


2019

Exploring Education Needs for Heart Failure Patients' Transition of Care to Home

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Walden University

College of Health Sciences

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Michelle Williams

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Walden University

2019

Abstract

Exploring Education Needs for Heart Failure Patients' Transition of Care to Home

by

Michelle Williams

MSN, Western Governors University, 2014

BSN, California State University Los Angeles 2008

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing Interdisciplinary Health

Walden University

February 2019

Abstract

Transitions of care is a model designed to ensure that patients have resources needed to assist them to care for themselves at home after hospital discharge, which helps to decrease preventable adverse events. For people with heart failure (HF) to transition home from the hospital successfully, specific education is needed that is individualized to the disease process, but most patients' educational needs after discharge are unmet. The purpose of this qualitative study, guided by the Meleis middle range theory of transition, was to explore the perspectives of people with HF about their educational needs in order to gather data that could inform better care practices for them once they are discharged from the hospital. Twelve participants with HF were interviewed post hospital discharge about their education experience at discharge and what they felt was needed for them to be successful in caring for themselves after discharge. Data were analyzed, and three themes emerged: discharge preparation, lifestyle changes, and transitions of care. Participants indicated that they had a positive experience with the education provided, that they had to make changes to their daily routines, and that the transition of care program was beneficial in helping them successfully care for themselves after discharge. Further studies should interview people of different ethnicities with HF, should include multiple sites in the study, and should extend the research to people with other illnesses to gain their perception of discharge education. Results contribute to positive social change because individuals with HF who know how to care for themselves at home will be able to improve their quality of life as they can effectively transition to home from the hospital setting.

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Dedication

There are so many different paths that I could have taken in life. As a young adult, I was unsure which direction I should go. I continued to go to school until I figured it out. Through the many years of my schooling, I had someone in my cheering section cheering me on along the way. She is my number one supporter my mother, Catherine Williams. She stood by me through this long journey. I am grateful to her for so many things. There is no possible way to count them all. It is because of her that I was able to pursue my goals in education and she has always supported me in my career. She has sacrificed a lot of her time to help me raise my children as I embarked upon this journey. Now that this long road is nearing its end, I want to say thank you mom for always being there for me and having my back. I want to thank my dad for the long talks and the constant words of encouragement through this process.

I also want to dedicate this dissertation to my children. They were understanding and sacrificed time with their mother so that I could complete school and obtain this degree. I love every one of you. Now we can explore life and other fun things together. There are also a couple of people in my life that mean a lot to me. They have been there throughout this long journey and I could not have made it without their help. E.W. and Liz Hernandez, this is also dedicated to you. Thank you, guys, for everything. You will always hold a special place in my heart. You have helped me so much over the years in various ways, there is no way that I can possibly pay you back (but I will try, lol).

Acknowledgments

I would like to take the time to thank Dr. Linda Burnes-Bolton for taking me under her wing and mentoring and nurturing my nursing career. I would like to thank Dr. Bernice Coleman who mentored me and helped guide my research study to ensure its completion on time. I would also like to thank Dr. Leslie Hussey. It was truly a privilege to learn from you and work with you throughout this journey. I have learned so much from you at the residencies and in class while attending Walden University. Thank you to Dr. Donna Bailey for being my committee member and providing valuable input. Thank you to Dr. Mattie Burton for being my university research reviewer. Finally, I would like to thank Travis Sands for my form and style editing. This is a daunting task, thank you. It takes a village and I could not have done this without all of you.

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Chapter 1: Introduction to the Study

Transitions of care is a model that helps patients with healthcare continuity during hospitalization and for a short time after discharge. The transitions in care period from hospital to home is designed to ensure that patients have the resources needed to assist them in caring for themselves, which help to decrease preventable adverse events. Transitions in care refers to a change in the provision of care setting which commonly means moving from a hospital to the community or even long-term care settings (Morrison, Palumbo, & Rambur, 2016). Transitions of care programs are needed for the heart failure (HF) patient population to help prevent readmissions after discharge. Most transition programs have used bundled interventions, which has made it difficult to determine the effectiveness and efficiency of specific interventions (Albert et al., 2015). For patients to transition to other settings post hospitalization, careful coordination is needed. Successful transitions for patients to go from one setting to another should include communication from the inpatient to the outpatient setting. Examples of communication include partnering with community physicians, having the ability to link the inpatient and outpatient medical records, and sending the discharge summary to the patient's primary care physician (Albert et al., 2015). These are some of the steps needed to be able to continue to meet the patient's needs after discharge.

However, most patients' needs after discharge go unmet, which could be due to lack of coordination of care transition, lack of patient education about their disease process and self-care, or lack of listening to the patients to determine their needs. Patient education plays a significant role in patients being able to care for themselves after

discharge from the hospital and is a key component in patients being aware of the resources available to them. Unfortunately, most education provided to the patients in hospital settings is provided on the day of discharge, which presents challenges. The content may be delivered in a rushed manner or at the last minute without careful consideration or planning, so the information may not be individualized based on the patient's specific learning needs (Knier, Stichler, Ferber, & Catterall, 2015). Patients may thus feel that the information they were given is not vital to them because it was being discussed briefly in a short conversation before discharge. Falun, Fridlund, Schaufel, Schei, and Norekval (2015) identified a need to find a different approach of communicating with patients at the time of discharge because the ability to affect lifestyle changes at discharge is limited. Education should begin on admission for HF patients. Educating a newly diagnosed person with HF involves assessing the patient's ability to learn as well as their readiness to learn. The potential positive social change implications of this study is for healthcare professionals to find the correct approach to provide patients with discharge education before the day of discharge, so patients will have adequate time to understand the lifestyle changes that are required once they leave the hospital.

This chapter includes sections on the background, problem statement, purpose of the study, research question, theoretical framework, nature of the study, definitions of terms, assumptions, scope and delimitations, limitations, and significance of the study.

Background

HF continues to be one of the main reasons for re-hospitalizations in the nation, costing the health care system \$41 billion annually (Hines, Barrett, Jiang, & Steiner, 2014). Hospitals continuously try to decrease readmissions for HF patients and improve patient outcomes. The Centers for Medicare and Medicaid Services (CMS) established the Hospital Readmissions Reduction Program in 2012, which reduces payments provided to hospitals with excessive readmissions. Often patients are readmitted because of lack of knowledge, medication mismanagement, and/or a lack of understanding of the education that is provided to them (Gunadi, Upfield, Pham, Yea, Schmiedeberg, & Stahmer, 2015; Salas & Miyares, 2015). A lack of coordination and collaboration among providers also leads to readmissions. In a study by Eassey, McLachlan, Brien, Krass, and Smith (2017), participants wanted more collaboration between their health-care providers because most issues and confusion with education were the result of the breakdown in communication among healthcare providers.

Knier et al. (2015) found that patient perception of the education they receive was vital to understanding whether the patients were ready to care for themselves after discharge. Healthcare providers are accustomed to telling the patients what they should and should not do after they leave the hospital, but they often do not collaborate with the patients to get the patients' perceptions of what they need to know to care for themselves after discharge (Harun, Finlay, Piguet, & Salek, 2017).

Problem Statement

For patients with HF to transition home from the hospital successfully, individualized education is needed that is specific to the disease process and circumstances. The transition of care from hospital to home must ensure continuity of care across the healthcare spectrum to avoid preventable poor outcomes among at-risk populations and promote the safe and timely transfer between settings (Gunadi, Upfield, Pham, Schmiedeberg, & Stahmer, 2015). However, the transition of care process is not well organized nor optimized to ensure that those with HF have the knowledge needed for successful self-care. One major issue is that heart failure patients see several care team members at various times during their follow-up appointments and check-ups after hospitalization (Morrison, et al., 2016), and as a result, the care is fragmented (Cusack-McGuirk, Deyo-Allers, & Kelley, 2015). Patients with HF often have many care providers due to the complexity of their disease. The care provided by one physician is not always communicated to other physicians who treat the patient. If the patient is hospitalized in one facility and is discharged but is readmitted into another facility, the facilities may not share or exchange information regarding the patient's treatment, causing the patient's care to be fragmented (Tsai, Orav, & Jha, 2015). With the implementation of the Affordable Care Act, integrated care has become the main premise using a team-based model (Tingley, Dolansky, & Walsh, 2015). In the team-based model, a high functioning team has effective communication and agreed upon shared goals for delivery of patient-centered care. One of the basic tenets of a team-based model is that

the team will assure that the patient is ready for the transition to the next level of care through the coordination of care and discharge planning (Mitchell et al., 2012).

Another issue that interferes with successful transition of care from the hospital to the home is a lack of attention to the patients' perspectives about what they think they need prior to being discharged, which is very important when education and other needs after discharge are discussed. Devore, Allen, and Eapen (2015) suggested that to evaluate treatments provided inside or outside of the hospital, the patients' perspectives should be included in the education they feel they need to care for themselves once they discharge from the hospital. Because of lack of knowledge and understanding of their disease process, patients frequently use healthcare services such as the emergency department for treatment, are nonadherence to medical therapy, and are unaware of symptom exacerbation (Vedel & Khanassov, 2015).

There is a gap in the literature regarding patients' perspectives about the education they receive versus the education they felt they needed before they were discharged from the hospital and if they felt they were prepared for the transition home (Falun et al., 2015). A nurse-led transitions of care protocol that includes the patient's perspective could enhance the continuity of care to be delivered across the healthcare spectrum and provide many resources to educate HF patients on self-care, such as videos and web-based learning, text messaging, phone calls, and emails. A qualitative research study involving information collected from the patients' perspectives about their discharge education is needed to explore if the HF discharge educational plan provided

by health care professionals is sufficient for self-care and what other strategies and education are needed to enhance self-care of HF and prevent hospitalizations.

Purpose of Study

The purpose of this descriptive narrative qualitative study was to explore the perspectives of people with congestive HF about their educational needs, so they could care for themselves after hospital discharge. I interviewed participants and analyzed interview data to determine if the patients felt the education they were provided was sufficient to care for themselves at home, so they could prevent avoidable readmissions and improve their quality of life.

Research Question

For this study, I explored two research questions. The research questions were:

RQ1: What are heart failure patients' perception of the education they need to transition home?

RQ2: What are heart failure patients' perception of how a transitions of care program could help prevent avoidable hospitalizations for heart failure patients?

Theoretical Framework

I used the Meleis middle range theory of transition as the theoretical framework for this study. This theory holds that there is a conceptualization of transition that leads to a holistic understanding of the conditions that influence the transition experience for patients (Schumacher & Meleis, 1994). This theory related to my study topic because HF patients are often seen by more than one healthcare provider who teach the patients different things which cause care to become fragmented. This results in patients' lack of

understanding of their conditions as well as a lack of knowledge of how to successfully manage symptoms. A patient's ability to transition through the healthcare spectrum while providing education and receiving feedback could impact safe home care. This theory addresses the actual illness of the patient and postulates a holistic approach to include the concept of readiness for discharge. This approach can help provide guidance on the transitions of care that are needed as the patient moves throughout the health care spectrum which could defragment care and assist in continuity of care (Cusack-McGuirk, Deyo-Allers, & Kelley, 2015; Yu et al., 2015). In Chapter 2, I present a more detailed explanation of Meleis middle range theory of transition.

Nature of the Study

There are five types of qualitative research methods: ethnography, narrative study, phenomenology, grounded theory, and case study. Qualitative research is used to explore and understand the meaning that individuals or groups assign to a social or human problem (Creswell, 2009). According to Creswell (2014), in ethnography, the researcher becomes a participant observer and experiences the environment first hand rather than relying on interviews. In a narrative format, the researcher collects information from in-depth interviews, documents, or other data from one or two individuals and presents findings as a cohesive story. The phenomenological approach involves different methods to collect data such as interviews, videoing participants, and other means in an attempt to understand the participant's perspective on the phenomenon being experienced. In grounded theory, documents and interviews are used primarily to build a theory based on the data. A case study involves a single entity to study in-depth to explain an event.

This was a descriptive narrative study. I chose this design because I was interested in exploring the patients' perspectives of their experience with the discharge instructions they received post discharge. My primary goal was to gain an understanding of the patients' perceptions of their discharge education, the education they felt they needed, and the role of transitions of care and how a transitions of care program could help prevent avoidable hospitalizations for HF patients. Qualitative procedures rely on text and image data, have unique steps in data analysis, and draw on diverse strategies of inquiry (Creswell, 2009). In keeping consistent with Meleis' theory, which focuses on transitions, I determined that a qualitative analysis of transitions of care for HF patients could help in identifying gaps and barriers with their discharge education and transition to home. This understanding could illuminate where the gaps are in the current transition to home/care setting that result in readmissions.

In this study, I collected data from the participants through face-to-face interviews and through phone interviews. The data was entered into Atlas.ti 8 software for storage and categorized into themes and analyzed. The results were then summarized.

Definition of Terms

There are several key clinical terms that I used in this study:

Heart failure: The definition of HF according to the European Society of Cardiology is an abnormality of cardiac structure or function leading to failure of the heart to deliver oxygen at a rate commensurate with the requirements of the metabolizing tissues, despite normal filling pressures (McMurray et al., 2012). It is a condition or syndrome that is characterized by high mortality, reduced quality of life, frequent

hospitalizations, and a complex therapeutic regimen (Stauffer et al., 2011; Whitaker-Brown, Woods, Cornelius, Southard, & Gulati, 2017).

Patient education: Any set of planned educational activities that may involve use of a combination of methods designed to improve patients' knowledge and health behaviors (Friedman, Cosby, Boyko, Hatton-Bauer, & Turnbull, 2011). Patient education requires building the patients' skills and helping them learn how, why, and when to make changes. It also requires a baseline assessment of needs to determine what the needs are and how to address them (Scaramuzzo, 2016).

Perception: The way a person thinks about or understands someone or something; the ability to understand or notice something easily (Merriam-Webster Dictionary, 2017).

Transition of care: Actions that are designed to ensure the coordination and continuity of care as patients transfer between one level of care to another level of care, which includes nursing facilities, patients' homes, and so on (Coleman, 2003).

Transitions of care is an emerging model in healthcare that is designed to reduce preventable adverse events and associated utilization of healthcare resources through temporary follow-up after hospital discharge (Morrison, Palumbo, & Rambur, 2016).

Transitions of care program: A program that involves coordination of care for patients who are discharged from an acute facility into another care setting in the community; it is designed to provide continuity of care (Whitaker-Brown et al., 2016).

Transitions of care is a time-limited, patient-oriented service with the goal of complementing, not replacing, primary care (Whitaker-Brown et al., 2016).

Assumptions

In this study, I assumed that healthcare professionals desired to understand patients' perceptions of their education and that people with HF desired to understand their disease process and how to care for themselves at home. People with HF wanted to understand how to take care of themselves. I also assumed that participants would feel comfortable enough to share their honest opinions and insights. Finally, I assumed that there is a knowledge deficit that has been overlooked in the transition process that would be revealed through interviews with patients about the perceptions they had.

Scope and Delimitations of Study

For this study, I examined the discharge planning protocols and guidelines given to patients. The patients' caregivers were not interviewed because I was interested in exploring the patients' perspectives. For this reason, I likewise did not interview healthcare professionals. Literature that was reviewed included research articles on patient education, transitions of care, readmissions, and heart failure. Only literature published within the last 5 years was considered because research and advances in healthcare occur often. The methodology for the study did not consist of questionnaires because I did not want to quantify the data, but rather sought obtain patients' true understanding of their education and educational needs. The population that I studied

included HF patients 18 years of age and older who had been discharged from the hospital for a minimum of 30 days and received HF education.

When reviewing the literature, I identified a gap regarding patients' perceptions in the education they received versus the education they felt they needed to successfully care for themselves after transitioning from an acute setting to home. Lack of knowledge about maintaining their health outside of a hospital setting could lead to frequent hospitalizations and possibly a decreased quality of life. In this study, I assessed the patients' perceptions of the education that was provided and their perceptions of the education that was needed to determine if the patients felt they were prepared to transition from hospital to home.

Limitations

A potential limitation of this study was external validity. Participants were all from one region and the outcomes could be different if the same study was conducted in another region due to culture. A second limitation of this study was that it was conducted at a single site, so it may not be representative of the true population of people in the area who were diagnosed with this disease. A third limitation was that this research was focused only on patients with HF, so it is not known if this research would be transferable to other disease processes. Another limitation of this study was that the population of participants selected were English speaking only, therefore participants with HF who did not speak English were excluded from the study. Last, the telephone interviews limited me from observing the participants' facial expressions, gestures, and body language. Having the ability to observe the participant would have allowed me to identify if the

participant was uncomfortable, if they did not understand the question, or if the questions caused any type of emotion in the participant.

Significance

HF readmissions are a problem for hospitals across the nation. In previous research, the focus has been on self-care, education, telemedicine, and the like. Although the previously mentioned modalities have been instituted, researchers have not queried patients to determine if they can safely and effectively care for themselves at home after discharge. Poorly executed transition of care at discharge could lead to an increase of readmissions (Cusack-McGuirk, Deyo-Allers, & Kelley, 2015; Peter et al., 2015). This research fills a gap by presenting the patients' perspectives on what education they felt they were lacking about caring for themselves after discharge. Findings from this study also may help define and guide the transitions of care that are needed as the patient moves throughout the health care spectrum which would enable providers to defragment care and provide continuity of care (Cusack-McGuirk, Deyo-Allers, & Kelley, 2015; Yu Lee, Stewart, Thompson, Choi, & Yu, 2015).

Research on HF and transition of care for patients is justified because there is a need to increase the level of safety for HF patients when they transition home. The lack of understanding of transitions of care not only impacts the quality of life for patients, but also impacts HF readmissions to the acute care setting. Hospitals are being penalized if patients are readmitted into the hospital within 30 days for any reason (CMS.gov, n.d.). Current financial pressures and an increased need to improve post-discharge outcomes

provide incentives to change methods of caring for HF patients (Devore, Allen, & Eapen, 2015).

The findings of this study could lead to positive social change. Examples of positive social change for HF patients are as follows: succinct transitions of care could increase patients' quality of life and allow them to be at home with their families; preventative care could educate patients, which would provide them with the ability to identify the onset of symptoms before they worsen and contact their healthcare provider; and it could free up healthcare dollars which could be used in other areas (Cusack-McGuirk, Deyo-Allers, & Kelley, 2014; Salas & Miyares, 2015). The families of patients who have been identified as having HF could benefit from social change by being able to enjoy their family members outside of the hospital setting and also not experience the caregiver burden as patients would be able to care for themselves. The social change that would be created for the community is that patients would be able to benefit from care and resources available in the community to help manage their disease which could positively benefit the community financially. Healthcare organizations would benefit from the social change by reducing preventable HF readmissions and focusing their efforts on extending their work into the outpatient arena.

Summary

Chapter 1 of this research provided an introduction to transitions of care and the importance of patient education. I explained why the study needed to be conducted and potential social implications of the study. I then briefly summarized the literature about the topic and explained the gap in knowledge in the discipline. I also provided the

problem statement, described the purpose of the study, introduced the research questions for this study, and outlined the theoretical framework for the study. Chapter 2 provides an in-depth review of the literature about HF and what practices have been established to reduce readmissions.

Chapter 2: Literature Review

Introduction

Transitions of care programs for HF patients are needed in the community to help patients avoid preventable readmissions and to assist healthcare providers with continuity of care. Transitioning care for HF patients outside of the hospital setting and into community settings such as the home and outpatient doctor's offices may improve the value of healthcare by reducing use of healthcare resources and improving discharge readmission rates and quality of life (Devore, Allen, & Eapen, 2015). The purpose of this study was to understand the transition process from hospital to home for HF patients. This literature review is organized into sections on patient education, transitions of care, and patient outcomes.

Synopsis of Current Literature

There are three areas in the current literature that show the relevance of this study's problem: (a) readmission rates, (b) patient perspectives, and (c) quality of life. There have been many efforts to reduce HF readmission rates across the United States. Many assumptions have been made in general as to why readmissions are not decreasing including blaming the patient for being non-compliant, blaming the provider for lack of oversight of the patient after discharge, blaming the payer (CMS) for imposing financial penalties to hospitals with high readmission rates, and blaming the researchers for failed clinical trials to help improve patient outcomes (Senni, Gavazzi, Gheorghide, & Butler, 2015). With national readmission rates for HF averaging 21-24%, hospital organizations are searching for the perfect combination of interventions to reduce these numbers.

Many studies have been published about patient education, what education health care professionals feel the patients need about their disease process, and how patients care for themselves once they are discharged from the hospital. There is a gap in the literature regarding the patients' perspective about the education they receive and the education they think they need to successfully care for themselves after being discharged into a community setting from the hospital. Peter et al. (2015) determined that to help identify the effectiveness of education, patients need to be interviewed so that their perspective about the education can be taken into consideration.

Patients living with HF remain at an all-time high, with over 5 million people in the United States having been diagnosed with the disease. HF is known to profoundly affect health-related quality of life (QOL). For individuals living with HF, the QOL remains poor and is associated with persistently high rates of morbidity and mortality (Graven & Grant, 2013). Most people who live with the physical symptoms of HF and who try to maintain the prescribed treatment regimen provided to them often feel stressed (Graven & Grant, 2013). My aim in this study was to reduce readmission rates and increase patients' QOL by obtaining patients' perspectives about the education they felt they needed compared to the education they received.

Preview of the Chapter

I open this chapter with a discussion of the literature search strategy and identification of the databases and search engines I used to obtain articles for this study. The next section outlines the theoretical foundation and shows why this theory is relevant to this study. The following section is the literature review, which identifies current

research and reveals gaps in literature that I used to further the study. The final section is the summary and conclusion, in which I summarize this chapter and provide a transition to the next chapter.

Literature Search Strategy

HF patients are often admitted to the hospital when their chronic condition appears to be deteriorating, resulting in their condition changing into acute HF. Patients who are readmitted within 30-days of discharge are seen as failures of treatment, and this failure is usually attributed to patient non-compliance or poor discharge planning and implementation (Senni et al., 2015). The typical scenario is one in which the patient gains control of their HF symptoms, receives discharge instructions, and is released to home or another care setting. Once discharged into another care setting, if the patient does not understand their discharge instructions, does not take their medication as instructed, or fails to follow their prescribed diet, then they are at risk for being readmitted into the hospital. To prevent hospital readmissions, HF patients can benefit from participating in a transitional care program. With this in mind, Meleis' transition of care theory was useful in beginning my search for programs to assist patients diagnosed with HF with resources after being discharged from the hospital.

The articles I used for this literature review were chosen by searching peer reviewed journals, scholarly books, scholarly papers, and recent dissertations. The search engine databases that I used included CINAHL, EbscoHost, Medline, OVID Nursing Journals, PROQuest, and SAGE. When reviewing the articles, I found a lot of information on patients with HF, and many of the articles addressed patient education and

discharge planning. To narrow the search, I used the following key search terms: heart failure readmissions, transitions of care, patient education, patient perception, discharge planning, and discharge education.

Theoretical Foundation

I used Meleis's theory of transition for this study. This theory was developed by Dr. Afif Meleis, who is a professor of nursing and social work at University of Pennsylvania School of Nursing. Meleis' focused on the theoretical development of the nursing discipline, the structuring and organizing of nursing knowledge, transitions and health, and global immigrant and women's health (Meleis et al., 2015). The transition theory is useful for studying a person's experience with change and their response to change. The origination of this theory included aspects of three paradigms: the role theory, the lived experience, and postcolonial feminism.

The role theory was developed by Dr. Ralph Turner. Turner's role theory framed Meleis's questions that explored how to help patients, clients, and families in their transition from one role to another, how to take on a new role, and how to change behaviors in a role (Meleis et al., 2015). From this paradigm, Meleis then developed the framework called role supplementation, which required the nurse to accurately analyze the goals and behaviors that were necessary for the new role they want to help the patient develop, and then modeling the new role for the patient to emulate (Meleis et al., 2015).

According to Meleis (2015), the second paradigm was associated with the work of Carper (1978) and involves lived experience and comparison of perceived views and received views. Questions related to the nature of the lived experience of the response to

change and the experience of being in transition are the focus in this paradigm. It calls into question what individuals know and how they come to know it (Meleis et al., 2015). The third paradigm of postcolonial feminism questions power relationships in society and institutions as well as links political and societal oppressions that shape responses to change. This paradigm provides the foundation for understanding the experience of transitions through the lenses of gender, race, ethnicity, and nationality (Meleis, et al. 2015). Although this paradigm is one of three that helped form the foundation for Meleis' theory of transition, I did not focus on gender, race, ethnicity, or nationality in this study.

Theoretical Propositions

The major theoretical propositions of the transitions theory are that it provides the framework to describe the experience of people who are confronted, living with, or coping with an event, situation, or a stage in growth and development that may require new skills, sentiments, goals, behaviors, or functions (Meleis et al., 2015).

Assumptions

There were several assumptions that are made in applying this theory to this research. According to Meleis et al. (2015), some of the assumptions that are applicable to this research:

- Change through health and illness events and situations trigger a process that begins at or before and extends beyond the event. Meleis et al. (2000) argued that transition from health to illness begins right before the individual starts to get ill and lasts through the time the individual regains a healthy status or through death.

- Outcomes of the experience of the transition are shaped by the nature of the experience. Daily lives, interactions, and the environment of individuals are shaped by the nature, conditions, processes, and meanings of the transition experience (Meleis, et al. 2000).
- Preventative and therapeutic actions can influence outcomes. Individuals who are engaged and aware that transitions are occurring will experience differing outcomes than those who are not engaged. Community, personal, or societal conditions may constrain or facilitate processes of healthy transitions and the outcomes of transitions (Meleis, et al., 2000).
- Individuals have the capacity to learn and enact new roles influenced by their environment. Caregivers adapt to their roles depending of the level of care that is needed by the individual whom they are providing care for (Meleis, 2000).
- Gender, race, culture, heritage, and sexual orientation are contexts that shape people's experiences and outcomes of health–illness events as well as the health care provided. Providing culturally competent care is important in establishing continuity in relationships between patients and health care providers (Meleis, 2000).
- Nursing perspective is defined by humanism, holism, context, health, well-being, goals, and caring. According to Meleis et al. (2000), nurses are usually the primary caregiver of patients and their families who are facing impending

transition. They facilitate the process of patients and families learning new skills that relate to the patient's overall health and illness experiences.

- Individuals, families, and communities are partners in the care processes. Support or lack of support from healthcare providers, family members, and community resources dictated the type of experiences for patients undergoing transitions (Meleis et al., 2000).

Previous Use of Theory

While reviewing the literature, I identified previous studies that used this theory. Meleis et al. (2015) used this theory in several studies with the intent to uncover emerging themes that may not have been originally a part of the framework. Inductive and deductive reasoning allowed for evaluation of the utility of the different components of the framework. Each of the studies used a qualitative design.

In the first study, seven African American women were interviewed about their experiences of deciding to conceive a child, going through the pregnancy, delivering the baby, and becoming mothers for the first time. The women revealed that they dealt with increased stress, stereotyping, racism, and negativity in their daily lives. These experiences were life changing events, and Meleis was interested in how the women transitioned through each phase of transition (Meleis et al., 2000). Another study involved parents going through the transition after finding out their newborn fetus was born with congenital heart disease. She collected stories from eight parents who had gone through the experience to study how they transitioned through the experience (Meleis et al., 2000).

Another study about transitions focused on caregivers who were caring for people diagnosed with cancer. The purpose of this study was to identify how people acquire specific roles and what patterns or conditions influenced the change in roles. Semi-structured interviews were conducted to explore illness care experiences, strategies, and interactions. The study revealed the constant change of care involvement during the transition into illness care roles (Meleis et al., 2000). These studies contributed to what we understand about transitions because it helps healthcare providers, families, caregivers, and communities prepare and navigate through the unique needs of patients to determine what interventions and resources are needed to help them be successful in transitioning from one level of care to the next (Meleis, 2015). Transitions helps us understand that there is a life change that is occurring or about to occur.

Transition changes usually have triggers. According to Meleis (2015), there are four types of situations that trigger change and the need for some transition to occur. The first trigger is a change in health transition that requires some type of intervention. The new health condition has unknowns and uncertainties because the person going through the change in health does not know what happens or the next steps. The new condition may require them to develop new coping strategies, new behaviors, and change relationships to establish new ones or sever others. The second trigger is developmental transition. This trigger highlights life phases such as age, going from adolescence to elderly or by roles, going from being single to getting married or going from married to divorce, or becoming a parent. This phase considers the health of individuals that are transitioning into these new roles because they are considered stressors and can trigger

responses depending on other activities or specific life events such as birthing, breastfeeding, weight changes, etc. that may be occurring in their lives (Meleis, 2015). This phase helps healthcare professionals research how to care for the needs of the patients. The third trigger is situational transition which focuses on experiences and responses to situations. These changes can include admission to a hospital, discharge from a hospital, skilled nursing facility, rehabilitation center, etc., graduating school, obtaining a new job, moving to a new location, etc. The fourth trigger is one that starts the process of transition that links organizational rules and functioning. This transition involves systemic changes for a whole organization and not just individuals. The changes could include widespread changes such as implementation of new technology, like the electronic health records, or acquiring a new executive leader, such as a new chief nursing executive. Experiencing transitions is a normal part of life, how individuals cope with transitions is still being studied.

The theory of transitions has been used extensively by researchers in various studies. For example, there was a study conducted by Rew, Tyler, and Hannah (2012), where the researchers wanted to understand how teenagers transitioned through high school. In this study, 216 students were given the opportunity to express their concerns as they transition through school. There were 21 categories of concerns identified and of those 21, 4 categories were mentioned frequently: education, expectations, relationships, and the future (Rew, Tyler, & Hannah, 2012). The concerns were consistent with the transitions theory. Researchers identified that further research needs to be done in this area.

Another study where the researcher used Meleis' transitions theory was in Portugal where the researchers wanted to study the impact of self-care on patients with heart failure, so strategies can be developed so that a therapeutic regimen can be implemented (Mendes, Bastos, & Paiva, 2010). In this study, the qualitative approach was used to conduct semi-structured interviews on five participants to identify factors in the health-illness transition process. Three categories submerged from these interviews. The categories were: "What do I do differently today", "What has changed in me," and "Factors that interfere with the transition". It was found that although patients have the ability to manage self-care, there are physical and psychological needs that need to be addressed by healthcare professionals (Mendes, et al., 2010).

Researchers Chiang et al. (2012), studied whether stress and care giver burden was alleviated in Taiwanese families and if family function was improved by combining discharge planning and telehealth using the transitions theory. In this quantitative study, Meleis' transition theory was used by measuring the indicators of successful transitions from the theory such as role mastery, subjective well-being, and the well-being of relationships. The study identified that combining telehealth with discharge planning helped caregivers with the transition from hospital to home for the patients they were caring for (Chiang et al., 2012).

Halding and Heggdal (2011), explored patient experiences with Chronic Obstructive Pulmonary Disease (COPD) as they transitioned through pulmonary rehabilitation. In this qualitative study with Meleis' transitions theory, eighteen patients were interviewed at different times. During the interviews, the participants described

their participation in pulmonary rehabilitation as they transitioned through learning how to live with the disease. Time limited therapy was analyzed while current trends towards patient-centered rehabilitation efforts that incorporate patient involvement and self-management education were supported (Halding & Heggdal, 2011).

Dr. Mary Naylor used Meleis' transitions model to help establish the New Courtland Center on Transitions and Health at the University of Pennsylvania in 2007. Currently, the center uses the model to focus on transitions of care for the elderly population (Meleis, 2015).

Rationale

The rationale for choosing this theory was because I wanted to conduct a qualitative phenomenology study on patients living with heart failure and gather information about their lived experiences of receiving discharge education for HF as they transitioned from an acute level of care into an alternate care setting. The theory of transitions was a good fit for my research study because I believe that the result of good nursing care should be a stable patient that is able to care for themselves at home without being readmitted to the hospital. I also believe it is essential to understand the lived experience of receiving discharge information from the patient's perspective. Patients do not live in isolation, so the transition conditions are not limited to the individual but also include community and society. There are many moving parts when patients transition and explore their personal experiences providing insight to areas in this chronology that may have been overlooked. The way that patients perceived their own understanding about the transition required asking them about their response. In their words, they

described the experience providing the who, what, when, where and how of the event and how it resulted in their readmission. The knowledge provided by patients built upon the existing theory of transitions. (See Figure 1 graph of Meleis transitions of care theory)

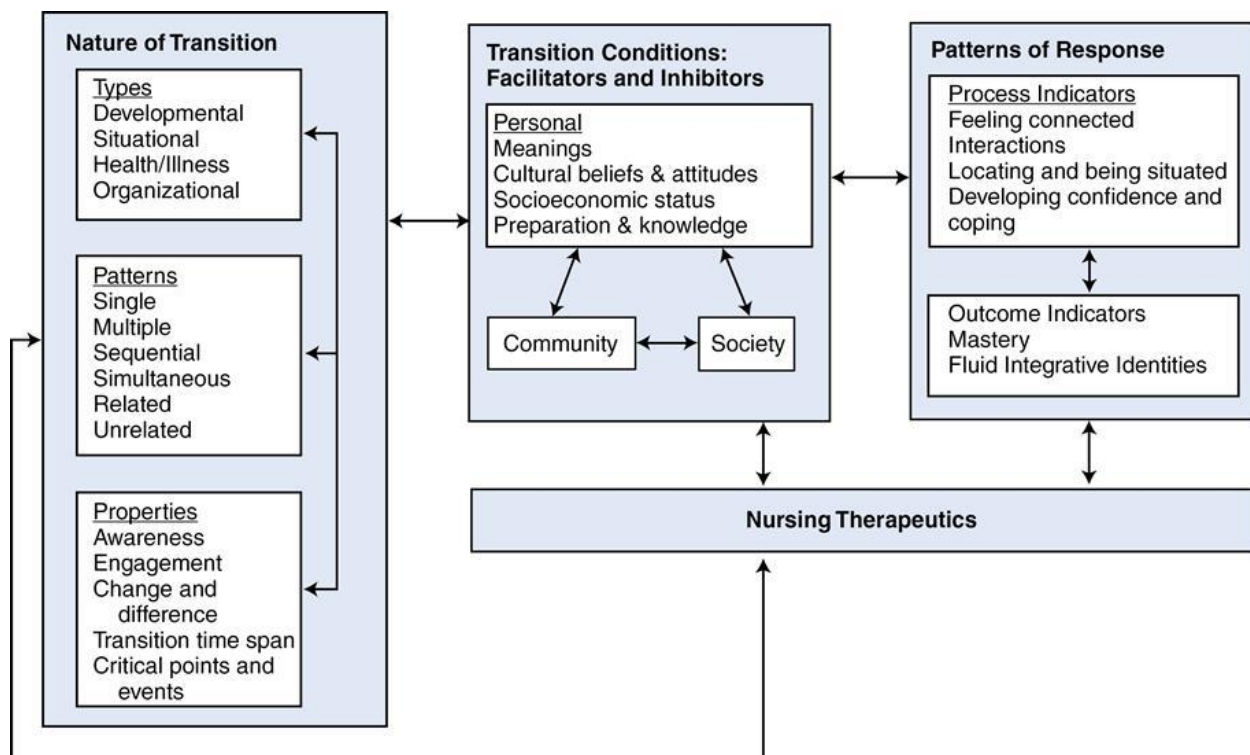


Figure 1. Transitions of care theory.

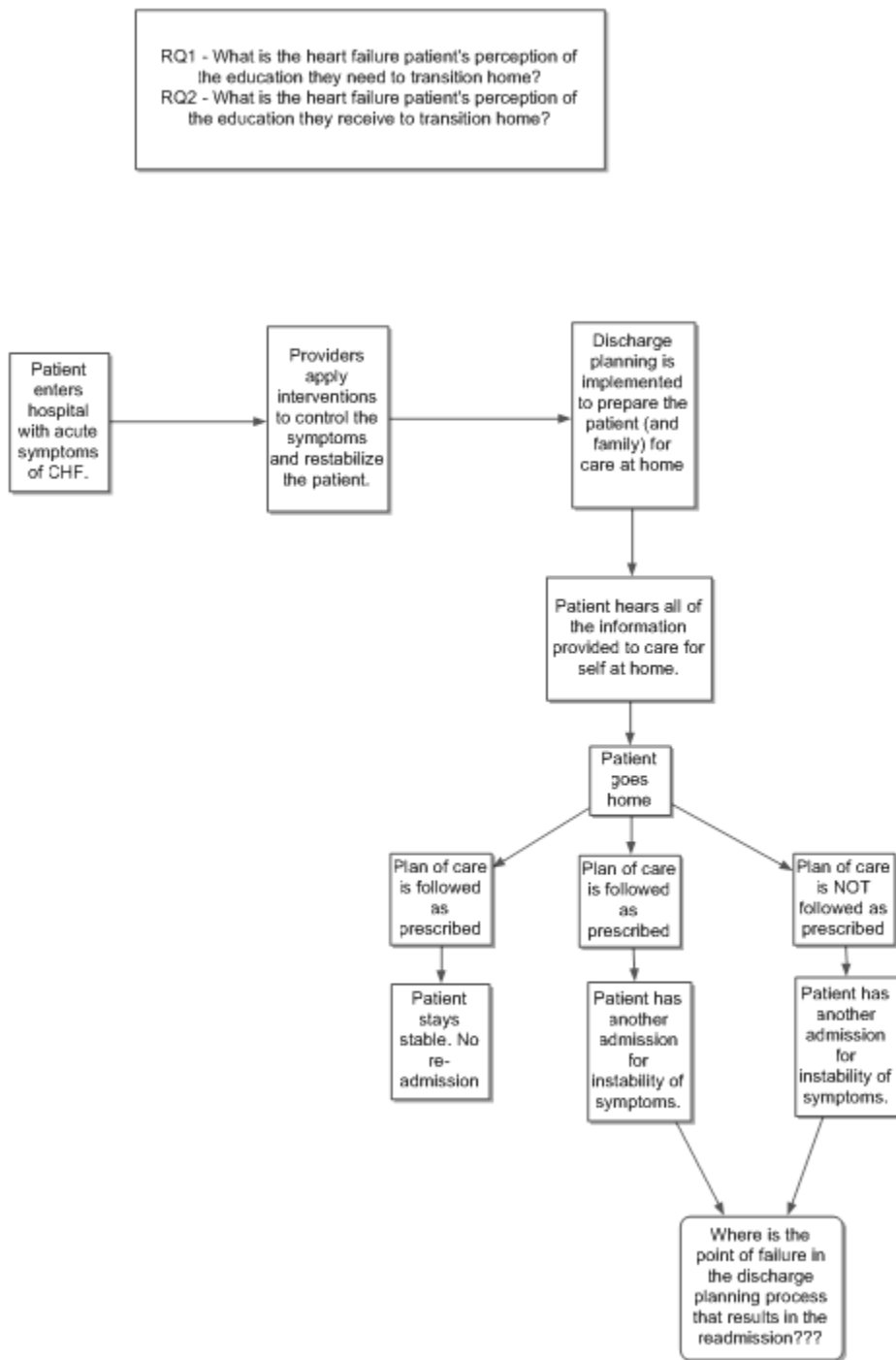


Figure 2. Theoretical concept map

Literature Review

According to the CDC, approximately 5.7 million people in the United States have HF. One out of every nine deaths were associated with HF in 2009 (Tingley, Dolansky, & Walsh, 2015). On average, over 825,000 new cases are diagnosed annually with a primary diagnosis of HF (Wever-Pinzon, Drakos, & Feng, 2015), with more than 1 million patients being hospitalized with a primary diagnosis HF. In over half of the hospitalizations, the patients present in advanced stages of the disease (Wever-Pinzon et al., 2015). In reviewing the literature, a significant number of articles about heart failure, transitions of care, and patient education was available. Many of the articles included bundled interventions from health care providers for treatment and for educating patients, demonstrating that multi-modalities were required to manage a patient with HF to prevent exacerbations and readmissions. Some of the interventions included providing the patient and their families with education on the disease process, symptom recognition, compliance with medication and diet, self-care, and following up with their physician on a regular basis (Feitell, Hankins, & Eisen, 2014). Patients that present with the diagnosis of HF accrue over \$30.7 billion in health care cost annually with the expectation that the estimated cost will increase to over \$69 billion annually by 2030 (Creaser, DePasquale, Vandenberg, Rourke, Chaker, & Fonarow, 2015). To lower cost and reduce readmissions, providers need to work with patients to identify ways to educate patients and successfully transition them into the community. There were no articles available that included the patient's perspective in the education provided. The following section discusses the review of literature on patient education.

Patient Education

Managing HF patients in an outpatient setting can be difficult, costly, and time consuming (Feitell et al., 2014). Patient education is essential to help health care providers manage this patient population. According to Creaser et al (2015), HF education and counseling is the cornerstone of management and adherence, and providing individualized comprehensive education is a key responsibility of the health care team. Although healthcare providers provided education to patients, it is the opinion of healthcare professionals that patients perceived their education as being both paternalistic and depersonalized due to short interactions (Falun, Fridlund, Schaufel, Schei, & Norekval, 2015).

Another issue with patient education was assessing the patient for health literacy (HL). HL is defined as the knowledge and social skills that determine the individual's motivation and ability to gain access to, understand, and use information given to them to promote and maintain good health (Suka et al., 2015). Patients must be able to understand the information being taught in order to apply what they learned about their care. A large part of assessing patients' readiness to learn was identifying their level of HL. Promoting effective health promotion interventions requires health professionals to have a better understanding of the extent HL contributes to health or illness in their patient population and what mechanisms are responsible for the association between HL and health status (Suka et al., 2015).

Perception of Education

In the research conducted by Falun et al., (2015) a qualitative interview was performed with 20 patients prior to discharge about their discharge education and three themes emerged. Some participants adopted the lifestyle change, most patients struggled to understand the context of living with their disease, having to manage the symptoms and understand the mitigating factors that caused the disease, other patients wanted to keep their lifestyle the same. Researchers identified the need to find a different approach to educate the patient prior to discharge by exploring person-centered care and individualizing education.

A quantitative study was conducted by Gentil and Costa (2016) to identify the differences in perception of discharge instructions between patients and health experts. A questionnaire consisting of 46 items related to discharge education was given to each group to rate the importance of each item. The discharge instruction themselves was not considered in this study. The results showed that there is a difference of perception in what the patients perceived was important and what the health experts perceived was important.

In research by Horstman et al., (2017) the role of discharge instructions for patients in postoperative recovery was examined. The aim of the study was to report themes related to the patient's perception of their discharge instructions and their experience post-discharge. Results showed that there was insufficient information given to patient's post-discharge. They did not know how to access appropriate personnel for

any concerns post-discharge or know how to navigate to health system for post-discharge appointments.

In a quantitative research study conducted by Knier et al., (2014) they wanted to measure the effectiveness of the interprofessional discharge and teaching process. The researchers used the Quality of Discharge Teaching Scale (QDTS) and the Readiness for Hospital Discharge Scale (RHDS) developed by Weiss et al., (2007) to measure patients perceptions of their readiness for discharge. This study noted that there was a significant difference in the education the patients perceived they needed versus the education they received.

Lin, Tirosh, and Landry (2015) examined patient comprehension of discharge instructions received by patients discharged from the emergency department. Patients were interviewed as well as chart reviews performed. It was found that although patients stated they understood their discharge instructions, they had poor comprehension.

Lithner et al., (2014) explored if the patients' perception of information they received to prepared them for their discharge home post-operatively. It was found that, overall, the patients felt they did not receive enough information to prepare them for the recovery period at home post discharge. This was especially true if the patient had a poorer physical status and lived alone.

Mosleh, Eshah, and Almalik (2016) conducted a study to compare the perceived learning needs of patients and compared them to the perceived needs of patients according to nurses. Patients and nurses were interviewed to assess what each group felt the top priority for educating the patient on discharge. There was a disparity between the

perception of what each group felt was a priority. It is important to collaborate between healthcare professionals and patients when determining discharge needs (Mosleh et al., 2016).

Peter et al., (2015) realized that despite ongoing efforts to educate HF patients before discharge, readmission rates remain high. Researchers conducted a chart review for HF patients that were discharged and there were common themes that were prominent: no documentation was found to indicate that the patient understood the discharge instructions, discharge instructions were not clear, there was no post discharge follow-up, and there was no clear understanding of who the primary care physician was post discharge (Peter et al., 2015). A teach-back program was piloted among this patient population and although the patients scored high in answering the questions correctly, it was determined that knowledge in itself does not guarantee behavior change. Teach-back can be beneficial in educating patients but it does not involve the patients' perspective.

In a qualitative study by Zakzesky, Klink, McAndrew, Schroeter, and Johnson (2015), the patients' perception of the discharge process was researched. The patients were interviewed on the day of discharge to provide information about their discharge experience. Patients felt that they were not collaborative partners in the discharge process and that their completion of designated tasks determined their readiness for discharge. This study did not explore patients' perception of their discharge education.

In the articles reviewed, there were many studies that examine discharge instructions from a quantitative approach and articles that looked at the discharge process. There are few studies that examine the patients' perspective using a qualitative

approach. In the articles mentioned in this study, it was evident that the perception of health care providers was different from the perception of the patient. The lack of research on patients' perceptions of the education they received versus the education they felt they needed was a reasonable next step to build upon this research. This study aimed to explore patients' perceptions of the discharge education they received compared to the discharge education they felt they needed to care for themselves after discharging from the hospital.

Transitions of Care

Transitions of care is a model of healthcare that was designed to decrease preventable adverse events and associated use of health care through temporary follow-up after discharge from the hospital (Morrison, Palumbo, & Rambur, 2016). Individuals with complex medical conditions often see multiple providers and need programs that facilitate and coordinate their care which is also called care transitions (Morrison et al., 2016). Transitions of care can be defined as a change in the setting where care is provided which can refer to the movement from the hospital to the community or long-term facilities (Morrison et al., 2016).

Transitions of care programs were designed to facilitate safe and efficient transitions from one setting to the next (Albert et al., 2015). In research by Al-Damluji et al., (2015) they proposed that the transmission of a high-quality discharge summary from the hospital to primary care providers may facilitate safer transitions of care by notifying them about the hospital course of their patient, so they would be able to follow-up with care in the outpatient setting. In this study, discharge summaries were obtained from

patients that retrospectively examined the timeliness of preparation, transmission of information to primary care provider, and the information that was provided in the discharge summary and compared them to the recommendations by the Transitions of Care Consensus Conference. Weaknesses of the study included researchers not verifying the accuracy of the discharge summary and the transmission of information to patients may have been underestimated.

Gunadi et al., (2015) developed and implemented a pharmacy-led transitions of care program with the aim of reducing hospital readmissions and increasing patient satisfaction. This program was designed so that all HF patients had a medication reconciliation on admission and discharge. The patients also received counseling on their medications before discharge. Salas and Miyares (2015), contended that in addition to medication counseling in their pharmacy-led program, they ensured that patients received discharge medications, follow-up phone calls and appointment reminders. The methods used in this study was proactive education about medication.

Labson (2015), interviewed healthcare providers at five health care organizations about their transitions programs and asked them to describe key steps, quality data, and results that they achieved. Each of the facilities had different protocols and different goals that they were measuring to reduce HF readmissions in their respective organizations. The researcher used interviews as the methodology in this article. Results showed that in all five facilities with frequent points of contact after discharge between the healthcare professional and the patients, readmission rates were reduced. The approach used for this research was appropriate to determine what methods organizations were using to help

reduce readmissions.

A systematic review was performed by Vedel and Khanassov (2015), to determine the impact of transitional care interventions on health care usage at acute hospitals by HF patients. Frequent use of healthcare services is mainly due to lack of understanding the treatment plan, irregular follow-up, non-adherence to medications, and lack of knowledge about symptom exacerbation (Vedel & Khanassov, 2015). The method used for this study was a meta-analysis of programs that are currently existing transitions of care programs incorporated into patient education can be beneficial for patients with HF and influence patient outcomes and quality of life. This research found that transitions of care programs that included telephone follow-up, home visits, and clinic visits were efficacious in reducing readmissions when all three interventions were involved.

Patient Outcomes/Quality of Life

The goal of educating patients on their disease process is to help improve patient outcomes and QOL. Albert et al., (2015) looked at the impact of health outcomes from transitions of care programs and determined that optimal transitions of care programs can decrease rates of avoidable readmissions due to medication safety and other discrepancies, but further research on transition of care is needed to determine outcomes such as recognition of symptoms, functional status, and QOL.

Whitaker-Brown, Woods, Cornelius, Southard, and Gulati (2017), found that emotions can influence a person's ability to manage their care, symptoms, and recovery from HF, thus reducing their QOL. Patients with HF often worry about their own daily living needs, finances, prognosis, transportation to appointments, and burdening their

family with their illness (Whitaker-Brown et al., 2017). The method used in this study was a pre- and post-test design that measured the QOL using the Minnesota Living with Heart Failure Questionnaire.

Summary and Conclusions

In this chapter, several themes were discussed. The introduction provided a synopsis of the literature and helped to establish why this problem was relevant to advance the research. The literature search strategy identified the search engines and databases that were used to review the literature and listed key search terms used to narrow down the search. The section on theoretical foundation provided the theory that was used for this research and the origin of the theory. Propositions and assumptions of the theory were also included in this section. A literature search was conducted to determine how this theory was used in previous research as well as the rationale for choosing this theory and how this theory can be built upon with this research. A literature review was conducted to determine what current studies reveal about the research topic and the methodology used in those studies.

Many studies that were conducted on heart failure were quantitative studies that focused on reducing readmission, and patient education. Those studies have been well documented and a well-known key factor in reducing readmissions for HF patients involved providing patient education. My study provided new information by interviewing patients and obtained their perspective on the education they received prior to discharge and solicited information about the education that they felt would make a difference for them to be able to care for themselves at home.

Chapter 3 includes the research design and the rationale for selecting that design. Information is provided on the role of the researcher. The methodology that was used is discussed including participant selection, instrumentation, procedures, and data analysis. Issues of trustworthiness is addressed, ethical procedures, and a summary.

Chapter 3: Methodology

Introduction

HF is a disease that affects over 5 million people in the United States (CDC, 2017). While hospitalized, patients are provided with education on diet, medications, intake and output, daily weights, and symptom recognition so that after discharge they will be able to care for themselves (Vaillant-Roussel et al., 2014). Despite education, some patients are still being readmitted into the hospital with HF exacerbation. Patients need additional resources to help them transition from the hospital to a community setting. Transitional care programs are needed to help patients with this transition. Although there are transitional programs available in some areas that help patients with their transition from the hospital, there is still a gap in the education that patients receive when they are discharged from the hospital.

When providing education to patients, it is important to assess their readiness to learn and get their perspectives on the education they are receiving. Without these two components, the education provided to the patient may not be understood and the patient is more likely to be readmitted into the hospital because she or he will not be able to identify symptoms of exacerbation. Healthcare professionals need to gain a better understanding of the factors that contribute to HF readmissions to provide the education needed to reduce HF readmissions. The purpose of this descriptive narrative qualitative study was to explore the perspectives of people with HF about their educational needs, so they can care for themselves after hospital discharge.

This chapter opens with a section on the study's research design (qualitative)

and rationale. It also includes a section on my role as the researcher and my commitment and obligations in the study. I then discuss the methodology I used to conduct the study before addressing issues of integrity and trustworthiness. I close the chapter with a summary that helps transition into the next chapter.

Research Design and Rationale

For this study, I explored two research questions:

RQ1: What are heart failure patients' perception of the education they need to transition home?

RQ2: What are heart failure patients' perception of how a transitions of care program could help prevent avoidable hospitalizations for heart failure patients?

According to Creswell (2009), there are five approaches to qualitative research: phenomenology, grounded study, case study, narrative, and ethnography. In this research study, I used the descriptive narrative approach to help understand the patients' perceptions of the education they needed and of the education they received prior to being discharged home. This qualitative method allowed participants to express their experiences through interviews about whether the education they received was enough to allow them to care for themselves at home and if there was additional education they could have benefitted from prior to discharge. The data collection procedure entailed personal visits prior to discharge from the hospital, invitations to participate through email, and then phone interviews.

My goal in this qualitative descriptive narrative study was to understand how people described their experiences of caring for themselves with the education they were

provided while hospitalized. According to Sandelowski (2000), qualitative descriptive studies provides a comprehensive summary of events and the everyday terms of the events. Researchers who conduct descriptive studies seek validity or accurate accounts of events that most people who are watching the same event would agree is accurate.

Narrative inquiry is an old practice that researchers use to study experiences as communicated via the stories individuals tell about their lives (Clandin, 2006). I chose this design because I was interested in obtaining participants' descriptions of and perspectives on the education they received in the hospital versus the education they felt they needed when they returned home. I was also interested in exploring if the patients were successful in their transition home, and if they were able to avoid being readmitted within 30 days.

Researchers use grounded study when there is not a theory related to what they are studying. Societal norms and individuals' behaviors are used as a basis for analytical method. It is a systematic generation of theory from systematic research (Cho & Lee, 2014). This method was not chosen because my goal was to gain the patient's perspective and grounded theory views human actions and assigns meaning to them.

Researchers use case study to explore events, processes, activities, or persons (Creswell, 2009). This method allows for an in-depth look into a case to gain a better understanding of that particular event, process, activity, or person. I did not choose this method because my interest was in a phenomenon of education provided to multiple HF patients and not one patient.

Biography is a self-told story that is recorded by the researcher about a self-told story about a person's life (Creswell, 2009). This method was not chosen because as the researcher, I am looking to gain an understanding about other's experiences about their discharge education.

Ethnography is a form of inquiry in which the researcher studies behavioral patterns, language, and actions of intact cultural group in their natural setting over an extended amount of time (Creswell, 2014). This method was not chosen because I interviewed participants about their experiences of education received prior to discharge. I did not need to spend an extended amount of time with the participants to observe the process and the education was not just provided to a single cultural group.

Role of the Researcher

The researcher can play several roles in research. The researcher is usually involved in research as a participant, an observer, or a participant-observer. In this research study, I was in the role of an observer and interviewer. As the interviewer, I explained the purpose of the study to the participants, answered any questions the participants may have had pertaining to the study, interviewed the participants, and recorded their responses to my questions. In the observer role, I observed the participant to determine if they understood the questions that were asked and if they were comfortable with the line of questioning. I also observed their emotions to see if they were fatigued and needed to pause for a break, or if the interview needed to be stopped and resumed at a different time.

As the researcher, it was my responsibility to plan the research and determine the inclusion-exclusion criterion. I determined how many participants were included in the study and I developed the interview questions for the study. I collected all the data, compiled it, stored it, coded and decoded it, and analyzed the results. It was also my responsibility to ensure that the data collected remained confidential and safe by ensuring it was locked in a secure location where only I had access to it.

In conducting this research study, I had no personal or professional relationships with any of the participants. I am an employee of the medical center in which the participants were recruited but had no direct relationship with the participants. I had no relationship that involved supervision, instruction, or power over the participants. Bias in this study was controlled by recruiting participants from the outpatient HF clinic. The participants were identified by a number, and information collected only included what was necessary for the purpose of the research that was conducted.

Methodology

Participant Selection

The population of participants included in this study were HF patients who were 18 years of age and older, and admitted into the hospital with a primary diagnosis of HF. I used purposive sampling, looking for qualified participants who met the criteria that was described in this study.

The participants were English speaking with a minimum education level of eighth grade, and no psychiatric disease that impaired their ability to consent. The participants must have been discharged from the hospital and received discharge instructions within

the 6 months prior to the interview. I used a checklist that listed inclusion/exclusion criterion to establish whether the participant was eligible to be involved in the study. In qualitative studies, the method used can help determine the appropriate sample size. I recruited 19 participants. The rationale for choosing this number of participants was that, according to Creswell (1998), a good sample size for a qualitative narrative study is 5-25 participants. I also looked to the sample sizes in other studies for comparison. In a qualitative study where the researchers aimed to describe the experiences of exercise platforms at home for HF patients, 14 patients were recruited and interviewed (Klompstra, Jaarsma, Martensson, & Stromberg, 2017). In this study, purposeful sampling was used to reach a variation in patients. In another qualitative study, researchers explored the patients' perspective on whether tele-monitoring in HF patients help empower them in self-care (Riley, Gabe, & Cowie, 2012). In this study, 15 patients were interviewed at two separate times. In yet another qualitative study that explored patient experiences with chronic obstructive pulmonary disease (COPD) as they transitioned through pulmonary rehabilitation, 18 patients were interviewed at different times using Meleis's transitions theory (Halding & Heggdal, 2011). Finally, five participants were interviewed in Portugal where the researchers wanted to study the impact of self-care on patients with HF, so strategies could be developed so that a therapeutic regimen could be implemented to identify factors in the health-illness transition process (Mendes, Bastos, & Paiva, 2010).

For this study, I recruited participants for this study through referrals by their primary care physician and transplant coordinators at the time of their follow-up visit

after being discharged from the hospital. I worked closely with the transplant coordinators and healthcare team of the recruited participants to determine eligibility and obtained consent to participate in the study. The relationship between saturation and sample size is peculiar. Researchers cannot assume that they have reached data saturation because resources have been exhausted, because saturation is not about the number of resources but the depth of the information in those resources. If there is no new data available, then it is probable that saturation has been reached (Fusch & Ness, 2015).

Instrumentation

The instruments that I used to collect data in this study was the researcher, an audio-recorder and a written interview protocol. I designed the interview protocol to collect information. The information from the interviews were transcribed from the audio tape to paper by myself. These instruments were sufficient to collect the data that answered the research questions that were presented.

Content validity of this instrument was established by ensuring the elements in the data collection process reflect what I was interested in studying and operational definitions are available. The instrument that was used in this study was developed independently by me because currently, there were no existing studies that explored the questions that were presented in this study. There are gaps in the literature about the patient's perspective of the education they received versus the education they felt they needed after discharge. In a study by Knier, et al. (2014), it was noted that further research need to be explored and monitored about the perception of the education patients feel they need compared to the education they actually received at discharge.

Data Collection

The method of data collection is an essential part of this research. I collected data directly from interviewing the participants. The interviews took place once and each interview took approximately 45-60 minutes, depending on the participants. I recorded the interview sessions with an audio recorder as well as wrote down notes about the interview and the responses given by the participant. After the interviews, I then transcribed the content of the audio recording. At the end of each interview, the participants were provided information in a debriefing session as to how they could obtain results at the conclusion of the study. Participants were notified that they would be contacted at a later date if I had any questions or needed clarification.

Data Analysis

The data collected for this study were responses that was provided to the researcher by the participants from the questions in the research protocol related to the specific research questions being asked. Prior to the data being collected, I assigned the participants a number to ensure confidentiality. The data was then entered into Atlas.ti 8 and placed into categories of responses and analyzed. I reviewed the data and determined themes present in regard to the patient's perception of the discharge education they received versus the education they felt they needed.

Issues of Trustworthiness

It is important for all researchers to address issues of trustworthiness. Issues of trustworthiness was developed by Guba in 1981 which consists of four elements which are: credibility, transferability, dependability, and confirmability. Guba (1981) feels that

the four elements listed reflected the underlying assumptions that is involved in much of the qualitative research that occurs.

Credibility in research is a way of determining internal validity. To establish credibility in qualitative research, the research must be believable from the participants' perspective (Guba, 1981). Credibility in this study was established by member checking and saturation. I reviewed the responses with the participants after each interview to ensure their responses were correct. According to Fusch and Ness (2015), data saturation will be reached when there is enough information available for the study to be replicated, when the capacity to obtain new information has been reached, and when further coding is not feasible.

Transferability is a way to determine external validity. To establish transferability, the researcher is responsible for ensuring that the research conducted can be transferred to other contexts or settings (Guba, 1981). In this study, I established transferability by providing a very detailed description of the methodology and how the study was conducted and provided the results of the study, so the study can be referenced, and the information could be transferable to other settings or another context.

Dependability in research determines reliability of the study. It is based on the assumption that the study can be replicated or repeated (Guba, 1981). To establish dependability in this study, the tool used was validated to establish if the data being collected was what was supposed to be collected for the purposes of this study and the data collected was audited for completeness.

Confirmability determines if the results can be confirmed or corroborated by others (Guba, 1981). To establish confirmability, I systematically explained every step of the research process so that the study can be replicated in future studies to determine if the results could be confirmed.

All issues of trustworthiness; credibility, transferability, dependability, and confirmability were addressed so the findings of the study would be valid. The results were summarized and taken back to the participants to allow them to provide context because they were the individuals who lived the experience. A very detailed description of how the study was conducted is provided as well as the tool used to collect data. Lastly, a systematic step-by-step process is available, so the study can be replicated, and results confirmed.

Ethical Procedures

Before this study was conducted, an application was completed, and permission was granted by the Institutional Review Board (IRB) to ensure that the study did not cause harm but protect the participants involved. Permission was also obtained from the institution in which the study was conducted, and participants seek care. Participant's private information was not shared before obtaining permission from the participant to do so. Participants was asked to sign an informed consent after they received a complete explanation of the study. Participants were notified that they can opt out of the study at any time. To maintain the confidentiality of the data collected the research records were stored in a locked cabinet in a secured location, the list that entailed the assigned number of participants was maintained separately from other research data, only the researcher

had access to the identifiable participant information, and the identifiable information of the participants was coded and de-identified. The data will be kept for a minimum of 6 years according to HIPAA requirements and destroyed after 7 years of the study's completion to protect the participant's information.

Ethical Concerns

I collected data for the study by interviewing participants. Participants were informed that if they felt uncomfortable answering any of the questions, then they were not required to answer the question. During the process, participants had the ability to refuse to participate or withdraw from the study at any time because participation was voluntary. If participants refused to participate or chose to withdraw from the study, their information was removed, and the data collected was destroyed. No further contact with the participant would be required.

Summary

In this chapter, the research design and rationale for choosing a qualitative study where the concept and phenomena of the study was discussed. This chapter also discussed the role of the researcher in the study and relationships between the researcher and participants. The methodology section of this chapter identified the population of participants in the study, the criterion for participation, procedures for recruitment, the instrument that was used in the study, data collection and analysis procedures. Issues of trustworthiness are also mentioned in this chapter to ensure credibility, transferability, dependability, and confirmability was established. This section also discussed ethical procedures and protection of the participants and their private information. The next

chapter reveals the results of the study and discussed patterns and themes of the patient's perception.

Chapter 4: Results

Introduction

The purpose of this descriptive narrative qualitative study was to explore the perspectives of people with HF regarding their educational needs, so they would be able to care for themselves after hospital discharge. The perception that patients have of the education they received is vital to understanding whether the patients were ready to care for themselves after discharge (Knier, et al., 2015). I invited participants to be interviewed so I could obtain their thoughts and opinions about the discharge education they received prior to transitioning home. Devore, Allen, and Eapen (2015) have suggested that to evaluate treatments that are provided inside or outside of the hospital, the patient perspective should be included in the education they feel they need to care for themselves once they discharge from the hospital. All the participants in this study were diagnosed with advance HF and had received a left ventricular assist devices (LVAD). The interview data were analyzed to determine if the patients felt the education they were provided was sufficient to care for themselves at home, if they felt the education would help prevent avoidable readmissions, and if it would be beneficial to improve their QOL.

There were two research questions that were proposed for this study: RQ1: What are heart failure patients' perception of the education they need to transition home? RQ2: What are heart failure patients' perception of how a transitions of care program could help prevent avoidable hospitalizations for heart failure patients?

In this chapter, I describe the setting, participant demographics, and data collection procedures. Also included are the data analysis and results of the interviews regarding participants' perceptions of the discharge education they received versus the discharge education they felt they needed prior to discharge and if the participants felt a transitions of care program would help prevent avoidable hospitalizations for HF patients. I also present evidence of trustworthiness and the results of the study.

Setting

I conducted this qualitative study in the HF clinic and the mechanical circulatory clinic affiliated with a magnet 886-bed tertiary academic medical center in the western United States. The organization has both an inpatient and outpatient setting in which HF patients visit healthcare providers. At the time of the study, there were no known personal conditions that influenced participants or their experience. With permission from the office administrator, I was provided with a basic list of HF patients who had scheduled appointments at the clinics who met the inclusion criteria of the study: 18 years of age and older who had been discharged from the hospital after 30 days and received HF education on discharge. Participants were recruited by phone and asked if they were interested in participating in the research study by coming in a little earlier on the day of their next scheduled follow-up clinic appointment. I also posted flyers in the clinic waiting area asking for volunteers to participate in the study. The administrative assistant assigned me conference rooms that I could use to conduct the interviews in a private setting. I purposefully sampled HF patients from the two clinics.

A total of 19 participants were scheduled to be interviewed; however, only 12 kept their interview appointments and were interviewed. Three participants did not show, and four others had to be cancelled due to scheduling conflicts.

Demographics

I obtained informed consent prior to the start of each interview session. Demographic information was also obtained in the process of interviewing the participants. The participants' demographic information is included in Table 1. Of the 12 participants, 10 were male and 2 were female. Their ethnic backgrounds were African American, Caucasian, and Hawaiian. The number of years in which patients were diagnosed with HF ranged from 2 years to 36 years. The number of years that the participants had an LVAD in place ranged from 5 months to 6 years. All participants had at least an 8th grade education. The ages of the participants ranged from 33 years to 81 years.

Table 1

Demographics of Participants

#	Gender	Ethnic/cultural background	Years with MCS*	Years diagnosed with HF	Age
Participant 1	Male	African American	10 months	17 years	55 years
Participant 2	Male	Caucasian	6 years	6 years	33 years
Participant 3	Male	African American	7 months	2 years	70 years
Participant 4	Male	African American	1 year	20 years	50 years
Participant 5	Male	Caucasian	3 years	30 years	81 years
Participant 6	Female	Caucasian	6 years	23 years	81 years
Participant 7	Male	African American	8 months	36 years	49 years
Participant 8	Male	Caucasian	11 months	11 months	39 years
Participant 9	Male	Caucasian	5 months	14 years	47 years
Participant 10	Male	Hawaiian	10 months	7 years	64 years
Participant 11	Female	African American	8 months	14 years	50 years
Participant 12	Male	Caucasian	14 months	9 years	66 years

*MCS = mechanical circulatory support.

Data Collection

After receiving IRB approval at both the interview site and Walden University, I contacted the coordinators at the interview site to inform them that I was ready to start recruiting patients for my research study. As stated in the approved IRB application #05-17-18-0586137, flyers were posted in the clinics (See Appendix B) and I began making phone calls to patients who expressed interest in participating in the study, met criteria, and had upcoming follow-up appointments to ask for participation and to secure interview dates and times. The recruitment period was 6 weeks. Each participant was screened to determine if they met inclusion criteria. For participants who met inclusion

criteria, interviews were scheduled for a private setting provided by the clinic. I conducted interviews from August 16, 2018 to September 13, 2018.

Prior to the start of each interview, I reviewed the purpose of the study and the consent with the participants. I informed them of their rights, including the right to withdraw from the study at any time. Participants were encouraged to ask any questions about the study and the interview process. Participants were asked to choose a pseudonym for themselves to be used in the interview so that their responses would be de-identified in the transcripts. Participants were also informed that the interview would be audio-recorded to ensure accuracy when transcribed. I also informed participants that a follow-up phone call or email may be necessary for any clarifications needed, as well as to invite them to review the typed transcript. They were also notified that I would send them an email at the end of the study once the analysis was completed to offer them the results of the study. The participants agreed and signed the consent prior to starting the face-to-face interviews.

Interviews were conducted using the questions in the interview protocol (Appendix A). I took notes on paper during the interview process while the interview was audio-recorded using an Olympus digital recording device. The interviews lasted from 25-60 minutes, with the average length of 55 minutes. At the end of the interview, I thanked the participants for their time and participation and explained the next steps in the process. Participants were provided with lunch for participating in the research study. I reminded them that, if necessary, they would receive a phone call or email to verify

accuracy of the interview and to provide clarification if needed. They would also be contacted by me at the end of the study to provide them with the results of the study. Once all the interviews were conducted, I transcribed the audio recordings from each participant's interview. The typed interview transcripts were saved as a Word document on an encrypted, password protected computer to protect the personal identity and other information of the participant. The audio recordings from the interviews were electronically downloaded and saved on the same encrypted, password protected computer. I kept the encrypted, password protected computer in a locked cabinet inside of a locked office. Data analysis was conducted after all the data were collected and transcribed from each interview. Saturation was reached at the end of the eighth interview. The last four interviews were conducted to ensure that data saturation was achieved. According to Gentiles, Charles, Ploeg, and McKibbin (2015), saturation refers to reaching a point of informational redundancy where additional data collection contributes little or nothing new to the study. In Chapter 3, I stated that I would use NVivo as my data analysis tool, but I did further comparison with other data analysis tools and found that Atlas.ti 8 better suited my needs to analyze the data. There were no unusual circumstances surrounding this change.

Data Analysis

I used a descriptive narrative approach in this study. Using this approach allowed me to capture the experiences of the participants using their own words. According to Creswell (2014), researchers use a narrative format to collect information from in-depth interviews, documents, or other data and present the findings as a cohesive story. I used

the participants answers to the interview questions to explore and understand the participants' perceptions of their discharge education as the form of data collection. Participants' interview responses provide descriptive narrative accounts of their knowledge and lived or subjective experiences (Lopez & Willis, 2004). After the interviews were transcribed verbatim, I established pre-set codes to use to capture the participant responses. Coding is the process of organizing and sorting qualitative data (Stuckey, 2015). The codes consisted of categories and short phrases in relation to the research questions. According to Stuckey (2015), researchers use codes to retrieve and categorize data into clusters that have similar meaning in order to identify the segments that relate to one another. It is important for researchers to know their data before they start to code. The purpose of my study and my research questions guided my coding process.

I developed the codes by reading the first transcript and analyzing the responses line by line to get a sense of direction and understanding about the responses. I created the categories by reading and analyzing the first transcript and developed the codes based on the research questions and the information the participants provided. In relation to Research Question 1, I developed codes to obtain the perception of the participants on their discharge education. The codes that I developed in relation to Research Question 2 were to obtain thoughts of a transitions of care program to avoid readmissions and increase QOL. Additional codes were added after reading subsequent transcripts. During the coding process, I was able to differentiate similar and different themes in the transcripts. In my initial coding process, I identified 8 codes and 48 subcategories. As I

continued to read and identify relationships, the codes further expanded to 10 codes and 54 subcategories. After all the interviews were transcribed and the codes were developed, I made an appointment with a qualitative research analyst to help me with the Atlas.ti 8 software so that I could sort through my data, run queries, and examine the themes that would emerge from the data. The software was able to capture the number of times certain words and phrases were used and quantified them, which was beneficial and allowed me to determine themes from the responses. There were no discrepant cases in this study.

Evidence of Trustworthiness

Evidence of trustworthiness needed to be established to make this study credible and contribute to the existing nursing body of knowledge. Trustworthiness is dependent on the quality of the data, the analysis of the data, and validation of the results. The four elements established by Guba (1981) credibility, transferability, dependability, and confirmability were maintained during the research process. The study received IRB approval from both Walden University and the host research site. IRB approval numbers for this study are 05-17-18-0586137 and Pro00044915 respectively.

Credibility

In research, credibility determines internal validity. It ensures that the study measures what it intended to be measured and if the research can be believed from the participant's perspective (Guba, 1981). Credibility in this study was established by participant validation and data triangulation. Participants were read back the responses that were given to the research questions to allow them to review and verify and/or

clarify their responses for accuracy. By performing member checking, it helped me avoid misunderstanding their responses and misinterpreting data.

Transferability

Transferability determines external validity. It explores if the research conducted can be transferred to other contexts or settings (Guba, 1981). Transferability of this study was established providing a detailed account of how the study was conducted. This included detailed descriptions of the participants' experiences during the interviews, description of the setting and study conditions, and the population of the participants being interviewed. Open-ended questions were used to interview the participants and direct quotes were captured and shared. Field notes were also taken during the interview process and detailed accounts of the interviews were recorded in the notes.

Dependability

Dependability determines reliability of the study. It assumes that the study can be replicated (Guba, 1981). Dependability in this study was established by using a systematic approach to collect data during the interview process. An audio-recorder was used to record the interviews because it gives an accurate account of the interview questions and responses. Field notes were written and later typed to capture thoughts, impressions, and body language of the participants. The notes could be referenced at any time during the research, so I would not have to rely on memory. The results included verbatim responses of the participants.

Confirmability

Confirmability determines if the results can be confirmed or corroborated by others (Guba, 1981). Confirmability in this study was established by systematically explaining every step of the research process and member checking. A detailed account was provided about data collection, data analysis, and data processing. Information was provided as to how the codes emerged and why they were expanded. I kept notes during the research process about recruitment efforts, data collection, and data analysis. Before conducting the study, I answered the research questions myself so that I could identify my own personal biases. I performed member checking during the interviews to confirm responses from the participants.

Results

The participants were asked a total of 9 interview questions regarding their perception of the discharge education they received prior to being discharged home. There were two research questions being explored from this line of questioning. The research questions correlated with specific questions in the interview protocol. This section provides results from the study in the participants own words. Based on the results of the study, there were three major themes that arose from the interviews. The themes focused on discharge preparedness, lifestyle changes, and suggestions for improvement.

Research Question 1

What are heart failure patients' perception of the education they need to transition home? The first research question correlated with questions two, three,

four, five, and six of the interview protocol (see Appendix A). The participants were asked a series of questions about the discharge education they received and if they felt the education they received prepared them to be able to care for themselves once they were discharged from the hospital. The codes that were developed from the participant responses were: discharge preparation, coping strategies, community education, patient management, and quality of life. These codes contributed to the themes of discharge preparedness and lifestyle changes. The following section entails how the participants responded to the questions in the different categories.

Discharge Preparation

They were very clear about instructions, they're very thorough, they did a great job. (Participant 4, 2018)

I felt good about it, they told me exactly how it was going to be.
(Participant 3, 2018)

The education was extremely thorough, they answered every question I could have had, every question I did have, any questions they could have anticipating me having, they answered that. They were extremely patient, so when I left here, I was one, very well prepared; two, I had a thorough knowledge of what was going on, what the device, what it entailed and means of care and everything. (Participant 1, 2018)

It was pretty straightforward. I mean just getting the muscle memory of doing it a couple of times—well, not for me but my caregiver. Things are

pretty simple, pretty straightforward, basically, everything well and just a matter of doing it. (Participant 7, 2018)

Yes, so they do a good job of teaching you and your caregivers and I was young. I was 27 when my had mine implanted, so I absorbed the information very easily and understood. (Participant 2, 2018)

They pretty much explained everything, and people came and talked to me before like patients and stuff. And they were pretty informative prior to the surgery and everything. (Participant 8, 2018)

I pretty much understood everything, and I had my lifeline, my wife. (Participant 9, 2018)

I think I was well prepared, I think they did an excellent job of making sure I knew everything I need to know to go home with the thing and even things that are going to arise, psychological problems and stuff like that, which I did have and end up getting a psychiatrist. (Participant 10, 2018)

Yes, they gave us classes and we took tests, me and my caregivers and I felt comfortable that they taught them a few times about changing the bandages and stuff. And kind of explained all these little things. (Participant 11, 2018)

That was meant more for my wife, because it wasn't much I could really do. But they told us exactly what I needed, as far as the machine, how to care for it. They made me go over steps, to plug it in, how to take it out, any emergency, what should I do. (Participant 4, 2018)

Coping Strategies

A lot of things that I took for granted, I do a lot more now. Like, we like to go to Santa Barbara a lot, and I would take that, and you know, just a common thing, I never like going to a casino, now I go play the slot machines. (Participant 3, 2018)

I go evangelizing. (Participant 12, 2018)

I have to get my mind off of my situation, my condition I start focusing on school work I ride my bicycle around and walk throughout the neighborhood, walk a couple of miles. I drive, got a hot little red sports car, six-speed, got a supercharged engine in it and everything. I said I've got to get back in my car, so I drive that around all the time, I ride around a lot on my bicycle, barbeque, go to the movies, go out to dinner, pretty active involvement with the church. (Participant 1, 2018)

I bought a 15-pound weight that I do curls now, I still go out and stuff. I have two scooters and I'm good. I take my granddaughter to the water park. (Participant 10, 2018)

We go in our motorhome out of town, and I usually walk a mile at two and a half to three miles an hour and then I do my weightlifting, leg exercises at the gym. (Participant 5, 2018)

Community Education

Both hospitals up there where I live, they didn't know what an LVAD was, paramedics came, they didn't know what it was, an LVAD.

(Participant 12, 2018)

Patient Management

Battery change, putting on my clothes, everything except taking a shower by myself, everything else. (Participant 3, 2018)

The only thing I do is I change my batteries, my wife is so comprehensive about this, she does all the dressing changes. She helps me with my shower and reminds me of my diet. (Participant 5, 2018)

I carry my iPhone around, get alarms during the day when it goes off, to remind me to take my medicine, I do excellent with the medication, and make sure I make all my doctor's appointments, so I do real good there, check on the wounds and the daily routines, as far as taking the blood pressure, charting it all in the book and everything. (Participant 1, 2018)

I actually live on my own, so I'm pretty self-sufficient. (Participant 2, 2018)

I care for myself for the most part, occasionally I get help. (Participant 7, 2018)

I manage my medications, I had been on medication for years because of my heart. It was the same, just more, more medications and stuff. I mean as far as like the batteries and things like that, the equipment and so forth. Yeah, I do all that, charging them and stuff and charging ones in the bag and always having them ready and then the car charger if I need it, things like that. (Participant 8, 2018)

My medications, my dressing. (Participant 9, 2018)

I change my own dressings and the equipment. (Participant 10, 2018)

I take care of me. I shower, I mean wash up. I can get dressed. I change my batteries, I pack my bag. I'm pretty much independent except my caregiver does my bandages every five days. (Participant 11, 2018)

So now I monitor my medications and I take them myself. I keep track and I order my refills or whatnot, or when my unit needs to be charged, and stuff like that, I manage that. (Participant 4, 2018)

Quality of Life

Being able to enjoy my wife, my grandchildren, my friends, and being able to go out and do a resemblance of what I used to be able to do. I just want to be able to walk around a little bit be on my own. There's so many things I can't do. I can't go swimming. I can't take a shower by myself. (Participant 12, 2018)

Whether my life is going to get better or worse. I can't do all the things I used to do, or that I can't walk or stand. (Participant 3, 2018)

Being able to do the things that you normally do, to point of satisfaction that you had prior to having the device implanted. (Participant 1, 2018)

Freedom and limitations and kind of what you can and can't do. (Participant 2, 2018)

Quality of life would mean being able to do the things that you want to do. (Participant 7, 2018)

The way I was living before with the heart like being able to breathe better and stuff like that. (Participant 8, 2018)

Dying. I've heard it many times in the past from like when my grandfather passed away. My grandmother passed away. It's like physicians or nurses or whatever, they say, 'Well, all we can do right now is try to make them comfortable for quality of life and eventually go to hospice.' So yes, that's what I think of. (Participant 9, 2018)

How well I feel I think. (Participant 10, 2018)

How you're going to get around and work and play. (Participant 5, 2018)

It's just how life is going, I mean how much of regular things you get back to or things of importance to you. (Participant 11, 2018)

How well you live, how healthy you are, just how good you're doing as a person. (Participant 4, 2018)

Discharge preparation, community education, and patient management correlated with the theme discharge preparedness and coping strategies and QOL correlated with the theme lifestyle changes.

Research Question 2

What are heart failure patients' perception of how a transitions of care program could help prevent avoidable hospitalizations for heart failure patients? The second research question correlated with questions seven, eight, and nine of the interview protocol (see Appendix A). These questions focused on the patient's perspective of if they felt the education of a transitions of care program would help heart failure patients

appropriately care for themselves thus avoiding re-hospitalization and what suggestions could enhance the improvement of such program. The codes that were developed from the participant responses for the question were: advice for healthcare providers (HCP) and advice for future patients. The participants responded to the interview questions that correspond with this research question by stating the following:

Advice for HCP

I think I was scheduled once to come tell other people before they get them, because I have the experience of having one. It would help me and help them both, because I know what I went through, and it would just make me feel better to give back. (Participant 3, 2018)

I cannot suggest anything outside of what's already been done, the care was just beyond our expectation. The staff, beyond our expectation. The professionalism and the knowledge, beyond anything I could have expected. (Participant 1, 2018)

It's good for me to hear from other people's experience and I don't feel like I'm just going through everything by myself, you know. It's not like some big deal to have some kind of sharing session, but just being here to interface with somebody or hear what they're been going through this was very useful to me. (Participant 7, 2018)

People need to know and understand and really understand the ramifications of what is going on and what the hospital's doing to help

you. But the possibilities of what can happen that are detrimental to their life. (Participant 8, 2018)

I think maybe someone that checks on you, comes and sees you, someone that understands the medical—that has medical training, that's not have a turnover of person that you don't see all the time. (Participant 9, 2018)

I think you guys have covered most of the bases, covered all the bases. (Participant 10, 2018)

I don't know. I think I had a pretty great team. A chatline or online group would be nice, because you're dealing with the team and everything like they have a lot of information about it, but they're never been through it. And sometimes you just want to talk to somebody who's been through it and know, is this normal that I feel this way or that this happens. Is it normal to you or is it just me? And it's be nice to talk to somebody. There are many questions that could be asked of others who have gone through this. (Participant 11, 2018)

I think the communication is very important. This is what you should expect, but it will get better. A lot of things are done without being thought of, so I'm glad you guys are doing this. (Participant 4, 2018)

Advice for future Patients

I'd tell them don't be afraid, trust your doctors, be very optimistic, and that, like I say, this, too, will pass. You will never be perfect again, but you'll be the best you can be. (Participant 3, 2018)

Same answer, except I wouldn't be so optimistic, I'd be more realistic that something could go wrong. You're doing major surgery, and if it works out fine, that's great. (Participant 12, 2018)

Reassure them that if they hang in there, if they have a mind to want to resume their life, they can. I would tell them to do it, I would tell them that their life will change for the better, because if they're in a position to where they need this, they've got to be in deteriorating health, end stage of life, and they shouldn't fear it, they shouldn't be apprehensive, do it. (Participant 4, 2018)

I'd tell them is if you actually want to do it, then go through with it. If you're going to go through the whole thing all the way to a heart. If you're not going to do it, it's like don't waste your time, don't waste your wife's time, other people's time, doctor's times, things like that. (Participant 8, 2018)

To do it, to understand the consequences of not having it done and embrace it. Be positive and understand that it's not about you. If you have loved ones around you, it's not about you. So other people are going to take care of you and help you, physically and emotionally. (Participant 9, 2018)

I would tell them, you want to live. (Participant 10, 2018)

I would tell them, it's scary at first and it is rough at first to get used to the things that I was getting to, it's a little rough road to get into it and just get started, but in the long run it's the best thing. (Participant 11, 2018)

Just make sure everything is explained, because prior to that I didn't know exactly what I would be going through, as far as what the entire procedure was, and the limitations and what to expect. (Participant 4, 2018)

The responses to the above questions, advise for HCP and advise for future patients correlated to theme suggestions for improvement.

Summary

In summary, the results from this study produced three main themes about discharge education from the patient's perspective and if they felt education from a transitions of care program would help them care for themselves at home after discharge thus avoiding rehospitalization. The participants stressed that education prior to discharge played a significant role of them being able to care for themselves once they transitioned home. The themes were consistent and were corroborated in the succession of interviews with each of the participants.

In this chapter, the setting was described, the participant demographics were disclosed, and data collection, data analysis, and the results of the study were described in a narrative form with a summary of the findings. This chapter also included evidence of trustworthiness. Chapter 5 will include the interpretation of the study findings, limitations of the study, study recommendations, and implications for further research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

HF readmissions continue to be a serious concern of CMS, healthcare organizations, and healthcare providers, and it continues to be one of the main reasons for re-hospitalizations in the nation, costing the health care system \$41 billion annually (Hines et al., 2014). Most patients' needs after discharge still go unmet due to lack of coordination of care transition, lack of patient education about their disease process, lack of self-care, or failure to listen to the patients to determine their needs. Patients are often readmitted because of lack of knowledge, medication mismanagement, and/or a lack of understanding of the education that is provided to them (Gunadi et al., 2015). Patient education is a significant factor that helps patients care for themselves after discharge from the hospital and is a key component that increases patients' awareness of the resources that are available to them. Peter et al., (2015) determined that to help identify the effectiveness of education, patients need to be interviewed so that their perspective about the education can be taken into consideration by healthcare providers.

The purpose of this descriptive narrative qualitative study was to explore the perspectives of people with HF about their educational needs, so they can care for themselves after hospital discharge, prevent avoidable readmissions, and improve their QOL. I interviewed participants and analyzed their responses to determine if they felt their educational needs were met. I conducted this study to contribute to the existing body of knowledge on discharge education, quality of care, and transitions of care. The three main themes I identified from this study were discharge preparedness, lifestyle changes,

and suggestions for improvement. I used the theoretical framework to explore transitions of care and how it relates to discharge education and the patients' ability to care for themselves after discharging home. This study confirmed the significant impact that discharge education has on transitions of care and QOL.

Interpretation of Findings

The findings of my study add knowledge to the literature about patients' perceptions of the discharge education they receive prior to being discharged from the hospital and whether they feel a transitions of care program will help reduce avoidable readmissions for their CHF. According to Falun et al. (2015), there is a gap in the literature regarding patients' perspectives about the education they received, the education they needed before hospital discharge, and how prepared they were for their transition home. Findings indicated that patients had a positive experience with the discharge education they received and felt the education provided was thorough and prepared them with knowledge necessary to take care of themselves upon returning home. They indicated that there were lifestyle modifications made for them to be successful in caring for themselves. Participants also reported that the transitions of care program was helpful and provided suggestions for improvement of the program to help reduce avoidable readmissions.

There were three themes that emerged from this study. The first theme I noted was discharge preparation. The participants were provided with education and discharge instructions after their health literacy and readiness to learn were assessed by healthcare providers. According to a Creaser et al. (2015), it is a key responsibility of the healthcare

team to provide individuals with individualized comprehensive education. In another study, Suka et al., (2015) found that patients need to understand the information being taught to be able to apply what they learned about their care. A key component in assessing patients' readiness to learn is identifying their level of health literacy. Fry et al. (2016) reported that patients' understanding of how to manage HF has been poor, which leads to a cycle of readmissions that disrupts the QOL for the patient and increases healthcare costs.

The second theme that I noted in this study was lifestyle changes that need to happen due to the participant's condition. The participants were aware of the proposed lifestyle changes but were not really prepared for the changes. In a study conducted by Falun et al. (2015), participants were told they had to make lifestyle changes. The researchers found that some were able to adopt the new lifestyle changes, some struggled to understand the disease process, while others wanted to maintain their same lifestyle and were unwilling to change. When patients are diagnosed with HF, they are told that there are certain modifications that need to be made in their lifestyle so that they can manage their disease. This includes changing their diet to low sodium meals, taking their medications as prescribed, weighing themselves daily and reporting major deviances, and limiting their fluid intake so they will not become overloaded with fluid. In a study on the impact of HF, patients described the lifestyle changes and modifications to their lifestyle as disruptive because their normal routine was interrupted (Fry et al., 2016). Patients with advanced HF and who had the MCS devices implanted not only had to be concerned about the teachings stated above, but also had to know how to care for the MCS device,

the surgical site, and know how to ensure the MCS device always has power and charged batteries. This requires major lifestyle changes which may include having a caregiver to help care for them, adjusting to new limitations, and learning to live with a machine being attached to them 24 hours a day. Due to the additional burden, their QOL may be affected.

The third theme that emerged was transitions of care programs are needed to reduce hospital readmissions for HF patients. Previous researchers have identified that transition of care programs help to reduce readmissions. According to Labson (2015), transition of care programs has been identified as one of the leading factors in reducing readmissions within 30 days of discharge and making improvements in other quality measures. Morrison et al. (2016) found that transitions of care programs helped decrease preventable adverse events. Albert et al. (2015) found that transitions of care programs facilitate safe and efficient transitions from one setting to the next. In another study, Vedel and Khanassov (2015) found that transition of care programs was efficacious in reducing readmissions when implemented properly.

The theory of transition developed by Meleis served as the framework for this study (see Schumacher & Meleis, 1994). The focus of the theory is on the transition of patients to lower levels of care, such as from acute to subacute facilities or their homes. The findings of my study were supported by this theory because, patients felt they were very well prepared to care for themselves at home once they transitioned home from the hospital due to the extensive education provided, and all the resources that were provided to them and their families prior to leaving the hospital. Participants and their families

were provided with education about the disease, symptom management, medication adherence and side effects, when to call the doctor, hands on demonstrations, and phone numbers for resources that they would need in the event of an emergency or if they had any questions. These tools made the transition from the hospital to home manageable, as suggested in Meleis' theory.

Limitations of Study

One of the limitations of this study was that the participants were recruited from a single site, so it may not be a true representation of other people with HF who live in other areas. Another limitation is that the participants were also from one region of the United States; outcomes could differ in another region. I also limited the study population to HF patients and did not include patients with other diagnoses. Another limitation was that, for patients who interviewed over the phone, I was limited from observing their gestures, facial expressions, and body language to be able to determine if they understood the questions or felt uncomfortable with them. Last, all participants of this study were English speaking only, eliminating patients who did not speak English who could have provided valuable insight.

Issues of trustworthiness was also addressed. For transferability, the methodology needs to be usable for participants with other disease process. The limitations of recruiting English speaking patients from a single site from one region relates to the issues of credibility and confirmability. For further credibility to be established, research should be conducted with participants who are non-English speaking, are of other ethnicities, and reside in other regions from multiple sites to ensure the information is

accurate and enough information is gathered to determine saturation. The issue of dependability can be determined by ensuring the study can be replicated with the different populations and the data collected is collected using a systematic approach.

Recommendations

My study contributes to the body of knowledge about the perspectives of those with HF who are discharged after being hospitalized with HF and transitions of care by sharing information from a qualitative perspective about the patients' perception about the education they received prior to being discharged and what they felt they needed to have an improved QOL and avoid rehospitalization. There are not many studies that explore the patients' perception of discharge instructions for heart failure patients. Previous studies have been conducted using quantitative methods to identify the differences in perception of discharge instructions between patients and healthcare experts (Gentil & Costa, 2016). In a quantitative study by Lithner et al., (2104) patients felt they did not receive enough information in their discharge instructions prior to being discharged home. In a quantitative study by Knier et al., (2015) patients were satisfied with the interdisciplinary discharge teaching. One qualitative study that explored the patients' perception of the discharge process not discharge instructions, noted that patients felt there were barriers such as tasks, timeline, communication, social support, etc. were barriers to discharge (Zakzesky, et al., 2015). Future studies in this area may include conducting more qualitative studies that explore the patient perception of discharge instructions for people who was diagnosed with HF. Further studies should be conducted in this area that include participants who speak languages other than English

and include participants from multiple facilities who have similar programs to compare the responses of those participants on their perception of the education that was given prior to discharge and if it helped with their transitions of care and quality of life. Other recommendations for future studies include examining the perceptions of people of other ethnicities to compare results, recruiting participants from multiple sites and in other regions to determine if the themes would be similar, and extending the research to participants with other disease processes to examine patients' perception of their discharge education, transitions of care, and QOL.

Implications

The insights obtained from this study provided invaluable information for healthcare providers about HF patients' perspectives on the patient discharge information they receive at hospital discharge. My study was needed because there is a gap in knowledge about how those with HF perceive the discharge education they receive that helps them care for themselves at home. These results could help healthcare providers understand why HF patients are constantly being readmitted to the hospital despite all the education available. The results of my study provided insight into what information people living with HF need to care for themselves at home. Knowing how to care for themselves at home contributes to positive social change because as the individual, they will be able to improve their QOL by reducing preventable hospitalizations. Positive social change for the family would include being able to spend time with their loved one in their natural setting and potentially not being burdened with large medical bills. Keeping those with HF at home will affect positive social change at the organizational

level because those who can care for themselves at home, the 30-day readmissions could be reduced alleviating penalties for the organization which would allow the revenue to be used for patient care. Positive social change at the societal level could be affected by having overall increased health for society and the HF population of patients.

Conclusions

In conclusion, discharge education is essential for patients to be able to care for themselves after transitioning home from the hospital. Meleis' theory of transition focuses on a person's experience with change and their response to change. In this study, the focus was on the HF patients' perception of discharge education and how the quality of the patient education helps the transition from the hospital to home and how the two can reduce readmissions. Eleven patients participated in this study and shared their perspectives about the discharge education they received prior to being discharged from the hospital. The results of this study indicated that discharge education is a significant factor in contributing to the quality of life for patients as they transition home after being hospitalized for HF. Readmissions for HF patients require a deeper analysis from organizations to help find ways to continue efforts to decrease preventable readmissions and increase QOL. The study findings suggest further exploration of perceptions from caregivers and all providers involved in the patient's care.

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Appendix A: Interview Questions

Semi-Structured Interview Guide

Patient Questions**Opening:**

1. **Introduce yourself using the participant number we gave you. Tell us, how long it has been since you were diagnosed with heart failure?**

Transition:

2. **Tell me how you felt the first 24 hours of being home after being discharged from the hospital?**

Education:

3. **What is the first thing that comes to mind where you hear the phrase *discharge instructions*?**
4. **Tell me about the education you received to help prepare you for caring for yourself at home.** (Prompt: How much time was taken to explain symptom recognition, medications, diet? Was there an opportunity for you to ask questions?)
5. **I am interested in capturing your feelings about your discharge process and if you feel you were prepared. Can you describe your feelings about the discharge process, including the education and support you received, and explain how well you felt like you could manage your care after discharge, etc.** (Prompt: Did you find it useful, was it overwhelming, did you understand it?)

1. **What were some of the benefits that you gained from the education or discharge instructions you received?** (Prompt: coping skills, lifestyle change, etc.)
2. **Do you feel you received all the information you needed prior to discharge? If not please explain what you feel was lacking in the discharge instructions, you received that you feel you could have benefitted from knowing and needed prior to going home?** (Prompt: any information they feel was omitted, or things they were unsure about)

General Questions:

3. **What would you suggest if anything to health-care providers to improve the experience of someone who is diagnosed with heart failure?** (Prompt: how they can help strengthen self-management, how to help improve quality of life; Delivery: in-person, phone, web-based. Type: education, social support. Audience: caregivers, community)

Ending:

4. **We've talked a lot today. Do you think we may have missed anything about discharge education, transitions of care, quality of life, and self-management for someone with heart failure?**

Appendix B: Recruitment Flyer

Appendix B



DO YOU HAVE HEART FAILURE?

➤ **HAVE YOU BEEN HOSPITALIZED IN THE LAST 30 DAYS?**

**PLEASE JOIN OUR RESEARCH STUDY BY
SHARING YOUR PERSPECTIVE ABOUT YOUR
DISCHARGE EDUCATION EXPERIENCE**



FOR MORE INFORMATION CONTACT:

Appendix C: NIH Certificate

