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Quality of Life in a Heart Failure Population

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QUALITY OF LIFE IN A HEART FAILURE POPULATION

By

Diane S Rexford

A THESIS

**Submitted to
Grand Valley State University
In partial fulfillment of the requirements for the
Degree of**

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Thesis Committee Members:

Kay Setter Kline PhD, RN

Linda Scott PhD, RN

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ABSTRACT

QUALITY OF LIFE IN A HEART FAILURE POPULATION

By

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The purpose of this secondary analysis was to identify what impact nursing approaches had on quality of life over time in a heart failure population. The sample was those patients who were receiving home care for heart failure.

The theoretical framework was the King theory of goal attainment. This secondary analysis used data from the study by Dr. Kay Setter Kline, Home Care Outcomes for Heart Failure: A Test of Two Nursing Interventions. The specific tools utilized were a demographic tool and the Ferrans and Powers Quality of Life Index: Cardiac Version III. The subjects received nursing approaches from graduate students at Grand Valley State University during eight scheduled sessions. The nursing approaches were developed utilizing the AHCPH guidelines for Heart Failure.

Improvements in quality of life scores were found. Measurement of quality of life using the QLI was compared from baseline, and at three and six month intervals, reflected improvement in quality of life ($F = 29.907, p = 0.000$).

DEDICATION

This research is dedicated to all patients with heart failure, but especially to my brother, Duane A. Roberts who was diagnosed with heart failure at age 45. Duane like other heart failure patients I have been privileged to meet have taught me the importance of family support and nursing education in improving their quality of life. Each have touched my life and have influenced how I provide nursing care to the patients I am privileged to serve.

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My appreciation is extended to Dr. Theresa Bacon-Baguley, for her assistance on my thesis committee. Her straightforward approach was appreciated. I would also like to thank Dr. Linda Scott for her meticulous attention to detail, her coaxing to strive for the best and most of all her statistical expertise, which has been a tremendous motivator for me.

Dr. Kay Setter Kline deserves special recognition for her contribution to this project. Kay not only provided expert research advice and editing, her encouragement has been deeply appreciated. Her love of nursing education and expertise is clearly visible in all that she does.

Pat Whitaker MNSc, RN, and Laura Schuring MSN, RN, friends and colleagues provided guidance, encouragement and constructive criticism throughout this project. They were available in trying times and provided never-ending support when I needed it the most.

Finally, I feel words cannot say enough about the love and support my family has provided to me throughout this project. For all the times my husband, Mike, sacrificed for me and for all the times my sons, Rob and David didn't see their mother, I will be forever grateful.

Something from each of you will remain with me forever. Thank you all.

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CHAPTER 1

INTRODUCTION

Currently over 4.6 million patients in the United States have the diagnosis of heart failure. It is estimated that 550,000 new cases of this chronic illness will be diagnosed every year (American Heart Association, 1999). Most nurses involved in the care of heart failure clients recognize the importance of treatment approaches, including diet, exercise, fluid restriction, and medications in symptom control. Heart failure with its symptoms of shortness of breath, edema, fatigue, and poor exercise tolerance has an effect on the patient's quality of life (Rich, 1997).

Chronic illnesses such as heart failure present a major challenge to nurses and other health professionals for finding effective management protocols. Currently heart failure protocols are based on knowledge generated by research. An example of this research by McKelive et al. (1999) is the "Randomized Evaluation of Strategies for Left Ventricular Dysfunction study" (RESOVLD, 1999), conducted at multinational centers to evaluate medication therapies in heart failure. Also Gorkin et al. (1993) conducted another study, "Strategies for Left Ventricular Dysfunction" (SOLVD, 1993), in which they investigated the effects of medication on mortality and the development of heart failure in asymptomatic patients with reduced left ventricular ejection fractions. Rapid changes in the pharmacologic treatment of this patient population have occurred during the past years, and many controlled clinical trials have evaluated the impact of various pharmacologic interventions on clinical

outcomes in patients with heart failure. Although these studies address treatment modalities, there are still many unanswered questions regarding quality of life in this population.

The Agency for Health Care Policy and Research (AHCPR) published the clinical practice guideline "Heart Failure: Evaluation and Care of Patients with Left Ventricular Systolic Dysfunction" (1994). This AHCPR guideline on heart failure recommends that providers assess patients' health related quality of life and recommends using this information to modify treatment and guides for patient and family teaching to facilitate adaptation to lifestyle changes as a result of heart failure (Konstam et al., 1994). Recommendations for assessment of quality of life include physical symptoms, physical functioning, and mental health.

The terms quality of life, health status, functional status, and health related quality of life are often used interchangeably in the literature. By their nature, quality of life measurements are characterized by personal, subjective responses. Several studies have been done on health related quality of life for persons with heart failure. These include: Dracup et al., 1992; Bulpitt et al., 1998; Gorkin et al., 1993; Green et al., 2000; Kostis et al., 1994; Rector and Cohn, 1992; Rector, Johnson, Dunkman et al., 1993; Rumsfeld et al., 1999; Stewart et al., 1989; Tandon et al., 1989; and Walden et al., 1989.

Quality of life measures have recently been used as guides to the successful outcomes of nursing interventions in chronic illness states. Bass et al. (1997) gave the following definition of quality of life in a study of chronic illness; "Quality of life in chronic illness is defined as a subjective, personal evaluation of and satisfaction with

the physical, psychological, social, vocational, and spiritual dimensions of one's life that are affected by the level of social support available and physical symptoms experienced" (p 27). Gorkin et al. (1993) concluded that health related quality of life measures are useful in treatment and evaluation of heart failure patients. Rector et al. (1993) evaluated different pharmacological therapies on heart failure patients and utilized quality of life measures as an outcome. Dracup et al. (1992) studied quality of life in patients with advanced heart failure (New York Heart Association Classification III & IV) to study the relationship among the multidimensional components of quality of life as predictors of psychosocial adjustment. All of these studies concluded that interventions are needed that focus on decreasing depression and hostility, as well as interventions that promote an increase in daily activity, therefore providing for positive effects on quality of life.

Health related quality of life has been reported in other disciplines, including medicine, medical social work, and psychology. Within the field of oncology, multiple studies have utilized systematic reviews of quality of life (Aaronson et al., 1986; deHaes & vanKimippenberg, 1985; Moimpour, 1989). These studies all led to the recommendation that quality of life be included as outcome measures in clinical trials involving oncology patients. For nurses to provide comprehensive care to heart failure patients, protocols and nursing approaches must continue to be developed utilizing rigorous research designs that include measurement of quality of life outcomes.

Without a clear understanding of the effects of nursing approaches on quality of life in heart failure patients, further evaluation and development of interventions to

decrease depression and hostility, and to increase daily activity will be difficult to monitor. Quality of life outcome measures are an important adjunct to objective data on heart failure patients when assessing effectiveness of nursing approaches. Measuring quality of life may assist in identifying which protocols or nursing approaches are effective. If nursing approaches are shown to have a positive effect on quality of life, nurses can optimize outcomes in heart failure patients. This research may benefit heart failure patients. It may benefit patients by improving personal satisfaction with the physical, psychological, social, vocational, and spiritual dimensions of one's life. With the patient's active involvement in this study, it is hoped that the knowledge gained and support given with the nursing approaches suggested by the AHCPH guidelines, will have helped the patients develop the tools necessary to experience improvements in quality of life.

Purpose

The purpose of this study was to identify what impact nursing approaches utilizing the AHCPH guide for heart failure had on heart failure patients' quality of life scores. These data can then be used to improve clinical assessment and plan services to meet patient needs related to improvement in quality of life. The descriptive study investigated quality of life scores for heart failure patients who received nursing approaches utilizing the AHCPH guide for heart failure. This descriptive analysis compared quality of life scores at baseline, and three and six month intervals.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

King (1981) developed the theory of goal attainment for nursing as outlined in the book, *Theory for Nursing; Systems, Concepts, Process*. This theory of goal attainment was the framework used to guide the study. King sought to describe the nature of nursing as “the way in which nurses, in their roles, do with and for individuals” (Fawcett, 1995 p.127). The terms, quality of life, heart failure, and nursing approaches were used in measurements of quality of life as outcomes related to nursing approaches in a theory of goal attainment utilizing King’s theory.

King’s theory of goal attainment King (1981) developed a theory of goal attainment. Within this theory, it is assumed that goal attainment is derived from an open systems framework. King (1981) states, “The major elements in a theory of goal attainment are discovered in the interpersonal systems in which two people who are usually strangers, come together in a health care organization to help and to be helped to maintain a state of health that permits functioning in roles” (p. 142). Nurses and patients mutually interact to establish goals and to explore and agree on means to achieve goals (King, 1981).

Goals are perceived as events that one values, wants, or desires. Goal attainment results in outcomes that are measurable events in nursing situations (King, 1981). “It is postulated that nurse and client interactions are characterized by verbal and nonverbal communication, in which information is exchanged and interpreted; by transactions, in which values, needs, and wants of each member of the dyad are

shared; by perceptions of nurse and client and the situation; by self in role of client and self in role of nurse; and by stressors influencing each person and the situation in time and space” (King, 1981, p.144).

The basic assumption in the theory is that generally patients and nurses communicate information, mutually set goals, and take action to attain goals (King, 1981). Measures of goal attainment determine effectiveness of nursing care. Effective nursing care leads to quality improvement in health, which enhances quality of life (King, 1994). By expanding the concept of what it means to be a human being in coping with complex human-environment interactions such as heart failure, studies can be done which will enhance quality of life (King, 1994).

A model of transaction designed by King (1981) shows the human process of interactions. Figure 1 shows the model that depicts theoretical knowledge used by nurses to help individuals and groups attain goals. Permission to use the model of transaction can be found in Appendix A. The nurse and heart failure patient come together during the application of the nursing approaches to set mutual goals. The nurse’s assessment of the patient’s concerns, problems, and disturbances in health affect his/her perception, judgment, and action leading toward goal attainment. The heart failure patient’s perception of the impact of his/her chronic illness may affect his/her perception, judgment, and action toward goal attainment. The sharing of this information during the application of the nursing approaches as outlined in the AHCPH guide for heart failure may assist the patient and nurse to attain the goals that were mutually identified.

Utilizing this model of transaction (Figure 1), it can be conceptualized how

the nurse providing nursing approaches interacts with the heart failure patient to achieve outcome goals. During application of the nursing approaches, each participant actively moves through the reaction, interaction, and transaction phases with ongoing feedback providing for effective goal attainment. The two nursing approaches utilized will be supportive/educative and mutual goal setting. Both of these nursing approaches were developed utilizing the AHCPR guide for heart failure education.

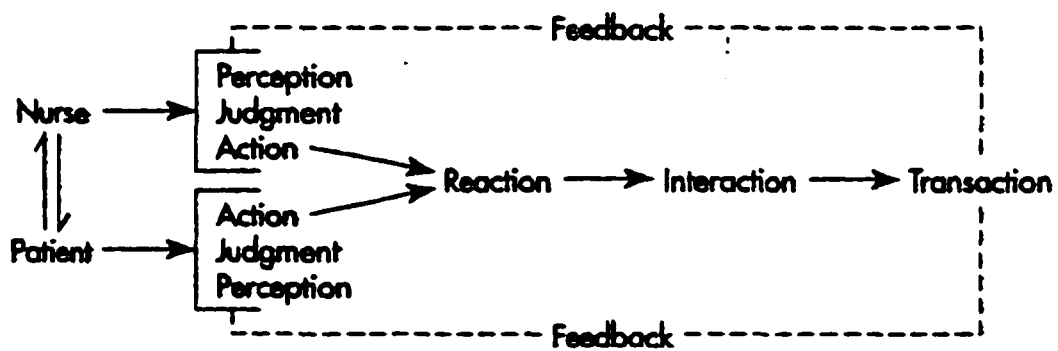


Figure 1: King's Transaction Model.

Used with permission from I. King. A model of transaction. A theory for Nursing: Systems, Concepts, Process (1981, p. 61). New York: Delmar.

Heart failure In order to acquaint the reader with a clearer understanding of heart failure, the concept definition used for this secondary analysis will be presented. Heart failure is a cardiovascular condition in which the heart is unable to pump an adequate amount of blood to meet the metabolic needs of the body's tissues. Heart failure is often not categorized as a disease. It is a syndrome caused by a variety of pathophysiologic processes, which may include but are not limited to coronary artery disease, hypertensive heart disease, cardiomyopathy, pulmonary emboli, and acute myocardial infarction. Heart failure is characterized by left ventricular dysfunction, reduced exercise tolerance, diminished quality of life, and shortened life expectancy (House-Fancher & Martinez, 1996). Kegel (1995) defined heart failure as "the pathophysiological condition in which an abnormality of cardiac function is responsible for the failure of the heart to pump blood at a rate commensurate with the requirements of the metabolizing tissue and/or to be able to do so only from an elevated filling pressure" (p.77). According to the Agency for Health Care Policy and Research (AHCPR, 1994), heart failure simply means that the heart's pumping power is weaker than normal. For the purpose of this secondary analysis heart failure is simply defined as the pathophysiological state in which an abnormality of cardiac function is responsible for the failure of the heart to pump blood at a rate able to meet the metabolic needs of the body's tissue. Heart failure is a permanent long-term syndrome with irreversible pathological change, characterized by reduced exercise tolerance, diminished quality of life, shortened life expectancy, and left ventricular dysfunction. For this secondary analysis heart failure was determined by the primary diagnosis for referral to home care.

Patients describe that the physical limitations of reduced activities of daily living and ability to work are often imposed by their diagnosis of heart failure and in this way affect their quality of life. In the literature, research related to quality of life evaluation involves that done to evaluate medical management (AVID, 1998; Bliley & Ferrans, 1993; Bulpett et al., 1998; Jaagosild et al, 1998; SOLVD, 1993). Research also has been conducted for evaluation of quality of life in heart failure related to dilated cardiomyopathy (Steptoe et al., 1999). Quality of life research conducted by Philbin et al. (1999) studied medical treatment supervised by cardiologist versus that supervised by non-cardiology health care providers. Quality of life measures for outcomes related to nursing approaches specifically are few, therefore, adding importance to the completion of this secondary analysis.

Review of the Literature

When conducting the literature review it was revealed that the data often did not specifically look at heart failure patients, or had difficulty with adequate sample size, data analysis, questionable instrumentation, and results collected over time. Studies that specifically addressed quality of life measurement in heart failure patients were of priority in the review. The following studies revealed specific difficulties related to quality of life measure in heart failure patients. The Dracup et al., (1992) and SOLVD (1993) studies utilized multiple tools for measurement of quality of life. The Bliley and Ferrans (1993), SUPPORT (1998), and Bulpett (1998) studies measured quality of life over time. Philbin et al., (1999) studied change in quality of life between provider treatment groups. Kinney et al., (1996) Bass et al., (1997) and Hawthorne and Hixon (1994) all reported on nursing evaluation of quality

of life with interventions. References to studies with these problems are provided in this literature review.

Quality of life Quality of life is a construct that is often defined as multidimensional. When measured, quality of life has been used to distinguish different patients or groups of patients to predict patient outcomes, and to evaluate therapeutic interventions (Gill & Feinstein, 1994). Quality of life within the confines of a chronic illness such as heart failure can be defined as a subjective, personal evaluation of and satisfaction with the physical, psychological, social, vocational, and spiritual dimensions of one's life that are affected by the level of social support available and symptoms experienced, the perceived impact of the chronic health problem on usual lifestyle and mood state (Bass et al., 1997). Quality of life may be simply conceptualized as the well being of an individual (Farquhar, 1995).

Quality of life also is defined within four domains: health and functioning, socioeconomic, psychosocial/spiritual, and family (Kinney et al., 1996). While many different definitions are used all have the common goal of capturing health status as perceived by the patient in areas of health identified to be of value to the patient. Quality of life measures of self-perceived health status can be used to evaluate the broad impact of heart failure on a patient and the effectiveness of nursing approaches. A quality of life measure can play a role in the clinical management of patients with heart failure by tracking the multidimensional impact of nursing approaches over time (Rumsfeld et al., 1999). Kinney et al. (1996) defines quality of life as a representation of four dimensions: symptoms and side effects, physical functional status, social functioning, and psychological status. Often the belief that quality of life, rather than

being a description of patients' health status is a reflection of the way that patient perceives and reacts to their health status and to other, non-medical aspects of their lives (Gill & Feinstein, 1994). For the purpose of this secondary analysis, quality of life was defined as the well being of an individual determined by his/her physical, psychological, physiological states, and social relationships, employment status, and ability to perform activities of daily living, as measured by how important these activities are to the individual. Quality of life measurement was done utilizing the Ferrans and Powers Quality of Life Index: Cardiac Version III. This tool measures the physical, physiologic, and psychological states, social relationships, and employment status, and perceived ability to perform activities of daily living. Also included in this tool is weighted measurement of the importance of each of these items to the individual heart patient.

Quality of life has been incorporated into clinical trials as an outcome measure in recent publications. In 1983, Fayer and Jones reported that during the period of 1978-1980, there were approximately 200 publications with quality of life in the title. In the years 1988-1989, over 1,400 publications considered quality of life in the body of the reports. Advances in medical care have made available an array of therapeutic options, with quality of life often being the only difference in treatment choice (Kinney et al., 1996). Many of the early studies that reported quality of life outcome measures were in the field of oncology and report treatment régimes and their effect on quality of life. Until recently, little has been documented in the literature regarding measurement of quality of life as an outcome in heart failure patients. However, there are a growing number of studies investigating quality of life

in a variety of settings in the heart failure population.

Measurement of QOL In a study done by Dracup et al. (1992), a group of 134 patients with advanced heart failure prior to cardiac transplantation were enrolled for the purpose of evaluation of self-reported quality of life. The study employed a multidimensional approach, including objective and subjective measures, as well as physical (functional) and psychosocial aspects (Dracup et al., 1992). One of the study questions was “what are the relationships among various components of quality of life, that is, to what extent do the levels of subjective and objective physical function associate with psychosocial adjustment” (Dracup et al., 1992). Quality of life was evaluated utilizing the Heart Failure Functional Status Inventory, Six-minute walk test, Multiple Affect Adjustment Checklist (MAACL), Psychosocial Adaptation to Illness Scale (PAIS), and the New York Heart Association Classification (NYHA) of heart failure.

The Heart Failure Functional Status Inventory is a 25-item questionnaire, with each item listing a specific physical activity to which the patient is asked to respond with one of the following, “Yes, I can do this,” “Yes, I can do this, but only slowly,” or “No, I can not do this.” If the patient responded with one of the two later choices, he/she was instructed to indicate whether the physical activity was limited primarily by shortness of breath, weakness without shortness of breath, fatigue, chest pain, or some other reason. Content validity of the tool was established by a panel composed of three experts in the field of cardiology. The six-minute walk was done to measure the distance covered in six minutes, which was an objective measure of functional status and exercise tolerance. The six-minute walk has high reliability; its

reproducibility is higher than that of a pulmonary function test (Dracup et al, 1992). The MAACL and the PAIS were used in the Dracup et al (1992) study to measure psychosocial perception. The MAACL is composed of 132 alphabetically arranged adjectives, giving scores if the patient checks them and minus scores if not checked. The PAIS is designed to measure the changes related to physical illness a patient experiences in psychological and social dimensions. The PAIS is a 46-item self-report questionnaire, with question responses marked from 0 (no disturbance) to 3 (marked disturbance). The total score range is from 0 to 138.

The results of the Dracup et al. (1992) study reflected that the 134 patients with advanced heart failure described their quality of life as significantly compromised by depression ($M=10.5$, $SD\pm 4.5$ on the MAACL). The patients described themselves as moderately anxious and hostile ($M=19.7$, $SD\pm 6.8$ on the MAACL). In the psychological distress category they described the most negative changes as having occurred in their relationships with friends and with members of their extended family, as well as in their own emotional state ($M=54.8$ $SD\pm 9.8$ on PAIS) (Dracup et al., 1992). The findings in the Dracup et al. (1992) study suggest that nursing approaches to improve quality of life of patients with advanced heart failure before heart transplantation need to be targeted at reducing depression and hostility, and increasing daily activity. These interventions for example could include an outpatient low-level exercise program, counseling, or a combination of the two (Dracup et al., 1992).

A limitation of the study is its inability to be generalized to female patients, as only 23 or 17.2% of this study's sample were female. Seventy-six or 56.7% were

New York Heart Association Class IV; the authors reported no relationship between NYHA classification and any of the measures of quality of life. Another limitation is the one time evaluation of quality of life measurement. Dracup et al. (1992) did not collect data at different points in time or follow different therapies or treatment modalities for effects on quality of life scores. Also, utilizing self-reported questionnaires may be limiting because it may have blended the weakness of low-response rate, missing items, and misunderstanding of questionnaires. Dracup et al. utilized multiple tools to measure quality of life, each having numerous steps and multiple questions, which can fatigue or overwhelm the heart failure patient. Therefore, utilizing a tool specifically designed for a cardiac population may lead to higher response rates due to the streamline application of the questionnaire. One such tool is the Ferrans and Powers Quality of Life Index: Cardiac Version III (Ferrans & Powers, 1985).

In the Study of Left Ventricular Dysfunction (SOLVD) trial, Quality of Life Substudy (1993), 318 patients were enrolled to measure the importance of improvement in aspects of a patient's quality of life against the importance of prolonging survival. Measuring quality of life against the importance of prolonged survival parallels with the purpose of this secondary analysis, which is the measure of quality of life as weighed against the importance of each of these items to the individual participant. The quality of life battery of tools for the SOLVD study included the Living with Heart Failure Scale, and the Rand Corporation's Mental Health Inventory. Again multiple tools were used as in the Dracup et al. (1992) study. All the tools in the SOLVD (1993) were administered at baseline, before the initiation

of therapy. The authors reported higher internal consistency ($\alpha = .94-.95$) with the Living with Heart Failure Scale. The Living with Heart Failure Scale is a 23-item Likert format scale used to assess the impact of heart disease on various aspects of life quality. The Rand Corporation's Mental Health Inventory has reported reliability of .79. This SOLVD substudy had a goal of evaluating the tools for further use in the SOLVD study at different time intervals. The results supported the inclusion of the SOLVD quality of life assessment battery in the evaluation of the course and treatment of left ventricular dysfunction and heart failure. The reliability scores ranged from ($n=99$) .80 on the health perceptions of the patient to ($n=138$) .98 on the social support tools.

The limitations of the SOLVD (1993) study include the use of data reduction. Missing items were replaced with the patient's mean value for the overall scale, thereby adding to the questioned validity of the scores. Also, the initial assessment lasted approximately 60 to 90 minutes and also included a 30-minute evaluation of cognitive functioning. This extensive amount of time could lead to participant fatigue and overload in the chronic heart failure population. This was a complex substudy in a clinical trial for medication evaluation of heart failure patients, thus limiting its application. However, conducting validity and internal consistency for the tools is necessary for future studies.

Quality of life measurement over time Bliley and Ferrans (1993) conducted a study on the impact of percutaneous transluminal coronary angioplasty (PTCA) on quality of life. The specific research questions for their study were: 1) Are there improvements in perceived quality of life after PTCA? 2) Are there improvements in

health-related quality of life after PTCA in the areas of cardiac symptoms, tolerance of physical activity, exercise capacity, perceived general health, return to work, and lifestyle changes? and, 3) What is the relationship between perceived quality of life and selected health-related quality of life indicators before and after PTCA? (Bliley & Ferrans, 1993).

The Bliley and Ferrans (1993) study was in a pre-post test format. Pretest data were collected the evening before PTCA and posttest data were collected 4-6 weeks after PTCA. The sample was taken from a large midwestern medical center and 40 subjects completed both pre-post test tools. The tool used was the Ferrans and Powers Quality of Life Index-Cardiac Version. Internal consistency reliability for this tool is supported by alpha coefficient of .90-.95 (Bliley & Ferrans, 1993).

The results of the Bliley and Ferrans (1993) study showed a significant improvement in perception of overall quality of life with score ranges from 0 - 30 (M= 20.32, SD+/- 3.36 before PTCA; and M=22.87 SD+/- 4.69 after PTCA, $p < 0.005$). This improvement was reportedly due to increased satisfaction with health and functioning. The study reported that patients at the six-week evaluation often found it difficult to maintain lifestyle changes required of cardiac patients such as diet, exercise, or smoking cessation. The results may be used to assist nurses implementing appropriate nursing approaches regarding continued support for heart disease patients after initial treatment. Limitations of this study included its lack of generalization to other than PTCA patients and to short time improvement in quality of life at the six-week point. Also the sample size was limited at forty. The Bliley and Ferrans study does give additional reliability and validity to the Ferrans and Powers

Quality of Life Index: Cardiac Version to be used in other cardiac patient populations.

In a study involving 1390 adult patients with the diagnosis of heart failure by Jaagosild et al. (1998) quality of life measurement, resources used, and survival data were collected. This study "Understand Prognosis and Preferences for Outcome and Risk of Treatment" (SUPPORT) was conducted at five teaching hospitals over two two-year periods of time. The Sickness Impact Profile (SIP), the Katz Index of Activities of Daily Living (Index of ADL) and several health perception instruments were utilized for data collection for quality of life. The SIP is a measure of perceived health status, with a score ranging from 0-100. A higher score describes worse health.

The Index of ADL is a scale from 0-7 whose grades reflect dependence in the following seven primary self-care functions: bathing, dressing, toileting, transferring, continence, feeding, and walking. Data were collected at study admission (while hospitalized), 60, and 180 days. The Index of ADL results at baseline $M=95$ ($SD\pm 8.4$) subjects reported dependence in greater than four self-care functions and at 60 days $M= 107$ ($SD\pm 11.8$) and at 180 days $M= 84$ ($SD\pm 11.0$). Participants reported four or greater dependence in self care functions. Quality of life measurement on the SIP at baseline for the median ($n= 621$) was fair (health rating 55); at sixty days it was reported as good (health rating 60), with improved comparison (mean health perception scores were 66.3% at 60 days and 59.8% at 180 days; $p < 0.001$).

Questions could be raised related to how these tools were used for measurement of quality of life, since the tools specifically used measured health perception, activity of daily living and sickness impact. All these items can be defined as aspects of quality of life. The SUPPORT study demonstrated that aspects of quality

of life are measurable for large numbers of patients hospitalized with heart failure and provided baseline aspects of quality of life data and change of aspects quality of life in time. The SUPPORT study validates the importance of measuring quality of life over time.

The authors pointed out that missing data are a common problem when using survey methods to measure quality of life over time. The common practice of excluding patients with missing or incomplete data from analysis may create biased samples. The SUPPORT study substituted quality of life data to increase the available sample size and to decrease possible bias associated with the correlation of disease severity and missing data (Jaagosild et al., 1998). The results of the SUPPORT study therefore may be generalizable to the younger patients who receive an aggressive approach including hospitalization with acute exacerbation of heart failure, since the subjects were hospitalized with acute exacerbation of heart failure.

Limitations of the SUPPORT (1998) study include the lack of application to patients treated in small or non-teaching hospitals or nursing homes, or to patients with exacerbation of heart failure that are not hospitalized. The SUPPORT study population tended to be younger and male, had fewer activity of daily living impairments, and experienced lower mortality rates compared with patients with similar severity of disease from the same geographical area that were not enrolled into the study (Jaagosild et al., 1998). Because the study was longitudinal, the threats of history and maturation existed.

Bulpitt et al. (1998) conducted a study of heart failure patients to evaluate long acting angiotensive converting enzymes (ACE) inhibitors (Cilazapril) with short

acting (Captopril). Both ACE medications are associated with acute improvements in hemodynamic measurements, which appear to be attenuated when these effects are measured during long-term treatment. Therefore, the authors hypothesized that quality of life improvements were expected with long acting ACE inhibitor treatment (Bulpitt et al., 1998).

This double blind placebo controlled trial (Bulpitt et al., 1998) was conducted in 12 different countries. Patients with the diagnosis of heart failure for more than three months, who had been clinically stable on digoxin and/or diuretics and were over the age of 18 years of age were enrolled. Quality of life measurement was done utilizing the Sickness Impact Profile (SIP), the Profile of Mood Status (POMS) and supplemented by questions to assess dyspnea and impact of heart failure on leisure and regular activities. The SIP is a questionnaire consisting of 12 dimensions ranging from ambulation to recreation and pastime activities. The POMS is a questionnaire of six-subscales related to tension-anger, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment. Quality of life measurements were completed upon enrollment into the trial, at 12, and 24 weeks, and on the final visit of study.

The Bulpitt et al. (1998) population consisted of 367 patients. Baseline quality of life measures did not differ statistically among the three treatment groups. The effects of both ACE inhibitors on exercise tests were statistically better than placebo ($F= 5.44$, $p = < 0.001$), but for quality of life the results were modest ($F= 3.56$, $p= 0.20$). The authors suggest that the small effect size may have resulted from the fact that the quality of life tools were not sensitive enough. The tools were not

specifically designed for use in heart failure populations. Despite large sample size, improvements in quality of life were not found in this study. The authors point out that the close relationship between quality of life measures in heart failure and objective measurements of exercise tolerance appear to exist in other reported studies. The authors suggest using the Minnesota Living with Heart Failure questionnaire in future studies, because this tool has been used to show sensitivity to the benefits of other inotropic agents in the SOLVD study.

A study by Philbin et al. (1999) was performed to determine whether severity of illness, treatment choices, and clinical outcomes varied among patients with heart failure treated by cardiologists and by non-cardiologists in the community hospital setting. Two thousand four hundred fifty-four patients with heart failure were studied to compare diagnostic tests and treatment strategies, hospital charges, readmission rate, and quality of life measure post-discharge. The quality of life tool utilized was the Ladder of Life score. The Ladder of Life questionnaire asked the patient to rank the quality of his or her life on a scale of 1 to 10 with 10 indicating the best possible life and 1 indicating the worst. The Ladder of Life scale was chosen to facilitate telephone follow-up among a large and geographically diffuse population. However, this tool was documented for use previously in a prostate cancer patient population, not a cardiac patient population.

The scores between the treatment groups for quality of life were not significant. The authors were not able to show superior care by cardiologists, and recommended further study before health manpower recommendations be made. This study was conducted on patients with heart failure as the primary reason for

hospitalization so the results cannot be generalized to patients who had heart failure as a secondary diagnosis. Strengths of the study included its large sample size and multi-site data collection. The Philbin et al. (1999) study documents that non-cardiologist care providers can affect results for heart failure patients that reflect improvement in quality of life. Therefore, further studies of nursing approaches, specifically those utilizing the Agency for Health Care Policy and Research guidelines for heart failure may show improvement in outcomes for the heart failure population related to quality of life.

Nursing approaches According to the American Nurses Association's Social Policy statement (1980), the unique function of the nurse is diagnosis and treatment of the human response to actual or potential health problems. Heart failure patients present important nursing responsibilities to 1) educate the patient about the physiologic changes that have occurred, and 2) to assist the patient to adapt to both the physiologic and psychological changes. Some of the nursing approaches include ongoing clinical assessments, monitoring vital signs, weight, and responses to therapies such as medications and education. These specific nursing approaches may enable the nurse and patient to identify problems and institute therapies to prevent future hospitalizations. The AHCPR guideline for heart failure has outlined specific nursing approaches for patient education. For the purpose of this secondary analysis nursing approaches were those developed utilizing the AHCPR guide for heart failure for patient education. The nursing approaches were provided during eight sessions with the client. A copy of the patient and family guide, "Living with Heart Disease: Is It Heart Failure?" was provided to each patient. Copies of this guide are available

from the US Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research. Request AHCPR publication No. 94-0614.

Nursing approaches in quality of life Kinney et al. (1996) conducted a meta-analysis of quality of life in cardiac patient research. This meta-analysis of 84 studies of quality of life research covered studies of pharmacological, mechanical, surgical, nursing, or other treatment on quality of life (Kinney et al., 1996). The purpose of the Kinney et al. study (1996) was to organize and synthesize medical and nursing research addressing quality of life in adult cardiac patients for a period of five years covering 1987 to 1991.

The Kinney et al. (1996) analysis suggests a small but significant effect of treatment on quality of life, regardless of the form of the treatment. The Kinney et al. analysis brought the concern that more than one half of the studies reviewed failed to define quality of life as a concept. In some instances, the researcher's intent to evaluate the effect of treatment on quality of life was found in the introduction or discussion only (Kinney et al., 1996).

Another problem noted in the Kinney et al. (1996) analysis was instrumentation. Almost two thirds of the instruments employed were unidimensional. The investigators developed one third of the instruments with little or no evidence of validity, reliability, or sensitivity to detect change. The Kinney et al. analysis also found the trend of quality of life data collection at only one point in time, or if longitudinal, for only three months or less. As noted by Fayer and Jones (1983), data are ideally collected before, during, and after treatment to provide a

continuous picture of change.

The Kinney et al. (1996) analysis assisted in providing a blueprint for measurement in this secondary analysis. Quality of life was defined as a concept, the instrument used for measurement had documented validity and reliability, and quality of life measurement occurred at more than one point in time to provide a continuous picture of change. It should be noted that of the 84 studies reviewed by Kinney et al. only one had a nursing approach intervention, 48 were pharmacological, eight were pacing, seven were medical, and others were a combination of treatment modalities. This also provides support to the importance of measuring and reporting changes in quality of life outcomes from nursing approaches as interventions in heart failure patients.

Sullivan and Hawthorne (1996) reported on a review of studies on nonpharmacologic interventions in the treatment of heart failure. The authors reviewed three major types of interventions, (1) exercise training and rehabilitation; (2) psychological and biobehavioral interventions; and (3) self-care strategies and patient education, which are essential to co-interventions to pharmacologic therapy in the treatment of patients with heart failure. Sullivan and Hawthorne worked with Duke University to establish interventions and protocols for heart failure patients. Within the guidelines of their protocols patient education is begun early in the hospital setting and continued during the first weeks after the patient's hospital discharge. This was achieved through nursing home visits, phone calls or weekly clinic visits.

Most of the data collection during the Sullivan and Hawthorne (1996) study

focused on stroke volume during exercise, physical endurance, and skeletal muscle response to exercise. They did not report methodology of study for quality of life measurement. The attention to psychological and emotional needs of the heart failure patient may decrease major depression in this population as stated in prior studies. The authors report that bibehavioral interventions of relaxation strategies may reduce depression and improve quality of life. The measurement of bibehavioral interventions was done utilizing the mortality and depression data. Those participants enrolled and followed after hospital discharge that had a diagnosis of major depression, reportedly had a higher predictor for mortality. The Sullivan and Hawthorne study did not report specific study statistics. Improved patient education and nursing follow-up may reduce morbidity is what the authors reported as indicated by their analysis. Bibehavioral interventions such as nursing approaches developed utilizing the AHCPR guidelines for heart failure may also improve quality of life and offer the potential to improve outcomes.

Sullivan and Hawthorne (1996) suggest that continued investigation focus on combinations of nonpharmacologic interventions such as moderate aerobic exercise, lipid management, and stress reduction as co-therapies with pharmacologic interventions for the heart failure patient. Future studies of these modalities can provide nursing with effective outcome measure to evaluate care planning with this heart failure population.

Baas, Fontana, and Bhat (1997) reported a pilot study to evaluate modeling and role modeling three different treatment regimens for heart failure patients. While the sample size was small at 38 and utilized a convenience sample, the results provide

validity to continuation of the pilot study. This pilot study supports the importance of testing nursing interventions for heart failure patients as related to evaluation of quality of life. The Bass et al. study was designed to evaluate global quality of life and health related quality of life. The tools utilized were the Self Care Resource Inventory, an instrument to measure the self-care resources the person perceived to be needed and available. It is a 35-item Likert type self-reporting instrument. Each item can be rated from 0 (none) to 4 (great deal) in relation to amount of resources available. The Human Activity Profile (HAP) is a 94-item checklist of activities that range in intensity. It is a reflection of the intensity of activity routinely performed by the respondent. The HAP has been used to study activity levels of persons with lung disease, renal disease and chronic pain, as well as post myocardial infarction. The Index of Well-being (IWB), and Short Form 36 Health Survey were utilized also as measurement tools of quality of life. This weighted questionnaire was developed to assess the general well being. The IWB was selected to provide a global measure of quality of life in the Bass et al. pilot study. Also utilized in the Bass et al. study was the Living with Heart Failure Questionnaire (LHFQ). The LHFQ assesses patients' perceptions of the effect of heart failure on their lives.

Bass et al. (1997) reported that those persons with higher levels of perceived available resources are able to achieve higher levels of global quality of life ($F= 20.15$ $df 1, 36, p < 0.0001$). Among the three treatment groups, subjects undergoing medical treatment for heart failure those awaiting transplant and those within the first month post-transplant reported many of the same needs and resources. Bass et al. reported it was interesting to note that the internal resources predicted a greater amount of global

quality of life than the external resources. Internal resources include such factors as hope, spirituality, optimism, self-esteem, and humor. External resources include factors such as family support, information, health care resources and financial resources. Bass et al. (1997) report that nurses are quick to devise interventions that facilitate the use of external resources, but internal resources may be more important in terms of enhancing global quality of life. The Bass et al. pilot study supports further investigation into nursing approaches and their effect on quality of life in heart failure patients.

Hawthorne and Hixon (1994) conducted a pilot study to evaluate the feasibility and effects of a model of nursing care designed to prevent or decrease recurrent hospitalizations in patients with chronic heart failure. Equally important to the authors was to evaluate treatment goals to preserve the patient's functional capacity and improve quality of life. Hawthorne and Hixon reported that information is needed to understand the needs of this rapidly growing population and to identify models of care, which improve the devastating outcomes, experienced by the heart failure patient group.

The Hawthorne and Hixon (1994) pilot study groups were randomized into either the control or experimental groups. All participants received standard team managed, individualized rehabilitation. In addition the experimental group was instructed in self-monitoring of failure symptoms and a cardiovascular clinical nurse specialist followed the patients at home. Data were collected over time at four data points, prior to hospital discharge, at one, three and six months following discharge. All subjects were administered the following instruments: Michel Uncertainty in

Illness Scale (MUIS), Profile of Mood States (POMS), Heart Failure Functional Status Index (HFFSI) and the Ferrans and Powers Quality of Life Index; Cardiac Version III (QLI).

The MUIS adult form is a 32-item, 5-point summative scale. The higher the uncertainty scores on the MUIS, the greater the subject's perceived inability to determine the meaning of illness-related events. Reported reliability for the MUIS is from 0.70 to 0.91. The POMS consists of 6 subscales: tension-anxiety, anger-hostility, depression-dejection, fatigue-inertia, confusion-bewilderment, and vigor. The higher the score on each domain except for vigor, the higher the subject's mood disturbance.

Quality of life was measured by the QLI. The QLI provides a global measure of quality of life based upon self-reports of satisfaction with 38 specific items including: physical independence, stress, leisure, health care, overall standard of living, job/employment, friends, education, life satisfaction, happiness, goals, peace of mind, faith in God, family happiness, and health. The subject ranks each item on a five-point scale according to his/her perceived satisfaction with that item. Then the subjects ranks each items in terms of its importance to the individual. Using the QLI scores reflect individual differences in perceived importance of the different components of quality of life.

Functional capacity was evaluated using the HFFSI. The HFFSI is a self-report questionnaire designed to specify exercise capacity and limiting symptoms. The HFFSI consists of 12 items each listing a specific activity and the subjects indicates his/her ability to perform each activity. The HFFSI provides information

about the frequency and type of associated limiting symptoms of the heart failure subjects.

Results of the Hawthorne and Hixon (1994) pilot study indicate that heart failure patients experience significant mood disturbance that appears to be greater than that reported by other cardiac patients ($F= 5.369$, $p= 0.049$). Mood disruption is also related to reported quality of life. Patients related the health and functioning domains as having the lowest quality compared to other domains, with family quality of life being rated the highest. This relative rank ordering did not differ overtime. There were no significant differences found for either group (experimental vs. control) membership. Those subjects with a reported higher HFFSI score had a significantly higher total quality of life score and these differences persist over time also ($F= 6.197$, $p=0.026$).

The Hawthorne and Hixon (1994) study supports the feasibility and potential benefits of nursing follow-up of heart failure patients. The authors report that the patients were never without questions for the caregiver. Several subjects were averted from either emergency room visits or rehospitalization by timely interaction with their nurse specialist. However, the authors report the need for continued study into cost-benefit and the need for further development of experimental interventions for this complex heart failure population.

In a study by Jaarsma et al. (2000) the goal was to determine the effects of a supportive educational nursing intervention on self-care abilities, self-care behaviors, and quality of life of patients with advanced heart failure. The Jaarsma et al. study included 179 patients admitted to a university hospital with symptoms of heart

failure. The authors hypothesized that a supportive educative intervention designed for patients with heart failure will increase self-care agency, and self-care behavior and have a positive effect on quality of life as reflected by three dimensions (functional capabilities, symptoms and psychosocial adjustment) and a high overall well-being score. The intervention included intensive education by a study nurse about the consequences of heart failure in daily life using of a standard nursing care plan developed by the researchers for older patients with heart failure. Patients were randomly assigned to either routine care or a supportive educational intervention. All patients were followed for a nine-month period. Data were collected at one, three, and nine-month intervals after discharge.

Outcome measurement included measuring self-care abilities by utilizing the Appraisal of Self Care Agency scale. Self-care behavior was measured by utilizing the Heart Failure Self-Care Behavior scale, and three dimensions of quality of life by using the functional capabilities symptoms, and psychosocial adjustment to illness, and overall well being by using the Cantril's Ladder of Life. Quality of life was evaluated by use of both objective and subjective dimensions. To assess functional capabilities, the Heart Failure Functional Status Index (HFFSI) was used. Symptoms were assessed by a questionnaire regarding occurrence, severity, and distress. A total score of symptoms was calculated by adding the number of symptoms (minimum=0, maximum=6). In addition patients were asked to rate symptom severity and distress on a 10-point scale. The number of symptoms and severity were assessed at all data collection points. The PAS was used to measure psychosocial adjustment to illness.

In the Jaarsma et al. (2000) study it was expected that the supportive

educational intervention would improve the heart failure patient's self-care behavior and in turn would improve quality of life. The effect on quality of life was limited. The reported difference between the intervention ($r=0.20$) and control group ($r= 0.27$) throughout the study period ($p= <0.05$) showed a slight relationship. Few randomized studies are available that test nurse-led interventions and their effect on quality of life, thus adding validity to the purpose of this secondary analysis. It is recommended by Jaarsma et al. that a supportive educational intervention should be included in a heart failure program that is aimed at changing patients' self-care behavior. However, to improve other outcomes such as quality of life, the program has to be tailored to the multifaceted needs of the patients, including enhancing psychosocial adjustment, increasing functional capabilities, and decreasing symptom occurrence. Improving quality of life is a major goal in treatment for patients with heart failure. Therefore, efforts should be made to gain insight into what really describes and influences quality of life in these often-elderly patients with heart failure and what can improve their quality of life.

Shively et al. (1996) reviewed eight studies that measured quality of life as an outcome for patients with medically managed heart failure. Shively et al. noted also a lack of definition of quality of life as a concept, single measurement of time, and a lack of standardized questionnaires for measuring quality of life. Shively et al. suggested that clinicians and researchers collaborate to identify the most appropriate questionnaire and plan for longitudinal tracking of this quality of life outcome. The Shively et al. review also provided support in design of this secondary analysis.

Summary

In summary, the literature review demonstrated the need to continue to investigate outcomes related to quality of life in heart failure patients. Measurement of quality of life can be used to predict patient outcomes and to evaluate therapeutic interventions (Gill & Feinstein, 1994). The study by Dracup et al. (1992) suggested that interventions to improve quality of life be targeted at reducing depression, hostility, and increasing daily activity. The Study of Left Ventricular Dysfunction (SOLVD, 1993) supported the inclusion of quality of life assessment in the evaluation of the course and treatment of left ventricular dysfunction and heart failure.

Bliley and Ferrans (1993) demonstrated improved quality of life over time with the medical intervention of percutaneous transluminal angioplasty. Also the Jaagosild et al. (1998) study reported on quality of life over time in heart failure patients who received medical interventions. Bulpitt et al. (1998) evaluated quality of life over time in heart failure patients and the use of ACE inhibitors.

The Philbin et al. (1999) study provides quality of life measures for heart failure patients in groups comparing results of treatment by cardiologists and non-cardiologist health care providers. The Philbin et al. study supports further research to evaluate quality of life treatments by non-cardiologist providers.

The literature review supports the assumption that heart failure affects the patient's perceived quality of life. It is suggested that more studies are needed to improve patient education and nursing follow-up in an attempt to reduce the psychological effects of heart failure and improve the patient's perceived quality of life with studies designed to measure change in quality of life over time. As the

Kinney et al.'s (1996) meta-analysis shows, research conducted measuring quality of life following nursing approaches as interventions is lacking. The Hawthorne and Hixon (1994), Jaarsma et al. (2000), and Bass et al. (1997) studies all report nursing intervention related to heart failure and quality of life measurements. All three studies suggest further investigation into what nursing interventions, supportive educational, modeling and role modeling, modeled nursing care plans or other approaches may be effective in influencing quality of life in heart failure patients.

Implication for Study

The increased reporting in recent years of measurement of quality of life in heart failure populations reflects the growing perception of the importance of this outcome in patients. It is through this measurement and evaluation that nurses can identify nursing approaches that are appropriate in assisting heart failure patients in achieving optimal quality of life. Heart failure is the fastest growing disorder in the United States. Given the considerable resources spent on heart failure, which often result in questionable or undetermined quality of life, there is increasing pressure to examine and justify interventions both from a clinical decision-making and evaluation point of view. Overall quality of life may encompass not only health related factors, but also many non-medical phenomena, such as employment, family relationships, and spirituality (Gill & Feinstein, 1994). These items are all important factors to be considered when selecting a tool for quality of life measurement. Although investigators often offer patients the opportunity to rate the severity or magnitude of pertinent problems, quality of life may not be properly characterized unless patients are also invited to rate the importance of the problem (Gill & Feinstein, 1994). The

challenges arise in measuring quality of life because, rather than being a mere rating of health status, it is actually a uniquely personal perception, representing the way that individual patients feel about their health status or general aspects of their lives and the importance of these aspects to each individual.

By providing nursing approaches that contribute to an improved quality of life positive gains by heart failure patients may be expected. Nursing approaches may assist to set realistic goals, to encourage active involvement in decision-making that affects the health of patients, and to direct their thoughts past the current state and into the future. It is important for nurses to be able to inform other nursing professionals and relatives about how the patient perceives his/her quality of life and what can be done to assist him/her.

Research Question

The question addressed through this secondary analysis was: What impact does providing nursing approaches based on AHCPR guidelines have on quality of life scores overtime for patients with heart failure receiving home care? The nursing approaches to be studied will be those that were developed with guidance from the Agency for Health Care Policy and Research guideline for heart failure.

Definition of Terms

The following operational definitions were utilized for this secondary analysis:

Nursing approaches: For the purpose of this secondary analysis nursing approaches will simply mean those nursing approaches developed utilizing the AHCPR guide for

heart failure in patient education.

Quality of life: The definition of quality of life that was developed by Ferrans and Ferrell (1990) that guided the development of the QLI was “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans & Ferrel, 1990 p. 15). This definition of quality of life was used as the operational definition in this secondary analysis.

Heart failure: As defined by the Agency for Health Care Policy and Research, heart failure is, “a clinical syndrome or condition characterized by (1) signs and symptoms of intravascular and interstitial volume overload, including shortness of breath, rales, and edema or (2) manifestations of inadequate tissue perfusion, such as fatigue or poor exercise tolerance” (AHCPR Quick Reference Guide for Clinicians, No.11 p. 1). For this secondary analysis heart failure is determined as the primary diagnosis for referral to home care.

Home care: Home care is defined as those heart failure patients who were receiving home care at the time of enrollment from a Visiting Nurse organization in West Michigan.

CHAPTER 3

METHODS

Design

This was a secondary analysis of the primary study designed by Dr. Kay Setter Kline. The Kline study: Home Care Outcomes for Heart Failure: A Test of Two Nursing Approaches was conducted at Grand Valley State University. The primary study was a blinded, experimental design. Subjects were randomly assigned to one of three nursing groups: a) placebo, b) supportive-educative, c) mutual goal setting. The primary study investigated the following outcomes to determine the effectiveness of specific nursing approaches, a) increased self-management of heart failure, b) improve quality of life, c) reduced cost of health care, d) reduced hospital readmission rates, e) decreased length of stay if admitted to a hospital. This secondary analysis utilized the heart failure study subjects who received nursing approaches developed with guidance from the AHCPR guidelines for heart failure. These nursing approaches were the supportive/educative and mutual goal setting. The subjects randomized to these groups were utilized in the secondary data analysis. A comparison of quality of life scores at two or more points in time within a single group (heart failure patients) was utilized. The Ferrans and Powers Quality of Life Index; Cardiac Version III (Appendix B) and a demographic questionnaire (Appendix C) were used to secure information from the subjects. The primary study with its experimental design has the strength of feasibility, practicality, and to some extent, generalizability.

The study group completed pre-test data collection, had exposure to the nursing approaches derived from the AHCPR guide for heart failure and completed post-test data collection. The collection of pre-test data allows for determining whether the quality of life scores for the study population were initially similar. For the purpose of this secondary analysis the nursing approaches were developed utilizing the AHCPR guide for heart failure. The nursing approaches were administered during eight scheduled meetings at the patient's place of residence.

A threat of internal validity could be whether factors other than the experimental treatment caused or affected the outcomes obtained. A measurement strategy to control for this type of threat is the time series design; the collection of information overtime before and after the treatment was instituted. Utilizing the time series design within this secondary analysis assisted in evaluation of the variables under study.

Since this secondary analysis utilizes the time series design, history may be a threat to internal validity. History is an external event that may occur which has an effect at any of the measurement points. History may also include the patient's ability to remember responses to questionnaires from one measurement to another.

The internal threat of bias will be controlled by randomization of the study population into the nursing approaches treatment groups. In the primary study, Home Care Outcomes for Heart Failure: A Test of Two Nursing Approaches, three different nursing approaches were studied. The differences in quality of life scores from baseline compared to three and six month testing was analyzed for those randomized into mutual goal setting or supportive-educative nursing approaches. This assisted in

evaluation of changes in quality of life scores over time for the population of heart failure patients receiving nursing approaches developed utilizing the AHCPR guidelines.

Maturation could also be another internal threat to this time series design secondary analysis. Maturation refers to the outcome that may occur within the study population during the course of the study as a result of the passage of time rather than as a result of the treatment (Polit & Hungler, 1995). Another internal threat could be sensitization to the quality of life tool. With first administration of the questionnaire sensitization may occur. This is also sometimes referred to as testing effects, the effects of taking a pre-test on the scores of the post-test. It will be impossible to segregate the effects of the nursing approaches from the effects of having taken the pretest. Attrition may be considered another threat to validity. Heart failure carries with it a higher mortality rate than that of the general population. The subjects for this secondary analysis were not declined for enrollment based on the New York Heart Association Classification scale, subjects were recruited and replaced until the total sample size was reached or the calendar deadline was reached.

Sample and Setting

For the primary study, the target population was all patients with the primary diagnosis of heart failure as the reason for home care. A convenience sample was used. The subjects consisted of heart failure patients who were under the care of a home health care agency at the time of initial data collection. Patients inclusion criteria were: (1) heart failure as primary diagnosis, (2) over the age of 18, with no upper age limit, (3) able to understand, speak and read the English language, and

(4) receiving home health care nursing visits related to heart failure as the primary diagnosis for referral. No restrictions in regard to gender, race, or socioeconomic status were stated. No specific exclusion criteria except for the lower age limit have been included. No criteria based on the New York Heart Association classification of heart failure were cited. It was anticipated that the secondary analysis population would be thirty or forty subjects.

The location of the primary study was the natural setting of the patients' place of residence, whether that is a single family home, apartment within an elder care facility, multi-family home unit, or an assisted living care center. No subjects enrolled were from the homeless population. All subjects were taken from those receiving home health care for heart failure from the two Visiting Nurse Association services in a Midwest state. The subjects were from rural as well as urban living sites. All study participants were asked to complete a demographic information sheet to use for data analysis. This information included age, marital status, income level, length of time with diagnosis of heart failure and other information (See Appendix C). Using a patient data sheet with demographic information supplies information that may be considered potential extraneous variables. Providing this information may assist in identification of these variables.

Characteristics of Subjects

Forty-nine individuals met inclusion criteria and were enrolled in the primary study as of the time of this secondary analysis. The subjects ranged in age from 42-94, with a median age of 75. Seventy-six percent were 71 years old or older. Data on highest level of education, category of health professional providing heart failure care

and years diagnosed with heart failure are provided in Table 1. As can be seen from Table 1, 77.6% (n = 38) of the patients had at least an eleventh grade education with one subject having a master's degree. A cardiologist provided care in 69.4% (n = 34). It was interesting to note that one subject was receiving care from a nurse practitioner. The subjects had a variation in years from diagnosis, 38.8% (n = 19) had been diagnosed less than one year to enrollment into the study, 28.6% (n = 14) had been diagnosed for greater than five years.

Instrument

To assess quality of life in the heart failure patient, the Ferrans and Powers Quality of Life Index; Cardiac Version III was utilized (QLI). The QLI lists seventy items to be rated on a six-point Likert type scale in the following format: (1) very dissatisfied, (2) moderately dissatisfied, (3) slightly dissatisfied, (4) slightly satisfied, (5) moderately satisfied, (6) very satisfied (See Appendix B). The QLI is scored on a weighted scale. The QLI is weighted to provide scoring subscales in health and functioning, social and economic, psychological/spiritual, and family. Score ranges are 0-30 within the QLI. Satisfaction responses are weighted by importance responses to provide overall total QLI scores. Permission to use this tool was received from Dr. Ferrans (See Appendix D).

Internal consistency and reliability for the QLI total scale are supported by Cronbach alpha values ranging from 0.84 to 0.98 across twenty studies. Content validity was previously established (Ferrans & Powers, 1985) on an extensive literature review of issues related to quality of life and on the reports of patients

Table 1**Characteristics of the Sample**

Characteristic	Frequency	Percentage
<u>Level of education</u>		
1 – 7	1	2 %
8 - 10	10	20%
11 –12	25	51%
Associate	10	20%
Bachelors	2	4%
Masters	1	2%
<u>Care Provided for Heart Failure By</u>		
Cardiologist	34	69%
Internist	20	41%
Family Practice	8	16%
Nurse Practitioner	1	2%
Physicians Assistant	0	0%
<u>Years Diagnosed with Heart Failure</u>		
< 1 year	19	39%
1 – 2	6	12%
3 – 5	10	20%
> 5	14	29%

Note: Some subjects received dual care from providers

regarding the quality of their lives. Support for content validity also was provided by using the Content Validity Index in a study by Olsen (1990). Sixteen intervention studies have been published in which QLI scores were found to be sensitive enough to detect a change in quality of life. The QLI scores changed significantly over time, when compared before and after an intervention in all studies. Calculated reliability coefficient for the QLI as it was used in this secondary analysis (n = 49), was alpha 0.8810.

Procedure

The two Visiting Nurse Associations (VNA) of a Midwest state identified potential subjects. All subjects with the primary diagnosis of heart failure were assessed for availability in the primary study. Once a potential patient was identified he/she was visited by a graduate student of Grand Valley State University (GVSU) Kirkhof School of Nursing for potential enrollment in the primary study. A scripted description of the primary study was reviewed with the potential subject (See Appendix E). If the patient agreed to participate in the primary study consent was signed (See Appendix F).

After explanation of the primary study and receiving consent, the graduate student obtained initial data collection. Initial data collection included the . demographic tools in addition to the QLI tool (Appendix B & C). The subject was then randomized into one of the two nursing approaches treatment groups. The subject received eight sessions with another graduate student of GVSU Kirkhof School of Nursing who provided the specific nursing approach instruction utilizing the AHCPN guide for heart failure. After completion of the nursing approaches the

subject again had a home visit with the initial data collector who administered the tools for quality of life measurement. (Appendix B). The timed intervals for data collection were, baseline (enrollment into the study), three, six, nine, and twelve months. For this secondary analysis only the baseline, three and six month data were utilized for analysis. Subjects were able to terminate their participation at any point without consequence.

The data collector remained available to answer questions while the subjects completed the questionnaire. The data were recorded on the Ferrans and Powers Quality of Life Index: Cardiac Version III; individual questionnaires were coded to correspond with the subjects demographic form to assure anonymity and to allow correlation between patient quality of life scores and the nursing approaches received. The data collector also recorded data on the subject's demographic form.

Risks in the primary study were relatively small. The scheduling of appointments at the subjects' convenience reduced a risk of the subject becoming distressed or fatigued. The appointments were not made in conjunction with any routine VNA visits. If a patient required re-admittance to the hospital, follow-up visits continued upon discharge. If signs of distress occurred during data collection or nursing approaches, the data collection or nursing approaches were terminated and the subjects were allowed to express their distress and discuss any issues with the graduate student.

The procedure used in the Ferrans and Powers QLI was designed to minimize discomfort to the subjects and had been used in the past (Ferrans & Powers, 1985). Confidentiality was protected by assignment of an identification number to each

subject's demographic and QLI material.

The secondary analysis focused on those subjects who received nursing approaches based on the AHCPR guidelines for heart failure. Grand Valley State University Human Research Review Committee granted approval for this secondary analysis on March 20, 2001. Evidence of approval is supplied in Appendix G.

CHAPTER 4

RESULTS

The purpose of this secondary analysis was to identify what impact nursing approaches utilizing the AHCPR guide for heart failure had on heart failure patients' quality of life scores. More specifically, this secondary analysis sought to identify if quality life changed from an initial assessment following the implementation of a nursing approach at three and six months. Data were analyzed using the Statistical Package for the Social Sciences (SPSS). In order to assess for changes in quality of life, repeated measures analysis of variance (ANOVA) and paired t-tests were performed. The statistical significance was predetermined to be $p = < 0.05$.

The independent variable for this secondary analysis was nursing approaches. Two of the nursing approaches in the primary study based on the AHCPR guidelines for heart failure were the supportive/educative and mutual goal setting. The groups were aggregated for examination in this secondary analysis. The dependent variable (the outcome) is quality of life scores at baseline, three, and six months as measured on the QLI. The quality of life scores were determined by weighting satisfaction with the importance of each identified item of the QLI. The scores of the QLI are summed and considered an interval scale of measurement. The final possible score range is 0 to 30.

Quality of Life Scores

When quality of life scores were measured at baseline the scores ranged from 8.81 to 26.99, with a mean of 21.00 (SD= 4.19). At baseline, 59.2% of the patients had scores that exceeded 20.00. At the three month interval, 77.1% of the patients had

scores greater than 20.00. The QLI scores at time (three month) ranged from 12.08 to 28.24 (M= 22.75, SD= 4.37). The scores at time six months ranged from 13.51 to 28.82 (M= 24.13, SD= 4.21). Eighty-one percent of the patients scored 20.00 or better at the six month evaluation point. These results are summarized in Table 2.

Table 2

Mean Quality of Life Scores

Time Period	Range	Mean	SD
Baseline	8.81-26.99	21.00	4.19
Three Month	12.08-28.24	22.75	4.37
Six Month	13.51-28.82	24.13	4.21

Research Question

What impact does providing nursing approaches based on AHCPR guidelines have on quality of life scores over time for patients with heart failure receiving home care? In order to analyze this research question a repeated analysis of variance (ANOVA) was utilized. The repeated ANOVA is a parametric procedure used to test the significance of differences between means within one group over time (baseline, three and six month data points).

According to the results there was a statistically significant difference in the quality of life scores (F= 29.907, p = .000). The data reflected an improvement in quality of life scores over time in the heart failure sample. To further determine where the changes in quality of life occurred paired t-tests were performed.

Results of the paired t-tests showed that a change occurred between baseline and three month ($t = -3.16$; $df = 34$; $p = .003$). Furthermore a significant difference was noted between baseline and six month ($t = -5.74$; $df = 31$; $p = .000$). However, there was not a significant difference found between three and six month ($t = -1.67$; $df = 29$; $p = .106$).

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Discussion

With heart failure prevalence increasing over the past several decades studies that provide groundwork toward improving the quality of life in this population are necessary. There has been considerable interest in measuring quality of life in patients with heart failure, since the symptoms of heart failure may impact on patients' lives to a degree not fully reflected by simple measures of symptom severity. As the purpose of this secondary analysis stated, it was important to identify what impact did nursing approaches utilizing the AHCPR guide for heart failure have on heart failure patients' quality of life scores over time.

It was interesting to note that quality of life scores significantly increased from baseline to three and six month evaluation points, but only modestly increased between three and six month data collection points. Could this result reflect the additional nursing time devoted to the subjects or be a result of the nursing approaches? Differentiation for this effect could not be evaluated. The findings validate nursing's importance in support, education, and mutual goal setting using nursing approaches based upon the AHCPR guidelines for heart failure. Successful management of heart failure usually requires adjustment by patients, which may have a negative effect on their perceived quality of life. As Jaarsma et al. (2000) reported, a supportive educational intervention may help patients learn to live with heart failure and it may affect the person's experiences of the severity of the symptoms and the level of distress. Jaarsma et al. recommended that efforts be made to gain insight into

what influences quality of life in elderly patients with heart failure and what can improve their quality of life. This secondary analysis has provided insight that utilizing nursing approaches based on AHCPR guidelines can have beneficial results in improving quality of life scores in a study group of mainly elderly patients receiving home care. As the sample reflected 77% (n=37) were seventy-one years old or older.

Since the sample was primarily older, it is interesting to note that baseline quality of life scores were 8.81 to 26.99. Is the wide range due to length of time with the disease or severity of the disease or care provided by different caregivers? It was impossible to determine this since the primary study did not classify the sample based on New York Heart Association (NYHA) Functional class, therefore individual subject stage of disease was unknown. Also variation in symptoms based on medical management was not monitored. The approach most commonly used in clinical practice to gauge the severity of symptoms is the NYHA functional classification. Although widely used, this classification has a high degree of interobserver variability and lacks sensitivity to detect small but significant changes in clinical status. Effective methods for determining severity of heart failure for study grouping have yet to be established. A qualitative study to determine severity of disease may provide this information for future reference.

Thirty-nine percent (n=19) of the sample had been diagnosed less than one year, while the other largest portion of the sample 28% (n=14) had been diagnosed greater than five years. Having the diagnosis of heart failure for less than one year may have resulted in the higher baseline quality of life scores. Those who

have been living with heart failure for less than one year may be enjoying less physical limitations from the disease. This alone may have been responsible for higher baseline quality of life scores, however this was not examined as part of this analysis. The physical limitations that accompany end stage heart failure in those with advancing disease may affect quality of life scores in a more negative way. Those diagnosed for greater than five years may have end stage or advanced heart failure.

Having a sample with patients at both ends of the heart failure continuum can provide valuable information related to care management. The Jaarsma et al. (2000) study reported that supportive/educative nursing interventions in the hospital and home is effective in improving self-care behavior, but failed to show effectiveness in improving quality of life scores. This secondary analysis did show improvement in quality of life scores over time. Whether that improvement is based on the AHCPR guideline based nursing approaches or just the added nursing intervention cannot be evaluated.

As King's (1993) model of transactions shows, nurses and clients can come together during nursing approaches developed with the guidance of the AHCPR guideline for heart failure, and have interactions that result in goal attainment. Utilizing this as a conceptual framework for the secondary analysis assisted in the accomplished goal attainment of improving quality of life of heart failure patients. Using nursing approaches developed with the guidance of the AHCPR guidelines for heart failure provided the individual patient with the tools necessary to cope with complex human-environment interactions and enhancement of quality of life.

Sullivan and Hawthorne (1996) suggested that biobehavioral interventions

such as relaxation strategies might improve quality of life in their review of studies of nonpharmacological interventions of heart failure. Sullivan and Hawthorne reported that future studies are needed to assess the effects of multifactor cardiac rehabilitation interventions on clinical outcomes and quality of life in the heart failure population. This secondary analysis demonstrated that nursing approaches utilizing the AHCPR guidelines for heart failure improve quality of life scores over time for heart failure patients receiving home care. By giving heart failure patients' education and some strategies for managing their chronic illness with the guidance of the AHCPR guidelines for heart failure education, quality of life scores did improve.

Bliley and Ferrans (1993), Jagsosild et al. (1998) and Bulpitt et al. (1998) all reported that measuring quality of life over time may reflect increased accuracy of evaluation of interventions, whether the intervention is medical/surgical treatment, pharmacological therapies, or nursing approaches. As Dracup et al. (1992) reported low quality of life scores in heart failure patients may often be related to depression or hostility due to loss of control and the physical manifestations of heart failure such as shortness of breath and decreased activity tolerance. Patients in the Dracup et al. study were all New York Heart Association Classification III or IV, indicating that all had advancing disease. By providing the heart failure patients with the tools to manage the chronicity of their disease through nursing approaches based on the AHCPR guidelines for heart failure improvements in reported quality of life may be found in subsequent evaluations.

This secondary analysis differs from cited studies in the following ways. The Dracup et al. (1992) and SOLVD (1993) studies utilized multiple tools to measure

quality of life and did a one time only quality of life evaluation this analysis examined QOL at three timed intervals. The results of the Dracup et al. and SOLVD studies showed that nursing approaches aimed to decrease depression and hostility and increase daily activity might improve a patient's quality of life. This secondary analysis demonstrated that nursing approaches based on the AHCPR guidelines for heart failure improved quality of life scores over time. This secondary analysis utilized one tool, (the Ferrans and Powers QLI) and measured quality of life over time at three different intervals, before intervention, three and six months after intervention.

The Dracup et al. (1992) and SOLVD (1993) studies were a comparison of medical/surgical and pharmacological therapies in heart failure patients in relationship to measurement of change in quality of life. In contrast this secondary analysis utilized the nursing approaches methodology for evaluation of change in quality of life scores over time. The SUPPORT (1998) study was a multi-intervention, multi-site evaluation done to evaluate quality of life scores over time. The SUPPORT study also showed that quality of life scores change over time in heart failure patients. The SUPPORT study reported the importance of following heart patients over time to evaluate the effectiveness of interventions on quality of life. Likewise this secondary analysis reports the effectiveness of nursing approaches based on the AHCPR guidelines for heart failure can improve quality of life over time in patients.

Limitations

A secondary analysis also has the possible limitations of problematic data set.

Polit and Hungler (1995) identified that performing a secondary analysis may be problematic in the sample used, variables measured or measurement tools utilized. In this secondary analysis problems related to the sample used could have been in the sample selection, the enrollment process and criteria. Since the process for the primary study's author determined sample selection and enrollment and the criteria, secondary analysis authors may question the methods. Also problems with this secondary analysis could have been related to variables measured, because those selected by the primary investigator may not have been congruent with the secondary authors. Another problem could have been the measurement tool selection in the primary study. If the tool utilized in the primary study was not specific to provide information related to the research questions in a secondary analysis problems may have resulted during data analysis. One such problem would be the data was not sufficient to answer the research question. As the author of this secondary analysis it is noteworthy to point out that problems were not encountered with the sample used, variables measured, or measurement tools utilized.

The limitation of history or testing effect could not be controlled. With first administration of the questionnaire sensitization could have occurred. It is impossible to segregate the effects of the effectiveness of the nursing approaches developed based on AHCPH guidelines for heart failure on quality of life from the effect of having completed the quality of life tool at baseline.

Maturation could also not be controlled. The physiologic changes that occur with heart failure over time could have either positively or negatively affected the outcome. If the subject experienced worsening of physiologic symptoms of heart

failure such as increasing fatigue and decreasing ability to perform activities of daily living, this could directly affect the quality of life scores obtained on subsequent questionnaires independent of the effectiveness of nursing approaches, and this variable is unable to be controlled. Conversely, if the subject was enjoying increased physical stamina with increased ability to perform activities of daily living and decreased shortness of breath the quality of life scores obtained may reflect an improvement without regard to the effectiveness of nursing approaches. This may necessitate further testing utilizing a control group of patients measured with those receiving nursing approaches utilizing the AHCPH guidelines for heart failure to evaluate quality of life over time.

This secondary analysis resulted in a smaller sample size than was originally anticipated. With a six month follow-up for subjects attrition can be anticipated. Since heart failure carries with it a higher mortality rate than that of the general population, some attrition was expected. The response to questionnaires at three months (n = 35) and six months (n = 31) was fewer than at baseline (n = 49). Bias was controlled with randomization of subjects into treatment groups or placebo. No control or monitoring was done over medical treatment provided each subject, whether change in medication occurred which may impact quality of life.

Heart failure patients who are not receiving home care were not eligible for enrollment. Future studies could possibly involve heart failure patients who may not be receiving home care. Heart failure patients requiring home care may have an advancing stage of heart failure, that is they may have a higher mortality rate than those not requiring home care. Quality of life scores may be affected in those patients

with advanced disease based primarily upon physical limitations and physiologic symptoms. Or it may be increased because they accept their condition and can be happier doing fewer things.

Implications

This secondary analysis adds to the knowledge base of quality of life in a heart failure population. These findings have implication for nurses in advanced practice, nursing education, nursing administration, and nurse researchers.

Advanced practice nurses have an obligation to incorporate outcome based nursing approaches into practice routines. Utilizing the AHCPR guideline for heart failure in patient education, support and mutual goal setting may continue to assist the heart failure population in achieving improved quality of life. Advanced practice nurses have an obligation to conduct research in this and other related areas of heart failure care. Utilizing the results of this secondary analysis it can be seen that advanced practice nurses should utilize nursing approaches based on the AHCPR guidelines for heart failure in patient education. By providing heart failure patients with the tools to manage their chronic illness through the use of nursing approaches based on the AHCPR guidelines, advanced practice nurses can impact quality of life in this population.

Nurse educators have an obligation to incorporate the findings of this and similar studies into their instructional activities so that students can be better prepared to assist heart failure patients. Furthermore, nurse educators need to assist students in development of nursing approaches, communication skills, and outcome measurement. Educators need to focus on teaching students how to promote the

patient's quality of life as well as to appreciate the care recipient's perspective. Exposing students to how chronically ill individuals cope with their disease enables students, as caregivers, to help these individuals more effectively. By utilizing AHCPR guidelines nurses and nursing students may have a positive impact on clients quality of life. Nurse educators also have a responsibility to expose nursing students to research based nursing approaches for care planning especially use of the AHCPR guidelines for heart failure.

Nurse researchers must continue to conduct studies into the areas of how specific nursing approaches affect outcomes with target populations. Particularly interesting would be further research on the effect of nursing approaches utilizing the AHCPR guidelines on quality of life of heart failure patients that are managed in nurse run heart failure clinics. Nurse researchers must also continue to develop guidelines to care for other populations of chronicity such as diabetes, pain, chronic fatigue syndrome, and multiple sclerosis, to list a few.

Nurse administrators must provide adequate financial and other support for clinical nurses, home care nurses, and advanced practice nurses to continue to provide nursing approaches based on AHCPR guidelines. Nurse administrators may also take responsibility for further study in this area. Nursing administrators could assist in grant application to the further research in quality of life, specifically for nursing approaches effect in heart failure patients.

Utilizing King's (1981) theory of goal attainment is timeless and easily applicable to this secondary analysis. The theory is functional in practice and research. As the nurse and heart failure patient interact during nursing approaches

developed utilizing the AHCPR guidelines for heart failure decision, making by each individual in the interaction is enhanced. The transaction model illustrates the interactions and progress toward goal attainment, which represents outcomes. In this secondary analysis the outcome was measured as changes in quality of life scores as measured by the Quality of Life Index.

Recommendations

Heart failure is a major public health problem in the United States. While the prevalence of most other cardiovascular diseases has declined dramatically over the past several decades, heart failure prevalence has increased markedly (Massie & Shah, 1997). The prevalence of the disease increases with age, affecting approximately 1% of persons in their fifth decade and nearly 10% of those aged 80 to 89 (Massie & Shah, 1997). An estimated \$23.1 billion was spent on inpatient care, \$14.7 billion on outpatient care, and \$270 million on heart transplantations in 1991 (O'Connell & Bristow, 1994). The total figure does not include indirect costs of heart failure, such as lost productivity and decreased quality of life.

Research designs need to continue to be predictive and prescriptive so that clinicians can identify patients at risk for poor quality of life. Replicated studies using the nursing approaches guided by the AHCPR guidelines are required using a larger sample size to validate results found in this secondary analysis. Longitudinal studies are needed to measure change in quality of life in patients with heart failure receiving these nursing approaches based on the AHCPR guidelines for heart failure.

Measurement instruments are needed that are consistent across studies of quality of life. The instruments should have reliability, validity and specificity.

Utilizing a consistent instrument to measure quality of life would allow for comparison and contrast of findings in studies of quality of life. The QLI as was utilized in the primary study is an example of one such tool and should be considered in future studies on the effect of nursing approach for change in quality of life scores over time. The QLI has tested reliability and validity in measuring change in quality of life scores over time (Ferrans & Powers, 1992).

Heart failure patients other than those receiving home care might be considered in future study for comparison of effect of nursing approaches utilizing the AHCPR guidelines on quality of life scores over time. The use of critical pathways and care planning based on the AHCPR guidelines for heart failure with heart failure patients could allow for supportive/educative and mutual goal setting continuum to be developed that transcends hospital and community based care.

A recommendation is to incorporate the nursing approaches based on the AHCPR guidelines for heart failure into care provided in nurse managed heart failure clinics, with studies done for evaluation. More research is needed that will validate nursing approaches based on the AHCPR guidelines that are effective for improving the quality of life in heart failure patients. This will continue to build the knowledge base in support of the findings of this secondary analysis.

A recommendation is to conduct studies utilizing a control group for comparison of results. It is recommended that future studies could evaluate change in quality of life over time in heart failure patients in groups receiving nursing approaches based on the AHCPR guidelines for heart failure compared with groups receiving routine follow-up with no additional intervention. Such a study may

validate changes in quality of life based upon interventions utilizing the AHCPR guidelines.

Summary

Improving quality of life is a major goal in treatment for patients with heart failure and therefore efforts should be made to gain insight into what really describes and influences quality of life in these often elderly patients with heart failure and what can improve their quality of life. It can be concluded that nursing approach developed utilizing the AHCPR guideline for heart failure can be effective in improving quality of life scores over time. To continue to improve outcomes related to quality of life, programs need to be tailored to the multifaceted needs of the heart failure patient, including enhancing psychosocial adjustment, increasing functional capabilities, and decreasing symptom occurrence. These outcomes may prove to positively affect quality of life over time.

APPENDIX A

Appendix A

Diane Rexford

From: "Imogene M. King" imk@juno.com
To: rexfordd@wmis.net
Sent: Saturday, December 09, 2000 6:46
Subject: Hello!

Diane, thank you for your e-mail. I have changed your address as you suggested and assume this will reach you.

This e-mail is sent to you to give you permission to use my transaction process model in your research.

Keep me posted as I am always interested in the results of these studies.
Thanks for using the ideas.

Sincerely,

Imogene M. King, RN, EdD, FAAN

APPENDIX B

Appendix B

Ferrans and Powers
QUALITY OF LIFE INDEX
CARDIAC VERSION – III

Part I. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. 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. The health care you are receiving?	1	2	3	4	5	6
3. The amount of chest pain (angina) that you have?	1	2	3	4	5	6
4. Your ability to breathe without shortness of breath?	1	2	3	4	5	6
5. The amount of energy you have for everyday activities?	1	2	3	4	5	6
6. Your physical independence?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your potential to live 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. Your ability to meet family responsibilities?	1	2	3	4	5	6
17. Your usefulness to others?	1	2	3	4	5	6
18. The amount of stress or worries in your life?	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. Your standard of living?	1	2	3	4	5	6
22. Your job? (If employed)	1	2	3	4	5	6
23. Not having 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. Your leisure time activities?	1	2	3	4	5	6
27. Your ability to travel on vacations?	1	2	3	4	5	6
28. Your potential for a happy old age/retirement?	1	2	3	4	5	6
29. Your peace of mind?	1	2	3	4	5	6
30. Your personal faith in God?	1	2	3	4	5	6
31. Your achievement of personal goals?	1	2	3	4	5	6
32. Your happiness in general?	1	2	3	4	5	6
33. Your life in general?	1	2	3	4	5	6
34. Your personal appearance?	1	2	3	4	5	6
35. Yourself in general?	1	2	3	4	5	6
36. The changes in your life that you have had to make because of your heart problem (for example, changes in diet, physical activity and/or smoking?)	1	2	3	4	5	6

Part II. 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
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 problem (for example, changes in diet, physical activity and/or smoking?)	1	2	3	4	5	6

APPENDIX C

APPENDIX C
Demographic Data
(To be collected at time of initial interview)

1. Age _____

2. **Martial 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 _____

6. **Health Care Provider (Who treats your heart failure?)**
____ Family Practice Physician
____ Cardiologist
____ Internist
____ 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 \$50,001

8. How long have you had heart failure?

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

9. List of current medical diagnoses.

APPENDIX D

UNIVERSITY OF ILLINOIS
AT CHICAGO

Department of Medical-Surgical Nursing (MC 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612-7350

Appendix D

October 12, 2000

Ms. Diane Rexford
3435 20 Mile
Kent City, MI 49330

Dear Ms. Rexford:

Thank you for your interest in the Ferrans and Powers Quality of Life Index (QLI). I have enclosed the cardiac IV version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, social and economic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate the subscale scores and overall scores.

At the present time there is no charge for use of the QLI. You have my permission to use the QLI for your study, which includes my permission to make as many photocopies as you need. In return, I ask that you send me a photocopy of all publications of your findings using the QLI. I then will add your publication(s) to the list that I send out to everyone who requests permission to use the QLI.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,


Carol Estwing Ferrans, PhD, RN, FAAN
Associate Professor

Phone (312) 996-8445
Fax (312) 996-4979
E-mail cferrans@uic.edu

Chicago

Peoria

UIC
66

Quad-Cities

Urbana-Champaign

Phone (312) 996-7900

APPENDIX E

APPENDIX E
Script to Obtain Consent

My name is _____, I am a registered nurse. I am taking classes at Grand Valley State University to obtain a Masters Degree in Nursing. I have been given permission by your home health care agency to come here today with your home health care nurse to determine if you are willing to let me explain a nursing research study that is being conducted with people like yourself who have been diagnosed with congestive heart failure and are receiving home care.

After your nurse has finished providing your care today may I stay a few minutes to explain the nursing research study we are doing?

(If verbal permission is granted, proceed with explanation of study and obtaining informed consent after the home care nurse has left.)

Explanation of Study

As nurses we are concerned with how people adjust to the medical diagnosis of heart failure. We want to find nursing approaches that will help you learn how to self-manage your heart failure. We believe that when you can self-manage your heart failure you will live a better life.

The study will consist of five (5) interviews of approximately 45minutes duration for the purpose of obtaining information about your health failure. You will be given \$10 at the completion of each of these five interviews as compensation for your time. The interviews will be spaced three months apart, starting this week. If you agree to participate you will be placed in one of three groups.

Each group will receive a different approach to managing health. Each of the nursing approaches will be provided in addition to the regular care you receive from your home care nurse at no extra cost. Another graduate nursing student who will call you to make an appointment to come to your home will provide each nursing approach to you in weekly 30-minute visits. If you participate in the study, I will give you the names of the students who call you. There will be a total of eight weekly visits. Each visit will provide you with information about managing your health. All visits will be scheduled at your convenience, similar to your current home care visits. You will not be given compensation for these eight visits.

Your participation in this study will in no way affect the regular care you receive from the home care agency, and it may help you improve your self-management of heart failure symptoms. The results of this nursing study may help nurses determine better ways to help other people with heart failure to improve their lives.

Because this is a nursing research study, I will maintain the confidentiality of the information obtained during the interview. Your name will not be identified with any of the information I collect. When reporting the results of the study only group results will be shared; no names of individuals will be published. The nurses providing you home care will not be told that you are participating in the study.

APPENDIX F

APPENDIX F
Informed Consent

- I _____ agree to participate in the nursing research study for persons with heart failure who are receiving home care. I understand that as a participant in this study: I will be interviewed for five (5) times for approximately 45 minutes each time, once within this week and again at 3, 6, 9, and 12 months. I will be compensated \$10 at the completion of each interview.
- I will receive information about managing my heart and that this information will be delivered by a registered nurse who is a graduate student at Grand Valley State University.
- I will receive this information once a week over the next eight weeks and that each visit will last approximately 30 minutes. I will not be compensated for receiving this information.
- I will be able to withdraw from the study at any time by notifying Dr. Kay Setter Kline, the principle investigator at 616-895-3517, and that my withdrawal will in no way affect the care I receive from the home care nurse.
- I will not be identified by name with any of the information obtained and that nay sharing of information obtained in this study will be in the form of group summaries of all participants.
- There is no identified risk from participating in this study and I may benefit from receiving information about ways to manage my health.
- If in the process of gathering information any symptoms are identified that might need attention the nurse gathering the information will refer me to either the home health care agency or my health care provider.
- I also give permission for review of my health records to verify my health care status.

If I have any questions about the research I may contact the Primary Investigator, Dr. Kay Setter Kline at 616-895-3517 or the Chair of the Research Review Committee, Paul Huizenga at 616-895-2472 at Grand Valley State University.

Signed

Date

Witness

Date

The names of the students who are participating in this study are:

_____, _____, _____,
and _____.

APPENDIX G



GRAND VALLEY
STATE UNIVERSITY

I CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

Appendix G

March 20, 2001

Diane Rexford
3435 20 Mile
Kent City, MI 49330

RE: Proposal #01-145-H

Dear Diane:

Your proposed project entitled **Quality of Life in a Heart Failure Population** 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,

A black rectangular redaction box covering the signature of Paul A. Huizenga.

Paul A. Huizenga, Chair
Human Research Review Committee

LIST OF REFERENCES

REFERENCES

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