

PREVENTING HEART FAILURE READMISSIONS UTILIZING A PALLIATIVE CARE
PROGRAM

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Chapter I

Introduction

Introduction

Heart failure, a chronic disease resulting from the heart's inability to efficiently pump blood to the body, is one of the most costly chronic diseases in the United States (U.S.). According to Heidenrieck et al. (2011) heart failure costs the U.S. an estimated \$34.4 billion yearly, with these costs including health care services, medications, and lost productivity. With the overall rising costs of healthcare and the changes in the healthcare system due to healthcare reform, hospitals across the nation are looking for methods to reduce the costs of many chronic illnesses. Due to the complexity of care associated with heart failure, many heart failure patients need help or extra support in caring for themselves on a daily basis.

The prevalence of heart failure in the United States is quite significant. According to Roger et al. (2012), about 5.7 million people in the U.S. have heart failure and about half of people diagnosed with heart failure die within 5 years of initial diagnosis. Deaths from heart failure are not unusual in the U.S. with 1 in 9 death certificates (about 281,437 deaths) citing heart failure (Roger et al., 2012).

According to the National Vital Statistics Report, heart failure is responsible for over 57,000 deaths in the U.S. yearly (Murphy, Xu, & Kochanek, 2013). Diseases of the heart, which include heart failure, topped the list of the 15 leading causes of death in 2010 (Murphy et al., 2013).

The cost of heart failure is substantial and readmissions from heart failure are quite common. In 2012, the direct care costs for a heart failure patient were estimated at \$39.2 billion (Kim & Han, 2013). In addition to the high costs of direct care of heart failure, unplanned heart

failure readmissions are estimated at \$17.4 billion annually (Kim & Ham, 2013). The impact of the cost of heart failure is only going to increase as The Centers for Medicare and Medicaid services (CMS) has stated it plans to decrease reimbursement or apply penalties for patients who are readmitted within 30 days of their initial heart failure readmission, regardless of the cause of readmission. A patient could have been discharged from the hospital on Tuesday after being treated for heart failure, been involved in a vehicle accident resulting in a fractured hip the following Saturday, and the readmission would count against the hospital, although there is no relation between the reasons for the initial admission and readmission. Due to these changes, hospitals are shifting their focus to performance improvement and patient outcomes in heart failure (Kim & Han, 2013).

Due to the changes in healthcare reform involving reimbursement, hospitals across the nation are adopting a “do more with less” mentality. The number of resources utilized to provide care for a heart failure patient and care of patients with chronic diseases such as heart failure needs re-evaluation. An article written by Hines, Yu, and Randall (2010) discusses the changes involved with health care reform and the strategies available to help organizations overcome these changes to provide the best care for the patient. Strategies discussed by the authors to help reduce heart failure readmissions include multidisciplinary follow-up, home health, transitional care models, heart failure clinics, and palliative care programs (Hines, Yu, & Randall, 2010). All of these programs have a focus of helping patients with symptom management and lifestyle adjustments associated with the diagnosis of heart failure. Preventing exacerbation of heart failure symptoms such as shortness of breath keeps patients out of the emergency room and decreases the potential for readmission.

A major component of palliative care programs is improving the quality of life for the patient and the family. In a chronic illness, quality of life is often associated with symptom management. According to Zambroski and Bekelman (2008), poor symptom management is often linked to frequent hospital readmissions. Poor symptom management also increases burden on patients and families who are dealing with the chronic disease (Zambroski & Bekelman, 2008). Palliative care programs are thought to help decrease hospital readmissions by assisting the patient with symptom control, thus improving the patient's quality of life and decreasing the likelihood of a visit to the hospital.

This is a systematic replication of Bakan and Akyol's (2008) study, utilizing the Minnesota Living with Heart Failure Questionnaire[®] (MLWHFQ) to determine quality of life and symptom burden in heart failure patients. The study determined the heart failure patient's perception of quality of life and symptom burden and utilized Roy's Adaptation Model to develop education for these patients. The 43 heart failure patients in Bakan and Akyol's (2008) study were divided into an intervention group and a control group. The intervention group adjusted well to their disease through use of the Roy Adaptation Model as evidenced by an enhanced quality of life, improved functional capacities, and increased social support (Bakan & Akyol, 2008).

In this systematic replication study, heart failure patients will be recruited from a regional acute care hospital in southern Indiana. This regional acute care hospital has an extensive cardiology department which includes an outpatient heart failure clinic. Study inclusion criteria are as follows: (a) age of 40 and older, (b) admitting diagnosis of heart failure, (c) documented past medical history of heart failure, and (d) ability to communicate verbally. A total of 50 patients will be enrolled in the study over a six month time frame. Phase I data collection will be

completed within the initial six month time frame. Phase II data collection (post palliative care intervention) will be completed after six months of palliative care treatment. A descriptive, quantitative study design will be used as framework for this study allowing for definition of patients' symptoms, trialing of intervention, and investigation of the cause-and-effect relationship among the patients' symptoms and trialed intervention. Written consent to participate in the study will be required.

Understanding of patient perceptions of symptoms, quality of life, and support in heart failure will assist in the development of a palliative care program with elements from Roy's Adaptation Model. The aims of this program will be to meet the needs of heart failure patients and their families, as well as offer support and keep them out of the hospital. Increased help and support for these patients will assist in decreasing exacerbations of heart failure, more proficient handling of exacerbations if they occur, and decreased medical costs through prevention of hospital readmissions.

Background and Significance

Due to the advances of medical technology, Americans are living longer. With the medications, treatments, and resources available today, Americans diagnosed with a chronic disease are able to live much longer than in the past. The increase in life span has resulted in an increased need of medical treatment for these patients, resulting in higher medical costs. The rise in medical costs has required insurance providers such as Medicare, to place stipulations on medical institutions regarding reimbursement of the treatment of these patients. Institutions are required to comply with specific core measures of treatment and are expected to keep these patients out of the hospital after discharge. If these qualifications are not met, the institution does not receive full reimbursement. According to Pritchard (2012), beginning year 2012,

hospitals can lose as much as 1% per diagnosis with as much as a 2% loss per diagnosis possible by year 2017.

Heart failure is a chronic disease that has become increasingly dominant over the past several years. Heart failure is considered to be a disease that limits the length of life as well as impacting the quality and functionality of life. Patients with heart failure are living longer and the heart failure population is growing. With the aging of the heart failure population also comes the addition of co-morbidities, thus making these patients more frail and requiring more health care resources. In addition to the burden placed on the health care system by heart failure, individuals with heart failure often experience personal burden as well (Goodlin, 2009). Palliative care has long been a valuable resource for patients and families of those diagnosed with cancer but have not been utilized as much in chronic diseases such as heart failure.

According to the Center to Advance Palliative Care (2013):

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment. (Defining palliative care, paras. 1 & 2)

Many patients with heart failure have supportive and palliative care needs that are unmet. Patients with heart failure also tend to have a decreased understanding about their disease as compared to cancer patients, resulting in decreased advance planning for their disease. Many

end-stage heart failure patients die in the hospital while still receiving invasive medical treatments. Past research has recommended that palliative care be offered throughout the trajectory of heart failure in order to succeed in providing the best quality of life for heart failure patients and their families (Johnson & Gadoud, 2011).

Statement of Problem

Heart failure (HF) has been an emerging health issue for the past several years, responsible for over 4 million outpatient visits, 300,000 deaths, and 1 million inpatient visits yearly (Granger, Sandelowski, Tahshjain, Swedberg, & Ekman, 2009). Costing 34.8 billion dollars in healthcare costs in 2008, heart failure is a leading cause of hospital admissions and mortality, affecting over 5 million people (Esposito, Bagchi, Verdier, Bencio, & Kim, 2009).

Purpose of Study

The purpose of this descriptive, quantitative study is to determine if the use of a palliative care program in heart failure patients would aid in the prevention of hospital readmissions and to develop an evidence-based palliative care program based on the study findings. This study is a systematic replication of the Bakan and Akyol's (2007) study, utilizing the Minnesota Living with Heart Failure Questionnaire[®] (MLWHFQ) to determine quality of life and symptom burden in heart failure patients.

Research Question

Would utilizing an evidence-based palliative care program decrease hospital readmissions in heart failure patients?

Organizing Framework

A descriptive, quantitative study design will be used as framework for this study. The goals of quantitative research are to define, trial, and investigate cause-and-effect relationships

among different variables. Quantitative research is considered to be formal, objective, and well controlled. Quantitative research also encompasses descriptive, correlational, quasi-experimental, and experimental research (Burns & Grove, 2009). The use of a descriptive study design is ideal for testing of theory, identification of issues in current practice, and validation of current practice, thus further providing a representation of circumstances as they naturally occur (Burns & Grove, 2009). Survey or questionnaire research is part of descriptive research and is used to gather opinions, attitudes, characteristics, and observe behaviors in a particular population.

Limitations

The chief limitation of this study is the use of a small sample size enrolled from one specific geographic area. The area is a smaller town with fewer resources than bigger U.S. cities. Participants will have to meet specific, restrictive criteria, thus eliminating the ability to utilize random selection. The number of participants in this study will be too small to represent the whole American population diagnosed with heart failure.

Assumptions

Considering the support of past research, it is assumed that patients enrolled in a palliative care program will have better quality of life as evidenced by lower scores on the Minnesota Living with Heart Failure Questionnaire[®] MLWHFQ than heart failure patients not enrolled in palliative care. It can also be assumed that the palliative care patients will have fewer exacerbations of their disease, thus spending less time in the emergency room or admitted to the hospital.

Summary

Heart failure patients and their families are heavily burdened with the management of the disease, often affecting their quality of life. In addition to the effects on their quality of life, heart failure patients are also at an increased risk of hospitalization, thus increasing health care costs. By understanding the symptom burden and effect on the quality of life of heart failure patients and their families, palliative care programs can be developed to assist in management of this chronic disease. Proper and effective management of heart failure will increase quality of life, decrease symptom burden, thus decreasing hospital readmissions.

A descriptive, quantitative study design will be used as framework for this study. The goals of quantitative research are to define, trial, and investigate cause-and-effect relationships among different variables. Participants will be asked questions regarding quality of life and symptom management in coping with their heart failure.

The purpose of this descriptive, quantitative study is to determine if the use of a palliative care program in heart failure patients would aid in the prevention of hospital readmissions and to develop an evidence-based palliative care program based on the study findings. This study is a systematic replication of the Bakan and Akyol's (2007) study, utilizing the Minnesota Living with Heart Failure Questionnaire[®] (MLWHFQ) to determine quality of life and symptom burden in heart failure patients.

Chapter II

Review of Literature

Introduction

The chronic disease of heart failure is known as one of the leading causes of death in the United States, accounting for 55,000 deaths yearly (Centers for Disease Control and Prevention, 2013). It is estimated that 5.7 million United States citizens have heart failure with around half dying from the disease within five years of diagnosis (Centers for Disease Control and Prevention, 2013). The diagnosis of heart failure includes many burdens for not only the patient but also the patient's family and caregivers. The diagnosis of heart failure often leads to disability due to decreased ability to perform activities of daily living. Heart failure treatment also includes a complex medication regimen, diet restrictions, and often use of home medical equipment such as oxygen. Heart failure patients often have frequent follow-ups with their primary doctor as well as appointments with a cardiologist. Heart failure patients may need to participate in a heart failure clinic or some form of cardiac rehabilitation program. Considering the needs of the heart failure patient, patients and caregivers often have difficulty fulfilling these needs. The inability to care for the heart failure patient often leads to unnecessary costs, stress, and hospital admissions. Palliative care programs that help to meet the complex needs of cancer patients have been in use for several years. With better utilization of palliative care programs in heart failure patients, hospital readmissions and patient and caregiver burden may decrease.

Organization of Literature

The literature review consists of a selection of articles with emphasis on symptoms of heart failure such as depression, dyspnea, coping, and quality of life, as well as the use of palliative care in chronic illness, adaptation to heart failure, and the use of palliative care in heart

failure patients in order to meet supportive needs. The supportive literature is separated into four sections: organizational framework, experience of heart failure symptoms, perceived quality of life related to heart failure, and patient/caregiver burden.

Organizational Framework

A descriptive, quantitative study design will be used as framework for this study. The goals of quantitative research are to define, trial, and investigate cause-and-effect relationships among different variables. Quantitative research is considered to be formal, objective, and well controlled. Quantitative research also encompasses descriptive, correlational, quasi-experimental, and experimental research (Burns & Grove, 2009).

The use of a descriptive study design is ideal for testing of theory, identification of issues in current practice, and validation of current practice, thus further providing a representation of circumstances as they naturally occur (Burns & Grove, 2009). Survey or questionnaire research is part of descriptive research and used to gather opinions, attitudes, characteristics, and observe behaviors in a particular population. The Minnesota Living with Heart Failure Questionnaire® (MLHFQ) is an evidence-based tool used to help determine health related quality of life in heart failure patients (Garin et al., 2009). The questionnaire consists of 21 questions related to the effect of heart failure on the patient within the past four weeks. Each question is to be rated by the patient on a six point (0-5) Likert scale, with 0 being no, 1 being very little, and continues through with 5 being very much.

This study will explore the effects of heart failure on the life of the patient within the past four weeks. Patients with a past medical history of heart failure and admitted with an exacerbation of their heart failure will be recruited from a local regional hospital. The Minnesota Living with Heart Failure Questionnaire® (MLHFQ) will be distributed to each patient by the

primary researcher. The primary researcher will help the patients with the completion of the questionnaire if needed. The scores of the questionnaires will be tallied with a lower score equating the least amount of effect that heart failure has on the patient's quality of life.

Experience of heart failure symptoms

Cortis and Williams (2007) conducted a study to discover the experiences of coping and quality of life in older adults diagnosed with heart failure. The authors interviewed elderly patients aged 80-90 years, with a documented diagnosis of heart failure. The goal of this study was to obtain a better understanding of the elderly patient's care needs and experiences in living with heart failure. The purpose of this study was to conceptualize the most appropriate palliative and supportive interventions for these patients.

Cortis and Williams' (2007) enrolled patients to participate in this qualitative study during a Heart Failure Support Program (HFSP). This study took place in the United Kingdom. Of the 24 patients considered eligible for the study, 15 agreed to participate. Due to the holistic, patient-centered nature of qualitative research, the design of the study consisted of qualitative semi-structured interviews. Themes emerged after the initial five interviews which prompted the authors to choose participants aged 80 and older for the rest of the interviews. A majority of participants in the early interviews lived alone thus additional participants living with someone else were sought to allow for a more complete description of coping strategies.

A total of 10 interviews were performed. Cortis and Williams (2007) provided the following demographic data about the participants: (50%) were male, (50%) were female; all were in the 80-90 year age group; the majority was widowed (60%); half (50%) lived alone, (40%) lived with spouse, and (10%) lived with family. The length of time with heart failure ranged from 10 months to three years with a mean of 21.8 months (Cortis & Williams, 2007).

Data for this qualitative study were collected via a single tape-recorded semi-structured interview. All of interviews took place in the participants' homes. The interviews were conducted between June and September 2005. The interviews lasted an average of 58 minutes. Participants living with spouse or family were asked if they wished for the spouse or family to participate in the interview process. The authors surmised that inclusion of spouse or family could offer increased understanding and would align with the palliative care beliefs of family participation. The presence of the spouse or family could also constrain the participant's responses during the interview, but the authors noted that the wishes of the participant must be taken into consideration.

Findings from the interviews demonstrated four themes: experiences of living with heart failure, ways of coping, constraints to coping, and developing resources for coping (Cortis & Williams, 2007). In regard to experiences of living with heart failure, all participants experienced symptoms such as breathlessness, fatigue, insomnia, and edema, which resulted in further experiences of anxiety, fear, and frustration. The authors identified the cause of frustration as resulting from the loss of independence, not being able to do things as they used to, or not being able to do things that they had done most of their life. Participants also described social, physical, and psychological isolation related to: being unable to leave the home; loss of spouses, family, or friends through death; and a diminishing social network. Participants also reported feelings of loneliness, worry, and depression. The authors identified the theme of coping demonstrated a sub-category of stoicism and acceptance. Participants felt they just had to deal with their disease, and move on and there was nothing that could be done. Participants also mentioned a fear of dying suddenly. Not wanting to be a burden and expectations of care were sub-categories demonstrated under the theme "constraints to coping." Participants did not want

to be a burden on friends or relatives and most felt their care required more than what they expected it to. With regard to the theme “developing resources for coping,” participants described the ways they developed these resources. These methods included adaptation of lifestyles and activities to enable them to cope with their disease. It was also important to the participants that they learn about medications. Most participants demonstrated a need for reassurance that their disease was being monitored (Cortis & Williams, 2007).

In conclusion, Cortis and Williams’ (2007) qualitative study of 10 elders with heart failure provided a description of their experiences of difficulties related to their diagnosis. Participants valued their independence and remained stoic when addressing the challenges of heart failure. The authors identified the coping resources for the participants varied and areas of needed palliative and supportive care in regards to coping. The authors concluded that a development of a palliative care support program for heart failure patients may provide ways to increase coping resources and result in higher quality of life in patients with chronic diseases such as heart failure.

In order to determine if utilizing palliative care in heart failure patients would improve their outcomes, it is imperative to investigate the use of palliative care in the inpatient setting. Previous research has focused on palliative care in outpatient care settings, so little is known about the effect of inpatient palliative care consultations on patient outcomes (Rabow et al., 2004). A study by Casarett et al. (2008) looks at this topic. The purpose of their study was to determine the effect of inpatient palliative care consultation on patient outcomes (Casarett et al., 2008).

This quantitative study was conducted in five Department of Veterans Affairs (VA) Medical facilities and their associated nursing homes and outpatient clinics. The sample targeted

for the study was patients who received any inpatient or outpatient care from any VA Medical facility during the last month of life between August 2006 and May 2007 (Casarett et al., 2008). While no exclusion criteria were used, patients were randomly omitted from the sample during instances of patient death exceeding the ability to conduct interviews in a timely manner. The patient's family member (next of kin, primary contact listed in the medical record, or durable power of attorney) was sent a letter four to six weeks after the patient's death. The letter described the study and included a toll free number to call if the family member wished to not participate. Phone calls were made to the family members who did not opt out about six weeks after the patient death. Interviewers made up to six attempts during a four week time frame with one attempt after 5 p.m. to contact the family member. Family members without a working telephone, those who did not speak English, those with hearing difficulties, and those who stated they could not evaluate their loved one's care were excluded from the study (Casarett et al., 2008). The sample consisted of 680 family members with 524 (77%) completing the interview.

The interviewers used the Family Assessment of Treatment at End-of-life (FATE) survey for this study. The survey consisted of 32 items pertaining to the current national guidelines in palliative care and evaluated outcomes with the use of frequency ratings (e.g., "How often did the patient's pain make him/her uncomfortable?") and yes/no responses (e.g., "Do you think the patient died where he/she wanted to?") (Casarett et al., 2008). The FATE survey was validated and demonstrated homogeneity with a Cronbach alpha of 0.91 and greater than 0.70 Cronbach alpha on all domains.

Of the 524 interviews completed, 296 (56%) received an inpatient palliative care consult in an acute or long term care setting (Casarett et al., 2008). A multivariable logistic regression model showed that patients with confusion, cancer, and more than one hospitalization were more

likely to receive a palliative care consult. Patients receiving a palliative care consult had significantly higher FATE scores in five of the six domains: information and communication, access to home care services, emotional and spiritual support, well-being and dignity, and care around the time of death (Casarett et al., 2008). In terms of alleviation of symptoms, patients who received a palliative care consult had higher FATE scores in pain management and symptoms related to post-traumatic stress disorder. There was no difference for symptoms of confusion or dyspnea. Limitations to this study included the sample consisting of only VA patients and the study only relying on families' perceptions of care rather than patient assessment (Casarett et al., 2008).

This study concluded that inpatient palliative care consults benefit patients who are near the end of life across nearly all domains of care. It also offers evidence to suggest that earlier consultations may improve communication and emotional support. It was noted by the authors that future research is required to determine what contributes to a palliative care consult's effectiveness (Casarett et al., 2008).

According to Proctor et al. (2000) world-wide, the most common cause of hospital readmissions in patients older than 65 years old is heart failure. Previous research has demonstrated that depressive symptoms are associated with increased readmission rates in patients with systolic dysfunction heart failure. More research is needed to determine if patients with a diagnosis of preserved systolic function heart failure with depressive symptoms are at the same risk for hospital readmission as those patients with systolic dysfunction (Song et al., 2009).

The purpose of this research study was to identify if depressive symptoms in preserved systolic function heart failure patients was a predictor of hospital readmission. The goals of this study included determining the prevalence of depressive symptoms in preserved systolic function

heart failure patients, determining if severity of depressive symptoms was correlated with timeliness of hospital readmission or patient death, and if the presence of depressive symptoms alone was a predictor of hospital readmission once other risk factors had been controlled (Song et al., 2009).

The design of this study was a prospective, descriptive study. Patients from six cardiology units from two university hospitals located in Seoul, South Korea, admitted with preserved systolic function heart failure between the dates of October 1, 2005 and December 31, 2005, were considered for this study.

The authors of this study used The Beck Depression Inventory (BDI) to measure depressive symptoms. The BDI consists of 21 statements, each rating severity on a 0 (not at all) to 3 (very much so) scale. The score range is 0-63 with the higher the score representing more severe depressive symptoms. All patients were placed into four categories according to their score. A score of 0-9 was described as no depressive symptoms, 10-16 as mild symptoms, 17-29 as moderate symptoms, and 30-63 as severe depressive symptoms. The reliability of the BDI was supported by a Cronbach's alpha coefficient of 0.90 (Song et al., 2009).

Patients were informed of confidentiality and informed consent was obtained. The patients completed the questionnaires by day three or four of hospitalization. If needed, a research assistant was available to help the patients complete the questionnaires. The patients were then monitored in person or by telephone for six months post discharge from January 2006-July 2006. If the patient was readmitted to the hospital during that time, a trained research assistant reviewed the inpatient record to verify diagnosis and admission date (Song et al., 2009).

Patients included in this study were over the age of 18, had a cardiologist determined diagnosis of heart failure, had a New York Heart Association (NYHA) functional classification \geq

II, and had a left-ventricular ejection fraction $\geq 40\%$. The diagnosis of heart failure was confirmed by the cardiologist using the Framingham criteria. A total of 170 patients met inclusion criteria and were asked to participate in the study. Of the 170 patients asked, three refused to participate and two patients were lost during the follow-up phase. Data from 165 patients were included in the study (Song et al., 2009).

The patient age ranged from 22-92 years with an even split by gender. The majority of patients were a NYHA functional class III. Ischemic heart disease was the underlying cause of heart failure in close to half of the patient population. About one-third of the patients had a prior hospital admission due to heart failure exacerbation. During the six month follow-up time frame, 53 (32%) of patients were readmitted for heart failure exacerbation and seven (4%) died. The cause of the patient deaths was determined to be sudden cardiac death. Of the 53 patients, 13 (8%) were readmitted more than once. Of these 13 patients, the authors considered only the first readmission for analysis. No depressive symptoms were reported by 20% of the patients with almost half of the patients reporting moderate to severe depressive symptoms. According to the authors, severe depressive symptoms were related to a higher rate of readmission and a shorter time to readmission from hospital discharge. Depressive symptoms were found to be an independent predictor of readmission when other risk factors were controlled (Song et al., 2009).

In conclusion, Song et al., (2009) found that heart failure patients with preserved systolic function are equally at risk for readmission due to depressive symptoms as those patients with systolic dysfunction. In addition, it was noted that interventions which begin in the hospital setting and extend to home may decrease the six month readmission rate associated with heart failure patients exhibiting depressive symptoms (Song et al., 2009).

Perceived quality of life related to heart failure

Heart failure is a chronic disease associated with many complications, resulting in high hospital readmission rates. Bakan and Akyol (2008) found that previous research studies show that the Roy Adaptation Model (RAM) has been useful in supporting adaptation in patients with other chronic diseases. The following study by Bakan and Akyol (2008) examines the use of the Roy Adaptation Model (RAM) as a framework for outpatient treatment in heart failure patients.

This quantitative study used a randomized, parallel, controlled clinical trial as the design. The data from this study was reported as a secondary analysis from the randomized controlled trial conducted during the first six months of 2005. The secondary analysis was performed at the end of 2005.

This study took place at a cardiology and internal disease clinic in a hospital in Turkey. The sample consisted of 44 patients, randomly divided between an intervention group and a control group. Each group consisted of 22 patients. One patient in the intervention group moved during the study timeframe and was dropped from the study. The remaining 21 patients in the intervention group completed three months of follow-up (Bakan & Akyol, 2008). The inclusion criteria for this study were the ability to read and communicate vocally, a diagnosis of heart failure for at least six months prior to the study, a New York Heart Association (NYHA) functional class II-III, an ejection fraction < 40%, no hearing or visual deficits, no history of mental disorders or myocardial infarction in the past year, and plans to remain local or be reached by telephone (Bakan & Akyol, 2008).

The researchers developed a patient identification form for demographic information and distributed it to each participant. They used an assessment form for physiological data which included body mass index (BMI), cholesterol, high-density lipoprotein (HDL), low-density

lipoprotein (LDL), changes in smoking and alcohol habits, dietary changes, and current medications to evaluate each patient during the study (Bakan & Akyol, 2008). This form also tracked hospital readmissions due to heart failure during the study. Quality of Life (QOL) was considered a latent variable and was measured using the Minnesota Living with Heart Failure Questionnaire® (MLWHFQ). The researchers used this questionnaire at beginning of the study and again at three months. The Minnesota Living with Heart Failure Questionnaire® (MLWHFQ) measured patient perspective on 21 items concerning disability, symptoms of heart failure, social interaction, work, and emotions. A six point response scale was used for each question (0-5) and the maximum score is 105. Lower scores indicated a higher quality of life (Bakan & Akyol, 2008). The questionnaire was further divided into three separate scale scores: physical, emotional, and total score. Cronbach's alpha coefficients for the separate scales were 0.87, 0.61, and 0.83 respectively. The researchers measured social support utilizing the Interpersonal Support Evaluation List (ISEL) short form. This 15 item instrument measured the perception of social support derived from the 48 item long form questionnaire (Bakan & Akyol, 2008). Three subscales of tangible support, appraisal support, and belonging support were measured on a rating scale consisting of completely false, somewhat true, and completely true. Cronbach's alpha coefficient for this questionnaire was 0.79.

The researchers measured the functional status of each heart failure patient utilizing the six minute walking test (6MWT). They recorded the patient's heart rate, respirations, and blood pressure before and after each 6MWT. Additionally, the physiologic mode of adaptation was evaluated with the 6MWT (Bakan & Akyol, 2008).

The intervention group participated in two "one-on-one" counseling sessions, two phone calls, and one group meeting over a time period of three months. The patient's spouse or

significant other was encouraged to attend the sessions as well. The control group had the usual care which did not include the counseling sessions and phone calls (Bakan & Akyol, 2008).

Differences between the intervention and control groups in scoring of QOL, walking distance, and social support demonstrated that the Roy Adaptation Model based program had an effect on physiologic, role function, and self-concept adaptation in heart failure patients. Patients in the intervention group showed increased QOL with lower scores at the three month follow-up in the physical and emotional dimensions, as well as the total score. Patients in the intervention group had increased six minute walk differences at the three month follow-up as compared to the control group. Intervention patients also showed a statistically significant increase in scores for social support at the three month follow-up (Bakan & Akyol, 2008).

This study concluded that using the Roy Adaptation Model (RAM) as framework for heart failure follow-up programs is effective, resulting in improvements of quality of life, social support, and exercise tolerance. The authors further surmised that future studies utilizing the RAM as framework would need to include larger sample sizes (Bakan & Akyol, 2008).

Coping with a chronic illness can be a difficult experience for both patients and their families. When it comes to coping with a chronic illness, individuals who feel they have significance, purpose, and a meaningful life are associated with a positive well-being (Park, Malone, Suresh, Bliss, & Rosen, 2008). The authors of this study investigated the relationship of coping strategies used in heart failure, meaning of life, and the effects of coping on quality of life.

The design of this study utilized a quantitative convenience sampling method of 202 study participants. Two medical clinics in Cincinnati, Ohio was the setting for this study. A total of 202 patients (191 men and 11 women) were recruited for this study during routine

medical appointments (Park et al., 2008). The inclusion criteria for this study were hospital admission for left-sided heart failure in the past year, age over 40, ability to speak English, and having no history of cognitive impairment. Of the original 202 patients recruited for the study, 155 men and eight women completed the follow-up assessment (Park et al., 2008).

Participants completed three questionnaires regarding meaning in life, coping, and health related quality of life at the beginning of the study and again at six months. The authors assessed meaning of life with the Perceived Personal Meaning Scale (PPMS); level of coping through specific questions on active coping, denial, social/emotional support, acceptance, mental disengagement, alcohol/drug abuse, religious coping, etc.; and health-related quality of life (HRQOL) via the Medical Outcomes Study Short Form health status questionnaire (Park et al., 2008). The Medical Outcomes Study Short Form health status questionnaire produces a score for mental health and a score for physical health (Park et al., 2008). The PPMS reliability was 0.92. Reliability for the coping question subscales ranged from 0.66-0.91 with reliability for the Medical Outcome Study Short Form health status questionnaire at 0.74 for the physical health portion and 0.77 for the mental health portion. Severity of heart failure was determined by left ventricular ejection fraction and New York Heart Association (NYHA) classification.

The authors found coping styles of acceptance, positive reinterpretation, and religious coping were related to increased meaning in life while coping strategies, such as disengagement and social support were associated with a decreased HRQOL (Park et al., 2008). Although meaning in life decreased over the six months of the study overall, the researchers observed higher levels of meaning in life in participants who engaged in positive coping mechanisms. Participants who coped with methods of acceptance, faith, and positivity demonstrated higher levels of life meaning over the six month time frame. The higher the meaning of life scores, the

better the physical and mental HRQOL scores. This finding was significant in that higher rated HRQOL has been positively linked to decreased re-hospitalization and mortality in heart failure patients (Park et al., 2008).

The study concluded that participants who accepted their chronic illness, used faith for coping, and made a valiant effort to understand their illness had better physical and mental health related quality of life (Park et al., 2008). A limitation described in this study included the “snapshot” approach of collecting data at only two time points. Individuals with chronic illness have ongoing changes that the “snapshot” approach of data collection may not address. The authors did conclude that meaning in life was strongly linked to improved physical and mental health related quality of life. In addition, the authors stated that health related quality of life has been strongly associated with patient outcomes, suggesting that a strong relationship exists between health related quality of life, re-hospitalization, and mortality in heart failure patients (Park et al., 2008).

Patient/caregiver burden

Palliative care is recommended for patients with heart failure nearing the end of life or with refractory symptoms (Bekelman et al., 2011). According to these recommendations, patients and families do not have the opportunity to experience the benefits of palliative care offered earlier in illness. According to Bekelman et al. (2011), previous literature regarding palliative care and heart failure provided insight on patients’ experiences, but do not offer direction on how a palliative care program for heart failure should be structured. The purpose of the study by Bekelman et al. (2011) is to assess the patient’s and family’s primary concerns and needs regarding heart failure and to determine how and when palliative care would be most appropriate for them.

Potential patients for the study were recruited from an outpatient cardiology and geriatrics clinic at the University of Colorado Hospital. Eligible patients had a New York Heart Association (NYHA) functional class of II-IV and a cardiologist confirmed diagnosis of heart failure (Bekelman et al., 2011). The exclusion criterion for this study was a diagnosis of dementia. A total of 38 patients were approached for participation; three patients were not interested and two patients felt they were too sick to participate. Each patient was asked to recognize a caregiver who helped them care for their heart failure. All caregivers appointed by the patient agreed to participate in the study. The patients and their prospective caregivers were interviewed at different times, either in their home or at the clinic (Bekelman et al., 2011).

This qualitative study used one-on-one, semi-structured interviews to obtain data from the patients and their caregivers. The interviews took place from 2007 through 2008. The patients and the caregivers gave informed consent, and the study was approved by the Colorado Multiple Institutional Review Board (Bekelman et al., 2011). The six domains of palliative care identified by the National Consensus Project's conceptual model of palliative care acted as the framework for the interviews. Interviewers asked open-ended questions to each patient and family member according to the six domains of palliative care. The term "palliative" was not used in the interview process (Bekelman et al., 2011). The interviews lasted from 60 to 90 minutes and a total of 33 heart failure patients and 20 caregivers participated in the interviews. The interviews were recorded digitally and transcribed verbatim. An ATLAS coding system was used for analysis of the interview data (Bekelman et al., 2011). Patients completed the Kansas City Cardiomyopathy Questionnaire (KCCQ) as a self-assessment tool pertaining to heart failure status. This assessment, which pertains to symptom burden, physical function, and quality of

life, scores on a scale of 0-100 with the higher scores reflecting better health status (Bekelman et al., 2011).

Upon analysis of interview findings, the authors found important insights related to the key themes of content, structure, and timing. Content of the program pertained to topics that should be addressed by the palliative care program. The participants felt the program should help with adjustment to limitations pertaining to their heart failure and describe the future course of their disease (Bekelman et al., 2011). The participants also felt the program should help reduce the symptoms they are experiencing from heart failure. Structure of the program involved how the palliative care services should be provided and who should be responsible for the services (Bekelman et al., (2011). The participants felt the structure of the program should involve their care provider being “familiar” with their heart disease, the care provider facilitating and coordinating communication regarding their care, and that a team approach should be utilized. In respect of timing of the program consisted of when palliative services should be offered and how long they should last.

Further analysis revealed nearly all patients and their caregivers described a need for assistance with adjusting to the lifestyle changes related to heart failure and the progression of the disease. The majority of patients and caregivers stated the most challenging part of living with heart failure was what the patient was unable to do, further expressing a desire to have increased energy, mobility, and activity level (Bekelman et al., 2011). Patients and caregivers also wanted to know more about the progression of the disease (Bekelman et al., 2011). Patients and caregivers alike were generally negative regarding symptoms of fatigue and dyspnea, feeling like there was nothing that could be done to relieve these symptoms (Bekelman et al., 2011). Caregivers stated that communication, coordination, and continuity of care were very important

and that family should be more involved in patient care. Patients and caregivers appreciated the team approach associated with palliative care. Both groups stated a necessity for assistance in adjusting to the disease at time of diagnosis or shortly after, with the ability to have assistance as needed as the disease progressed (Bekelman et al., 2011).

Bekelman et al. (2011) concluded that palliative care services of coordination, communication, caregiver support, and facilitation of needs were important to patients and caregivers affected by heart failure. It was noted that study participants valued the involvement of the caregiver or family in patient care, which is a significant part of palliative care programs. The team approach associated with palliative care was also seen as potentially beneficial to the care of heart failure patients and caregivers.

Care of patients with chronic disease can be complex and is often considered suboptimal, with many patients reporting inadequate symptom relief (Gade et al., 2008). Patients and families often need assistance in understanding the prognosis of their chronic disease as well as treatment options. Palliative care programs have been developed to assist with the deficits of symptom and care management in patients with chronic disease. It has been noted by Gade et al. (2008) that research is lacking as to whether palliative care services have a positive impact on patient satisfaction, clinical outcomes, and health care expenditures post hospital discharge. A study conducted by Gade et al. (2008) examined the impact of palliative care services on patient satisfaction, clinical outcomes, and health care costs.

Patients for this study were randomly selected from the same health plan among three regions: Denver, Colorado; San Francisco, California; and Portland, Oregon. Participants enrolled for the study between June 2002 and December 2003. A total of 1,168 patients were referred for the study. To be eligible for participation, patients had to be over 18 years of age

and hospitalized with at least one chronic disease. A short life expectancy defined as the physician “would not be surprised if the patient died within 1 year” was also criteria for participation (Gade et al., 2008, p.181). Exclusion criteria for this study consisted of cognitive impairment with no surrogate and previous enrollment in hospice or other studies involving palliative care. Of the 1,168 patients referred, 517 qualified and were enrolled in the study. These participants were randomized into two groups. The intervention group (N = 280); and usual care (N = 237) (Gade et al., 2008).

Upon hospital admission, patients enrolled in the study were administered a baseline questionnaire. Participants were randomly divided by computer software into an intervention group and a “usual care” group.

Interdisciplinary inpatient palliative care consultation services (IPCS) were assigned to the intervention group. The IPCS intervention team consisted of a palliative care physician, nurse, hospital social worker, and chaplain who assessed the patients’ needs for symptom management, spiritual care, psychological support, post discharge care, and, if appropriate, end of life care (Gade et al., 2008). The IPCS team met with the patient and the patient’s family to discuss symptoms, diagnosis, disease prognosis, and specific goals of care (Gade et al., 2008). Advance directives were also discussed during this time. The attending physicians used a provided treatment recommendation.

Discharge planning was also initiated during the patient consultation process and communicated to the patient’s attending physician. Patients were given the Physical, Emotional/Relationship, Spiritual, Place of Care Environment, and Doctors, Nurses/Other Care Areas of the Modified City of Hope Patient Questionnaires (MCOHPQ) upon study enrollment and again within two weeks of hospital discharge. These questionnaires measured symptom

control, emotional and spiritual support, and patient satisfaction (Gade et al., 2008). Higher scores on the MCOHPQ indicated greater symptom severity, better support, and better perceptions of caring, respect, and understanding. Cronbach alpha scores were adequate for all areas of the questionnaire except Emotional/Relationship, whose Cronbach alpha score indicated a lack of agreement for that area (Gade et al., 2008). The researchers calculated the costs of care for all health related service areas utilized within six months post discharge. They calculated the cost of the palliative care team by multiplying total time taken for the study for each member by the team member's salary.

Results of the study indicated better patient satisfaction with care and communication, fewer Intensive Care Unit (ICU) admissions, and lower health care costs post discharge for patients in the IPCS group (Gade et al., 2008). The IPCS group completed significantly more advance directives prior to hospital discharge than the usual care group, but there was no difference in the use of hospice services between the IPCS group and usual care group. The IPCS group did show 1 day faster enrollment to hospital services than the usual care group. Scores for the Physical, Emotional/Relationship, Spiritual, and Quality of Life Areas showed no difference between the IPCS group and usual care group (Gade et al., 2008).

This study concluded the use of palliative care services may positively impact patient satisfaction scores and decrease total costs of health care. Communication with health care providers and the patient's experience with care were both improved in the IPCS group versus the usual care group. Other data obtained from this study also indicated that palliative care services may increase hospice service utilization and decrease ICU admissions (Gade et al., 2008). While no difference was indicated in the amount of hospice admissions between the

IPCS and usual care group, patients in the IPCS group were enrolled in hospice quicker during hospitalization than the usual care group.

Patients living with heart failure often experience many symptoms that affect their activities of daily living and their quality of life. Dyspnea is one of the most common symptoms of patients with heart failure. Caregivers often struggle with supporting these patients suffering from dyspnea. The purpose of this study conducted by Malik, Gysels, and Higginson (2013) was to compare caregivers' experiences regarding patients suffering from dyspnea and explore dynamics involved with caregiver burden and positive caring experiences.

Potential participants of this cross-sectional descriptive and comparative study were identified from two hospitals located in South London. Heart failure patients and families who attended weekly heart failure clinics and received care on general cardiac care units were invited to participate. Inclusion criteria consisted of being a caregiver of a patient over the age of 18 with dyspnea which affected daily life (Malik et al., 2013). The recruitment period for the study was 18 months with a total of 195 patients and caregivers enrolled. Ninety-four refused to participate in the study, leaving a total of 101 caregivers willing to complete the questionnaires. Of the 101 patient/caregiver participants recruited for the study, 51 were heart failure patients (Malik et al., 2013).

Caregivers consenting to participate in the study completed eight questionnaires in a setting of their choice. These questionnaires were regarding experiences of caring for symptoms of the patient and their own needs. The questionnaires used in this study are as follows: modified Borg Breathlessness Scale, Zarit Burden Interview Short Form 12 (ZBI-12), Hospital Anxiety and Depression Scale, Pittsburg Sleep Quality Inventory (PSQI), Short Form-36 (SF-

36), Brief COPE instrument, Palliative Care Outcome Scale-Symptom (POS-S), and the Palliative Care Outcome Scale-Core (POS-C) (Malik et al., 2013).

Patients' caregivers reported symptoms of fatigue and dyspnea in over 90% of cases. Caregivers of heart failure patients also reported the need for additional assistance in activities of daily living, such as transfers and going up stairs (Malik et al., 2013).

Many caregivers reported severe caregiver burden, with 19% of heart failure caregivers and about 20% of total caregivers, stating they felt stressed about caring for their family member and keeping up with other responsibilities (Malik et al., 2013). In addition to stress related burden, heart failure caregivers also reported suffering from mild to severe (74%) sleep disturbances. Caregivers also reported symptoms of anxiety and depression, with anxiety scores showing higher than depression scores (Malik et al., 2013). When asked about coping with anxiety and depression, caregivers reported eight different coping strategies. Acceptance was shown to be the most common coping strategy with over 90% of heart failure caregivers utilizing this strategy. Overall, this study found that those caring for patients with dyspnea or shortness of breath reported more burden and greater levels of unmet needs (Malik et al., 2013). The authors noted that due to the duration of heart failure, the caregiver's isolation and exhaustion may increase, resulting in increased burden and restrictions in life.

Malik et al. (2013) noted that heart failure caregivers reported several needs and burdens which were not being fulfilled. Additionally, they surmised from past evidence that just as the patient needs support for their illness, caregivers need physical and emotional support as well. Services should be available for caregivers, providing additional interventions for patient and self-support. Even with the lack of support reported by caregivers, very few heart failure patients, and subsequently their caregivers, receive palliative care. The authors concluded that

palliative care is often thought of being restricted to cancer patients, but palliative care services should be available according to symptom severity and patient and caregiver need, not just based on the diagnosis of the patient (Malik et al., 2013).

Summary of Findings

Cortis and Williams (2007) investigated the care experiences of older adults diagnosed with heart failure. The purpose of the study was to obtain a better understanding of their palliative and supportive needs and determine possible interventions for these patients. Interviews with these patients demonstrated the struggles of living with heart failure in terms of symptoms, social issues, and ordinary living. Conclusions suggested a need to individualize services according to the palliative and supportive needs of the patient and identify areas of insufficient care in order to determine the appropriate interventions for the patient.

Casarett et al. (2008) conducted research to investigate if the use of inpatient palliative care services improved the quality of care from the patient's or family's point of view. This study's purpose was to determine whether or not utilizing inpatient palliative care services resulted in better patient outcomes. Domains of care investigated in this study included well-being, information and communication, emotional and spiritual support, management of symptoms, access to home care services, and care and access to benefits at the time of death. Conclusions indicated that patient outcomes were improved across all domains of care when inpatient palliative care services were utilized. The study also provided evidence supporting palliative care consultation earlier in the disease process.

Song et al. (2009) conducted research to determine if depressive symptoms increased the risk for rehospitalization in patients with preserved systolic function. Past research had shown that patients with depression and decreased systolic function were at higher risk for

rehospitalization due to heart failure, but very little was known about patients with preserved systolic function. Conclusions indicated that heart failure patients who had preserved systolic function and moderate to severe depressive symptoms were also at risk for rehospitalization from heart failure. The authors determined that nurses should be assessing these patients for signs of depression and refer to treatment if indicated.

The purpose of the study conducted by Park et al. (2008) was to explore coping, quality of life, and meaning of life in patients diagnosed with heart failure. The objectives of the study consisted of determining what, if any, coping strategies were being used to manage heart failure and determine if these coping strategies were related to meaning and quality of life. The authors concluded that coping was related to meaning of life and also contributed to an increased meaning of life. Life-meaning was found to be significant in these patients living with a chronic illness, such as heart failure. It was also found that coping was directly related to increased meaning of life over time.

The study by Bakan & Akyol (2008) was performed to investigate the effects of a Roy Adaptation Model focused intervention program on management of heart failure patients. Past research has suggested that the use of the Roy Adaptation Model has been useful in patients adapting to a chronic illness but research is lacking on the usefulness to heart failure patients. The authors concluded that the use of the Roy Adaptation Model as a framework for a heart failure follow-up program was effective, resulting in improvements of quality of life, social support, and exercise tolerance.

Bekelman et al. (2011) conducted a study to investigate how a palliative care program for heart failure patients should be structured. Past research exists regarding patients' experiences regarding palliative care and heart failure but is lacking in information on what needs are highest

priority and how the program should be structured. The purpose of this study was to determine what needs and concerns were deemed highest priority to heart failure patients and their families and also to determine when palliative care would be most useful for them. Conclusions from this study showed the patients and family supporting early palliative care intervention, especially with symptom management and psychological issues. A multidisciplinary team approach was preferred.

Gade et al. (2008) realized the use of palliative care in patients hospitalized with a chronic illness improves care and reduces cost, but research on the impact of palliative care on patient satisfaction, outcomes, and subsequent costs of care was lacking. The objective of this study was to measure the effect of an interdisciplinary palliative care service on patient satisfaction, clinical outcomes, and the cost of healthcare for six months post discharge. The authors concluded that the patients participating in the interdisciplinary palliative care service reported better satisfaction with their care, better communication with their care providers, and decreased total care costs after hospitalization. It was also discovered that if patients were readmitted for any reason, admissions to the ICU on readmission were less in patients participating in palliative care services.

The study by Malik et al. (2013) was done to compare caregivers' experiences regarding patients suffering from dyspnea and explore dynamics involved with caregiver burden and positive caring experiences. Palliative care was often seen as a service reserved for cancer patients, regardless of the symptoms experienced with other chronic illnesses. Dyspnea was one of the most common, stressful symptoms in patients with advanced chronic disease and caregivers were expected more than ever to support these patients at home. The authors concluded caregivers felt the patients' needs were not being fulfilled. Caregivers of heart failure

patients reported several needs and burdens of the patients were not being met. Caregivers of these heart failure patients also needed physical and emotional support, which was not being provided. The authors determined that palliative care services should be available according to symptom severity and patient and caregiver need, not just based on the diagnosis of the patient.

Chapter III

Methodology

Introduction

Heart failure patients often experience many bothersome sequelae as a result of their chronic disease. Heart failure patients endure symptoms, such as shortness of breath and depression, which often lead to a decline in functionality and inability to care for oneself. These patients also require frequent physician follow-ups. As a result of the patient's decline, family members or other types of caregivers often experience burden and stress in supporting the patient with daily needs. These issues tend to overload the patient and family, resulting in the need for rehospitalization. The purposes of this descriptive, quantitative study are to determine if the use of a palliative care program in heart failure patients would aid in the prevention of hospital readmissions and to develop an evidence-based palliative care intervention (program) based on the first section of the study. This study is a systematic replication of Bakan and Akyol's (2007) study, utilizing the Minnesota Living with Heart Failure Questionnaire® (MLWHFQ) to determine quality of life and symptom burden in heart failure patients. This chapter contains research questions; the setting, population, sample; methods of data collection; and methods of data analysis pertaining to this study. Information concerning protection of human subjects is also included in this chapter.

Research Question

Would utilizing an evidence-based palliative care program decrease hospital readmissions in heart failure patients?

Setting, Population, Sample

This study will take place in Vincennes, Indiana. Participants will be recruited from a regional acute care hospital. Inclusion criteria will include: (a) age of 40 and older, (b) admitting diagnosis of heart failure, (c) documented past medical history of heart failure, and (d) ability to communicate verbally. A total of 50 patients will be recruited over a six month time frame. Phase I data collection will be completed within the initial six month time frame. Phase II data collection (post palliative care intervention) will be completed after six months of palliative care treatment.

Protection of Human Subjects

A research study proposal will be presented to the Ball State University Institutional Review Board and also to the participating regional hospital's Institutional Review Board (IRB) for approval. The institution's right to refuse and voluntary participation will be explained to the Hospital IRB. Potential recruits for participation in the study will be informed both verbally and in writing regarding the purpose of this study. The total anticipated time commitment required by the study will be explained to potential participants. If a patient chooses to participate in the study, written informed consent will be obtained by the researcher. If the patient is unable to sign, written informed consent will be obtained from the patient's Power of Attorney (POA) in the presence of the patient.

Each study participant will receive an envelope containing information about the study. The contents of the envelope will include an explanation and purpose of the study, potential risks and benefits to study participation, and a consent form. Participants will be informed that they will not be compensated for their participation in the study and have the right to withdraw from the study at any time without consequence. The Health Insurance Portability and Accountability

Act (HIPAA) will be rigorously followed in an effort to protect participant privacy and confidentiality throughout the study. All data collected will remain anonymous. There are no identified risks to the participants in this study at this time. The benefit to the patient would include the potential for learning about ways to manage and cope with their chronic heart failure.

Procedures

As described above, there will be two phases to this study, phase I (pre-intervention phase) and phase II (post-intervention phase). The principal investigator will identify patients admitted with heart failure at the regional acute care hospital. Patients who are identified with a ‘first time’ diagnosis of heart failure will not be eligible to participate in the study. During participant recruitment, the principal investigator will explain individually to each participant: the purpose of the study, the study’s objectives, and the risks and benefits of study participation. The investigator will explain how confidentiality for participants will be maintained throughout the study. Once the researcher feels the participant thoroughly understands their rights and role regarding the study, eligibility criteria will be confirmed and the researcher will obtain written informed consent. The principal investigator will then identify a time that is best for participant for the researcher to return and collect data for the study. The study participant will be given an opportunity to participate in the final portion of the study related to the development of the palliative care program developed from the initial findings of this study. Participation in the palliative care program will be considered phase II of the study.

Method of Data Collection

In phase I of the research study, each study participant will be given the Minnesota Living with Heart Failure Questionnaire® (MLWHFQ). The questionnaire will be explained to the participant in its entirety. Each participant’s understanding of how to take the questionnaire

will be assessed using Teach-back methodology. The participant's ability to "teach-back" the instructions to the principle investigator will ensure accurate answers to the questions listed on the questionnaire. The participants will be given 24 hours to complete the questionnaire. The principal investigator will schedule a time that is convenient for the participant to collect the completed questionnaire. Demographic information will also be collected during the initial meeting. Demographic information will include: participants' sex; age; length of time with their diagnosed heart failure; if they live alone; and if they have assistance and support as needed. The participants will also be asked if they are currently using any assistive or supportive services.

Data will be collected on 50 participants over a six month time frame. Participants wishing to participate in the palliative care program developed from the results of phase I will be again be given the Minnesota Living with Heart Failure Questionnaire® (MLWHFQ) after six months of palliative care therapy. Phase II data collection will occur in the participant's home. The principal investigator will schedule a time to visit with the research participant. The Minnesota Living with Heart Failure Questionnaire® (MLWHFQ) will be distributed to the participant's home by the primary researcher and the completed questionnaires will be picked up 24 hours later.

The questions included on the Minnesota Living with Heart Failure Questionnaire® (MLWHRQ) are as follows:

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by:

1. causing swelling in your ankles or legs?
2. making you sit or lie down to rest during the day?

3. making your walking about or climbing stairs difficult?
4. making your working around the house or yard difficult?
5. making your going places away from home difficult?
6. making your sleeping well at night difficult?
7. making your relating to or doing things with your friends or family difficult?
8. making your working to earn a living difficult?
9. making your recreational pastimes, sports, or hobbies difficult?
10. making your sexual activities difficult?
11. making you eat less of the foods you like?
12. making you short of breath?
13. making you tired, fatigued, or low on energy?
14. making you stay in a hospital?
15. costing you money for medical care?
16. giving you side effects from treatments?
17. making you feel you are a burden to your family or friends?
18. making you feel a loss of self-control in your life?
19. making you worry?
20. making it difficult for you to concentrate or remember things?
21. making you feel depressed?

Method of Data Analysis

During phase I, the questionnaires will be collected after 24 hours. Each of the 21 questions on the questionnaire will be examined and the Likert scale response will be recorded for each question from each research participant. The six-point (0-5) Likert scale responses are

as follows: 0 being no, 1 being very little, and continuing through with 5 being very much. Each individual questionnaire score will be totaled with lower scores indicating better quality of life and symptom management. Combined totals for each question on the questionnaire will be obtained and recorded for an overall depiction of quality of life and symptom management among the participant population. The individual scores on the questionnaires will be compared to the demographic data obtained from each research participant. This data will be analyzed to identify possible themes among quality of life, symptom management, participant age, participant sex, and perceived support from the participant. Areas with higher scores on the questionnaire will be identified as possible opportunities for improvement and the palliative care program will initially focus on improving these areas. The questionnaire results for phase II will be analyzed in the same fashion as phase I. Results from phase II of the study will determine whether the palliative care program was effective in symptom management and preventing hospital readmissions

Summary

A descriptive, quantitative study design will be used as framework for this study. The goals of quantitative research are to define, trial, and investigate cause-and-effect relationships among different variables. Participants will be asked questions regarding quality of life and symptom management in coping with their heart failure.

The purpose of this descriptive, quantitative study is to determine if the use of a palliative care program in heart failure patients would aid in the prevention of hospital readmissions and to develop an evidence-based palliative care program based on the study findings. This study is a systematic replication of the Bakan and Akyol's (2007) study, utilizing the Minnesota Living

with Heart Failure Questionnaire[®] (MLWHFQ) to determine quality of life and symptom burden in heart failure patients.

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