decreasing rate, blood pressure, contractility or neurological stimulus. These same medications contribute to symptoms such as fatigue, dizziness, or nausea.

Although most studies evaluate the treatment of heart failure based on objective findings, the process of having patients assess their own response to heart failure is an important component of evaluation (Dracup, Walden, Stevenson, & Brecht, 1992). As patients identify their own productivity, ability to perform daily activities, or satisfaction with life, they express a value that is unique to them.

Experts attempt to address responses to heart failure and functional abilities. The Agency for Health Care Policy and Research guidelines (1994) have identified improving quality of life as a major goal and a search of the literature reveals various physical, emotional, and psychological elements related to quality of life (Friedman & Griffen, 2001). However, quality of life or these elements may not be what persons with heart failure would identify as valuable to them. Parse (1994) encourages health care providers to examine patient responses based on the lived experience of the patient that is unique and unfolds for an individual throughout his/her lifetime.

Significance of the Problem to Nursing

The experience of living with heart failure is faced by an increasing number of persons in the United States (AHA, 2000). Living with heart failure may include changes in energy levels and functional abilities for the individual.

In an attempt to manage changes in functional abilities, nurses interact with patients experiencing heart failure in various settings including outpatient cardiac

rehabilitation clinics, home care agencies, and in-hospital settings. Nurses are consulted by the health care team to assess and manage the impact of heart disease on the life of an individual. It is imperative that nurses have an understanding of the severity and priority of issues, especially energy/fatigue or changes in functional abilities as defined by those living with heart failure.

Information to patients and families is often used by nurses to increase understanding of issues related to changes in health from diseases such as heart failure. Educating patients about treatment issues and symptom management, as well as rationale concerning specific treatment interventions may be expected to lessen frustrations involved in living with heart failure. If patients are given more information concerning heart failure, they may have greater control over managing their illness and therefore, experience less frustration. It is important that the nurse is aware of the perceived experience of living with heart failure in order to develop a plan for education with the patient.

In order to increase the understanding by nurses of the perceived experience of heart failure, a method is needed to quantify and relate the changes in functional abilities that affect a person's lived experience over time to the individual's defined quality of life. As nurses provide care for a very large population of persons, they must be focused on the areas of life that represent the greatest difficulties for those with heart failure.

Purpose

The lived experience of heart failure may impact an individual's quality of life. A person, family, and community share in the experience of living with heart failure. It is important to examine how this experience relates to quality of life in order to improve quality of life for an increasing number of persons with heart failure.

Therefore, the specific aim of this study was to examine the relationship between the experiences of living with heart failure (specifically, changes in functional abilities and energy/fatigue levels) and quality of life in heart failure patients. An improved understanding of this relationship can assist health care providers in communicating with heart failure patients about changes in functional abilities encountered throughout their lived experience.

CHAPTER TWO

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Theoretical Framework

Principles of Theory

First principle. Parse's nursing theory of human becoming is the theoretical framework for this study. She describes three basic principles in her theory. The first is that "structuring multidimensional meaning is a continuous process of co-creating reality through languaging of valuing and imaging" (Parse, 1998, p. 28). The meaning changes with or molds to different possibilities, depending on the lived experience of the individual and of those with whom he/she interacts. Parse defines the lived experience as "the human living moment to moment with changing and shifting perspectives" (Parse, 1998, p. 31). This concept is closely related to both quality of life and Parse's entire framework of human becoming. She sees the lived experience as a continuous process of change.

The process of change will connect past events to future events in an individual's life. This process also occurs in the lives of others with whom that the human being interacts. The human co participates with the universe in a mutually emerging manner. However, there are specific patterns of relating that distinguish an individual from the universe. This pattern is unique to that individual at that specific moment in time.

Second principle. The second principle of Parse's theory indicates that "co-creating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating" (Parse, 1995, p. 7). This principle means that human becoming is an emerging rhythm of similar ways of living. These ways of living are paradoxical, lived with some type of rhythmical pattern, and are recognized in

the human-universe process as a type of pattern.

Revealing-concealing recognizes a phenomenon of the pattern of disclosing-not disclosing occurring at the same time. For example, a person with heart failure may choose to reveal some of his/her understanding and involvement with therapy while concealing his/her disbelief in the benefits of lifestyle changes. If this disbelief remains unidentified, it will frustrate his/her health care provider and inhibit the person's actions or management of heart failure.

Enabling-limiting is living the opportunities-restrictions present in choosing all-at-once. In choosing, a person moves in one direction that restricts movement in another; there are both opportunities and restrictions in what is chosen or what is not chosen. This concept is very important when considering heart failure because the pathology of the disease greatly integrates all body systems thus making them dependent on each other. The patient's quality of life may be impaired by the significant physical complexity of heart failure. If the patient chooses one action (i.e. participating in a social function) it may inhibit another function (the ability to have energy for cardiac rehabilitation class).

Connecting-separating is being with and apart from others, ideas, objects, and situations all-at-once. "The road not taken" has meaning for an individual in every moment of living. As a person looks at treatment goals developed to manage changes in functional abilities and quality of life issues, that person will define and embrace life values while letting go of possibilities related to those same therapeutic options.

Third principle. Parse's third principle describes how human becoming is moving beyond in new ways of viewing what is familiar and unfamiliar (Parse, 1998). Hopes and dreams continue to fuel change along with the continual pushing-resisting in the creation of new thoughts and ways of evaluating life.

An assumption of Parse's theory is that the "human is open, freely choosing meaning in situations, bearing responsibility for decisions" (Parse, 1998 p. 21). A foundation of this theory is that "humans co author their becoming in a mutual process

with the universe, co creating distinguishable patterns that specify the uniqueness of both humans and the universe” (Parse, 1998, p. 6). Parse describes the experience of the human as unique among other beings in the universe in that it is “touched by birthings and dyings which are rhythmical happenings of day-to-day living” (Parse, 1998, p. 21). As the person assigns meaning to these happenings, the possibility of personal becoming is created. The birth and death process of another affects each person, and this person’s experience will live on to affect another human being.

Another assumption by Parse is that “becoming is the human’s patterns of relating value priorities” (Parse, 1998, p. 24). Becoming is the style of living chosen by the person based on cherished beliefs or values. The specific value of focus in this secondary analysis is that of specific elements of health perceptions in patients with heart failure.

Health is viewed as the quality of life experienced and described by the person (Parse, 1998). There is no separation between “biological,” “psychological,” “social,” or “spiritual” aspects of health. The meaning given to a phenomenon as experienced by a person is the unique definition for that person. A person’s beliefs and values, relationships with other people and the universe, and choices that involve living or dying, all define health.

Utilizing Parse’s Theory

Parse’s (1998) theory of human becoming provides an excellent tool to examine heart failure patients and their issues concerning quality of life and to examine changes in their experiences over time. In a more traditional approach, specific indicators would define these concepts in an attempt to quantify the status of body systems, along with emotional, psychological and spiritual well-being phenomena.

However, as the review of the literature will demonstrate, it is extremely difficult to evaluate these processes. Parse’s theory would argue that our efforts to evaluate quality of life have been viewed from the wrong perspective. Parse (1998) theorizes that all phenomena need to be examined from the continually changing life experience of the

individual and must be examined on the basis of a continuum.

The goal of Parse's (1998) practice for the nurse is to focus on functional abilities and quality of life issues as the individual experiences them in a variety of environments and interactions with other people. This will occur on a continual and ever-changing basis as the patient's perspective determines it. The meaning of life changes or stretches into different possibilities based on lived experiences.

Parse's theory is internalized by the nurse rather than simply applied to another individual (Parse, 1998). Health care providers must not only understand a person's value of freedom, but also respect and respond by encouraging a person to choose his/her own way and in his/her own time. This is challenging in that decisions by a person are on a continuum and are affected by environment, interactions, and experiences.

In this proposed secondary analysis, the lived experience of heart failure is described by all three basic principles of Parse's theory (Appendix A). Living with heart failure is a continual and sometimes paradoxical experience. As demonstrated in the diagram, the lived experience of heart failure is centered and is continually influenced by processes in the person, environment and persons that lived in the past or will live in future times.

Another variable examined in this secondary analysis was that of functional abilities. Functional abilities in this study related to the levels of energy/fatigue experienced by a person as well as his/her ability to participate in the activities of his/her life. Functional abilities are best demonstrated by the principle that specifically addresses revealing-concealing, enabling-limiting, and connecting-separating. A person with heart failure and extreme fatigue may refuse attending cardiac rehabilitation on the basis of not having the resources to attend while concealing a fear of potential energy loss through exercise. Similar paradoxical happenings in older persons with heart failure can be seen as they make decisions to take or to not take medications that improve their cardiovascular function while making them extremely nauseated.

The last variable in this study was quality of life in individuals with heart failure. Quality of life is represented by the entirety of Parse's framework (Appendix A). The nurse needs to bear witness to the quality of life as defined by the lived experience of the person with heart failure rather than attempt to provide care or interventions based on a pre-determined definition of quality of life.

Literature Review

Introduction

Multiple studies have been conducted to explore the relationship between heart failure and quality of life (Dracup, Walden, Stevenson, & Breech, 1992; Steptoe, Mohabir, Mahon, & McKenna, 2000). There are a few studies in the literature that explore relationships between lived experience and heart failure (Moser & Dracup, 1995). More studies are available that explore lived experiences and chronic disease. However, very few studies could be identified which could provide concrete empirical support relating to the lived experience of heart failure and quality of life. In an effort to provide a basis for studying the relationship between the lived experience of persons with heart failure and quality of life, the categories of lived experiences, quality of life and heart failure were explored.

Lived Experiences

A description of how women and men with autoimmune deficiency syndrome find meaning through their life experience was reported by Coward (1994) in a phenomenological research approach of 20 persons, ranging in age from 32 to 50 years old. Data were analyzed using Colaizzi's phenomenological analysis technique.

Coward's (1994) results included a report by all 20 participants of experiences in increased self-understanding and connectedness to others that related to meaning and a sense of well being in the context of terminal illness. Life experiences were identified by participants as important in finding meaning in their life and in dealing with their premature death.

Coward (1994) also identified common themes related to life experiences that were different for men and women. Common themes identified among the male participants included: taking care of themselves, accepting that which cannot be changed, and connecting with others. Common themes identified among the female participants included: finding inner strength, experiencing uncertainty, and reaching out to receive and to give to others.

Coward (1994) concluded that persons with a serious illness need help in identifying choices that allow experiences of greater meaning and emotional well being. The results of Coward's study may increase our understanding of how the lived experience of persons with a chronic and often terminal disease relate to their values and quality of life experiences. Coward's study demonstrates that a relationship may exist between lived experience and a chronic and often terminal disease. Heart failure is identified as a chronic disease and is often terminal five years after an established diagnosis (Friedman & Griffen, 2001).

Moser and Dracup (1995) studied 176 subjects, with a mean age of 63.9 years, who had experienced a myocardial infarction and or cardiac revascularization. A longitudinal comparative design was used to determine a relationship between patients who indicated a high perception of control at baseline with those who had a low perception of control at baseline. These scores were compared to examine differences in psychosocial recovery outcomes at a six-month interval.

In Moser and Dracup's study (1995), baseline patient characteristics of the phenomenon of low psychosocial control and high psychosocial control groups were compared by Chi Square and independent t tests. Multivariate analysis of variance was used to compare psychosocial recovery at 6 months between the groups and to explore the interaction between sex and control. Results of the Moser and Dracup study (1995) showed statistical significance for patients with feelings of high control (n = 85) versus those with feelings of low control (n = 91; p = 0.006). The measures for psychosocial

recovery quantified anxiety, depression, and overall psychosocial adjustment and reported a significant relationship to cardiovascular illness. The patients with feelings of high control had less anxiety ($F = 3.5; .002$), less depression ($F = 2.7; p = .001$) and less hostility ($F = 3.4; p = .004$) than those with feelings of low control (Moser & Dracup, 1993). Two-way multivariate analysis of variance demonstrated that no differences existed in psychosocial recovery based on the interaction between sex and control ($p = .649$) or on the direct effect of sex ($p = .141$).

Moser and Dracup (1993) concluded that feelings of perceived control are important for psychosocial recovery of patients with cardiovascular compromise. The study by Moser and Dracup (1993) supports the need for this secondary analysis with evidence that the life experience for those with a high sense of psychosocial control had less anxiety than those with a low sense of psychosocial control.

Life experiences in patients with renal failure were reported by Eibach and Shaefer (1998). This report was of interest when examining the relationship between lived experiences and heart failure. Both renal and heart failure occur over a length of time with variations in symptoms that affect the life experience of the individual and family.

Eibach and Shaefer (1998) reported on how persons arrive at decisions of self-determination in treatment of end-stage renal disease. In a report of 258 dialysis patients, 80% of the patients indicated by their responses to a seven question individual questionnaire that a conversation between themselves, their family and physician would be preferred over pre-written statements regarding their care at the onset of their illness (Eibach & Schafer, 1998).

The patients questioned by Eibach and Schafer were persons who had already been suffering from serious chronic disease for a period of time. Eibach and Schaefer (1998) reported that the patients valued their own understanding of kidney disease, what they had seen in other patients with kidney disease and the expertise of their physician over any type of pre-conceived directives while in a healthy state.

A limitation to the study by Eibach and Schafer(1998) is the small number of questions in the survey and the uncertainty as to what extent the survey answers are representative for patients with other serious diseases such as heart failure. However, the report by Eibach and Schafer (1998) demonstrates that it may be better to include utilization of the life experiences for patient, family and physician when determining care for heart failure patients.

Quality of Life

The relationship between quality of life and psychological well-being was the focus of a study by Steptoe, Mohabir, Mahon, and McKenna (2000). Steptoe et al. studied 106 adult patients with dilated cardiomyopathy (mean length of diagnosis = 42 months). A random design utilized self-report surveys by 99 adult patients with a mean age of 47.6 years of age. The survey included the short form health survey (SF -36), the hospital anxiety and depression (HAD) scale and the six-item sleep problem index developed in the medical outcomes study (MOS).

Steptoe et al. (2000) compared psychological well-being and quality of life for patients with cardiomyopathy with previously published studies that examined similar issues by using t tests. Using multiple regression methods to further analyze the data, a multivariate analysis of factors associated with quality of life and psychological well-being was completed. Steptoe et al. (2000) found that patients with cardiomyopathy reported significant restrictions in their quality of life ($p < .025$) that were only partially attributed to clinical status and severity of disease. The results showed that patients who were poorly adjusted to the cardiomyopathy had a more limited physical function ($M = 51.9$; $SD = 21.6$, $p < 0.05$), a poorer perception of their health ($M = 39.3$, $SD = 21.6$, $p < .001$), and a greater impairment of their psychological health ($M = 9.03$, $SD = 4.1$, $p < .05$) as compared to those that reported good adjustment to their condition.

A limitation in the study by Steptoe et al. (2000) was that their response rate of surveys was only 60% and so the data may not completely represent the relationships of

quality of life and psychological well being. However, the results add to the understanding of the multiple and complex issues related to quality of life.

Another complex issue related to quality of life and heart failure is that of pharmacological management. Stevenson (1998) examined the relationship between inotropic agents in advanced stages of heart failure and improving patient comfort. Stevenson (1998) states that life-threatening arrhythmias are more prevalent in patients with heart failure and the associated use of inotropic agents. In addition, the risk of sudden death is increased with the use of milronone or other inotropic agents used in managing end stage heart failure.

Stevenson discussed various elements such as energy/fatigue levels, medication side effects, and functional limitations, as well as treatment decisions made by patients with advanced heart failure. His conclusion was that “patients for whom no other conventional therapies are available are quite willing to accept a greater risk of death in exchange for the promise of an improved quality of life” (1998, p. 1849).

In another study concerning quality of life issues, Jaarsma, Tan, Huijjer Abu-Saad, and Dracup (2000), looked at the effect of education on quality of life and self-care abilities for patients with heart failure. The study design was an experimental, random assignment that included 179 patients with a mean age of 73 years, a gender representation of 58% males and heart failure (NYHA class III or IV) as an admitting diagnosis.

Jaarsma et al. (2000) evaluated quality of life by a multidimensional approach with objective and subjective dimensions. The Heart Failure Self-care Behavior Scale was used to assess functional capabilities and provided objective data. Statistical evaluation was done through chi-square testing to compare discrete data. A Student t-test compared continuous variables. Relationships between the dimensions of quality of life and the self-care variables were assessed by the use of Pearson correlation coefficients.

Jaarsma et al. (2000) found that symptoms and functional capabilities showed no

significance when compared to self-care behavior ($t = 1.8, p = .07$). They concluded that improved ability to do tasks involved in self-care does not always lead to a better quality of life outcome. Patients who had a greater functional ability in relationship to their heart failure did not report improved quality of life (QOL) scoring in a significant difference. When examining the relationship between quality of life and life experiences, Jaarsma's study is important because it highlights that a patient's perceptions concerning quality of life issues are composed of more than physical status, functional health, and symptoms of illness.

Dixon, Lim, Powell, and Fisher (2000) studied 1304 patients between the ages of 20-85 years of age (64% were greater than 65 years old) with the discharge diagnoses of acute myocardial infarction, unstable angina, stable angina pectoris, chronic ischemic heart disease or heart failure. They used the MacNew Quality of Life after Myocardial Infarction (QLMI) questionnaire with additional questions focusing on gender specific emotional and psychological responses to cardiac disease. The study design was non-experimental, longitudinal and utilized a self-report survey. The data were analyzed using a 95% confidence interval using STATA version 5-0. Differences between sexes, age groups, and medical history were examined with chi square analysis and with group median age rankings done with a Wilcoxon rank-sum test.

Dixon et al. (2000) validated an earlier study by Jaarsma (1998) showing continued psychosocial ($n = 34, SD = 46, p = .004$) and physical problems ($p = .012$) in at least 50% of the participants at a four-month interval date after discharge. Females ($n = 48$) more than males ($n = 34$; Wilcoxon p value <0.001) experienced increased physical and emotional symptoms related to ischemic heart disease. The findings of Dixon et al. are important in examining the relationship between life experiences and quality of life issues since they report differences in quality of life, psychosocial issues and physical functional abilities related to gender and specific cardiac diagnosis.

Heart Failure

The American Heart Association describes heart failure as syndrome with multifaceted symptoms that contribute to the restriction of heart failure patients' daily physical activities (Grady, Dracup, Kennedy, Moser, et al., 2000). The purpose of a study by Friedman and Griffen (2001) was to examine the relationship between physical symptoms and physical functioning to depression in adult patients with heart failure.

Friedman and Griffen (2001) used an exploratory, correlational longitudinal design to examine the relationship of physical symptoms and physical functioning to depression in patients with heart failure. The subjects ($n = 170$) ranged in age from 50-93 years with a mean age of 72.7 years ($SD = 9.6$). Interviews by trained nursing research assistants during hospitalization for heart failure and again in a phone interview at a four-six week interval were used in the research design. The tool was a questionnaire that consisted of a 13-item symptom checklist of physical functioning indicators generated from the heart failure practice guidelines contained in the Agency for Health Care Policy Research (1994) and the 10-item scale from the Medical Outcomes Study Short Form Health Survey (SF-36). The CES-D scale Short Form (10 items) was used to measure depression.

The mean number of symptoms reported at the first interview was 7.4 ($SD = 2.5$) and at the second interview the number of symptoms reported decreased to 3.98 ($SD = 2.7$). Fatigue, shortness of breath, and weakness were the three most frequently reported symptoms (Friedman & Griffen, 2001). The mean physical functioning score was 33.3 ($SD = 26.3$) at the first interview and showed a slight decrease to 32 ($SD = 26.6$). The possible score for this test was 100, so the authors noted that both scores indicated moderate impairment in physical functioning. A lower score indicated worsening physical function. Multiple regression analyses revealed that the physical symptoms ($r = 0.48$; $p < .001$) experienced by the patients explained a greater portion of the variance in depression for the patients than physical functioning ($r = -.32$; $p < .001$).

Friedman and Griffen's study (2001) reported that physical symptoms have a

stronger relationship to a patient experiencing depression as compared to limitations in physical functioning. Patients with heart failure who experienced more physical symptoms and less physical functioning also experienced greater depression. Friedman and Griffen's (2001) study is important because it describes the lived experience of heart failure as it relates to physical symptoms, physical functioning, and depression. Friedman and Griffen felt that further research is needed to assess the impact of treating physical symptoms on both physical functioning and psychosocial issues.

Another study in the literature concerning heart failure was conducted by Levenson, McCarthy, Lynn, Davis, and Phillips (2000). Levenson et al. designed a retrospective secondary analysis of data to characterize the experiences of patients with heart failure during the last six months of life (2000). The data set consisted of interviews with patients or surrogates at four observational windows and chart reviews that originally were part of the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, 2000).

The study sample for Levenson's et al. (2000) secondary analysis consisted of 539 heart failure patients with a mean age of 71.0 with one of the following three conditions: 1) New York Heart Association III or IV despite medical treatment, 2) Class IV status at the time of hospitalization, or 3) diagnosis of congestive heart failure and ejection fraction of less than 20%. Patient interviews were reviewed at four different intervals six months prior to death with two intervals being within the last week prior to death. Emotional and physical symptoms and functional abilities were among the eight outcomes that were measured.

In Levenson's (2000) study, patients' functional status were measured using a modified form of the Katz Index of Activities of daily living with a range between 0-7. An instrument with a 0-5 Likert scale characterized the physical symptoms of pain, confusion, and dyspnea. Chi-square tests were done on the categorical variables while Kruskal-Wallis tests were done on the continuous data taken from the SUPPORT study.

Levenson et al. (2000) reported that physical symptoms increased over time with significance reported for both pain ($n = 206$, $p < .001$) and dyspnea ($n = 87$, $p < .001$). No significance was found in relationship the physical symptom confusion in the last six months of life with heart failure ($p = .151$). The patients in the SUPPORT study that survived one year after entry into the study reported a significantly higher quality of life score ($p < .01$) as well as a better functional status ($p < .001$) as compared to the non-survivors in the study. Levenson et al. (2000) concluded that as death approaches during the last six months of living with heart failure that the symptoms of dyspnea and pain become more severe. There is no significant decrease in quality of life in severe disease states as death approaches (no p value recorded).

The study by Levenson et al. (2000) reports that the relationship of increased symptoms and disability in late heart failure is not related to a reported decrease in quality of life right up to the time of death. A limitation of this study was that it was a secondary analysis of a very large database and there were multiple issues being examined making it difficult to maintain focus while reviewing. Increased clarity of the data tables would have facilitated the review of Levenson's et als. study. Perhaps more research needs to be done specifically on identifying unique quality of life issues in heart failure patients.

Summary

Overall, there are complex concepts and relationships described in the literature relating to life experience, quality of life, and heart failure. While the need to examine the relationship between lived experience of persons with heart failure and quality of life issues is recognized, they are identified in multiple contexts and often in qualitative studies. There is a need for more evaluation of the relationship between lived experience as defined by changes in functional abilities and the quality of life in persons with heart failure.

Research Question

What are the relationships between the lived experiences of functional abilities and energy/fatigue, with the quality of life in heart failure patients?

Hypotheses. The first hypothesis for this secondary analysis was that heart failure patients with greater functional abilities will have a higher quality of life. Conversely, heart failure patients with lesser functional abilities will have a lower quality of life.

A second hypothesis for this secondary analysis was that heart failure patients with greater energy levels will have a higher quality of life. Conversely, heart failure patients with decreased energy levels will have a lower quality of life.

Definitions of Terms

- 1) Quality of life - defined as the index calculated by use of the Ferrans and Powers Quality of Life Cardiac Index III. It is a multidimensional linear analog scale that includes items relative to psychological well being, physical well being, and symptom control.**
- 2) Lived experience – is defined as the unique experience that unfolds for persons throughout their lifetime (Parse, 1994). In this secondary analysis, a specific part of the life experience (i.e. scores obtained by quantifying energy/fatigue levels and physical functional abilities) as reported by the patient was examined. The specific functional abilities measured were that of energy/fatigue levels and disability scores from the Self Management Tool of the primary study by Kline (1999).**

By attempting to do a quantitative analysis, both the quality of life and the lived experience were evaluated at one specific interval in time. This is consistent with Parse's (1998) theoretical framework in that it is recognized that changing and evolving patterns are inherent in the human life. This secondary analysis will, in essence, examine life at one moment in time.

- 3) **Heart failure--defined by criteria of entry into the primary study (i.e.primary diagnosis given to a patient for referral to the home care agency).**

CHAPTER 3

METHODOLOGY

Research Design

A secondary analysis of data was used from a primary study completed by Dr. Kay Setter Kline, R.N., Ph.D., and Professor at Grand Valley State University, Kirkhof School of Nursing as the principal investigator. The primary study was entitled, "Home Care Outcomes for Heart Failure: A Test of Two Nursing Approaches." The goal of the primary study was to determine the effectiveness of two nursing approaches (specifically, mutual goal setting and supportive-education) for self-management of heart failure patients in the home setting. Kline's (1999) study was a longitudinal study over the period of two years with data collected at the initial visit and then again at three, six, nine and twelve month intervals. In the secondary analysis, only data from the initial visit was examined.

Sample and Setting

In the primary study, subjects were recruited from two home care agencies in two different cities. All subjects were at least 18 years of age, had heart failure as their primary diagnosis for referral to home care and were English speaking. Persons were not excluded from the study based on ethnicity, gender, or socioeconomic status. The primary study used a convenience sample with random assignment to treatment groups made by the Principal Investigator. The secondary analysis utilized data collected at the initial visit from the primary study.

Characteristics of subjects. There were 86 respondents in this study whose ages ranged

from 35 to 94 years of age with a mean age of 75.27 (SD = 11.63). Over 95% had been married at sometime in their life with 43% (n = 37) being currently married and 46.5% (n = 40) reporting a widowed status.

All but four of the respondents in this study had at least an eighth grade education. Seventy seven percent had an eleventh grade education and 22% had some college education. Ninety nine percent were unemployed, with only one person reported working approximately 2 hours per week.

The mean annual income for this population was between \$10,000 and 20,000 dollars (44.2%). Twenty six percent reported an income between 20,000 and 30,000 dollars with approximately six percent having an income between 30,000-40,000 dollars. Twenty three percent (n = 20) respondents reported an annual income of less than 10,000 dollars. One person did not provide information on annual income.

Ninety one percent (n = 78) of the respondents had Medicare as their health insurance with seventeen percent (n = 15) receiving Medicaid. Supplemental insurance was available for 33.7% (n = 29) and 15% (n = 13) reported some type of separate insurance coverage.

The respondents were asked to categorize the number of years since diagnosis of heart failure. Of the 86 respondents, 38% (n = 33) had heart failure for less than one year, 12.8 % (n = 11) had heart failure for 1-2 years, and 19.8 % (n = 17) had heart failure for 3-5 years. Twenty-five respondents had heart failure for over five years.

Instruments

Three instruments were utilized from the primary study. In the secondary analysis, data provided from the disability and energy fatigue portions of the self-management tool (SMT-Appendix B) and the Ferrans and Power's Quality of Life Index—Cardiac Version III-Appendix C) and demographic tool (Appendix D) were used. Specifically, data obtained from the questions on the SMT pertaining to issues relating to energy/fatigue levels, and disability (referred to as functional ability throughout this thesis) were used in

the secondary analysis.

Kline (1999) adapted the SMT from the works of Lorig et al.(1996) for the primary study to include components from the AHCPR Patient and Family guidelines for heart failure (1994). These components included references to measurements of prognosis, energy/fatigue levels, and assessment of health status.

Ordinal level measurements of energy/fatigue were obtained by the use of a six-point Likert scale with 0 associated with “none of the time” and 5 associated with “all of the time”. The scores ranged from 0-30 with a higher score corresponding to a greater level of energy.

There were six questions relating to energy/fatigue levels in the SMT. The first five questions were from the health status section developed by Lorig et al.(1996) and had a test-retest reliability of .85 and an internal consistency reliability of .89. The sixth question on shortness of breath had a test-retest reliability coefficient of .87. In this study, the reliability index for the six energy/fatigue questions was Cronbach’s alpha = .75.

Ordinal level measurements were also used to assess the subject’s perception of functional ability in a four-point Likert scale with 0 associated with “without any difficulty” and 4 associated with “unable to do”. The scores ranged from 0 to 60 with a higher score indicating greater functional ability. All 20 questions from the disability section of the self-management tool were included in this secondary analysis. The test-retest coefficient for these questions is .95 with an internal consistency of .86 (Lorig, et al., 1996). In this study, the reliability index for functional ability was Cronbach’s alpha = .92.

The independent variable in this secondary analysis study was the lived experience of heart failure as defined by changes in energy levels and functional ability at the baseline entry level into home health care.

The dependent variable in this secondary analysis was quality of life as quantified by the Ferrans and Powers Quality of Life Index: Cardiac Version III (QLI). This is a

weighted tool consisting of 36 statements to which subjects respond in two ways. First, they indicate how satisfied they are with areas of their life. These are reported on a 6 point Likert scale ranging from “very dissatisfied” to “very satisfied”. Secondly, they are then asked to respond to the same statements by indicating how important each area is to their life. Responses range from “very unimportant” (1) to “very important” (6). Total scoring for the QLI ranges from 0-30 with a higher score indicating a greater perception of quality of life. The internal consistency with cardiac subjects has been reported to be .86 to .96 (Biley & Ferrens, 1993) and the tool has been used in multiple research studies involving cardiac patients. In this study the reliability for the quality of life index was Cronbach’s alpha = .91.

Procedures

Subjects for the primary study were recruited from two separate home health agencies. The data collector (a graduate nursing student) initiated the inclusion of clients in the study from patients that were admitted to two home health agencies. The home care nurse conducted an initial home interview to seek verbal permission from the client to explain the study. Next, the data collector explained the study and obtained written informed consent. Initial data collection was either at this time or at a separate interview based on the client’s health status. The initial data collection consisted of completing the demographic, the quality of life and the self-management tools. Data collection also occurred at baseline and the 3,6,9,and 12-month intervals excluding a repeat of demographic data. This timeline supported the AHCPR guidelines for future research (1994).

Permission to conduct the secondary analysis was obtained through permission granted by the Human Research Review Committee at Grand Valley State University. Access to data was obtained from the Principal Investigator of the primary study (Appendix E).

CHAPTER 4

RESULTS

The purpose of this study was to examine the relationship between the experience of living with heart failure (specifically, changes in functional abilities and energy/fatigue levels) and quality of life in heart failure patients. The research question for this secondary analysis was, “What are the relationships between the lived experiences of functional abilities and energy/fatigue, with quality of life in heart failure patients?”

The two hypotheses developed in this study were: 1) persons with heart failure and greater functional abilities would have a higher quality of life, and 2) persons with heart failure and greater energy levels would have a higher quality of life.

Data were examined in this study using the Statistical Package for Social Sciences (SPSS) Grand Valley State University. The level of significance was $p < .05$ for all statistical procedures.

Findings

Functional abilities. Each item related to functional abilities had responses ranging between 0 and 3. Reversed scoring of data was performed in order to have a higher value correspond to higher functional ability. Functional abilities as they relate to activities of daily living were measured by 20 questions with cumulative scores ranging from 0 to 60. The minimum reported score was 10 with a maximum score of 59. A mean score of 38 (SD = 12) was obtained with 75% of the responses being “able to do without any

difficulty” or “able to do with some difficulty” to most items. Responses from the lowest 25% of participants were at or below a score of 30. Only 6 (7%) of the respondents had scores below 20 with response items of “with much difficulty” or “unable to do”.

On review of individual items on the functional abilities tool, the data revealed many interesting themes. Respondents experienced greatest abilities in tasks related to activities of daily living (see Table 1) such as being able to put full cup to mouth (mean = 2.9; SD = .27) and being able to brush/comb hair (mean = 2.8; SD = .59). Lowest specific items (see Table 2) included tasks such as being able to walk several blocks (mean = .63; SD = .97) and being able to do household chores (mean = .99; SD = 1.1).

It is of interest to note that functional abilities needed to dress, feed and provide personal hygiene were grouped together in the highest seven scores. Respondents perceived greatest functional abilities in items needed for personal care and their values are reported in Table 1. Functional ability scores were lower for tasks that involved greater activity or physical movement. It is of interest to note that the mean score and frequency percentage for being able to walk several blocks is much lower than scores pertaining to eating and personal hygiene.

Energy. Perceptions of energy in persons with heart failure were measured by six questions with a range of possible scores from 0 to 30. Reversed scoring was performed on the first, third and sixth question in order to have the higher number correspond with a greater energy level. The mean score was 9.8 (SD = 5.3). The range of scores was between 0 and 27.

Sixty three percent of the scores for energy levels were in the bottom third of possible scores (i.e. a score of 10 or less.) Twenty-seven percent of the responses were

Table 1

Mean Scores of Functional Abilities Related to Personal Care

Item	Mean	SD	"without any difficulty" or "with" some difficulty"
Full cup to mouth	2.9	2.7	100%
Brush/comb hair	2.8	.59	96%
Cut food	2.7	.56	96%
On/off toilet	2.7	.56	94%
In/out of bed	2.7	.58	94%
Wash/dry body	2.4	.89	87%
Dress self	2.4	.77	87%

Table 2

Mean Scores of Five Lowest Functional Ability Scores

Item	Mean	SD	"unable to do" or "much difficulty"
Carry groceries	1.2	1.2	57%
Run errands	1.0	1.1	62%
Flight of steps	1.1	1.1	66%
House chores	.99	1.1	66%
Walk several blocks	.63	.97	79%

between a score of 11-20 or in the middle third of reported scores. Only three persons were in the top third with scores ranging between 21-27.

Quality of life. Quality of life was represented through an index value that reports satisfaction weighted by importance of life issues. The range of responses was from 7.6 to 28.25 ($M = 20.7$, $SD 4.85$) for the quality of life index with a possible range from 0-30.. Fifty six percent of the scores were 20 or higher, with this group containing the median value of 21 for the quality of life scores. A score of 25 or greater represented 25% of respondents. The lowest reported actual value for the quality of life index was 7.6, and only 3.5% of the respondents reported a number less than 10. Twenty five percent of the respondents scored quality of life at a value of 17 or less.

Personal experiences of study participants. While 80% of respondents indicated that physical independence was very important, only 60% were satisfied with their physical independence. Twenty percent reported being very dissatisfied with the amount of independence that they experienced. In a related finding, 92% of the participants indicated that being able to take a vacation was very important to them. However, over half of the participants reported being dissatisfied with their ability to vacation, and 35% were “very dissatisfied”.

In looking at personal experiences, the majority of respondents were dissatisfied, and a third reported being “very dissatisfied,” with the amount of energy that they had for daily activities. When correlating this finding with importance, 80% identified having enough energy for daily activities as being “very important.”

In looking at the relationship of importance and satisfaction indicators for quality of life, it was interesting to examine the respondent’s perception of usefulness to others in

their environment. Ninety eight percent felt that it was important, and 72% designated “very important “to feel useful to other persons”. However, only 53% reported some satisfaction in their ability to be useful to others.

Research Question

The research question for this study was: What are the relationships between the lived experiences of functional abilities, and energy/fatigue with quality of life in heart failure patients?

In order to determine the strength of the relationship between the functional status and quality of life, a Pearson’s r correlation was conducted. The results revealed a significant positive relationship of moderate strength between these two variables ($r = .51$; $p = .000$).

A second Pearson’s r correlation was conducted to test the strength of the relationship between energy levels and quality of life. Again, the results revealed a significant positive relationship of moderate strength between energy/fatigue and quality of life ($r = .44$; $p = .000$).

Hypotheses

Separate t tests were performed to test the two hypotheses for this study. Functional abilities and energy levels were divided into higher and lower groupings in order to further examine differences on perceived quality of life.

Hypothesis #1. Persons with heart failure and greater functional abilities would have a higher quality of life index. The difference between quality of life and functional abilities was examined. The median scores for functional abilities were used to create a higher and a lower grouping. The mean score for the higher functional abilities grouping

was 22.9, SD = 4.76 and the mean score for the lower functional abilities grouping was 18.8, SD = 4.06. A statistically significant difference was found between functional abilities and quality of life ($t = -4.29$; $df = 82$; $p = .000$). The first hypothesis concerning a significant difference between functional abilities and quality of life was supported by this study.

Hypothesis #2. Persons with heart failure and greater energy levels would have a higher quality of life index. The difference between quality of life and energy/fatigue levels was examined. The median scores for energy/fatigue levels were used to create a higher and a lower grouping. The mean score for the higher energy grouping was 22.5, SD = 4.9 and the mean score for the lower energy grouping was 18.9, SD = 4.9. A statistically significant difference was found between energy/fatigue levels and quality of life ($t = -3.76$; $df = 84$, $p = .000$). The second hypothesis concerning a significant difference between energy/fatigue levels and quality of life was supported by this study.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

The purpose of this study was to examine the relationship between the experience of living with heart failure (specifically, changes in functional abilities and energy/fatigue levels) and quality of life in heart failure patients. Data analyses revealed significant relationships between both energy/fatigue levels and functional abilities of heart failure patients with quality of life. The human becoming theory by Parse (1998) provided the conceptual framework for this study and allowed a means to interpret its findings.

Discussion of the Findings

Based on the findings of this study, quality of life for individuals with heart failure is closely related to their functional ability and energy level. Respondents reported scores in the upper two thirds of possible scores for both quality of life and functional abilities. Energy levels were reported in the lower third of possible scores corresponding with being unable to do or having difficulty performing activities. Previous studies (Friedman & Griffen, 2001; Grady, Dracup, Kennedy & Moser, 2000) reported that decreased energy levels are a progressive change in heart failure. The results of this study also support lower energy levels in persons with heart failure. In addition, a moderate positive relationship was found between quality of life and energy even in the presence of lower energy levels.

A moderate positive relationship between functional abilities and quality of life was demonstrated in this study ($r = .51$; $p = .000$). This is in contrast to Jaarsma et al. (2000) who concluded that improvement in ability to perform self-care behavior did not necessarily lead to an improvement in quality of life. In contrast to the above findings,

Jaarsma et al's study employed a different tool to gather information concerning self care behaviors and had a larger number of subjects. The conflict in these two findings may be explained by Parse's (1998) first principle of co-creating. This principle states that meaning for an experience changes as a continuous process and has different values and expressions at any given moment in time and for each individual experience.

As reported earlier, respondents indicated rather low levels of energy (mean = 9.8; highest possible score = 30). A significant difference was found between quality of life and the lower energy group and the higher energy group. Of interest was that the grouping of all data related to energy levels fell into a fairly tight range with 50% of scores between the values of 6-12. The energy scores in the lower group were clustered between values of 0-9 and the higher groups had a broader range between 10 and 27. A specific level of energy seems to be closely shared in the lower energy group.

When considering this specific level of energy, the human becoming theory (Parse, 1998) would encourage health care professionals to not simply focus on the seemingly clustered low energy levels, but instead to focus on what is important to that individual at this moment in time. At times, health providers use information such as self reported levels of energy and they make assumptions concerning activities for persons. This is done in the absence of exploring the value an individual may place on specific activities. According to Parse (1998), health providers must explore the uniqueness of each person's experience and to be aware how this will change over time.

In discussing quality of life in heart failure patients, psychological well-being, physical well being and the amount of control over symptoms of heart failure are all involved. In this secondary analysis, the tool used to measure quality of life addressed both the satisfaction and the importance of issues concerning functional abilities and energy/fatigue levels. Quality of life is determined by weighting the level of satisfaction with the level of importance for the same item.

The disparity reported between importance and satisfaction in items related to

functional abilities suggest that it is imperative to assess value as well as ability to attributes related to persons with heart failure. In her first principle, Parse (1998) states multi-dimensional meaning must be structured around experiences. The value assigned to physical independence or to being able to take a vacation may be different than the actual ability to perform it, but valuing its importance will contribute to an increase in quality of life.

In the earlier discussed study of Dixon et al. (2000), participants reported significant difficulties in psychosocial adjustment to physical limitations related to heart failure. This finding may explain the conflict involved in identifying having energy as important in a person's life and yet being dissatisfied at the amount of perceived energy as reported in this secondary analysis.. A person with heart failure may suffer from anxiety or other evidences of disrupted psychosocial well being in an effort to resolve the conflict between what is important (i.e. having energy) with what is experienced (decreased amounts of energy).

Parse (1998) would also identify the importance of encouraging and identifying choices by persons with heart failure based on perceived energy levels. The principle of enabling-limiting identifies the continual conflict between valuing energy and being dissatisfied at the amount of energy available for daily activities.

The other personal experience that was reported in this study concerned the low satisfaction of participants as to their usefulness to others and yet the self report that this was a "very important" part of their life. . Moser and Dracup (1993) may explain this finding from their study based on the significance of perceived control for psychosocial recovery in patients with cardiac disease. They found that patients with higher perceived control over their disease management and their interactions with others reported a higher quality of life. The dissatisfaction in the respondents' abilities to be useful to others was in conflict to the value that this interaction had to the respondents. Again, as clinicians it is important to acknowledge and minimize this conflict in the life experiences of persons

with heart failure.

Limitations

A limitation of this study was that it is one of the first quantitative studies utilizing the human becoming theory (Parse, 1998) as a framework. The model fit well with the concepts of quality of life and the life experience (see Appendix A). Both of these concepts are continual in nature and influenced by person, environment and past and future generations. However, it was difficult to describe the events at a single moment in time and to halt the fluidity in the life experience of patients with heart failure.

Since most studies utilizing Parse's (1998) theory are qualitative in nature and involve the researcher intimately observing the life experience of subjects over time, it was difficult at times to fit the results into the framework. In addition, since this was a secondary analysis of data from a previous study, no adjustment to the method of obtaining the information could be made.

Utilizing the interview technique may have limited the study. Over 60% of the subjects reported, "being worn out" a good bit or greater amount of the time. This may have contributed to cognitive difficulty in processing and responding to the questions.

Application for Nursing Administration

Administrators in nursing practice must continue to advocate for recruitment of the staff necessary to assess and implement an individualized plan of care for persons in multiple health care settings. Nursing leaders must have a vision for nursing as a profession, and they must be able to motivate others to see how important it is to assess and value all details of an individual's life experience (i.e. energy/fatigue levels, functional abilities and perceived quality of life in persons with heart failure). Since according to the findings, a significant relationship exists between both energy/fatigue levels and functional abilities with quality of life in heart failure patients, administrators must provide funds needed for equipment, and staff training in efforts to conserve energy or improve functional abilities. Mutual, multi-disciplinary and creative care planning

takes time and expertise to develop.

Application to Nursing Practice

Based on the findings of this study, maximizing functional abilities of persons experiencing heart failure is important in improving their quality of life. Specifically, assisting abilities that allow increased function within the home (use of appropriate furniture, supports in kitchen/bathroom) may improve quality of life for the person with heart failure.

Activities outside of the home (such as being able to run errands or walk around the block) were scored with “able to do with much difficulty” or “unable to do.” The more that caregivers can support some of these more complicated activities (i.e. coordinating deliveries to the home or perhaps assisting with a wheelchair for an outdoor activity) the greater the opportunity perhaps to influence the individual’s quality of life.

The seven highest scored functional ability items related to personal hygiene and an ability to feed oneself. Persons in this study reported minimal or no difficulty with these tasks and, at the same time, reported fairly low amounts of energy. Based on these findings, it would be important to review changes in a person’s daily self-care abilities at routine progress checks. Inability to perform self-care behaviors may be a warning sign of exacerbation of cardiac disease as well as a possible threat to a person’s quality of life.

Evaluation of supports for self care behaviors must be consistently communicated among various providers such as home care, cardiac rehabilitation clinics, cardiology offices, and family health offices. Specific therapies and supports designed in the rehabilitation clinic should be carried through by the home health provider and monitored by the primary health care provider.

Application for Nursing Education

Nurse educators must be aware of latest opportunities and techniques designed to conserve energy and increase functional abilities that may improve quality of life for persons with heart failure. Curricula designed to help nurses identify and value

individual life experiences may foster creative ideas and patterns of assessing and caring for patients. This study reflected the specific planning needs of heart failure patients to include energy/fatigue levels and functional abilities.

Application to Nursing Research

The following recommendations for further research concerning lived experiences of heart failure and quality of life issues have been generated by this study:

- 1) development and validation of more tools that quantify other aspects of the lived experience of heart failure;**
- 2) investigation into other tools that can quantify elements of the human becoming theory;**
- 4) in addition to this study, looking at the relationships between specific functional abilities and energy levels in persons with heart failure;**
- 5) investigation of changes over time that may occur in energy/fatigue levels, functional abilities and quality of life in persons with heart failure and**
- 6) development of educational tools to help nurses assess elements of lived experiences and incorporate them into a nursing plan of care.**

Appendices

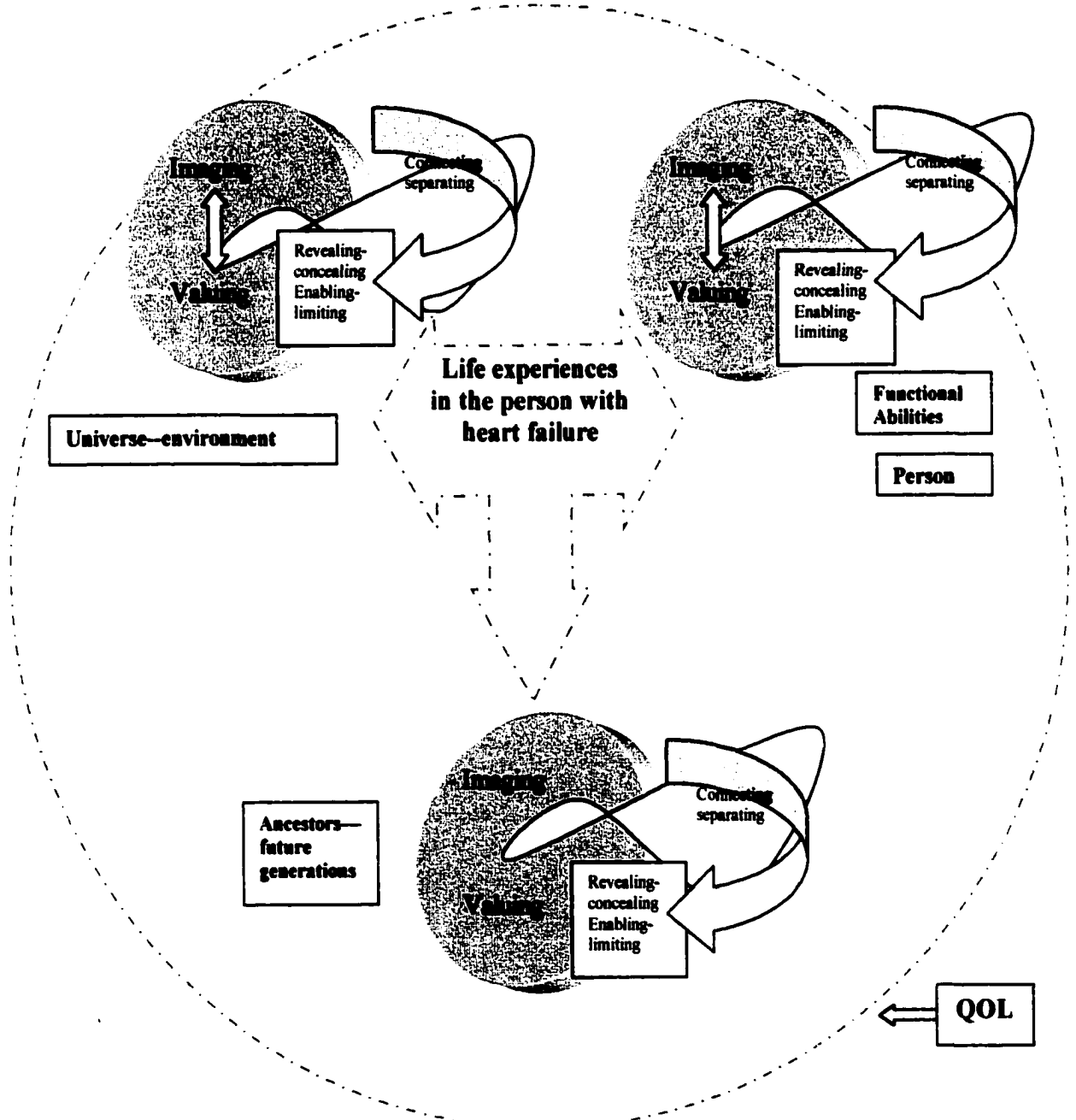
APPENDIX A
Conceptual Framework and Study Variables

Appendix A

Principle I
Structuring
 multidimensional
 meaning is a continuous
 process of co-creating
 reality through languaging
 of valuing and imaging

Principle II
 Co creating rhythmical
 patterns of relating is
 living the paradoxical
 unity of revealing-
 concealing and enabling-
 limiting while
 connecting-separating

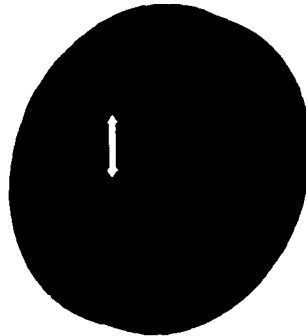
Principle III
 Co transcending with the
 possible is powering
 unique ways of originating
 in the process of
 transforming



Key to Theoretical Framework

Principle I:

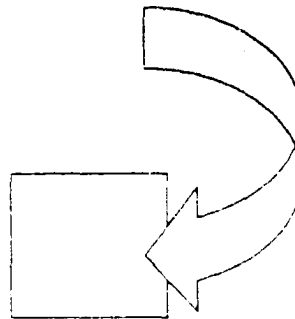
Multi-dimensional meaning that is co-created involving valuing and imaging and involving person, universe, and previous and future generations.



Cylinder represents multi-dimensional properties of person, env or past/future

Principle II:

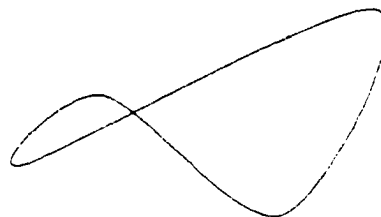
Rhythmical continual patterns of paradoxical concepts involved with person, universe, and previous and future generations.



Paradoxical concepts that continue to intercept with each other and with person, env or past/future

Principle III:

Continual co-transcending is affecting the process at all times and involved with person, universe, and previous and future generations.



The continued process of change based on choices made and not made—by the person, env and in the past/future

APPENDIX B

Functional Abilities

Appendix B

Functional Abilities

Response options: Respondents were asked to circle the response that best described their usual abilities. Options varied from: 0-without any difficulty; 1-with some difficulty; 2-with much difficulty; 3-unable to do

1. Are you able to dress yourself, including tying shoelaces and doing buttons?
2. Are you able to brush/comb your hair?
3. Are you able to stand up from an armless straight chair?
4. Are you able to get in and out of bed?
5. Are you able to get up from off the floor?
6. Are you able to cut your food with a knife or fork?
7. Are you able to lift a full cup or glass to your mouth?
8. Are you able to walk outdoors one block on flat ground?
9. Are you able to walk outdoors several blocks on flat ground?
10. Are you able to climb up five steps?
11. Are you able to climb up one flight of steps?
12. Are you able to wash and dry your entire body?
13. Are you able to get on and off the toilet?
14. Are you able to take a tub bath?
15. Are you able to reach and get down a 5-pound object from just above your head?
16. Are you able to bend down?
17. Are you able to run errands and shop?
18. Are you able to do household chores?
19. Are you able to carry a bag of groceries across a room?
20. Are you able to get in and out of a car?

APPENDIX C

Energy/Fatigue Levels

Appendix C

Energy/Fatigue levels

Response options: Respondents were asked to circle the response that best described their energy/fatigue level during the past month. Options varied from: 0-none of the time; 1-a little of the time; 2-some of the time; 3-a good bit of the time; 4-most of the time; 5-all of the time

1. During the past month, how much of the time did you feel worn out?
2. During the past month, how much of the time did you have a lot of energy?
3. During the past month, how much of the time did you feel tired?
4. During the past month, how much of the time did you have enough energy to do the things you wanted to do?
5. During the past month, how much of the time did you feel full of pep?
6. During the past month, how much of the time did you experience shortness of breath?

APPENDIX D
Demographic Data

Appendix D

Demographic Data

DEMOGRAPHIC DATA

(To be collected at time of initial interview)

Record Number: _____

Subject Number: _____

1. Age _____

2. Marital Status

___ Never Married

___ Married

___ Divorced

___ Widow/Widower

3. Employment Status

___ Employed (hours per week)

___ Unemployed

4. Highest Level of Education

___ 1st-7th grade

___ 8th - 10th grade

___ 11th-12th grade

___ Associate's Degree

___ Bachelor's Degree

___ Master's Degree

___ Doctoral Degree

5. Insurance Provider

___ Private Insurance (Name of Company) _____

___ HMO (Name of Group) _____

___ Medicare

___ Medicaid

___ Supplemental Insurance (Name of Company) _____

___ PPO (Preferred Provider Organization) _____

___ Other _____

(Continued on next page)

6. Health Care Provider (Who treats your heart failure?)

___ Family Practice Physician

___ Cardiologist

___ Internist

___ Family Nurse Practitioner

Physician Assistant
 Other _____
-

7. Annual Income in Dollars:

- less than \$10,000
- \$10,001 - 20,000
- \$20,001 - 30,000
- \$30,001 - 40,000
- \$40,001 - 50,000
- over \$50,000

8. How long have you had heart failure?

- less than 1 year
- 1-2 years
- 3-5 years

9. List current medical diagnoses. _____

APPENDIX E

Permission to Conduct Study

Appendix E

Permission to Conduct Study



GRAND VALLEY
STATE UNIVERSITY

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49801-9403 • 616/895-4611

August 29, 2001

Sharon VanLeeuwen
7708 Cardinal Drive
Jenison, MI 49428

RE: Proposal #02-21-H

Dear Sharon:

Your proposed project entitled **Exploring the Relationship Between Life Experiences and Quality of Life in Patients with Heart Failure** has been reviewed. It has been approved as a study, which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,



Paul Huizenga, Chair
Human Research Review Committee

*Sharon - you have
my permission to run data
for the primer study
for your thesis.
My Sincerely,
Paul Huizenga*

APPENDIX F

Ferrens and Powers Quality of Life Index Cardiac Version III

APPENDIX F

Ferrans and Powers QUALITY OF LIFE INDEX CARDIAC VERSION - III

Part 1: For each of the following, please choose the answer that best describes how important that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Health care?	1	2	3	4	5	6
3. Being completely free of chest pain (angina)?	1	2	3	4	5	6
4. Being able to breathe without shortness of breath?	1	2	3	4	5	6
5. Having enough energy for everyday activities?	1	2	3	4	5	6
6. Your physical independence?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living a long time?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your relationship with your spouse/significant other?	1	2	3	4	5	6
13. Your sex life?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from others?	1	2	3	4	5	6
16. Meeting family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6

(Please Go To Next Page)

APPENDIX F

Part I continued:

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
18. Having a reasonable amount of stress or worries?	1	2	3	4	5	6
19. Your home?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. A good standard of living?	1	2	3	4	5	6
22. Your job? (if employed)	1	2	3	4	5	6
23. To have a job? (If unemployed)	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Your financial independence?	1	2	3	4	5	6
26. Leisure time activities?	1	2	3	4	5	6
27. The ability to travel on vacations?	1	2	3	4	5	6
28. Having a happy old age/retirement?	1	2	3	4	5	6
29. Peace of mind?	1	2	3	4	5	6
30. Your personal faith in God?	1	2	3	4	5	6
31. Achieving your personal goals?	1	2	3	4	5	6
32. Your happiness in general?	1	2	3	4	5	6
33. Being satisfied with life?	1	2	3	4	5	6
34. Your personal appearance?	1	2	3	4	5	6
35. Yourself?	1	2	3	4	5	6
36. The changes in your life that you have had to make because of your heart problems (for example: changes in diet, physical activity and/or smoking?)	1	2	3	4	5	6

APPENDIX F

Ferrans and Powers QUALITY OF LIFE INDEX CARDIAC VERSION - III

Part 2: For each of the following, please choose the answer that best describes how important that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Health care?	1	2	3	4	5	6
3. Being completely free of chest pain (angina)?	1	2	3	4	5	6
4. Being able to breathe without shortness of breath?	1	2	3	4	5	6
5. Having enough energy for everyday activities?	1	2	3	4	5	6
6. Your physical independence?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living a long time?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your relationship with your spouse/significant other?	1	2	3	4	5	6
13. Your sex life?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from others?	1	2	3	4	5	6
16. Meeting family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6

(Please Go To Next Page)

APPENDIX F

Part 2 continued:

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
18. Having a reasonable amount of stress or worries?	1	2	3	4	5	6
19. Your home?	1	2	3	4	5	6
20. Your neighborhood?	1	2	3	4	5	6
21. A good standard of living?	1	2	3	4	5	6
22. Your job? (if employed)	1	2	3	4	5	6
23. To have a job? (If unemployed)	1	2	3	4	5	6
24. Your education?	1	2	3	4	5	6
25. Your financial independence?	1	2	3	4	5	6
26. Leisure time activities?	1	2	3	4	5	6
27. The ability to travel on vacations?	1	2	3	4	5	6
28. Having a happy old age/retirement?	1	2	3	4	5	6
29. Peace of mind?	1	2	3	4	5	6
30. Your personal faith in God?	1	2	3	4	5	6
31. Achieving your personal goals?	1	2	3	4	5	6
32. Your happiness in general?	1	2	3	4	5	6
33. Being satisfied with life?	1	2	3	4	5	6
34. Your personal appearance?	1	2	3	4	5	6
35. Yourself?	1	2	3	4	5	6
36. The changes in your life that you have had to make because of your heart problems (for example: changes in diet, physical activity and/or smoking?)	1	2	3	4	5	6

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