ABSTRACT

COMPARISON OF BIVENTRICULAR/ICD THERAPY AND PALLIATIVE CARE ON THE QUALITY OF LIFE OF CONGESTIVE HEART FAILURE PATIENTS

By Amy M. Hopfensperger

Congestive heart failure (CHF) is a major public health problem in the United States. One in eight people develop CHF, with the trend continuing to increase. Individuals' diagnosed with CHF are confronted with multiple complex problems, as they attempt to cope with chronic illness. Palliative care is one method to care for patients, which is meant to improve care to these patients. The purpose of this quantitative study was to determine if palliative care, consisting of medication management of CHF, affects the quality of life in congestive heart failure patients. A comparison was done with non-palliative care patients in a cardiology clinic who are receiving biventricular pacemakers.

Kolcaba's Theory of Comfort (1997) was the theoretical framework for this study. Placing the goal of comfort within a framework or theory for nursing provides nurses with rationale for enhancing patient comfort. A thorough literature review revealed that there is a scarcity of data on the effects of palliative care on CHF patients.

A non-experimental quantitative design was used. A convenience sample of patients was selected from two different clinics in northeast Wisconsin, -- one cardiology clinic and one palliative care clinic. Data were collected using a demographic survey and the Minnesota Living with Heart Failure Questionnaire (MLHFQ). Results were limited by low rates of visits to the palliative care clinic. Descriptive statistics are reported for the 14 heart failure patients seeking care in cardiology and one heart failure patient in palliative care. Data were analyzed using descriptive and inferential statistics. Recommendations include future analysis of palliative care as a method of care delivery to other methods of care for patients with CHF.

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by

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This paper is dedicated to my godson, Noah Raab. I would have never made it through this program without his wonderful smile and stories every time I needed a break. The paper is also dedicated to my mom, who taught me independence and perseverance, and to my best friend, Meredith, for giving me the will to continue and allow me to be involved in her children's lives.

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CHAPTER 1

INTRODUCTION

This study seeks to compare quality of life of two treatment options for congestive heart failure (CHF). Congestive heart failure is a growing public health problem in the United States. In the U.S., more than 5.7 million men and women are living with heart failure, with 670,000 new cases diagnosed each year (American Heart Association [AHA], 2009). The magnitude of the problem of CHF is currently large, but is expected to get much worse in the future. As more cardiac patients survive and live longer with their disease, their chance for developing CHF increases, and the future growth in the elderly population will likely result in increasing numbers of persons with this condition.

In one of the two overarching goals for our nation's health, Healthy People 2010 sets forth the goal to improve the quality and years of healthy life for individuals (Healthy People, 2010). These are also the assumed goals for healthcare. Two approaches to treatment of CHF have similar goals. The hope would be that the use of these treatments would increase both years and quality of life. Given that quality of life is one expected outcome of treatment, the quality of life of patients receiving different treatment options should be studied in order to better inform patients of their options and the potential outcomes. As Healthy People notes, increase in years of life is not a sufficient goal if that increase in life does not come with an increase in quality.

There are several options for care in many CHF patients. One is interventional treatment with ICD and the other is to treat with medications and extensive support, which is considered palliative care for CHF. "Palliative care is a healthcare specialty that is both a philosophy of care and an organized, highly structured system for delivering care” (National Palliative Care Research Center, 2008). Palliative care focuses on relieving suffering and achieving the best possible quality of life for patients and their families. There has been little quantitative research related to quality of life of the CHF patients specific to this highly organized method of delivering care with a focus on quality of life. The majority of past research on both CHF and palliative care has been conducted qualitatively, with a majority of it done in the United Kingdom.

Significance to Nursing

Congestive heart failure is a complex clinical syndrome that can result from many structural or functional cardiac disorders that impair the ability of the ventricle to fill with or eject blood. The cardinal manifestations of heart failure are dyspnea and fatigue, which may limit exercise tolerance and fluid retention. Supporting patients to improve quality of life and to deal with chronic illness is one of the important and challenging goals of nursing. Quality of life is thought of as the patient’s ability to enjoy normal life activities. If nurses have the basic understanding of what the patient’s quality of life expectations are, they are able to further meet the needs of the patient. Understanding what palliative care is and when it should be implemented is an important factor in improving a patient’s quality of life. Assessments of the patients’ expectations are a prerequisite to planning care for the patient with congestive heart failure. Providing palliative care to the congestive heart failure patient will improve their quality of life.

Problem Statement

One in eight people develop congestive heart failure. As the population ages, this number will continue to increase, and it will be imperative for the healthcare provider to identify factors that improve the quality of life of the congestive heart failure patient. This study is aimed at determining whether palliative care increases the quality of life of a congestive heart failure patient.

Purpose of the Study

The purpose of this study was to determine if palliative care with medications and forgoing biventricular/ICD placement affects the quality of life in CHF patients. This study will aid advanced practice nurses to develop interventions that provide care to the congestive heart failure patient.

Research Question

Is there a difference in the quality of life between congestive heart failure patients who receive palliative care versus those who receive biventricular/ICD therapy?

Definitions of Terms

Conceptual Definitions

Congestive heart failure: A condition in which the heart is not able to pump enough blood to the body's other organs (AHA, 2009).

Patients: Male and female individuals who are treated by health providers.

Quality of Life: The degree of enjoyment and satisfaction experienced in everyday life. It refers to the patient's ability to enjoy normal life activities.

Biventricular pacemaker: Adding a third lead to the pacemaker to help the left ventricle contract at the same time as the right ventricle.

Implantable cardioverter defibrillator (ICD): A device that is implanted in the chest to shock the heart when having episodes of rapid heartbeat.

Palliative care: Care that focuses on relieving suffering and achieving the best possible quality of life for patients.

Operational Definitions

Quality of life: In this study, quality of life was measured using the Minnesota Living with Heart Failure Questionnaire.

Congestive heart failure: ICD-9 code 428; Class III or IV on the NYHA classification scale.

Patients: Individuals, male and female, having a diagnosis of congestive heart failure, receiving treatment at a pacemaker or palliative care clinical in Northeast Wisconsin.

Palliative care: Treatment as provided by a palliative care clinic.

Assumptions

1. Quality of life is a goal for patients with congestive heart failure.
2. Comfort is a desirable outcome for congestive heart failure patients.
3. Patients have equal health care opportunities.
4. Different treatment modalities have an impact on a patient’s quality of life.
5. Patients will report their heart failure symptoms honestly.

Summary

Congestive heart failure is a chronic illness in which the ultimate outcome and prognosis is poor. Increased growth of the congestive heart failure population is inevitable, with incidence rates continuing to rise due to older and sicker patients. Palliative care is a newer treatment modality that focuses on improving the quality of life of patients. This investigator hypothesized that the CHF patient receiving palliative care would exhibit a higher quality of life score than the patient receiving biventricular/ICD therapy.

CHAPTER II

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

The purpose of this study was to determine if palliative care affects the quality of life in congestive heart failure patients. In this chapter, Kolcaba's Theory of Comfort will be used as the theoretical framework. Additionally, this chapter presents what this investigator has found to be the most pertinent aspects of the literature reviewed. Major topic areas that will be presented are: causes and diagnosis of CHF, treatment modalities of CHF, and the palliative care approach in CHF.

Theoretical Framework

"Comfort is the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, social, and environmental)" (Kolcaba, 2003). It is a term that has historical and contemporary significance for nursing. Since the time of Florence Nightingale, it is cited as a desirable outcome of nursing care. The term can indicate both physical and mental phenomena and can be used as a verb and a noun. Placing the goal of comfort within a framework or theory for nursing provides nurses with rationale for enhancing patient comfort.

Kolcaba's Theory of Comfort is a mid-range theory that is illustrated by the three main components of comfort: relief, ease, and transcendence. Relief is the state of a patient who has had a specific need met. This is commonly seen as the absence of specific previous discomforts, a familiar one being pain. Ease is the state of calm or contentment and is the absence of specific discomforts. Transcendence is the ability to rise above discomforts when they cannot be eradicated or avoided.

Comfort care entails three types of comfort measures: technical comfort measures, coaching, and comfort food for the soul. Technical comfort measures are those interventions designed to manage pain. Coaching is a comfort measure designed to relieve anxiety, provide reassurance, listen, and instill hope. Comfort food for the soul are those comfort measures that are unexpected by today's patient, but are welcomed because they entail basic nursing care. Like comfort food that you eat, these measures make patients feel strengthened in a personalized way. Such comfort foods can include massage, imagery, music therapy, and hand-holding.

Case Study

This model case study embodies the concept of comfort, as experienced by a patient. Mrs. Smith is an 81-year-old patient being seen at the cardiology office today for shortness of breath. An echocardiogram is performed and shows an ejection fraction of 20%. The cardiologist offers her a biventricular pacemaker and an ICD because of her risk of sudden cardiac arrest. She doesn't understand why the doctor wants to put a piece of metal in her chest to maybe help her live a few more months when she's already 81 years old. He goes through the risks and benefits of the procedure, and she opts not to have either device placed. As a last offer he refers her to the palliative care clinic for symptom management.

Mrs. Smith establishes a relationship with her palliative care doctor and nurse practitioner and visits with them every month. At the initial appointment at the palliative care clinic, she is experiencing discomfort and lack of ease and is offered technical measures meant to ease her symptoms. At that point, she has experienced and gone through the first two stages of Kolcaba's theory. She is able to carry out daily tasks with little to no symptoms and feels no different than before, despite her terminal diagnosis.

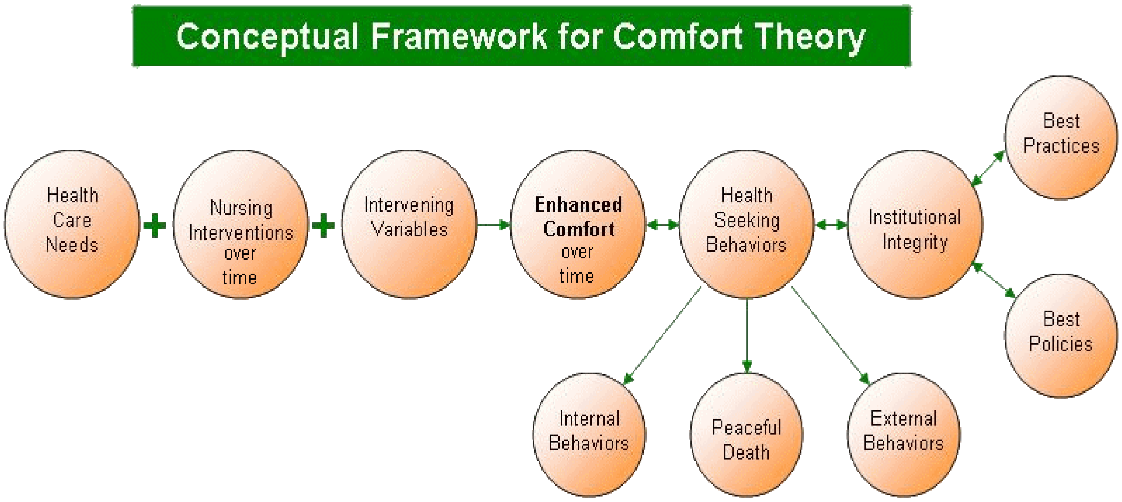

Figure 1. Comfort Theory Diagram (Kolcaba, 2007).

Review of Literature

The final component of this chapter is a review and analysis of literature. The literature that was reviewed consists of research studies, articles, and texts. A review of causes and diagnoses of CHF will be discussed first. This will be followed by various symptoms common to the CHF patient, and concluded with treatment modalities for patients suffering with CHF and the palliative care approach to CHF related to quality of life for these patients. An extensive review of the literature was conducted seeking information on CHF treatment modalities of palliative care compared to invasive cardiac procedures such as placement of a biventricular/ICD.

Causes and Diagnoses of CHF

The most common causes of CHF include coronary artery disease, hypertension, valve deformity, diabetes, and cardiomyopathy (American Heart Association, 2009). There is no single test to diagnose heart failure, but a thorough history and physical examination provide the foundation for diagnosis of it. Often, this will reveal classic symptoms, including dyspnea and fatigue, as well as, the classic signs of edema and rales on physical examination. An echocardiogram is often used to identify structural abnormalities and measure the ejection fraction.

Heart failure often begins insidiously, but its end stage is a lethal syndrome which affects every organ system in the body. Patients with CHF face an overwhelming array of physical and emotional symptoms. The two primary physical symptoms are dyspnea and fatigue. Dyspnea can manifest as acute shortness of breath, a cough, orthopnea, or paroxysmal nocturnal dyspnea. The host of additional physical symptoms for these patients usually relate to decreased perfusion of end-organs as a result of cardiac dysfunction. These symptoms include edema, chest pain, weight gain, sleep disturbances, ascites, anorexia, nausea, and bloating. “Often, these symptoms occur at rest or with minimal exertion despite maximal medical therapy” (Zambroski, 2006). Patients with heart failure also experience a variety of psychological symptoms, such as fear, boredom, frustration, social isolation, anxiety, and depression.

In order to establish the best course of therapy, physicians often assess the stage of heart failure according to the New York Heart Association (NYHA) functional classification system. This system relates symptoms to everyday activities and the patient’s quality of life. As seen in Table 1, stages are classified from Class I to Class IV, or from mild to severe. In Class I the patient has no limitation of physical activity. In

Class II the patient reports slight limitation of physical activity, but comfortable at rest. In Class III the patient has marked limitation of physical activity, but remains comfortable at rest. Class IV describes when the patient is unable to carry out any physical activity without discomfort, and reports symptoms of cardiac insufficiency at rest (Heart Failure Society of American [HFSA], 2006). Most CHF patients belong to NYHA functional class III or IV and social isolation is familiar in this population. "Social isolation is accentuated in ill individuals with functional impairments that further compromise their spontaneity and ability to socialize" (Riegel & Carlson, 2004).

Table 1

NYHA Classification

Class	Patient Symptoms
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
Class IV (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

Heart Failure Society of America, 2006

Common Symptoms

Understanding the needs of patients with CHF requires further information about symptoms and other factors related to their quality of life. A study in Massachusetts used a sample of 103 patients with Class III/IV heart failure on the NYHA scale. The primary outcome of the study was quality of life, and it was measured using various assessment scales. The most prevalent symptoms were lack of energy (66%), dry mouth (62%), shortness of breath (56%), and drowsiness (52%) (Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008). Pain was also reported by about one-third of the patients, and the researchers concluded that quality of life was moderately compromised. It was found that impairment in the patients' quality of life was significantly related to high symptom distress, poorer psychological wellbeing, and poor functional mobility.

A similar study done by Rodriquez, Appelt, Switzer, Sonel, and Arnold (2008) explored patients' knowledge regarding their heart failure diagnosis, the understanding of their treatment recommendations, and their views concerning the impact of heart failure on their daily lives and prognosis. The researchers collected data through 25 telephone interviews to patients being followed for heart failure at a veterans medical center. The most common symptom described by patients in the study was dyspnea; other symptoms mentioned included chest pain, fluid retention with swelling or weight gain, irregular heartbeat, fatigue, weakness, dizziness, and chronic cough. Discussions with patients about how heart failure had changed their life typically focused on reduced physical functioning and decreased quality of life. One patient said, “A lot of things you'd like to do around the house you can't do” (Rodriquez et al. 2008). In regard to their ability to enjoy normal life activities, most patients expressed concerns about not being able to do as much social and recreational activities, such as attending church or going fishing. The study also found that for the patients aged 65 years and younger, financial problems and distress caused by reduced work or unemployment impacted their lives greatly.

CHF and Treatment Modalities

The two main approaches to care are placing a biventricular pacemaker (BVP) and implantable cardioverter defibrilator (ICD) or medical care, including the use of amiodarone and medical support. A more intense support system of care is called palliative care, and this is the form of care examined in this study. A brief description of each type of care is provided, and then a review of literature on the subject follows. Both BVP and ICD care and palliative care with Amiodarone treatment are reviewed below.

Placing a biventricular pacemaker involves making a shallow cut in the upper chest and placing pacemaker leads through a puncture into a vein. The leads are then screwed into the heart muscle, and the incision is closed. A biventricular pacemaker does not increase the heart rate, but helps coordinate the pumping action of the heart. It paces both ventricles of the heart and allows the heart to pump blood more effectively. Implantable cardioverter defibrillators (ICDs) are inserted the same way a biventricular pacemaker is, but involves a different wire being placed in the ventricle to defibrillate the heart if a patient has a lethal heart rhythm. It is indicated in CHF patients if their ejection fraction (EF) is less than 30%. Most BVPs are also ICDs, but occasionally a patient will only receive one. The American Heart Association (2009) summarizes the potential complications of biventricular/ICD placement, noted in the literature as hematomas, bleeding requiring transfusion, infection, pneumothorax, and cardiac perforation. Early mortality (within 30 days of procedures) is not higher for the biventricular/ICD group as compared to a group receiving medications (AHA, 2009).

One study demonstrating this lack of improvement in mortality is Strickberger et al. (2003), who hypothesized that an ICD was more effective than the medication Amiodarone for reducing mortality in CHF patients. The study had 103 patients with nonischemic dilated cardiomyopathy, an EF less than 35%, and asymptomatic nonsustained ventricular tachycardia. The patients were randomized to receive either Amiodarone or an ICD. The study was stopped when the prospective stopping rule for futility was achieved. The study concluded that mortality and quality of life in patients with nonischemic dilated cardiomyopathy and nonsustained ventricular tachycardia treated with Amiodarone or an ICD were not statistically different. “There is a trend towards a more beneficial cost profile and improved arrhythmia-free survival with Amiodarone therapy” (Strickberger et al., 2003). Thus, the current study seeks to determine if there is an increase in quality of life, given there is a lack of data supporting increased survival rates.

Sears et al. (2006) state that large randomized trials have suggested that ICD shocks are associated with quality of life outcomes in CHF patients. Patients, quality of life outcomes may be highly dependent on the minimization of ICD shocks. Stuart (2007) completed a descriptive study on palliative care and hospice in advanced heart failure. This study focused on the risk and benefits of many different treatment modalities. The study clarified that, although ICDs may prevent sudden death, they do not always prolong life, and actually might worsen a patient’s symptoms. “Approximately one third of patients with an ICD experience inappropriate shocks, lead problems, infections, or device malfunction that is associated with long-lasting physical and psychological ill effects in both patients and caregivers” (Stuart, 2007). The study explains that many patients who receive a shock, and many that do not, experience psychological disturbances, including anxiety, depression, panic disorder, and posttraumatic stress disorder. This study concludes by stating that the fear of repeated shocks can lead to diminished quality of life.

Gabriel et al. (2007) conducted a study that examined the potential benefits of biventricular pacemakers in Class III and IV heart failure. They found that the EF improved, and the patient’s ability to exercise increased. The authors did not quantify the improvements in EF or to what degree a patients’ ability to exercise had increased. They also did not assess any other quality of life symptoms.

Saxon et al. (2002) performed a similar study using 15 pacemaker-dependent patients who underwent the placement of a left ventricle lead to upgrade their pacemakers as a biventricular device. Every patient in the study had an EF of less than 35%, and this was monitored before, during, and after the upgrade. The results showed that long-term use of BVPs reverses heart remodeling and improves heart function; but while these results are promising, the fact that the literature does not support an improved mortality outcome leads to the current research on whether these potential improvement leads to an increased quality of life.

Palliative Care Approach to CHF

Sears et al. (2006) define health-related quality of life as the impact of disease and medical treatment on patient overall functioning and well being. Many research studies and articles center around a multidisciplinary approach to managing CHF on an ongoing basis. According to the World Health Organization (2008), palliative care is:

> (A)n approach that improves the quality of life of patients and their families facing the problems, associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

The World Health Organization (2008) states that palliative care provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible, offers a support system to help the family cope during the patients illness, uses a team approach address the needs of patients and their families, and overall enhances the patients quality of life.

Fitzsimons et al. (2007) conducted a study in the United Kingdom using a mixed methodology approach to explore the palliative care needs of patients with a non-cancer diagnosis from the perspectives of the patient, significant other, and clinical team responsible for their care. It found that deteriorating health status was a central theme derived, and that it led to decreased independence, social isolation, and family burden. Patients dying from chronic illness in this study had many concerns and unmet clinical needs, and the care teams were frustrated by the lack of resources available to them. Some clinicians admitted to difficulty in talking openly with the patient and family regarding the palliative nature of their treatment. Fitzsimons et al. (2007) concluded that an earlier and more effective implementation of the palliative care approach is necessary if the needs of patients in the final stages of chronic illness are to be adequately addressed.

Horne and Payne (2004) conducted a similar study in the United Kingdom to explore the experiences of patients with heart failure and identify their needs for palliative care. They used a qualitative design with semi-structured interviews for data collection. Common themes found throughout the study were: difficulties in walking, extreme fatigue, and problems managing daily activities. They also reported that having to rely on family and friends caused feelings of being a burden, loneliness, and isolation.

Patients also talked about dying, as well as their own fears and frustrations in living with heart failure. None of the patients in the study had been referred to palliative care services. Horne and Payne (2004) concluded, "…patients' experiences were similar to those of patients living with advanced cancer and yet they receive little support." Their recommendations were to perform a comprehensive routine assessment of the palliative care needs of patients living with heart failure.

Summary

In this chapter, the theoretical framework of Kathryn Kolcaba and literature review were presented. The Theory of Comfort describes a patient-centered practice and is important to determine if comfort measures are important to the patient. A literature review revealed that there is a scarcity of data on the effects of palliative care on congestive heart failure patients. "The lack of comprehensive and effective palliative care is clearly evident in a number of studies describing the end of life for patients with heart failure" (Zambroski, 2006). Patients with heart failure have been portrayed as having poorly managed physical and psychological symptoms that may remain unrelieved until the time of death.

CHAPTER III

METHODOLOGY

Introduction

The purpose of this study was to determine if palliative care affects the quality of life in CHF patients. This chapter describes the research design, population, sample, setting, data collection procedures, questionnaire used, and protection of human subjects.

Research Design

The study was a non-experimental, descriptive design to determine whether a positive correlation between palliative care and quality of life exists in comparison to cardiology intervention. The purpose of a non-experimental study is to describe and document aspects of a situation and is commonly used when a researcher is seeking to establish cause-and-effect relationships. There was no experimental manipulation or random assignment to groups in the study. The independent variable in this study was the different treatment modalities, whether it is the biventricular/ICD or palliative care group. The dependent variable was the patients' score on the Minnesota Living with Heart Failure Questionnaire. Control of extraneous variables was attempted by having a thorough demographic form attached to the questionnaire.

Population, Sample and Setting

The target population for this study was CHF patients in the Midwest. The accessible population, which led to a convenience sample, was patients that are seen at either a pacemaker clinic or palliative care clinic in Appleton, Wisconsin. Inclusion criteria was that the participants were classified in a Class III or IV on the NYHA classification scale, must have an EF less than 30%, and must have a medical diagnosis of CHF, as determined by a physician. Exclusion criteria included participants that had any other terminal illnesses or if they are currently in the hospital.

Data Collection Instrument

Two instruments were used for data collection: a demographic questionnaire and the Minnesota Living with Heart Failure Questionnaire (MLHFQ). Permission has been obtained to use the original questionnaire. The MLHFQ was developed to represent the ways heart failure and treatments can affect the key physical, emotional, social, and mental dimensions of quality of life. There are also questions that address side effects of different treatments. The most recent version of the MLHFQ asks about side effects of treatments, rather than medications, to reflect the growing use of non-pharmaceutical treatments for heart failure. The questionnaire contains 21 questions, asking each person to answer by circling 0 to 5, using a 6-point scale. A Likert scale will be used to analyze the data and to see how much each of the 21 facets prevented them from living as they desired.

The total MLHF score is reliable, as demonstrated by a correlation (r) of 0.93. A measure of internal consistency, such as Cronbach's alpha coefficient (α), was estimated to be 0.94. Rector (2005) states that "high internal consistency suggests that the total MLHF score measures a single construct-presumably interrelated effects of heart failure on an individual's quality of life."

Data Collection Procedures

The sample was obtained from two different clinics in Appleton, Wisconsin. The Human Subjects Committee at the University of Wisconsin Oshkosh approved the research proposal before implementation of the study. Permission to perform the investigation at two clinics was obtained from the company administrator and clinic manager.

The investigator met with agency personnel to further explain the study and to request their assistance in handing out the questionnaires to eligible participants. The subjects were assured of confidentiality. After the Institutional Review Board for Protection or Human Participants (IRB) and facility participation was approved, a demographic questionnaire and cover letter describing the study were given to patients at the clinics, along with the MLHFQ. The medical personal documented the patient's EF on the demographic form before it was handed out. Respondents were handed the questionnaires when they were checking in at the clinics and completed them while waiting in the exam room. They were sealed by the patient in an envelope and placed in a lockbox at the clinic.

Data Analysis

The data was analyzed using the Statistical Package for Social Sciences (SPSS). The demographic and quality of life data collected was analyzed with the use of descriptive statistics, including mean, mode, standard deviation, t-test analysis, and paired samples correlations to measure significance. The original plan was to analyze the data with correlation coefficient to summarize the magnitude and direction of the relationship between variables. Due to a small sample size, the data was analyzed with descriptive statistics. The reasons for the small sample size are also reported.

Limitations

The limitation of small sample size was identified early in the process. Steps were taken to avoid this outcome. Frequent contacts with the clinics, reminders, and encouragement to staff were part of the interventions. Despite efforts, the study is limited by a small sample size, and as is noted, this decreases the generalizability of the study results. Other potential limitations would be in the comfort of subjects in completing the survey. Some subjects may not reveal their true feelings, which could cause bias in the findings. The anonymous nature of the study should improve the chances that subjects answer honestly.

Summary

The researcher used a quantitative, non-experimental design to determine if quality of life is superior in CHF patients attending a palliative care clinic in Appleton, Wisconsin. The researcher was responsible for providing the different clinics with a consent form, demographic survey, and MLHFQ. Data collection procedures and specific statistical tests were described and potential limitations were acknowledged.

CHAPTER IV

PRESENTATION AND DISCUSSION OF FINDINGS

This chapter focuses on the analysis of the data obtained from the subjects. The Minnesota Living with Heart Failure Questionnaire (MLHF) was distributed to patients who were being seen at either a pacemaker clinic or palliative care clinic in Appleton, WI. Questionnaires were returned by a total of 15 patients; 14 from the pacemaker clinic and one from the palliative care clinic. The purpose of this study was to determine if palliative care with medications and forgoing biventricular/ICD placement affects the quality of life in congestive heart failure patients. Given the low number of participants from the palliative care clinic, a comparison in quality of life between the groups was not possible. The following provides the descriptive statistics on all CHF patients combined and analyzes the quality of life found.

Demographic Data

Reported demographic data consisted of gender, age, length of diagnosis of congestive heart failure (CHF), ejection fraction (EF), race, whether they had health insurance, and whether they had a pacemaker and/or a defibrillator. There were 13 males (87%), and 2 females (13%) who participated in the survey. The subjects ranged from 41 to 90 years of age, with a majority of the patients being 71 to 80 years of age (53%),

The common EF noted was 20% and 30% (each 33%). A majority of the patients were diagnosed with CHF more than 5 years ago (73%). Four (27%) patients were diagnosed between 2 years and 5 years, and none of the patients in the study were diagnosed less than 2 years ago. All patients in the study had health insurance at that present time. Fourteen of the 15 had a BVP and/or ICD, but the patient from the palliative care clinic did not have either device.

Table 2

Demographic Data

	Frequency (n = 15)	Valid Percent
Age		
41 – 50	2	13
51 – 60	2	13
61 – 70	2	13
71 – 80	8	53
81 – 90	1	7
Race		
Caucasian	14	93
African American	1	7
Gender		
Male	13	87
Female	2	13
EF		
15	2	13
20	5	33
25	2	13
27	1	7
30	5	33
Years of Heart Failure		
<2	0	0
2 – 5	4	27
>5	11	73

Minnesota Living With Heart Failure Questionnaire

The Minnesota Living with Heart Failure questionnaire (MLHF) was designed in 1984 to measure the effects of heart failure and treatments for heart failure on an individual's quality of life (Rector, 2005). It contains 21 items and evaluates the experiences the patient encounters when living with heart failure over the past month. It is a disease-specific instrument composed of 21 items and three scales that measure:

the physical dimension (eight items), the emotional dimension (five items), and the overall score on health-related quality of life (21 items). Eight separate items, which do not assess a single construct or dimension of health-related quality of life, measure social and economical impairments patients relate to their heart failure and are part of the overall score. To measure the effects of symptoms, functional limitations, psychological distress on an individual's quality of life, the MLHF questionnaire asks each person to indicate, using a 6-point Likert scale (0-5), how much each of 21 facets prevented them from living as they desired. The score is the sum of the items, ranging between 0 and 105. High scores on the MLHF questionnaire scales indicate a high negative impact of CHF on the assessed aspects of quality of life.

Results

Analysis of responses on the overall questionnaire questions, as presented in Table 2, reveals that the majority of patients feel that CHF plays a very minimal role in their lives. The average answer to all questions is 2, showing that patients felt that CHF did not impact their lives significantly in the last 4 weeks.

Table 3

MLHF Questionnaire Results

Questions	Mean*	SD
1. Causing swelling in your ankles or legs?	1.1	1.7
2. Making you sit or lie down to rest during the day?	2.3	1.9
3. Making your walking about or climbing stairs difficult?	2.2	2.0
4. Making your working around the house or yard difficult?	2.3	2.1
5. Making your going places away from home difficult?	1.4	1.9
6. Making your sleeping well at night difficult?	1.1	1.7
7. Making your relating to or doing things with your friends and family difficult?	1.3	1.6
8. Making your working to earn a living difficult?	1.5	2.1
9. Making your recreational pastimes, sports, or hobbies difficult?	1.9	1.8
10. Making your sexual activities difficult?	2.5	2.4
11. Making you eat less of the foods you like?	1.9	1.9
12. Making you short of breath?	1.8	1.7
13. Making you tired, fatigued, or low on energy?	1.9	1.7
14. Making you stay in a hospital?	0.4	0.9
15. Costing you money for medical care?	2.3	1.5
16. Giving you side effects from treatments?	1.1	1.5
17. Making you feel you are a burden to your family or friends?	1.1	1.6
18. Making you feel a loss of self-control in your life?	1.4	1.8
19. Making you worry?	1.7	1.9
20. Making it difficult for you to concentrate or remember things?	1.5	1.6
21. Making you feel depressed?	1.2	1.7

*1 is lower impact and 5 is higher impact on patient on Likert scale

Discussion

As noted above, the researcher is unable to answer the proposed question of if there is a difference in the quality of life between CHF patients who receive palliative care versus those who receive biventricular/ICD therapy, because of the limited sample obtained from the palliative care clinic. Although the research question was not able to be answered, descriptive information was collected and data were processed on all patients. Below is an analysis of the heart failure questions alone with the EFand demographic data.

The New York Heart Association (NYHA) functional classification system is a system that relates patients' symptoms to everyday activities and the patient's quality of life. This classification system goes from Stages I to IV, or from mild to severe symptoms. Even though this scale does not directly list ejection fractions in the scale, it follows the symptoms directly for patients. As their ejection fraction lowers, they rise to a different stage in the NYHA scale. As patients rise in the NYHA scale, their symptoms are worsened, and their quality of life is greatly impacted. This is a direct correlation to their EF, also. In this study a majority (80%) followed the presumed trend of, as their EF decreased, their total quality of life score increased, meaning the variables in the questionnaire had a greater impact on their quality of life.

Table 4

Ejection Fraction and Total Score

EF	Mean*	SD	N
15	8	9	2
20	44	33	5
25	40	50	2
27	5		1
30	37	27	5
Total	34	30	15

*Higher mean is more impact on quality of life.

With a comprehensive literature review completed, no data were found regarding whether patients' quality of life differed based on how long they had been coping with congestive heart failure. The study did not involve any patients that had been diagnosed less than 2 years ago, but a significant difference was found in the resulting data. This study demonstrated that patients who were diagnosed with CHF longer had a lower quality of life score on the questionnaire, and that it did not impact their lives as greatly. It is this researcher's conclusion that patients who have had a CHF diagnosis for more than 5 years have fewer symptoms and cope more effectively than patients who have had a congestive heart failure diagnosis for 2 to 5 years. This may represent a survival bias, in that those patients who have survived longer may have less severe symptoms than those who had died earlier. This also may represent coping strategies and acceptance of limitations that occurs over time. Within Kolcaba's theory, this would be those patients who have, through their own efforts and coaching by health professionals, arrived at transcendence.

Table 5

Years of Heart Failure and Total Score

Time HF	Mean*	SD	N
2 - 5 years	45	38	4
>5 years	30	28	11
Total	34	30	15

*Higher mean is more impact on quality of life.

There have been multiple studies that differentiate men and women and heart disease, but none have looked at the differences in quality of life scores of congestive heart failure patients. This researcher found that women's total quality of life score appeared to be higher than men's, but the difference was very minimal (between 31 and 34). This result is not able to be generalized because a majority of the sample (87%) was male.

Table 6

Gender and Total Score

Gender	Mean*	SD	N
Male	31	29	13
Female	34	40	2
Total	34	30	15

*Higher mean is more impact on quality of life.

Most studies conducted on CHF patients have a mean age of 70 years, and few have any patients less than 40 years of age. Sanders, Hlatky, and Owens (2005) conducted a study on cost-effectiveness of implantable cardioverter defibrillators and found that on average, one device costs $139,312. Although the study demonstrated a significant device-related reduction in mortality, a study performed by Rodriquez et al. (2008) found that for the patients aged 65 years and younger, financial problems and distress caused by reduced work or unemployment impacted their lives greatly. This researcher's study showed that finances had a moderate impact on patients' quality of life score for a majority of the patients (67%). Unlike previous studies, finances were not found to impact patients less than 65 years of age. This may have been found to be significant if the sample size was larger. As a whole this researcher found that patients 61 to 70 years of age had the highest impact on quality of life, but again the sample size for this age group was only two (13%).

Table 7

Age and Total Score

Age	Mean*	SD	N
41 - 50	41	55	2
51 - 60	40	50	2
61 - 70	63	20	2
71 - 80	25	24	8
81 - 90	17		1
Total	34	30	15

*Higher mean is more impact on quality of life.

Summary

This chapter presented the demographic data, the Minnesota Living with Heart Failure questionnaire, and findings from the researcher's study. When looking at each individual question in the questionnaire, the average answer to all questions is two, showing that patients felt that CHF did not impact their lives significantly in the last 4 weeks. In general, a lack of sample size is a major problem in an attempt to generalize this researcher's results. Chapter V will discuss the results, implications for nursing, limitations to the study, and recommendations for further research.

CHAPTER V

SUMMARY, CONCLUSIONS, LIMITATIONS, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study was to determine if palliative care with medications and forgoing biventricular/ICD placement affects the quality of life in CHF patients. This purpose was not able to be carried out due to the lack of sample size, but descriptive data were collected. This chapter will give a brief summary of study findings, limitations, implications, and recommendations for future research.

Summary and Conclusions

In this study, patients reported that CHF did not impact their lives significantly in the last 4 weeks. The data processed showed that like previous literature has stated, as a patient's EF lowers, their total quality of life score increases, meaning CHF has a greater impact on their quality of life. Although the sample size was low, an interesting finding was found when looking at the time since the patient had been diagnosed with CHF. This study found that patients who have had a CHF diagnosis for more than 5 years have better quality of life scores than patients who were diagnosed between 2 and 5 years. The study also found that patients aged 61 to 70 years had the highest total score or were the most impacted by CHF, but neither of these results are to be generalized because of the small sample size.

"Comfort is the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, social, and environmental)" (Kolcaba, 2003). It is a term that has historical and contemporary significance for nursing. Since the time of Florence Nightingale, it is cited as a desirable outcome of nursing care. The term can indicate both physical and mental phenomena and can be used as a verb and a noun.

Patients with CHF face an overwhelming array of physical and emotional symptoms. The two primary physical symptoms are dyspnea and fatigue. Interestingly, in this small sample, a majority of patients rated the impact of CHF lower on the quality of life questionnaire despite their low ejection fraction. Placing the goal of comfort within a framework or theory for nursing provides nurses with rationale for utilizing the comfort theory and enhancing patient comfort.

Limitations

The findings of this descriptive study are limited to the sample under study, and the information is not generalizable beyond this group. This study was based primarily on subjects who went to an outpatient pacemaker clinic, with only one patient who went to an outpatient palliative care clinic. The researcher was not able to answer her research question due to only having one patient from the palliative care clinic. This study would be more helpful if more outpatient pacemaker and palliative care clinics were involved and the sample size was larger. This study had one African American patient, and although that is representative of this area, if the sample size was larger, there would also have been more heterogeneity. With a larger sample size it is also likely that the male to female ratio would be close to equal.

One other limitation is that the questionnaire did not discuss pain at all, and multiple studies listed this as common complaint in CHF patients. The study also showed that being admitted to the hospital within the last 4 weeks was rare, but other studies have shown that re-admittance rates are very high among patients with this condition. It would have been potentially significant if the patient were to be asked about being admitted for CHF within the last 3 to 6 months instead of 4 weeks.

Implications for Nursing

Congestive heart failure remains a serious health problem around the world. In the U.S., more than 5.7 million men and women are living with heart failure, with 670,000 new cases diagnosed each year (AHA, 2009). The magnitude of the problem of CHF is currently large, but is expected to get much worse. The future growth in the elderly population will also result in increasing numbers of persons with this condition.

Although this study showed that a majority of patients felt that CHF was affecting their quality of life, there are a large amount of previous studies that have been done and show that there are numerous symptoms that patients report when having this illness. Palliative care focuses on relieving suffering and achieving the best possible quality of life for patients and their families. This study is not generalizable, but yields questions about the care of CHF patients and about future research. One implication is that there are very few patients that are seen in palliative care with CHF. The researcher's assumption is that there are few providers currently practicing that are aware of the palliative care services and the potential benefits. This researcher would like to educate primary care providers on the palliative care services that can be offered to patients that decide they do not want to have any invasive treatments. Further evidence of the improvement in patient quality of life may also increase the referrals to palliative care. Therefore, the original purpose of this study -- to examine the effective palliative care compared to other treatments -- remains as a pertinent research question.

To improve a patient's comfort, the nurse must identify all the factors that affect a patient living with CHF to assist the patient to obtain positive outcomes. A systems approach to the care of a patient with CHF may be one of the most crucial aspects of achieving positive results. The goal of a systems approach is to take a patient-centered approach to maintain their optimal state of health. The advanced practice nurse has the ability to focus not only on the clinical needs of the patient, but the educational and supportive needs, as well. It is also imperative to identify and solve issues that are barriers to the patient achieving a high quality of life. Based on the results of this study, an emphasis should be placed on identifying symptoms of CHF and improving the patient's quality of life.

Recommendations for Future Research

1. Further research with a larger sample size, including various pacemaker and palliative care clinics, should be done to provide more generalizable conclusions for patients living with congestive heart failure.
2. Conduct a longitudinal study to better determine how a group of CHF patients with pacemakers perceive their quality of life over time and to determine if there is transcendence or coping that occurs over time for those who survive.
3. Either use a different questionnaire or edit the current Minnesota Living with Heart Failure Questionnaire to ask about pain as a variable in the questionnaire.

Congestive heart failure is a major public health problem in the United States. The advanced practice nurse must understand the illness and its associated symptoms to provide the support and guidance the patient needs to live with CHF. The advanced practice nurse has the ability to focus not only on the clinical needs of the patient but the supportive needs, as well. Understanding the various treatment options for patients with CHF is crucial and needs to be individualized from patient to patient.

APPENDIX A

Demographic Survey

Demographic Survey

(Please don't complete one if you already have)

EF:______

Age: (please circle one) 30-40 41-50 51-60 61-70 71-80 81-90 91-100

Gender:

Race:

How long have you had heart failure? (Please circle one)

0-1 year 2-5 years more than 5 years I don't know

Do you have health insurance? YES NO

Do you have a defibrillator? YES NO

Do you have a pacemaker? YES NO

APPENDIX B

University of Minnesota Copyright Use Permission

Re: U/M Docket 94019, License #1090-0579
License # 7/23/2008 10:38 PM

Dear Ms. Hopfensperger:

The University has received and accepts your Copyright Users Agreement to use the Minnesota Living With Heart Failure Questionnaire for the purpose of -- A student or teacher who will use the Work only for a student project(s) or didactic purposes as identified in Article 6.1.1.

MAPI research Institute provides translations of the questionnaire for a nominal fee. Please contact Christelle Berne at cberne@mapi.fr for further information.

Thank you for choosing MLHF Questionnaire

Rachel

****
Rachel Muntean
Direct: (612) 624-3545
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APPENDIX C

Minnesota Living With Heart Failure© Questionnaire

MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE

(Appendix C)

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -	**No**	**Very Little**				**Very Much**
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

APPENDIX D

University of Wisconsin Oshkosh Informed Consent

UNIVERSITY OF WISCONSIN OSHKOSH

INFORMED CONSENT

My name is Amy Hopfensperger and I am a graduate nursing student in the MSN Program with Family Nurse Practitioner emphasis at the University of Wisconsin Oshkosh. I am conducting a study that will compare quality of life in congestive heart failure patients who choose different care options. The study will compare quality of life for those who choose pacemakers to those who choose palliative care and no pacemaker.

The information you provide will inform health care professionals how you feel about your care and provide further understanding about the effects of medical care on the health of patients which has the potential to benefit the care provided to you and others.

Participation in this study will take 10 minutes to complete a “Minnesota Living with Heart Failure Questionnaire” survey consisting of 21 questions. In addition either the nurse or I will gather the ejection fraction, a marker of your disease status to place on your questionnaire. The status of your disease may also have an effect on your quality of life. This information will be used to analyze the group data. The personal information and the ejection fraction data used in this study will be analyzed without connection to your name. Once you turn in the information there will be no way to connect it to your name. You will remain anonymous. Your participation in the study is completely voluntary—you do not have to participate and you can stop at any time. If you refuse to participate now, or withdraw from the study later, it will have no effect on any regular services or benefits available to you at this clinic, health system or the University of Wisconsin Oshkosh.

When you are finished please put the questionnaire in the provided envelope, seal it, and drop it into the box provided in the waiting room. I will analyze and summarize the information I obtain through the questionnaires. Information obtained will be used solely for the purpose of this. If you would like to see the results of the study, please contact me at the address provided below. If you have any questions, comments, or concerns about this study please feel free to contact me. Thank you very much for helping with this important study.

Amy Hopfensperger, RN, BSN, MSN Candidate
1299 Hoot Owl Ct.
Neenah, WI 54956
(920) 419-4008

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board
For Protection of Human Participants
c/o Grants Office
UW Oshkosh
Oshkosh, WI 54901
(920) 424-1415

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary.

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