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Readmissions of Heart Failure Patients: The Caregiver’s Perception

Jill Pansini
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Jill Pansini

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Review Committee
Dr. Cynthia Fletcher, Committee Chairperson, Nursing Faculty
Dr. Mary Catherine Garner, Committee Member, Nursing Faculty
Dr. Carolyn Sipes, University Reviewer, Nursing Faculty

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Sue Subocz, Ph.D.

Walden University
2020

Abstract

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MSN, Walden University, 2009

BSN, Pace University, 1989

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Abstract

Heart failure patients account for 27% of readmissions within 30 days of discharge, which is an indicator of poor quality of care. Additionally, heart failure patients report that they do not receive adequate discharge planning, pointing to a need for improved discharge planning and practitioner follow-up. As the severity of heart failure increases, caregivers may be the key to decreasing readmissions. The purpose of this qualitative, hermeneutic phenomenological study was to explore the lived experiences and challenges faced by caregivers of heart failure patients ages 65 and over readmitted within 30 days of discharge. The transitional care model guided the understanding of the caregivers' experiences during the patient transition from hospital to home. Purposeful sampling was used to recruit participants caring for a heart failure patient. Eight face-to-face and telephone interviews were conducted using an interview guide with open-ended questions. The data analysis consisted of transcribing the interviews verbatim and hand coding. Four process themes were identified: being vigilant, seeking support, receiving support, and experiencing challenges. Caregivers are attentive to needs of the heart failure patient, they look to others for support, and experience many challenges. The results of this study may provide a better understanding for health care providers about the challenges experienced by caregivers and help guide the development of programs with the potential to prevent readmission.

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Dedication

First, I dedicate this dissertation to my family. I am most grateful for the support and understanding of my husband and three daughters. My husband, David, would be sure he was in the “man cave” when I needed solitude and concentration time. My daughters, Stephanie, Sloane, and Madison were all in school while I was feverishly working to achieve and complete my PhD. They each understood the time and dedication I needed. When I said I had to do homework they knew Mom would be at her computer desk. They would coach me on by saying “keep going” and “you got this.” When I said I need quiet time to work on my dissertation they knew exactly what I meant. Thank you all for the endless times you tiptoed in the door coming home from work or kept the dogs quiet while I was in my chair meetings.

I would be remiss if I did not dedicate this dissertation to the greatest gift of all; the strength and wisdom of God. Each day I sat at my computer and I would reflect upon Matthew 19:26 “With God, all things are possible.” This was a constant reminder that I could do whatever I set out to do.

Acknowledgments

My dissertation committee has been a tremendous help as I moved through the process during this academic journey. The support of Dr. Cynthia Fletcher, Dr. Catherine Garner, and Dr. Carolyn Sipes has been greatly appreciated. Each provided timely feedback, guidance, and support. I would like to extend a special thank you to Dr. Fletcher, my chair, for the many hours, meetings, and phone calls. She was patient, encouraging, and knew exactly what to say. You, Dr. Fletcher, have gone above and beyond to ensure my success.

I would like to acknowledge the nurses who distributed the recruitment flyers; thank you. Lastly, I would like to thank the participants who shared their experiences caring for the heart failure patient. Without your stories this dissertation would not be possible.

Thank you all for all you have done!

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Chapter 1: Introduction to the Study

Chronic disease in the United States continues to increase, and about 6 million American adults suffer from heart failure (Phelps, 2018). Heart failure costs are an economic burden (Cameron, Rhodes, Ski, & Thompson, 2016; Farmer et al., 2016), and heart disease is expected to increase by 25% by 2030 (Farmer et al., 2016). Heart failure patients have a high rate of comorbidities and account for 27% of inpatient readmissions within 30 days of discharge (Ahmad et al., 2016). Fifty percent of all hospitalized heart failure patients are readmitted within 6 months of discharge (Farmer et al., 2016). Readmission rates and costs are high (Ziaeian, & Fonarow, 2016), and readmissions are a direct link to poor quality of care or suboptimal patient care (Gunadi et al., 2015; Retrum et al., 2013).

The high rate readmissions of heart failure patients exist across the continuum of health care facilities (Radhakrishnan, Jones, Weems, Knight, & Rice, 2015; Salata et al., 2018). Therefore, the federal government has instituted regulations where hospitals face monetary penalties for patients that are readmitted within 30 days (Centers for Medicare & Medicaid Services [CMS], 2014; CMS, 2018; Institute for Health, 2012). This regulation brought national recognition to hospitals that patient’s care is directly related to readmissions (Gunadi et al., 2015). Interventions for the patient while still in the hospital before discharge is necessary for readmission prevention.

Hospital facilities began looking at interventions to prevent patients from being readmitted; specifically, patients with chronic diseases such as heart failure (Gunadi et al., 2015; Retrum et al., 2013). To ensure the effective management of heart failure patients after discharge from the hospital, improved discharge planning and practitioner follow-up are significant (Retrum et al., 2013; Ziaeian, & Fonarow, 2016). Because caregivers of heart failure patients are placed in a position to make decisions on behalf of the patient, it is important to understand challenges they may be faced with in caring for heart failure patients. Challenges experienced by the caregiver of the heart failure patient after discharge are understudied and require more attention.- In Chapter 1 I will discuss the background of the study, the problem statement, the purpose of the study, the research question, the theoretical framework, the nature of the study, and the significance of the study.

Background

In the United States, 5.7 million people suffer from heart failure (National Institute of Health [NIH], n.d.), and globally, 23 million people are affected by heart failure (Sharifi, Rezaei, Heydari Khayat, & Mohammadinia, 2018). Heart failure is the most common chronic condition leading to hospitalization, especially in people age 65 and over on Medicare (NIH, n.d.). Further, the national 30-day readmission rate is approximately 23% to 26% (Inamdar & Inamdar, 2016). The median heart failure readmission rate from 2009 to 2012 was 23% (Ziaeian, & Fonarow, 2016).

The cost of heart failure readmissions has become a global issue (Cameron et al., 2016; Farmer et al., 2016). Heart failure patients have high readmission rates within 30 days of hospital discharge, which is consistent with a decrease in the quality of patient care (Gunadi et al., 2015; Johnson et al., 2014; Retrum et al., 2013). Studies related to readmission of heart failure patients identify the need for discharge planning and follow-up care to decrease 30-day readmission of patients, recognition of the role of the primary caregiver in facilitating the care of the patient post-discharge, and the importance of communication among the health care practitioner and the patient and primary caregiver for compliance with care regimen (Cameron et al., 2016; Farmer et al., 2016; Hagedoorn et al., 2017).

Caregivers provide an important role in assisting in the navigation of care of the chronically ill patient (Farmer et al., 2016; Howitt, 2011). Caregivers are an integral part of the care of the patient post-discharge and are a critical contact for medical personnel (Farmer et al., 2016). They are the primary care person for the heart failure patient and may be the key to improving readmissions of heart failure patients (Shahrbabaki, Nouhi, Kazemi, & Ahmadi, 2016; Sharifi et al., 2018). Heart failure patients report that having a caregiver improves their quality of life (Shahrbabaki et al., 2016). Recognizing symptoms requiring medical attention is affected by patient and caregiver knowledge (Sharifi et al., 2018). Thus, the caregiver's perceptions may identify issues related to quality of care leading to strategies for readmission improvement and prevention (Ahmad et al., 2016; Shahrbabaki et al., 2016; Sharifi et al., 2018).

Caregivers' viewpoints have identified factors hindering the care of the heart failure patient that may be related to readmission (Ahmad et al., 2016; Cameron et al., 2016). Caregivers have listed reduced independence, stress, and personal characteristics of the patient as barriers to the self-care management of the patient (Ahmad et al., 2016). Additionally, caregivers have identified physical, emotional, and cognitive challenges as factors that hindered the care abilities of the heart failure patient (Cameron et al., 2016).

Further, patient symptoms, the progression of chronic disease, psychological and social environmental factors, self-care adherence, and health system factors all attribute to the readmissions of heart failure patients (Retrum et al., 2013; Shahrbabaki et al., 2016). Heart failure patients also indicate that there is a deficit in the supportive network for coping with heart failure (Shahrbabaki et al., 2016). Poor health and poor awareness of symptoms by patients and caregivers leads to erroneous choices for health care management that may be related to heart failure readmission (Sharifi et al., 2018). Heart failure patients are not being educated effectively regarding their care, meaning that they do not understand their medication instructions upon discharge (Johnson et al., 2014; Knight, Thompson, Mathie, & Dickinson, 2013; Santana et al., 2014; Ziaeian & Fonarow, 2016). Noncompliance with the care regimen may be attributed to ineffective education as well as communication among patients, providers, and caregivers (Farmer et al., 2016; Johnson et al., 2014; Santana et al., 2014). Therefore, better communication between patients, caregivers, and practitioners is needed to improve the coordination of patient care and decrease noncompliance with care regimen (Farmer et al., 2016; Johnson et al., 2014; Retrum et al., 2013; Ziaeian & Fonarow, 2016). In addition, patients do not have to schedule follow-up appointments arranged prior to hospital discharge, which leads to using the emergency department (Johnson et al., 2014).

Hospital facilities began looking at interventions to prevent heart failure patients from being readmitted (Gunadi et al., 2015; Retrum et al., 2013). Some of the strategies that are being utilized to decrease readmission rates are transitional care tools, support medication reconciliation, patient education, communication with providers, and post discharge follow-up (Gilmore et al., 2015; Jun & Faulkner, 2018; Ziaeian & Fonarow, 2016). Transitional care models (TCMs) support patient medication reconciliation, education, and follow-up with patients’ pre- and post-discharge to improve heart failure readmission (Hammond, 2015). Education by nursing with the patient and family about medications has reduced readmissions by 56.2% (Ziaeian & Fonarow, 2016). Implementing an electronic transfer of care tool has also been suggested to improve communication between physicians, patients, and families, which has led to a better understanding of their medication and how best to manage their health problems (Santana et al., 2014). Additionally, screening at-risk patients, care planning, encouraging self-management, medication education, communication, patient characteristics, social support and follow-up appointment within 7 to 10 days of discharge may decrease readmission rates (Johnson et al., 2014), though discharge planning and practitioner follow-up are underutilized (Johnson et al., 2014; Retrum et al., 2013; Ziaeian & Fonarow, 2016). Regardless of the intervention, studies show that they are more effective when health care systems and communities combine their efforts for interventional strategies (Retrum et al., 2013; Ziaeian & Fonarow, 2016). Improving communication between the caregiver and health care provider is an important beginning (Knight et al., 2013).

Despite concerted efforts to decrease readmission rates the readmission rate continues to be a problem (Sharifi et al., 2018). Heart failure patients report that they do not receive adequate discharge planning and are not always compliant in their care. Caregivers are an essential component of the heart failure patient in providing a contact for communication for medical providers. However, the challenges caregivers experience when providing care for heart failure patients at home has not been investigated. There is a need for further studies to identify factors surrounding the triad of patient, provider, and caregiver that may decrease readmission of heart failure patients (Farmer et al., 2016; Shahrbabaki et al., 2016; Sharifi et al., 2018). An understanding of these challenges by health care providers may help guide the development of discharge programs to facilitate the care of the patient at home, which is what this study addressed.

Problem Statement

Readmission rates and costs of the heart failure patients are high (Ziaeian, & Fonarow, 2016). But improved discharge planning and practitioner follow-up can ensure the effective management of heart failure patients after discharge from the hospital (Retrum et al., 2013; Ziaeian, & Fonarow, 2016). Caregivers are often taking part in coordinating the care and making decisions on behalf of the chronically ill patient (Levine & Feinberg, 2012; Li et al., 2018), supporting the care of the patients and partnering with the health care providers (Hagedoorn et al., 2017). Because caregivers are recognized as the one who often decides to seek hospital-based care for the patient, they may be the key to decreasing readmissions of heart failure patients (Farmer et al., 2016). Thus, understanding the challenges that patients and caregivers experience after they leave the hospital may identify factors to improve their home care coordination (Farmer et al., 2016; Johnson et al., 2014; Retrum et al., 2013; Ziaeian & Fonarow, 2016). This can result in reduced readmission rate for this population (Ahmad et al., 2016).

The viewpoint of the caregiver may identify reasons or issues related to readmission leading to strategies for readmission improvement and prevention. (Ahmed et al., 2016; Shahrbabaki et al., 2016; Sharifi et al., 2018). Caregivers are a primary contact for health care providers (Farmer et al., 2016). Therefore, understanding caregiver perceptions of the challenges they face caring for the heart failure patient may open the opportunity for further strategies to improve patients and caregiver's ability to manage the care of the heart failure patient at home and decrease the readmission rate (Ahmad et al., 2016; Shahrbabaki et al., 2016; Sharifi et al., 2018).

Purpose of the Study

The purpose of this qualitative, hermeneutic phenomenological study was to explore the challenges experienced by primary caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. Phenomenology is a philosophical method of understanding life experiences (Patton, 2015; Ravitch & Carl, 2016). The phenomenological approach is used in interviews where the main interest is the lived experiences of the participants (Ravitch & Carl, 2016). The phenomenological approach for this study involves semistructured interviews to better understand the lived experiences of participants who are caring for patients before and after discharge. A better understanding of their experiences may guide the development of strategies to increase communication between the patient, caregiver, and the health care provider prior to patient discharge and thus increase the potential to prevent readmission of heart failure patients.

Research Questions

The research question that will guide this study is “What are the lived experiences of caregivers while caring for heart failure patients prior to being readmitted within 30 days of discharge from an acute care organization?”

Framework

The TCM is derived from an earlier model by Eric Coleman known as the care transitions intervention (Tornow Chai, 2011). The care transitions intervention model was developed to improve the quality of life through the self-care of patients and the assistance of their caregivers (Tornow Chai, 2011). The TCM was developed in 1981 by Mary Naylor with a concentration on older patients to improve readmissions through nursing led interventions (Hirschman et al., 2015; Naylor, 2000; Penn Nursing, n.d.). The TCM initially targeted populations who are vulnerable needing a lesser hospital stay in response to shifts in length of stay nationwide (Naylor, 2000). However, Medicare’s repayment system led to earlier discharge for the older population decreasing the hospital stay by nearly 2 days, resulting in a need for increased care needs at home (Naylor, 2000). The TCM is comprised of nine components: (a) screening, (b) staffing, (c) maintaining relationships, (d) engaging patients and caregivers, (e) assessing/managing risks and symptoms, (f) education/promoting self-management, (g) collaborating, (h) promoting continuity, (i) and fostering coordination (Hirschman et al., 2015). The TCM is focused on the health care provider, patient, and caregiver (family, friend, significant other) during the transition from hospital to home (Hirschman et al., 2015; Naylor & Berlinger, 2016). These components complement each other to support smooth continuity of care from hospital to home among health care and home care providers (Naylor & Sochalski, 2010).

Maintaining relationships, engaging patients and caregivers, collaborating, and promoting continuity are the components applicable to this study because identifying the lived experiences of caregivers may guide the development of strategies to prevent readmission of heart failure patients. The TCM is often used in decreasing readmission rates, improving care, and decreasing costs (Hirschman et al., 2015; Naylor & Berlinger, 2016; Radhakrishnan et al., 2015). Thus, the TCM supports the participation of the caregiver in the patient's discharge planning for the education of medications and continued care from hospital to home (Hammond, 2015; Hirschman et al., 2015). The caregiver is the primary person making health care decisions for the heart failure patient at home and understanding their experiences may help health care practitioners to develop discharge planning programs to better prepare the patient and family for self-care after leaving the hospital and decrease readmissions.

Nature of Study

The nature of this study was qualitative using a hermeneutic phenomenology approach. Qualitative research is a method for discovering and understanding the significance people attribute to an identified problem (Creswell & Creswell, 2018). Within this method, interviews are a means to evaluate and explore the lived experiences of individuals (Mitchell, 2015). Open-ended questions were used for this qualitative study (Mitchell, 2015). Semistructured, face-to-face or telephone interviews were conducted based on availability and preference of the participant. After these interviews, content analysis was used to format information in an orderly and systematic fashion (Patton, 2015). Content analysis research is a method to classify material for understanding and interpreting information collected in a qualitative study (Shahrbabaki et al., 2016).

Additionally, interpretive phenomenological analysis (IPA) is often used in researching the lived experiences of people through semistructured interviews (Peat, Rodriguez, & Smith, 2019; Smith & Osborn, 2015). Audio recording semistructured interviews is an adjunct to qualitative data collection to aide in transcribing verbatim what the participant is stating (Creswell & Creswell, 2018). A 7-step conceptual framework is used to guide IPA analysis: reading and rereading, note taking, developing themes, making connections within themes, bracketing themes, identifying patterns, and interpretation (Charlick, Pincombe, McKellar, & Fielder, 2016; Peat et al., 2019). In this study, interviews were recorded, transcribed, and the data broken down into codes, categories, and themes, including any body language collected during the interview process using an interpretive analysis. I planned to use a qualitative software tool NVivo to analyze data for codes, categories, and themes but instead used hand-coding and Microsoft Word.

Definitions

Caregiver: The caregiver is an individual who may be a friend, relative, family member, significant other, or neighbor who assists a chronically ill person, such as a person with heart failure, with daily activities and management of health care symptoms (Family Caregiver Alliance, 2014).

Heart failure: Heart failure is a chronic condition causing the heart to ineffectively pump blood (NIH, n.d, 2018). This condition necessitates continual management of care (NIH, n.d.).

Readmission: Readmission is a return admission to the hospital within 30 days of a prior acute care admission (NIH, n.d.).

Assumptions

It was assumed that participants who are caregivers of heart failure patients want to be involved with the care of the heart failure patient to improve their quality of life and prevent their readmission. Additionally, it was assumed that the participants would understand the interview questions and respond to the interview questions honestly. Finally, it was assumed that the caregiver interviews would provide insight to reducing heart failure readmission.

Scope and Delimitations

The scope of this study was to interview caregivers of heart failure patients readmitted to an acute care organization within 30 days of discharge. Purposeful sampling was used to identify participants from one hospital in the Northeast United States. The heart failure discharge nurse distributed a recruitment flyer to caregivers of readmitted heart failure patients. Caregivers of heart failure patients ages 65 and over willing to be interviewed were included in this study. Caregivers of patients outside this age limit, with other medical conditions, and caregivers from other regions of the United States were not included.

Limitations

The sample size was recruited from one institution; therefore, the results may not be generalizable to other groups (Ravitch & Carl, 2016; Rudestam & Newton, 2015). In addition, to obtain the necessary information the participants were purposefully selected. Purposeful or purposive sampling is used to obtain information from participants to gain insight of a specific phenomenon (Patton, 2015). However, this may decrease the generalizability of the findings (Rudestam & Newton, 2015). Furthermore, I am a novice researcher, which may have affected my ability to recognize when data saturation was achieved (Fusch & Ness, 2015). But working with the dissertation committee guided the research and analysis. Lastly, the responses of the participants were subjective, and they may have withheld information. There is no way to be aware if the participant withheld information, but I tried to elicit as much information as possible with the guided questions in the interview protocol.

Significance

Readmissions may reflect suboptimal discharge planning (Retrum et al., 2013), as heart failure readmissions can be avoided by 60% through effective discharge planning and improved management of care (Knight et al., 2013). Pre- and post-discharge provision of patient medication reconciliation, education, and follow-up can decrease heart failure readmission (Hammond, 2015). Further, family members and friends are often the caregivers who act as the bridge between the patient and health care provider in supporting the care of the patients (Hagedoorn et al., 2017). As the chronically ill heart failure patient symptoms become increasingly difficult over the long-term illness, the caregiver is expected to continually support the patient (Hagedoorn et al., 2017). Thus, it is important to understand the factors that help them in making decisions on behalf of the chronically ill patient (Li et al., 2018). Health care providers contribute to the patient's well-being and quality of care by ensuring that the caregivers have the information necessary to follow-up with the recommended plan of care. Coordinating patient care between providers using a TCM may decrease readmission rates (Radhakrishnan et al., 2015).

The results of this study have the potential for positive social change for patients, caregivers, practitioners, and hospitals. Health care providers' understanding of the challenges experienced by caregivers of heart failure patients may help to design effective discharge plans of care for the heart failure patient. Improved communication between providers, patients, and caregivers may provide caregiver support in effectively caring for the heart failure patient and improve the patient quality of care and quality of life. Additionally, decreasing the rate of readmissions will decrease the financial burden on the hospital.

Summary

Twenty-three percent of heart failure patients are readmitted within 30 days of discharge (Inamdar & Inamdar, 2016; Ziaeian & Fonarow, 2016). Medicare has intervened to decrease hospital costs and reimbursement leading to shorter hospital stays, but this means the greater need for at home care. Heart failure admissions need discharge planning, follow-up, and interventions to improve readmission rates (Gunadi et al., 2015; Johnson et al., 2014; Retrum et al., 2013; Ziaeian & Fonarow, 2016). The TCM is a framework used in decreasing readmissions and supports caregiver participation in planning care for the heart failure patient (Hammond, 2015; Hirschman et al., 2015). Though caregivers are often the main communication for the heart failure patient to the health care providers, there is no literature acknowledging the challenges caregivers perceive related to the readmission of the heart failure patient. The purpose of this qualitative, hermeneutic phenomenological study was to explore the challenges experienced by primary caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. In Chapter 2, a detailed review of the literature will support this gap and need for this study.

Chapter 2: Literature Review

Introduction

There are approximately 6 million people in the United States suffering from heart failure, with a projected increase of 25% by 2030 (Farmer et al., 2016; Phelps, 2018). Heart failure is a chronic condition associated with a high rate of readmissions to health care facilities (Radhakrishnan et al., 2015; Salata et al., 2018). The readmission rate of heart failure patients within 30 days of discharge from an acute care organization ranges from 23%–27% (Ahmad et al., 2016; Inamdar & Inamdar, 2016). Hospitals face monetary penalties from the federal government for patients readmitted within 30 days of discharge, bringing recognition to hospital facilities to institute strategies to improve the heart failure readmission rate and improve costs (CMS, 2014, 2018; Gunadi et al., 2015; Institute for Health, 2012; Retrum et al., 2013; Ziaeian, & Fonarow, 2016). Although interventions to improve the readmission rate of the heart failure patient have been instituted, the rate remains high (Sharifi et al., 2018). There is a need for further investigation to decrease the readmission of heart failure patients.

Further, despite the high prevalence of heart failure readmissions within 30 days of discharge from hospital to home, there is little in the literature regarding the details on the role and challenges of the caregiver. Though studies have required the caregiver to write a list of items to respond and identified the caregiver point of view of the patient’s ability to provide self-care (Ahmad et al., 2016; Cameron et al., 2016), these studies did not look at the lived experience of challenges caregivers perceive in caring for the heart failure patient at home after discharge. The purpose of this hermeneutic phenomenological study was to explore the challenges experienced by the primary caregiver of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. A better understanding of the caregiver experiences may help guide the development of programs to prevent readmission of heart failure patients.

This chapter will cover the literature search strategy, conceptual framework of the study, and literature review. The four primary concepts of this study are congestive heart failure, readmission, interventions or strategies to improve or decrease the readmission rate, and the caregiver for the heart failure patient.

Literature Search Strategy

Information for the literature review was attained through searching for databases electronically. The primary database was Thoreau Multi-Database, which allows searches of multiple databases at the same time. Cumulative Index of Nursing and Allied Health Literature (CINAHL) and MEDLINE combined search, ProQuest Health & Medical Collection, and Google Scholar were also explored. The databases were searched from December 2016 to the current time to identify pertinent resources, with a focus primarily from 2013 to present. The following key words were used to search the databases: *heart failure, readmission, readmission rate, 30-day readmission, caregiver, carers, rehospitalization, perception, intervention, strategies*, and *transition of care*. Several combinations of the terms were utilized to increase the number of citations and obtain information.

The Internet was also used to search the same keywords. Websites such as the NIH, the Agency for Healthcare Research and Quality, the American Heart Association, and CMS were searched for resources and historical readmission data. Any articles relevant to the search criteria were reviewed and the article reference list scrutinized for additional pertinent resources. Duplicate articles and dissertations were removed, whereas articles more closely related to explaining the variables providing informative information to the study were retained, resulting in 65 articles.

Conceptual Framework

Transitional Care Model

This study used the TCM as a guide, which was developed by Mary Naylor in 1981 with a focus on improving readmissions of older patients (Hirschman et al., 2015; Naylor, 2000; Penn Nursing, n.d.; Rezapour-Nasrabad, 2018). The model was originally intended for vulnerable populations to decrease hospital stays in the United States (Naylor, 2000). However, a shift in the government's reimbursement system led to earlier discharges and a need for earlies home care (Naylor, 20000). There are nine components of the TCM: (a) screening, (b) staffing, (c) maintaining relationships, (d) engaging patients and caregivers, (e) assessing/managing risks and symptoms, (f) education/promoting self-management, (g) collaborating, (h) promoting continuity, (i) and fostering coordination (Hirschman et al., 2015). Each of these components blends into one another to foster a seamless transition from hospital to home and are explained as follows:

- Screening is identifying patients that are at risk for readmission.

- Staffing is managing the care of patients during their acute health care illness by an advanced practice registered nurse.
- Maintaining relationships is the formation of a trusting relationship between patient and family caregivers who take part in taking care of the patient.
- Engaging patients and caregivers is the active involvement and participation in the coordination and execution of their care, including personal goals and values.
- Assessing/managing risks and symptoms is the ability to identify disease symptoms and risk factors.
- Education/promoting self-management takes place when patients and caregivers can recognize symptom changes.
- Collaborating between the patient and health care providers establishes a unity of the patient's plan of care.
- Promoting continuity between health care providers from hospital to home avoids interruptions in the plan of care.
- Fostering coordination improves the communication link between patient and health care providers.

Maintaining relationships, engaging patients and caregivers, collaborating, and promoting continuity are the components applicable to this study because identifying the lived experiences of caregivers may guide the development of strategies to prevent readmission of heart failure patients. The TCM focuses on the patient, health care provider, and caregiver, who may be the relative, friend, or significant other. This framework supports the patient and caregiver participation in planning care upon discharge from hospital to home (Hammond, 2015).

Application of Transitional Care Model

Transitional care promotes activities to provide coordination and continuity of patient care form one level of care to another (Ho, Kuluski, & Gill, 2015). The transition of care has been used for many studies since the inception of the TCM in 1981. This program supports the continuum of care for the patient during the transition from hospital to home with the inclusion of the health care providers and caregiver. Research has been conducted on the patient discharge experience regarding the transitional period after being discharged from the hospital (Ho et al., 2015). Researchers have identified patient concerns in relation to the discharge process, personal consequences, and personal needs (Hirshman et al., 2015; Ho et al., 2015). Other researchers have explored heart failure patient management of medications taken at home, identifying errors in medications and not following the treatment plan because patients were overwhelmed with the complex medication regimen, which can be resolved with a program such as the TCM (Knecht & Neafsey, 2017; Shahriari, Alimohammadi, & Ahmadi, 2016). Additionally, electronic tools may improve care transition, with physicians communicating from one level of care to another electronically by completing patient care summaries (Santana et al., 2014). However, other research has shown that the readmission was unchanged between the control group and the transitional care group (Williams, Akroyd, & Burke, 2015).

Literature Review

Heart Failure

Congestive heart failure, commonly referred to as heart failure, is a chronic disease characterized by the heart's inability to pump the blood needed to supply the body (NIH, n.d., 2018). Heart failure is caused by other medical conditions such as high blood pressure or diabetes (NIH, n.d., 2018). Nearly six million people in the United States are affected by heart disease. Heart failure patients present with symptoms including shortness of breath, fatigue, and swelling in the lower extremities, which places a strain and weakness on the heart (NIH, n.d., 2018). This disease is incurable, but it can be managed with changes in lifestyle and medications (NIH, n.d.). Heart failure patients require a lifetime of continued care. Lifestyle changes such as maintaining a healthy weight and eating habits, exercising, and avoiding smoking may decrease hospital admission and readmission (NIH, n.d.).

Readmissions

Readmission is a return admission to the hospital within 30 days of a prior acute care admission (NIH, n.d.). High readmission rates mean increased costs for medical care and expenses for the patient, provider, health care facility, and government (Gunadi et al., 2015; Hammond, 2015; Johnson et al., 2014; Shahriari et al., 2016; Zohrabian, Kapp, & Simoes, 2018). The Hospital Readmissions Reduction Program was instituted by the United States government to identify hospital readmissions as an area needing improvement of continuity of care to enhance patient care and decrease hospital costs (Zohrabian et al., 2018). The CMS instituted a regulation in 2012 in which hospitals face monetary penalties for patients that are readmitted within 30 days of hospital discharge (CMS, 2014, 2018; Gunadi et al., 2015; Hammond, 2015; Institute for Health, 2012; Ziaeian, & Fonarow, 2016; Zohrabian et al., 2018). Several factors were identified as being associated with readmission, including noncompliance with care regimen due to poor education, ineffective communication among patients, providers, and caregivers, lack of follow-up care, individual patient characteristics, and social support (Farmer et al., 2016; Johnson et al., 2014; Sharifi et al., 2018). Patients reported they have ineffective communication with health care providers and difficulty realizing that they need to have a support system (Farmer et al., 2016). Lack of a supportive network, communication, and education contribute to readmissions (Johnson et al., 2014). The various educational levels of individuals; patient and caregiver, hinder their ability to comprehend care needs (Sharifi et al., 2018).

Heart failure has the highest readmission rate within 30 days of discharge for patients ages 65 and over and is projected to increase by the year 2030 to eight million or by 25% (Ahmad et al., 2016; Farmer et al., 2016; Gunadi et al., 2015; Heidenreich et al., 2013; Radhakrishnan et al., 2015; Salata et al., 2018; Zohrabian et al., 2018). A qualitative study was conducted to explore heart failure through the patients’ perspective about the reasons for readmission post-discharge (Retrum et al., 2013). The research study consisted of 30 to 60-minute interviews of 28 patients that had been readmitted within 30 days of discharge. Patient symptoms, the progression of chronic disease, psychological and social environmental factors, self-care adherence, and health system factors including poor communication between health care workers, discharge planning, and follow-up all contribute to the readmission of heart failure patients (Retrum et al., 2013). The researchers identified a need for further research with in-depth patient participation. Another qualitative study was conducted to examine hindrances to coping related to supporting patients based on the perceptions of heart failure patients, nurses, cardiologists, and family members (Shahrbabaki et al., 2016). The authors conducted interviews of 20 people consisting of the patients, cardiologists, nurses, and family members of heart failure patients. The data analysis resulted in a deficit in the collaborative teamwork for coping with heart failure patients; a lack of knowledge and support hinders patients' ability to cope.

Researchers explored patient and provider perspectives on readmission using a qualitative interview approach (Farmer et al., 2016; Retrum et al., 2013; Smeraglio et al., 2019). Semi-structured patient interviews were conducted, the interviews analyzed, and information compared to patient charts (Retrum et al., 2013). Many patients reported developing medical issues before their scheduled follow-up appointment (Retrum et al., 2013). The study concluded patients have multiple perceptions of different factors associated with readmission, which makes the results challenging to categorize but identifies patient information that will aide in identifying interventions. (Retrum et al., 2013). Qualitative interviews of heart failure patients and providers consisting of free text, multiple choice, and yes/no design were conducted to identify factors contributing to readmission and to compare the patient and provider results (Smeraglio et al., 2019). Many patients felt they were discharged too early from the hospital while the providers indicated that nothing could be adjusted to prevent readmission, but report patient factors could be the cause of readmission (Smeraglio et al., 2019). The researchers noted patients often identified suggestions to improve the discharge process including follow-up and skilled home care. Factors reported to contribute to readmissions are education, timeliness of care, and communication. However, a similar qualitative study of semi-structured interviews with providers was conducted to compare a case study of two municipalities to explore physician decision-making challenges and the impact on readmission (Glette, Kringeland, Røise, & Wiig, 2018). The study revealed poor communication, lack of continuity of care, nurse staffing shortages, nursing competence, patients and family choices, and time constraints were factors related to readmission. This study has the potential to offer data that may lead to strategies to improve discharge planning.

Strategies to Decrease Readmission Rate

Since the onset of the federal government’s monetary penalties for readmissions of heart failure patients within 30 days of discharge, hospital facilities have instituted strategies to decrease the readmission rate (Ziaeian, & Fonarow, 2016). Conceivable interventions to improve readmission include education of nursing staff, use of electronic applications, patient education, medication reconciliation, and follow-up post-discharge (Gilmore et al., 2015; Jun & Faulkner, 2018; Phelps & Sutton, 2018; Santana et al., 2014). Patient education regarding medications, pharmacist-generated medication reconciliation, and pharmacist follow-up telephone calls improved readmission rates in one study by 0.9% (Gilmore et al., 2015). A literature review of issues contributing to readmissions identified nursing factors including work environment, staffing, and heart failure knowledge (Jun & Faulkner, 2018). Another study developed a Patient Advisory Nurse Department to telephonically educate and follow-up with patients (Phelps & Sutton, 2018). Patients who were contacted within 48 hours of discharge showed a readmission rate of 20% in 2015 as compared to a readmission rate of 15.27% in 2016; a *t-test* to compare the data was not significant (Phelps & Sutton, 2018). The researchers identified that nurses who were not familiar with the program process did not educate patients effectively (Phelps & Sutton, 2018). Electronic patient care summaries were identified to improve communication between physicians, patients, and families (Santana et al., 2014). Patients reported an improved understanding of their medication regimen and heart failure symptoms (Santana et al., 2014).

Patient-centered care is a central focus on the understanding of only the patient and their needs (Ho et al., 2015; Johnson et al., 2014). Lean Startup is a methodology of innovative techniques used to focus on patient-centered care to explore and identify interventions to improve readmission rates for heart failure patients at an academic facility (Johnson et al., 2014). Electronic medical records and real-time data collection identified potential factors related to readmission including education, follow-up, and communication (Johnson et al., 2014). Concurrently with the study, the facility implemented efforts to improve readmission including screening at-risk patients, care planning, encouraging self-management, educating on medication education, and scheduling follow-up appointments within 7 to 10 days of discharge. The results of the study identified that using a patient-centered framework of interventions may potentially provide improvement with chronic disease management during transition from hospital to home (Johnson et al., 2014). The transition of care programs is a viable method in identifying strategies and improving heart failure readmission (Knecht & Neafsey, 2017; Santana et al., 2014). Despite the proposed and current use of interventions to improve the readmission rate of the heart failure patient, this is still an issue that needs further investigation. In one study, the patient and caregiver did not agree about heart failure symptom management (Sharifi et al., 2018). Caregivers for cancer patients reported a lack of communication and time with health care providers was a barrier to symptom management at home (Han et al., 2018).

Caregivers

The caregiver is an individual who may be a friend, relative, family member, significant other, or neighbor who assists a chronically ill person (Family Caregiver Alliance, 2014). Caregivers who are the primary care person for the heart failure patient may be the key to improving readmissions of heart failure patients (Shahrbabaki et al., 2016; Sharifi et al., 2018). Family members and friends are oftentimes the caregivers who act as the bridge between the patient and health care provider in supporting the care of the patient (Farmer et al., 2016; Hagedoorn et al., 2017). It is important to understand the factors that help them in making decisions on behalf of the chronically ill patient (Li et al., 2018). There is limited information regarding the challenges experienced by caregivers who care for heart failure patients. Therefore, there is a need to investigate the challenges experienced by this group (Farmer et al., 2016; Shahrbabaki et al., 2016). Health care providers may contribute to the patient’s wellbeing and quality of care by ensuring that the caregivers have the information necessary to follow-up with the recommended plan of care (Farmer et al., 2016).

Caregivers of patients with other medical conditions have been studied. These include qualitative studies of caregivers of children with Autism spectrum disorder and hospice cancer patients (Grace, Catherine, Mala, Kanniammal, & Arulappan, 2018; Han et al., 2018). The results of a focus group study by Grace et al., (2018) with parents of autistic children revealed that as caregivers they faced many challenges daily requiring direction and support. Challenges identified include the attitude of others due to the child's specific condition, not getting the care they need, financial and caring hardships, religion, and culture. A study by Han et al., (2018) focused on the challenges caregivers face when managing cancer patients' pain. Secondary data was used from audio recordings of hospice nurses' home visits and a conceptual framework for pain management including the caregiver's ability to manage pain, their knowledge, communication, teamwork, and organizational skills (Han et al., 2018). Researchers identified caregiver knowledge and skills with the coaching of the hospice nurse will improve patient comfort and decrease caregiver burden (Han et al., 2018).

Few studies have been conducted on the lived experiences of the caregivers' view of readmission of the heart failure patient (Ahmad et al., 2016; Cameron et al., 2016). A study conducted by Ahmad et al., (2016) asked caregivers to write a list of words they believed identified the patient's reasons for or contributing factors leading to readmission. Caregivers indicated patients were readmitted due to their lack of independence, stress, stubbornness, lack of listening, breathing difficulty, and laziness.

Caregivers identified stress and moodiness of heart failure patients as contributing factors leading to lack of self-care and readmission (Cameron et al., 2016). Challenges reported by caregivers from their perspective when managing heart failure patients in the home setting included stress of the heart failure patient, self-care deficits, and poor listening skills of the heart failure patient; these challenges need to be further clarified and categorized (Ahmad et al., 2016; Cameron et al., 2016). In-depth interviews of the caregivers were not explored regarding their experience as caregivers and the challenges they experience.

Heart failure is a chronic disease affecting six million people in the United States. Readmission of the heart failure patient within 30-days of hospital discharge remains high. Interventions have been implemented, but the readmission rate continues to be a problem (Sharifi et al., 2018). The caregiver for the heart failure patient is the primary person caring for the patient daily and may provide viable information that may be used by practitioners to improve the readmission rate. This study will assist in filling this gap.

Summary and Conclusions

The concept of proposed interventions for the readmission of heart failure patients has been studied from different views in the literature. What is known about readmissions is that the rate is high, and many strategies have been attempted to improve the readmission rate. The TCM developed by Mary Naylor in 1981 has been used in studies to evaluate and develop strategies for improving the transition of patient care from hospital to home. Multiple databases and Internet searches resulting in 65 viable resources that provided information for this study. The search terms used for this literature review were four concepts including heart failure, readmissions, proposed interventions, and caregivers. Education, follow-up, and the continuum of care from hospital to home resonates in the literature. The literature shows studies have been conducted mainly with patients and health care providers. The interventions are poorly understood and lack congruence throughout the literature as a factor to improve the readmission rate. Although there have been studies with caregivers, those studies examined caregiver perceptions of patient self-care and symptom management. Caregivers of the heart failure patient take on an important role in providing a connection for communication with medical providers. Studies were not found that investigated the lived experiences of caregivers while caring for heart failure patients at home after discharge. The aim of this study was to explore the challenges experienced by caregivers through a phenomenological hermeneutic process using in-depth interviews. In Chapter 3 the research design and rationale, the role of the researcher, methodology, and issues of trustworthiness for this study will be discussed.

Chapter 3: Research Method

Introduction

More than 6 million people in the United States suffer from heart failure (Phelps, 2018), and approximately 23% to 27% of all heart failure patients are readmitted within 30 days of discharge from an acute care organization (Ahmad et al., 2016; Inamdar & Inamdar, 2016). The CMS instituted penalties for facilities experiencing readmissions (CMS, 2014, 2018). Thus, facilities have been seeking innovative ways to aid in improving the readmission rate; however, the high rates continue to be an issue. One strategy is continual monitoring and management of the heart failure patient, which is essential from in-hospital provider care through at home follow-up with the patient, provider, and caregiver. Without follow-up and management of care patients are often readmitted (Sharifi et al., 2018).

Because, caregivers often need to make a decision on behalf of the heart failure patient, understanding the caregiver experience may lead to program development to improve the rate of readmissions for heart failure patients. The purpose of this qualitative, hermeneutic phenomenological study was to explore the challenges experienced by primary caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. This chapter will review the methodology used to examine the caregiver experiences. The areas discussed include the research design and rationale, role of the researcher, and issues of trustworthiness.

Research Design and Rationale

A qualitative approach using a hermeneutic phenomenology was used for this study. Qualitative research is a technique for learning and understanding the meaning people attribute to a recognized problem (Creswell & Creswell, 2018). Further, IPA often uses semistructured interviews in researching the lived experiences of people (Peat et al., 2019; Smith & Osborn, 2015). In contrast, a quantitative approach would not capture the in-depth lived experiences of individuals.

Research Questions

The research question that guided this study was "What are the lived experiences of caregivers while caring for heart failure patients prior to being readmitted within 30 days of discharge from an acute care organization?"

Central Concepts

The main concepts of this study are heart failure, readmissions, strategies to decrease readmissions, and caregivers. Despite strategies to decrease readmission, the increase rates continue to be a concern. Thus, I investigated caregivers' experiences with patients with heart failure readmitted within 30 days. Caregivers are often the primary individual taking care of the heart failure patient and are a connection between the patient and health care provider in supporting the care of the patients and through communicating and collaborating with the health care providers (Hagedoorn et al., 2017).

Role of the Researcher

The role of the researcher in a qualitative study is to be reflective (Sutton & Austin, 2015). To be reflective I had to be clear in questioning and communicating the phenomenon of interest to retrieve the feelings and thoughts of the participants in the study (Sutton & Austin, 2015). I fulfilled this role as an observer–participant through face-to-face interviews with the participants. I do not have any personal or professional relationships with the participants. Researcher bias was also avoided through verbatim transcription so that reliability and trustworthiness could be established (Halcomb & Davidson, 2006; Patton, 2015).

Methodology

Population

The population for this study was caregivers of heart failure patients ages 65 and over who have been discharged within 30 days from an acute care organization. The participants were from a hospital in the Northeast United States.

Sampling

A purposeful sample was used to obtain participants from an acute care organization readmission database in the Northeast United States. The participant sample size must be enough to provide valuable, rich information (Patton, 2015). Sample size can range between five and 25 participants (Patton, 2015). The intended sample size for this phenomenological qualitative research study ranged from eight to 12 participants; this is within the range of the sample size identified in the literature (Fusch & Ness, 2015; Patton, 2015; Ravitch & Carl, 2016). In addition, participants were interviewed until data saturation was achieved (Patton, 2015). Saturation is achieved when no new information is obtainable.

Criteria for inclusion and exclusion. Caregivers of heart failure patients ages 65 and over willing to be interviewed were included in this study. Caregivers must be able to speak, read, and write in English, live in the Northeast United States, be age 18 or older, and caring for a heart failure patient at least one year. Caregivers of patients outside this age limit, with other medical conditions, and caregivers from other regions of the United States were not included.

Procedures. Participants were recruited from an acute care organization in the Northeast United States. I met with the Chief Nursing Officer of the facility to explain the purpose of the study and request permission to distribute recruitment flyers. The facility's institutional review board (IRB) was also contacted, and a meeting was scheduled to explain the purpose of the study and request permission to recruit caregivers of heart failure patients from their facility. The recruitment flyer included the purpose of the study and the criteria for participation. Participants were able to contact me via a phone number on the flyer if they were interested in learning more about the study. I identified the following information to those who called to learn more about the study: the purpose, the length of the interview, what they will be expected to do, the criteria for participating, and the voluntary nature of the study. During the phone call, participants were screened to determine if the participant met the inclusion criteria (Appendix A).

Participant name and contact information was obtained if they were interested in volunteering to participate in the study. I emailed or mailed, whichever was more convenient for the participant, the consent document to those who met the criteria and were willing to participate in the study. After obtaining signed consent, the interviews were conducted in person in a location of the participants' choosing that provided privacy or via the telephone if more convenient for the participant (Appendix B).

Interview time was approximately 30 to 60 minutes; this is within the range identified in the literature (Ahmad et al., 2016; Retrum et al., 2013). Participants had the opportunity to ask questions prior to the interview. Each interview was recorded with the Philips Voice Tracer Audio Recorder (Model DVT2710), an audio recording device, and notes were taken. I transcribed each interview verbatim by myself following the interview while all the details of the interview were still fresh in mind. Participants were asked if they agree to a follow-up phone call if additional clarification was needed. Participants were provided a one to two-page summary of the results of the study.

Data Analysis

All data including audio recordings, consents, and notes were stored electronically on a password-protected computer. In addition, the participants personal identifying information was stored on a separate file with a password known only to me. The data was collected through open-ended face-to-face interviews that were recorded and in which notes were taken. Because computer software programs can assist in coding, storing, and comparing qualitative data (Patton, 2015), the information was entered and organized into an Excel document. Qualitative data analysis software enables the researcher to transcribe and interpret interview data including face-to-face interviews, email interviews, telephone interviews, Internet interviews, and even focus group interviews (Predictive Analysis Today, 2016b). Qualitative data analysis software can help save time and improve the validity and credibility of research data (Predictive

Analysis Today, 2016a). Additional observational field notes, memos, and documentation can also be organized. I planned to use a qualitative software tool NVivo to analyze data for codes, categories, and themes but instead used hand-coding and Microsoft Word. The data was interpreted to identify similarities for codes and categories.

Issues of Trustworthiness

Credibility

Credibility or internal validity is the ability of the researcher to explore and evaluate all aspects in the research (Ravitch & Carl, 2016). Credibility is established by demonstrating the knowledge of a research issue (Rubin & Rubin, 2012). Credibility can be validated through triangulation, participant validation or member checks, thick description, and prolonged interaction (Ravitch & Carl, 2016). Credibility for this study was established through developing honest relationships with the participants.

Transferability

Transferability or external validity is the ability of one study to be adapted to other research situations (Ravitch & Carl, 2016). Transferability can be validated through in-depth description of data (Ravitch & Carl, 2016). This study ensured transferability through the detailed procedure and conducting interviews with thick description of lived experiences of the participants.

Dependability

Dependability is the reliability of the data completed within the study (Ravitch & Carl, 2016). Dependability can be validated through organizing procedures (Ravitch &

Carl, 2016). All audio recordings were translated verbatim following the interview. This study was completed by the researcher who conducted, transcribed, collected and analyzed the data, and maintained a chronological log.

Confirmability

Confirmability is the objectivity of the researcher (Ravitch & Carl, 2016). Confirmability can be validated through researcher reflexivity (Ravitch & Carl, 2016). The researcher's preferences should not be part of the interpretive results, only the information of the participants. Confirmability was achieved through a verbatim transcript and interview notes.

Ethical Procedures

The IRB has specific guidelines for protecting participants (Patton, 2015). Walden IRB approval and the facility's IRB approval were obtained. Considerations included securing data storage, removing any form of personal identifiers, and obtaining informed consent (Sanjari, Bahramnezhad, Fomani, Shoghi, & Cheraghi, 2014). Data obtained from the study was secured by a confidential password known only to me. To ensure confidentiality and privacy, participant names were not used in the study report, only names for coding such as Participant 1, Participant 2, etc. Informed consent outlining the study purpose was obtained at the first participant interaction. Participation in the study was voluntary and the participants were able to withdraw at any time. I work within a branch of the participant site; however, participants were recruited from a different division.

Summary

In summary, I have delineated the methodological procedures for this study. The purpose of this study was to explore the challenges experienced by caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. The main concepts of this study were heart failure, readmissions, strategies to decrease readmissions, and caregivers. A hermeneutic phenomenological qualitative approach was used to interview caregivers in researching their lived experiences in caring for heart failure patients at home after hospital discharge. The role of the researcher was to collect data through observer-participant interviews. The researcher must be thoughtful and clear when interviewing and communicating with the participants. Trustworthiness was established through in-depth description and maintaining an audit trail. In Chapter 4 data collection, data analysis, and results will be discussed.

Chapter 4: Results

Introduction

The purpose of this qualitative, hermeneutic phenomenological study was to explore the challenges experienced by primary caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. The proposed sample size for this study was eight to 12 volunteers who met the criteria for participation, and eight participants were interviewed. After the seventh participant no new information was obtained, indicating saturation of data. One additional participant was interviewed to ensure saturation, and the information obtained was redundant. The phenomenological approach was used through semistructured interviews to capture the lived experiences of the participants (Ravitch & Carl, 2016). The results of the study and a better understanding of caregiver experiences may aid in developing strategies to improve programs to prevent the readmission of heart failure patients.

The research question that guided this study was “What are the lived experiences of caregivers while caring for heart failure patients prior to being readmitted within 30 days of discharge from an acute care organization?” There were four main interview questions asked to produce the information needed for data collection. These questions include:

1. Will you tell me about your role as a caregiver of a patient with heart failure?
2. What information did you receive to help you in caring for the patient with heart failure prior to discharge?

    a. How did the care team provide the information to you about the care needs after discharge (video, written, person to person)?
    b. What was your understanding about the care needs of the patient after discharge?
    c. What was your understanding about how to respond to changes in the patient's condition after discharge?

3. What are the challenges you have experienced when caring for the patient with heart failure at home?
4. What helped you in caring for the patient with heart failure at home?

This chapter presents the results of this study, the setting of the participant interviews, relevant participant demographics, and the procedures for data collection and analysis. Evidence of trustworthiness is also described including credibility, transferability, dependability, and confirmability.

Research Setting

The research setting was the Northeast United States. The participants were recruited from an acute care organization. Interviews were conducted in person or via telephone—whichever was more convenient for the participant. The interview time was also based on participant convenience. The face-to-face interviews occurred in a private location where the conversations could not be overheard. Individuals who participated in the phone interview were encouraged to secure a location where their conversations could not be overheard. Data were collected over a 4-month period from November 2019 to the end of February 2020.

Demographics

Eight caregivers of patients with heart failure who were readmitted to the hospital were interviewed. Three of the interviews were in person, and the other five interviews were by telephone. The relationship between the caregiver and the heart failure patient varied. Three participants were daughters caring for their mother. One was a daughter caring for her father. One participant was a daughter-in-law caring for her father-in law. Two participants were wives caring for their husband, and one participant was a son caring for his mother (see Table 1).

Table 1

Demographic Information

Characteristic		# of Participants	Percentage
Gender	Male	1	12.5
	Female	7	87.5
Caring for	Parent	6	75
	Spouse	2	25
Living with	Parent	4	50
	Spouse	2	25
	Neither	2	25
Employment	Working	6	75
	Not working	2	25

Data Collection

Data for this study were collected as explained in Chapter 3. Approval was obtained from Walden IRB before contacting the chief nursing officer of the acute care organization for permission to distribute recruitment flyers at their facility. The chief nursing officer was supportive of the study and distributing flyers at the acute care organization. The proposal was also submitted through the IRB process at the organization and approval from the research committee. Once permission was granted, I met with the heart failure nurses on October 31, 2019 to provide the flyers to be distributed. The participant criteria, purpose of the study, and contact information were included in the flyer. Caregivers were able to contact at a time of their convenience either by telephone or e-mail.

Recruitment

A total of eight participants were recruited and interviewed over a 4-month period. The first voluntary participant called me 3 weeks after the flyer distribution began. I would routinely reach out to the heart failure nurses at the facility to provide additional flyers. The heart failure nurses shared with me the challenges they experienced recruiting participants. These reasons included caregivers denying that the patient had heart failure, the caregiver was not always present when the nurse went to speak to the patient and caregiver to distribute the flyer, and the nurses felt that caregivers may not want to participate because they felt intimidated about calling or e-mailing me. Recruitment was slow and after 2 months and only two participants I revised my Walden and the organization’s IRB application to include snowball sampling and a $10 Wawa gift card to the volunteers to thank them for their time and participation. These requests were granted.

Informed Consent and Conducting the Interview

Once the participant contacted me, I explained the study and to determine their eligibility I used a screening criteria questionnaire (Appendix A). Informed consent was obtained prior to each interview either in person or by e-mail. The participant was given the option of either completing the interview in person or via telephone. As noted in the demographic information, most participants preferred to be interviewed via telephone as this was most convenient for them. Each interview was recorded using the Philips Voice Tracer and transferred to my computer for verbatim transcription. All transcripts were password protected without identifiers, so the names of the participants remained confidential. The interviews lasted anywhere between 20 minutes to 47 minutes (Table 2). There were no unusual situations or variations encountered during the interviews.

Table 2

Interview Details

Participant #	Interview Date	Length of Interview (min:sec)	Interview Location
Participant 1	11/25/2019	20:53	conference room
Participant 2	12/26/2019	26:08	office
Participant 3	12/30/2019	46:04	conference room
Participant 4	01/22/2020	35:35	telephone
Participant 5	02/17/2020	22:30	telephone
Participant 6	02/25/2020	26:38	telephone
Participant 7	02/28/2020	34:26	telephone
Participant 8	02/28/2020	23:15	telephone

Data Analysis

Data analysis consisted of transcribing the interviews verbatim, coding, categorizing, and organizing each interview by hand (Sutton & Austin, 2015). Once the interviews were transcribed, then pieces of the text were coded or labeled, sorted, compared, and combined into concepts or themes (Rubin & Rubin, 2012). Coding is a technique to organize the textural data (Creswell, 2018). Each interview was transcribed, and the transcript was edited for clarity. Line-by-line coding was done using the comment feature in Microsoft Word (Saldaña, 2016). Once the comments were completed, they were extracted from the transcribed interview using a Microsoft Word feature called DocTools. DocTools pulled all comments from each interview into a table format and the table was placed in an Excel spreadsheet.

Additionally, IPA was used, which includes reading and re-reading, developing themes, making connections within themes, and interpretation (Charlick et al., 2016; Peat et al., 2019). The interview transcription and comments were reviewed for accuracy. After the second interview was completed and transcribed, the information was reviewed side-by-side to get a general sense of the material (Creswell & Creswell, 2018). By the seventh interview saturation was met, but an eight interview was conducted, and no new information obtained. Each interview generated between 30 to 87 lines of code with no limit on codes per interview. Manual coding of all interviews was conducted for identifying themes and subthemes.

Evidence of Trustworthiness

Several factors are associated with trustworthiness in qualitative research. These include credibility, transferability, dependability, and confirmability. Each criterion was accounted for in the planning of this study and discussed in Chapter 3.

Credibility

Credibility or internal validity is the researcher's ability to explore and assess all facets in the research (Ravitch & Carl, 2016). Strategies to validate credibility of this study included participant validation or member checks, thick description, and prolonged interaction (Ravitch & Carl, 2016). An honest relationship was built with the participants through study explanation, consent, and the interview process. The interview questionnaire was used during each interview to ensure the same line of questioning was provided to each participant. Participants were able to speak freely to provide rich information. During interviews participant information was validated through repeating their response to ensure their meaning is understood. Recordings were reviewed to ensure questioning was consistent among the participants.

Transferability

Studies that can be generalized and conducted in other settings or populations means there is transferability. In this study, transferability was validated through in-depth data description (Ravitch & Carl, 2016). Honesty gained a relationship with the caregivers, which instilled confidence to speak openly and provide rich, thick information of lived experiences of caregivers.

Dependability

The reliability of the data within the study is dependability (Ravitch & Carl, 2016). I collected and organized all data. Recorded interviews were transcribed verbatim and rechecked for accuracy. A separate document or log was kept with each participant interview date, length of interview, and demographic information.

Confirmability

For the study to have confirmability, the researcher needs to be impartial (Ravitch & Carl, 2016). In this study, the interview guide was used for each participant interview to ensure each caregiver was asked the same questions without deviation unless an additional probing question was needed for more rich detail of information. The interview recordings were transcribed verbatim while the information was still fresh in mind.

Results

I transcribed and hand-coded the data. The interview transcription was reviewed line by line until no other codes could be identified. The results of the study were organized into four themes and 13 associated subthemes. The themes and subthemes developed from the data are displayed in Table 3.

Table 3

Themes and Subthemes

Themes	Subthemes
Theme 1: Being vigilant	
	Attending to daily treatments Watching physical condition Scheduling appointments
Theme 2: Seeking support	
	From family From health care providers From the Internet/social media
Theme 3: Receiving support	
	From health care providers From family From others
Theme 4: Experiencing challenges	
	Feeling stressed, frustrated, and financially burdened Patient non-compliance Having no life/personal time Lack of education, understanding, and information

Theme 1: Being Vigilant

Being vigilant was the first notable theme to emerge. Someone who is vigilant is being careful, attentive, and watchful (Claypoole, Neigel, Waldfogle, & Szalma, 2019;

Riley, Owora, McCleary, & Anderson, 2019). Information related to this theme was evident in the responses of all eight participants. There were 102 responses of being vigilant. All eight participants (100%) reported being vigilant in daily treatments. Seven out of eight participants (87.5%) reported they would monitor the physical condition of the heart failure patient, including understanding of care needs and signs of complications, while another 87.5% expressed they participate in scheduling follow-up appointments as part of the caregiver role. Being vigilant entailed attending to daily treatments, watching daily physical condition, and making appointments.

Attending to daily treatments. Participants shared their attentive process for daily medications to ensure the heart failure patient was taking the right medication at the right time. One participant stated, "I do set it up after 2 weeks every med that she has to take, and I have separate containers for those that she takes in the morning and those that she takes in the evening." Another participant shared, "I, we prepared her medications. We had one of those big Sunday through Friday with like four or five rows in it and my sister and I were there every other weekend, one of us." She added, "So, on the weekends when we were there, we did the med. prep for the week."

Participants shared how they would organize the heart failure patient's medication regimen and monitor a low-salt diet. Three out of the eight participants (37.5%) described how they would set up medications in daily containers including non-prescription medications or vitamins. Two out of those three participants reported they separated the medications based on time of day, such as morning, afternoon, and evening.

Watching physical condition. Participants shared how they would watch over the heart failure patient so they would not have to be readmitted to the hospital. One participant said she would check the weight, lungs, the oxygen level, and the blood pressure all the time. Another participant shared the doctors would look for swelling of the ankles, but she noticed when his “stomach look[ed] bloated.” Another caregiver kept a weight log for daily weights stating, “And, you know, making sure that I, you know, keep his weight and everything. So, I made up a little log and it sits in the bathroom by the scale.”

Seven out of eight participants (87.5%) indicated they understand and could recognize signs of complications. If there was any shortness of breath or difficulty breathing, they would call the doctor or call 911, depending on the severity. One caregiver stated:

> Depending on the severity we will call 911 and get somebody there and get her to the hospital as we did on Monday. Um, but if it’s not too severe, she shows signs of improvement when she is sitting you know and she feels okay you know, I don’t know how else to respond to it, I’m not gonna run her to the hospital every time she takes a breath.

Scheduling appointments. Caregivers shared they made sure the heart failure patients went to the doctor for regular and follow-up appointments. One participant stated, “I take part in all his caregiving, I go to all doctors’ appointments with him.” Another caregiver shared, “We usually coordinate it around my schedule. If I know he’s going to see the cardiologist I usually go with him.” A similar response from another participant was “I try to go to as many [appointments] as I can” and adds that he tries to make them for afternoon hours, so he is able to accompany his mother around his work schedule.

Theme 2: Seeking Support

The theme of seeking support was verbalized by seven of the eight participants (87.5%). There was a total of 28 instances reported by caregivers of their attempt to seek support in caring for the heart failure patient. They were seeking support from family, health care providers, and the Internet.

From family. Six out of the eight participants (75%) asked family members for support in caring for the heart failure patient. One caregiver shared “It was in the middle of the night. I called my daughter and her fiancé. Her future husband was visiting her, and they helped take him to the hospital.” Participants wanted to discuss caregiving decisions with family members. A caregiver had this to say about her sister:

> So, me and her go back and forth with my mom and everything, but she is going through her own personal health issues so that’s a challenge for her, but, you know if I need to reach out to her, you know and say what should I do and you know am I doing the right thing you know she just confirms that what I’m doing that we are both on the same page.

Another caregiver stated,

> The doctor was just mentioning today about this procedure to go through the groin to repair her aortic valve, but she’s 92. It’s just kind of like at that age to

> put her through this. So, I don't know. Gotta weigh it all out and we have to really discuss it as a family.

From health care provider. Five out of eight participants (62.5%) were seeking support from a health care provider. The participant would either reach out to the nurse, doctor, or another health care worker. One caregiver shared she reached out to the heart failure nurse for caregiving support and education. Another caregiver said the doctors always "go for his ankles all the time when they check for his fluid retention." She added:

> And I go for around his stomach, when his stomach looks bloated. Yeah, I notice it in the stomach, but whenever we go to the doctor, they're always checking his ankles. I said to the doctor, I notice it in his stomach. And he says, "well yeah you can retain water in your stomach too."

Another participant stated,

> I just decided to go to the pharmacist to see if they feel that all this medication that she's taking is okay. And she has difficulty sleeping at night and so I was trying to find something for her to sleep you know if that will be okay with all of the medication she's taking right now and so he recommended melatonin and so she's taken melatonin in the past and it didn't work. But then he suggested 5 mg melatonin and it is helping her.

From Internet/social media. Three out of eight participants (37.5%) utilized the Internet or social media for information to assist in caring for the heart failure patient. One participant shared she would use the Internet to look up information while her husband was in the hospital. One participant stated, “I’m always googling things like if there is an issue.” Another participant indicated she used Facebook marketplace to purchase medical equipment.

Theme 3: Receiving Support

All eight participants (100%) identified instances where they received support. There was a total of 45 instances reported by caregivers of receiving support. Support was received from health care providers including doctors, nurses, other ancillary health care services, family members and others.

From health care providers. All eight (100%) caregivers reported receiving support from health care providers. Seven out of eight participants (87.5%) received support from nurses. One participant stated, “The nurse went over the medications. Um, you know just went over like the follow-up and everything is printed out, we signed it, they kept a copy, so you know I thought it was as thorough.” Another participant stated, “They told me I had to watch his weight. That was the big thing and uh his fluid intake should be normal. You know, uh not excessive and to basically watch what he eats. No salt you know that kind of thing.”

Four out of eight participants (50%) received support from doctors. One participant stated, “In ICU they had like a robotic doctor that does rounds daily. Which was really nice because I’d be staying with him and when the doctor came by, we kind of went over things.” She went on to say, “I like it because I felt like we reviewed everything. Like he had everything in front of him. All his lab work, all his x-rays., all his results, he was very knowledgeable.” Another participant shared, “Well any questions that my sister or I had we can always call the doctor and say what do you think? Do you want to see her? Should we try something different?"

From family. Five out of eight participants (62.5%) reported they received support from a family member. Although they received family support, the caregiver was reluctant to ask, because they felt the family member was too busy. One participant shared:

> My children are helpful, but you know they work as well so I mean my son has picked her up and taken her to a couple of appointments. He is an adult and he has taken her to a few appointments and of course my daughter will stop by and visit every now and then. And my wife as well. You know she has been very good; she will stop by and visit. If I can't get there, um, and we try, you know we try to divvy up the time, but she dismisses us very quickly when we come by.

Another participant stated,

> I had my family who was here to help me even though they don't live with me, but two of our daughters are nearby. Uh, I mean not in the same town, but not too far away. And they were helpful when I needed them.

From others. Four participants (50%) received support from other ancillary services. Ancillary services included a pharmacy service that would mail medication, meals on wheels that would deliver meals, Medicaid services, and therapy. Therapy services included physical, occupational, and rehabilitation.

One caregiver shared his mother had a program in the community, called dial-a-ride, that would take her for her appointments. Another caregiver stated, "Well, I can say this, how about the understanding of my boss. She is very understanding. I'll call her at the drop of a hat and say I gotta go and she just says go. That helps."

Theme 4: Experiencing Challenges

The theme of challenges was evident for every participant. All eight participants (100%) shared caring for a heart failure patient is challenging. There was a total of 171 instances of caregivers experiencing challenges when caring for the heart failure patient. The challenges include feeling stressed, frustrated, and financially burdened, patient non-compliance, lack of /no time for self, lack of education, and inability to understand information.

Feeling stressed, frustrated and financially burdened. All participants (100%) shared they experienced stress and frustration, and/or felt burdened while caring for the heart failure patient. One participant stated, "A lot of it is the stress from being the only caregiver. It's the stress of having multiple responsibilities." Another caregiver shared, "But, it's as the caregiver it's very stressful. You can't have any other important things in your life." A few of the caregivers specifically said they were frustrated. One participant stated, "When he first went to the rehab center he just didn't know where he was, you know. It is very frustrating." Another caregiver shared, "It is very frustrating, and I believe you know to try to be an advocate it's very hard."

Four out of eight participants (50%) admitted it was challenging to care for the heart failure patient due to financial issues. One caregiver admitted, "I mean it's gonna be a financial burden." Another participant shared, "I am, try to stay on top of him I see financial issues also are a reason why he doesn't get the correct care that I can give him," adding later, "it would cost him hundreds of extra dollars."

Patient noncompliance. All participants (100%) shared that the behavior of the heart failure patient, including forgetfulness, noncompliance, and stubbornness, contributed to the challenges they experienced. One participant shared the following story about their heart failure patient:

> The biggest challenge is trying to get her to stay put and try not to get somebody to get her to go someplace like she loves going to the church and I understand that and there's times when she shouldn't go, with bad weather and stuff, but if one person doesn't say they will pick her up then somebody else will and that's kind of a challenge, to let her know her God will forgive her if she doesn't go to church on any given day.

Another participant shared,

> Some of the challenges are like activities of daily living, he does fine and he is very independent but then he overdoes it. So, like I would get upset like if he was lifting weights at the gym or he was climbing a ladder to clean the windows on top of the house. Like I find that silly or shoveling or cutting the grass. Those kinds of over exertional activities that he doesn't really need to do.

Having no life/personal time. Seven out of eight participants (87.5%) shared they had either no time or no life due to their commitment to caring for their family member. One participant bluntly stated, "I don't have a life anymore." Another participant claimed, "It's a 24 hour a day job." Yet, another participant shared:

> Even though I do the shopping, she wants to go all the time and that's been a challenge keeping her home. You know, it's a lot more driving for me, it takes, something that takes me a half an hour by the time I would get her put her in the car, bring her to the supermarket, walk around, a half an hour job turns into 2 hours of work and it cuts into my time. You know that I don't have much of. You know, working full-time myself.

Lack of education, understanding, and information. Six out of eight participants (75%) shared they felt a lack of education, understanding, or information, from health care providers. When discussing their heart failure patient's diet, one participant stated, "And, um, I mean I don't know what a heart [failure diet] would be. What low fat? You know, I try not to have him eat fatty things."

Another participant shared a time when the heart failure patient went to the doctor's office without her. She could not make it due to work. The patient came home saying the doctor said his medication can be taken every other day instead of every day. The caregiver was not comfortable with that medication change and contacted the doctor. This is how the participant explained the conversation: "The doctor said it was okay every other day. He did? And then when I called him, the doctor to ask he's like no I didn't say that. So, I said well should he take it every day or every other day? He was like no, just tell him to stick with it every day." This was very frustrating for her because she did not believe the change was appropriate, and if she did not contact the doctor to understand this contrary information the patient would have taken the medication every other day instead of every day.

Three participants targeted the discharge instructions as not providing adequate information. One participant stated, “So, she got the standard discharge paper instructions. Um, she had some ongoing education about her diet and um level of activity. Um, not much else I’d have to say.” Another stated, “You get the pamphlets at discharge and that’s pretty much it.” A third participant shared he was given discharge instructions while driving his car on the way to the hospital and felt it was probably to expedite the discharge process.

Summary

In Chapter 4, I discussed the research setting, demographics, data collection, data analysis, evidence of trustworthiness, and results. Eight participants meeting the inclusion criteria were recruited and interviewed. Each participant consented in person or by email to explore the lived experiences of caregivers of heart failure patients.

Each participant was interviewed using the interview protocol questions. Additional probing questions were asked when more in-depth clarification was needed. Data saturation was met after the seventh interview; however, an additional participant was interviewed, and no new information was obtained. Each interview was recorded and transcribed verbatim by me. The transcribed interviews were manually coded resulting in four themes and 13 subthemes. The themes are being vigilant, seeking support, receiving support, and experiencing challenges. The interpretation of the findings will be discussed in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore the challenges experienced by caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. Data were obtained from interviewing eight participants face-to-face or by telephone. The study was conducted over a 4-month period in the Northeast United States. The findings of this study identified the perceived challenges of caregivers of heart failure patients. Caregivers are vigilant, seek support, receive support, and are faced with daily challenges. This chapter includes the interpretation of the findings, limitations of the study, and recommendations.

Interpretation of the Findings

Comparison with the Literature

The literature review in Chapter 2 correlates with the findings of the caregiver experiences identified in the interviews. The findings of this study also further exemplify the challenges caregivers of heart failure patients experience. To follow are the details of the findings for each theme and associating subthemes identified in the data analysis.

Theme 1: Being Vigilant

Caregivers in this study were always vigilant in attending to daily treatments, watching the heart failure patient’s physical condition, and scheduling appointments. All participants shared that they were being vigilant in organizing and monitoring the care of the heart failure patient. The NIH (n.d.) reports heart failure is an incurable disease that can be managed with lifestyle changes and medications; thus, the heart failure patients need a lifetime of nonstop care. The caregivers were attentive to preparing daily medications in containers to ensure the patient was taking the right medications at the correct time of day. Caregivers also reported checking the patients weight daily for fluctuations, as changes in lifestyle such as healthy weight may decrease admission to the hospital (NIH, n.d.). Furthermore, caregivers expressed that they had to arrange and attend doctors' appointments.

The findings of this study extend the knowledge of the caregiver experience the literature has identified in heart failure patient research. Researchers have explored patient and provider perspectives with limited caregiver research (Farmer et al., 2016; Retrum et al., 2013; Smeraglio et al., 2019). But possible interventions to improve readmissions are medication reconciliation and follow-up are identified in the literature (Gilmore et al., 2015; Jun & Faulkner, 2018; Phelps & Sutton, 2018; Santana et al., 2014).

Theme 2: Seeking Support

Seeking support from family, health care providers, and the Internet or social media was identified by 87.5% of the caregivers. Caregivers would reach out to family members to ask them their opinion and assistance in making decisions on behalf of the caring of the heart failure patient. Caregivers would also reach out to a nurse, doctor, or another health care provider for support in decisions and education on the care of the patient. Furthermore, to further educate themselves and seek information to assist in caring for the heart failure patient, the caregiver would search the Internet or use social media. The literature does not confirm that caregivers of heart failure patients are seeking support. However, caregivers of patients with other medical conditions have been studied, which has shown knowledge and teamwork can improve patient well-being (Grace et al., 2018). A lack of collaborative teamwork, knowledge, and support hinders the ability to cope for heart failure patients (Shahrbabaki et al., 2016).

Theme 3: Receiving Support

All caregivers in this study identified receiving support from a health care provider, family member, or from others. Health care providers such as nurses and doctors supported caregivers by providing information about medications, follow-up after discharge, watching weight for changes, and not adding salt to the diet. Patient education on medications and pharmacist follow-up calls has improved readmission rates (Gilmore et al., 2015). Caregivers also received support from family members stopping by for a visit or help with an errand such as taking the patient to a doctor's appointment. Patients who lack support from family members have trouble getting to doctors' appointments and obtain their medication prescriptions (Farmer et al., 2016). Additional services such as mail medication, meals on wheels, and community services were also supportive to the caregiver.

Theme 4: Experiencing Challenges

Challenges were experienced by all the participants in this study. Challenges included feeling stressed, frustrated, and financially burdened. Patient noncompliance, having no life or personal time, lack of education, understanding, and information were also challenges experienced by the caregivers. Stress and frustration were evident by the "heavy weight" on their shoulders of being the only one to care for the heart failure patient, having multiple responsibilities, and having to make decisions on behalf of the heart failure patient. Caregivers also shared that the heart failure patients were set in their ways, stubborn, and forgetful. Caregivers shared caring for the heart failure patient left them no time for anything else. Caregivers also experienced uncertainty in not knowing what to do, not getting the correct information from the doctor, and not getting the complete information or understanding the discharge instructions. These findings may extend knowledge of the challenges experienced by caregivers of heart failure patients, as caregivers of patients with conditions other than heart failure have been studied. Researchers have reported financial and caring hardships are challenges for caregivers of patients with other conditions (Grace et al., 2018). Additionally, patient noncompliance with diet and medications are associated with readmission, which may be due to lack of communication and education (Ahmad et al., 2016; Farmer et at., 2016; Johnson et al., 2014).

Findings and Conceptual Framework

The conceptual framework chosen to guide this study is the TCM. The TCM is focused on improving readmission of older patients (Hirschman et al., 2015; Naylor, 2000; Penn Nursing, n.d.; Rezapour-Nasrabad, 2018). Four of the nine components of the model are applicable to this study: maintaining relationships, engaging patients and caregivers, collaborating, and promoting continuity. The TCM is concentrated on the quality of the relationship among the patient, health care provider, and the caregiver. The findings of this study correlate with the TCM. Based on the results, caregivers and patients have a trusting relationship. The caregivers attend to the heart failure patient needs daily to ensure care is not interrupted, prepare medications, watch their weight, and schedule appointments. Caregivers are advocates speaking on behalf of the patient and reaching out to the health care provider as they feel necessary. But although the caregiver manages the heart failure patients' medications and appointments after discharge, at times, the caregiver is challenged by the lack of understanding and information from the health care provider.

Limitations of the Study

The limitations of this study are as outlined in Chapter 1. One acute care organization was used to obtain the purposefully selected participants. The participants are caregivers of readmitted heart failure patients. Thus, the results of this study may not be generalizable to other groups (Ravitch & Carl, 2016; Rudestam & Newton, 2015). As a novice researcher, I may have also not recognized when data saturation had been attained (Fusch & Ness, 2015). However, an interview guide was used for each interview to ensure each participant was asked the same question. I personally collected all the data, audio recorded the interviews, and translated them verbatim, and analyzed the data using the IPA technique. The dissertation committee reviewed the data and guided my analysis and identification of codes and the related themes.

Recommendations

The study has identified the in-depth lived experiences of caregivers of heart failure patients. There are studies of caregivers of patients with other conditions that have similar findings such as financial burden and patient noncompliance. As such, this study has extended the knowledge about the lived experiences of caregivers. Caregivers are attentive to the everyday needs of the heart failure patient, they look to others for support, and experience many challenges. Further research is recommended to expand this study to investigate the relationship of caregivers' stress, support, and quality of life.

Implications for Social Change

The results of this study have implications for positive social change for patients, caregivers, health care providers, and hospitals. This study has identified challenges caregivers experience in the Northeast United Stated. Health care providers' understanding of these challenges faced by the caregiver may improve the experience of the caregiver and quality of care for the patients to improve the rate of hospital readmissions. Health care providers may contribute to the patient's quality of care by ensuring that the caregivers have the necessary information to follow-up with the suggested plan of care (Farmer et al., 2016). Discharge planning programs promoting continuity of care and coordination of care may decrease hospital readmissions.

Conclusion

Heart failure is a chronic condition associated with a high rate of readmissions. This study was conducted to explore the challenges experienced by caregivers of heart failure patients ages 65 and over who were readmitted within 30 days of discharge from an acute care organization. Caregivers shared their experiences being vigilant in attending to daily treatments, appointments, and monitoring the patient's physical condition. They sought support from health care providers, family, and the Internet or social media. The caregivers also received support from health care providers, family, and others. Lastly, they shared an abundance of daily unforeseen challenges. They were feeling stressed, frustrated, financially burdened, challenged with patient noncompliance, had no time for themselves, and had a lack of education, understanding, and information. This study has provided new insight to the experiences of caregivers of heart failure patients that have the potential to develop programs to improve quality of life for patients and caregivers, improve discharge programs for patients, and decrease readmission rates. Further studies are needed to explore the relationship among stress, support, and quality of life for caregivers of patients with heart failure.

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Appendix A: Screening Criteria Questionnaire

1. Are you a primary caregiver for a heart failure patient age 65 and over who has been readmitted to the hospital within 30-days of discharge?
    - Yes
    - No
2. Are you able to speak, read, and write English?
    - Yes
    - No
3. Are you a resident or distance caregiver?
    - Resident
    - Distance
4. Are you age 18 year or older caring for a heart failure patient at home for at least 1 year?
    - Yes
    - No

Appendix B: Interview Protocol

Interview Protocol: Readmissions of Heart Failure Patients: The Caregiver's Perception

Date of Interview:

Name of Interviewee:

Location/Format of Interview:

Interview Start Time:

Interview End Time:

Interviewer: Jill Pansini

Data Record No./Code of Interviewee:

Thank you for your voluntary participation and time in this interview on the caregiver's perception of heart failure readmissions. This interview will contribute to obtaining information on the lived experiences of caregivers of heart failure patients who have been readmitted within 30-days of discharge from an acute care organization. The information may provide strategies to assist in reducing 30-day readmissions and improving health care costs. As a reminder, your interview will be audio recorded to ensure accuracy in capturing your responses. Your information will be completely confidential.

Interview Questions

1) Will you tell me about your role as a caregiver of a patient with heart failure?
2) What information did you receive to help you in caring for the patient with heart failure prior to discharge?

    a. How did the care team provide the information to you about the care needs after discharge (video, written, person to person)?
    b. What was your understanding about the care needs of the patient after discharge?
    c. What was your understanding about how to respond to changes in the patient’s condition after discharge?
3) What are the challenges you have experienced when caring for the patient with heart failure at home?
4) What helped you in caring for the patient with heart failure at home?

Closing Statement

Thank you for your time and participation in this study. The results of this study and your contribution of information may be of valuable input to the heart failure community. Can I contact you if I have additional questions? I will provide you with a 1-2 page summary of the results of the study.