Theses and Dissertations--Nursing

College of Nursing

2019

CAREGIVERS’ INFLUENCE ON PATIENTS’ HEART FAILURE SELF-CARE, HOSPITAL READMISSION AND MORTALITY

Linda Clements

Univeristy of Kentucky, lclem2@uky.edu

Digital Object Identifier: https://doi.org/10.13023/etd.2019.380

Right click to open a feedback form in a new tab to let us know how this document benefits you.

Recommended Citation


https://uknowledge.uky.edu/nursing_etds/48

This Doctoral Dissertation is brought to you for free and open access by the College of Nursing at UKnowledge. It has been accepted for inclusion in Theses and Dissertations--Nursing by an authorized administrator of UKnowledge. For more information, please contact UKnowledge@lsv.uky.edu.
STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student’s advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student’s thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Linda Clements, Student

Dr. Debra K. Moser, Major Professor

Dr. Debra K. Moser, Director of Graduate Studies
ABSTRACT OF DISSERTATION

CAREGIVERS’ INFLUENCE ON PATIENTS’ HEART FAILURE SELF-CARE, HOSPITAL READMISSION AND MORTALITY

Background: Heart failure (HF) is a leading cause of hospitalization, readmissions, and death in the United States. Patients hospitalized for HF are at risk for readmission, in-hospital mortality, and early post-discharge death. In the United States, inpatient care has been estimated to cost $83,980 over the lifetime of each patient with HF. The majority of patients with HF depend on caregiver support for successful HF self-care, which is essential for optimal patient outcomes. Support from caregivers is thought to be important for better self-care, and lower readmission and mortality rates. Yet, there are few studies considering the influence of caregivers on HF patient self-care, readmission, and mortality.

Objective: The purpose of my dissertation was to determine the influence of HF caregivers on patient self-care, readmission, and mortality. The specific aims of this dissertation were to: (1) to determine if caregiver depressive symptoms mediate the relationship between family functioning and caregiver quality of life, (2) to determine if there is an association between living arrangements (living with someone vs. living alone) and all-cause readmission and death in patients with HF, and (3) to determine the efficacy of an in-hospital, multi-session, educational intervention for caregivers on heart failure patients’ self-care and 30 day readmission rate, and to evaluate the efficacy of the intervention on caregivers’ knowledge, self-efficacy and perceived control.

Methods: Specific aim one was addressed by a secondary analysis of data from one-hundred and forty-three HF caregivers recruited from an outpatient clinic. Multiple regression with mediation analysis was used to determine whether depressive symptoms mediated the relationship between family functioning as measured using the three scales of the Family Assessment Device (i.e., general, problem-solving, communication) and caregiver quality of life. Specific aim two was addressed by a retrospective chart review of all 398 patients with a primary diagnosis of HF admitted to an academic medical center in one year. We collected data on patient sociodemographic, clinical characteristics, and patient living condition. The independent association of living alone with all-cause readmission or all-cause death was evaluated using Cox proportional hazards modeling adjusting for covariates. Specific aim three was addressed using a two-
group (educational intervention for caregivers of patients with heart failure vs. usual educational care), prospective, repeated measures randomized controlled trial of 37 patient and caregiver dyads in which caregivers only received in-hospital HF education. Outcome measures included patient self-care, and patient all-cause readmission or all-cause death, as well as caregiver self-efficacy, knowledge, and perceived control. Patient self-care, and caregiver self-efficacy, knowledge, and perceived control were assessed at baseline (in hospital), at discharge, 7 and 30-days after patient discharge. Patient readmissions and death were assessed by a phone call at 30-days follow-up. The intervention directed only at caregivers consisted of three in-hospital, educational sessions with telephone follow-up. The educational sessions were designed to deliver HF information and skills to caregivers, thereby providing them with the resources needed to improve their self-efficacy, perceived control and HF knowledge thus improving patient self-care and readmission rates.

Results: Specific aim one: The three subscales of the Family Assessment Device predicted depressive symptoms ($p < 0.001$) and caregiver quality of life ($p < 0.001$). Depressive symptoms also predicting caregiver quality of life ($p < 0.001$). The inclusion of depressive symptoms in the final model with each subscale of the Family Assessment Device (i.e., general family functioning, problem-solving, communication) decreased the significance of family functioning as a predictor of caregiver quality of life indicating mediation by depressive symptoms. Specific aim two: Heart failure patients living with someone experienced a significantly longer time to rehospitalization than those living alone (290 vs. 201 days, $p=0.005$). In a Cox regression hazard regression model, adjusting for covariates, patients who lived alone were 1.42 times more likely to be rehospitalized one year after discharge than those who lived with someone ($p=0.013$). The relationship between living alone and all-cause death was not significant after adjustment for covariates. Specific aim three: A linear mixed-model analysis revealed that patients whose caregiver was in the intervention group had significantly better self-care maintenance ($p<0.001$) and self-care management ($p < 0.001$) across time. Cox survival analysis demonstrated that patients whose caregiver did not receive the educational intervention were 11 times more likely ($p=0.002$) to experience cardiac readmission than patients whose caregiver did receive the educational intervention. Caregivers who received the educational intervention had higher perceived control ($p < 0.001$) for up to 30-days post-intervention versus the control group, however, there were no differences between caregiver groups in self-efficacy and HF knowledge.

Conclusion: In this dissertation, we found caregivers to play an important part in improving patient outcomes of self-care and readmission after discharge from a hospitalization for HF. Future large-scale studies are needed to develop and test interventions focused on caregivers to improve both patient and caregiver outcomes. Such studies will assist clinicians in understanding how better to support caregivers in their ability to positively influence HF self-care and readmission rates in patients with HF.

KEYWORDS: caregivers, heart failure, self-care, caregiver education, caregiver support
Linda Clements
Student’s Signature

September 9, 2019
Date
CAREGIVERS’ INFLUENCE ON PATIENTS’ HEART FAILURE SELF-CARE, HOSPITAL READMISSION AND MORTALITY

By

Linda Clements

__________________________
Debra Moser, PhD, RN
Director of Dissertation

__________________________
Debra Moser, PhD, RN
Director of Graduate Studies

__________________________
September 9, 2019
Date
Dedicated to my sons, Richie and Matthew, my boys, who are my joy and to my mother and father, Ollie and Eugene Wells, you always told me I could do anything that I desired, if I worked hard. Thank you!

In memory of my Dad, Eugene Wells.
ACKNOWLEDGMENTS

Throughout my life I have been blessed with exceptional people around me who saw in me more than I saw in myself. My life, career as a nurse and this dissertation are a result of their support. My first and most influential mentors, my parents, provided love and support and sacrificed in ways that continue to influence me every day. My mother who gave unselfishly in ways I could never explain and my father who gave everything to his county until he could not give anymore, I love you both and thank you. I come from a large family and each brother and sister contributed to who I am as a person, mother and student.

My older sisters, the hardest workers I know, have supported me unendingly. My brothers have been great examples of ambition and intelligence and have demonstrated generosity to me in times of need. However, my greatest support came from God. He is my father and supports me every day and in every way. I have had a personal relationship with him since I was eight years old.

For the past 30 years, I have learned to nurse from my colleagues from the University of Kentucky. My nursing ability is related to their exceptional skill at mentoring. My personal friends, Theresa Loan, Vickie Mock, and Linda Holtzclaw, have been confidants and supported me over this entire period. I could not have made it without them.

Over the last 11 years, I have been a doctoral student in the college of nursing. The faculty and staff have guided me through the journey that is research. They have taken the passion that I have for research and focused it into the best of what I can do. Dr. Moser, my chairwoman, mentor, and advisor, has given of her time and expertise to mold
me into a researcher worthy of being her student. I thank you! I want to thank Dr. Frazier, Dr. Chung, and Dr. Lennie for their advice and knowledge on heart failure research. Your dedication to my education will not be forgotten. I would like to thank Sigma Theta Tau for their grant of $1600.00 to complete my study on caregiver heart failure education.

To my boys, Richie and Matthew, you inspire me. I hope in some way, that when you read this you know, that anything is possible with perseverance. My life’s work has been to create a role model for you so that you can be so much more than me. I know you both will, and I love you and support you in whatever you do. I thank God for you every day. Even though these last years of school have been difficult, I want everyone to know that this accomplishment has brought me great joy and pride. I hope that in some way this accomplishment brings my family great joy and pride. It is truly ours to share.
# TABLE OF CONTENTS

ACKNOWLEDGMENTS ........................................................................................................ iii

LIST OF TABLES .............................................................................................................. vii

LIST OF FIGURES .......................................................................................................... viii

CHAPTER ONE  Introduction ........................................................................................... 1
  Family Functioning, Caregiver Depressive Symptoms, and Quality of Life .......... 4
  Living with Someone and Heart Failure Readmission and Mortality ............... 6
  Caregiver Education and Patient Self-Care, and Readmission ....................... 8
  Conclusion .................................................................................................................. 10
  Aims of the Dissertation ........................................................................................... 10
  Summary of Subsequent Chapters ........................................................................ 11

CHAPTER TWO  The Mediator Effects of Depressive Symptoms on the
  Relationship between Family Functioning and Quality of Life in Caregivers of
  Patients with Heart Failure....................................................................................... 14
  Abstract .................................................................................................................... 15
  Introduction ............................................................................................................. 17
  Methods ................................................................................................................... 19
  Results ...................................................................................................................... 24
  Discussion ............................................................................................................... 27
  Conclusion ............................................................................................................... 32

CHAPTER THREE  Living Arrangements, Readmission and Mortality in Patients
  with Heart Failure .................................................................................................... 45
  Abstract .................................................................................................................... 46
  Introduction ............................................................................................................. 48
  Methods ................................................................................................................... 49
  Results ...................................................................................................................... 52
  Discussion ............................................................................................................... 53
  Limitations ............................................................................................................... 57
  Conclusion ............................................................................................................... 57

CHAPTER FOUR  Improvement in Heart Failure Self-Care and Reduction in
  Patient Hospital Readmissions with Caregiver Education: A Randomized
  Controlled Trial ........................................................................................................... 65
  Abstract .................................................................................................................... 66
  Introduction ............................................................................................................. 68
  Methods ................................................................................................................... 72
  Results ...................................................................................................................... 80
  Discussion ............................................................................................................... 82
  Conclusion ............................................................................................................... 86

CHAPTER FIVE  Dissertation Conclusion ..................................................................... 98
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 2.1</td>
<td>Characteristics of caregivers of patients with heart failure</td>
<td>34</td>
</tr>
<tr>
<td>Table 2.2</td>
<td>The mediator effects of caregiver depressive symptoms on the relationship between family functioning and caregiver physical QOL</td>
<td>37</td>
</tr>
<tr>
<td>Table 2.3</td>
<td>The mediator effects of caregiver depressive symptoms on the relationship between family functioning and caregiver mental QOL</td>
<td>40</td>
</tr>
<tr>
<td>Table 3.1</td>
<td>Characteristics of heart failure patients in the total sample and compared between those living alone compared to living with someone</td>
<td>58</td>
</tr>
<tr>
<td>Table 3.2</td>
<td>Cox regression model showing the association between living with someone and all-cause readmission</td>
<td>61</td>
</tr>
<tr>
<td>Table 3.3</td>
<td>Cox regression model showing the association between living with someone and all-cause death</td>
<td>62</td>
</tr>
<tr>
<td>Table 4.1</td>
<td>Baseline Patient Participant Characteristics</td>
<td>88</td>
</tr>
<tr>
<td>Table 4.2</td>
<td>Baseline Caregiver Participant Characteristics</td>
<td>90</td>
</tr>
<tr>
<td>Table 4.3</td>
<td>Comparison of Patient Outcomes Across Time Between Intervention and Usual Care Groups</td>
<td>93</td>
</tr>
<tr>
<td>Table 4.4</td>
<td>Comparison of Caregiver Outcomes across Time between Intervention and Usual Care</td>
<td>94</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

| Figure 1.1 | Conceptual framework ............................................................................. 13 |
| Figure 2.1 | Steps to test for direct and mediator effect ........................................ 44 |
| Figure 3.1 | Cox regression plot of living with someone and all-cause rehospitalization ............................................................................. 63 |
| Figure 3.2 | Cox regression plot of living with someone and cardiac rehospitalization ............................................................................. 64 |
| Figure 4.1 | Participant Flow through the Study .......................................................... 96 |
| Figure 4.2 | Cox regression plot for caregivers who received educational intervention versus the usual care group ........................................ 97 |
CHAPTER ONE

Introduction

Heart failure (HF) is a leading cause of hospital readmissions and death in the United States (U.S.) and worldwide.\textsuperscript{1} Heart failure affects approximately 6.5 million people over the age of 20, with the prevalence expected to increase by 46% in the U.S. population by 2030, affecting approximately 8 million people.\textsuperscript{2,3} At 40 years of age, the lifetime risk of developing HF for both men and women is 20% regardless of age.\textsuperscript{1} Survival of patients with HF is improving over time related to new technologies and pharmaceuticals, yet most HF management still takes place at home.\textsuperscript{4} Unplanned readmissions for HF patients result in a total expenditure exceeding 40 million dollars in the U.S. alone.\textsuperscript{1} Given that more than half of HF readmissions are deemed to be preventable, with most attributed to poor self-care, there is a clear need to improve HF self-care to prevent poor HF patient outcomes.\textsuperscript{5}

Recently, a published meta-analysis of 20 randomized controlled trials confirmed that improvement in patients’ HF self-care is associated with decreased mortality and readmission rates.\textsuperscript{6,7} Self-care is defined in heart failure as a process of decision-making and behaviors influencing actions to maintain health stability, to recognize symptoms of changes in condition, and to respond deliberately to those changes.\textsuperscript{8} Heart failure patients practicing successful self-care have fewer readmissions, better quality of life and lower mortality than those performing poor self-care.\textsuperscript{9-11} However, most patients do not perform HF self-care successfully.\textsuperscript{12} Heart failure patients are on multiple medications, follow a specific low sodium diet, and monitor their daily weight making HF self-care very difficult. Major characteristics that are known to inhibit a patient’s ability to perform
self-care is the presence of co-morbidities, cognitive impairment, depressive symptoms, anxiety, and poor health literacy.13

Because HF self-care is resource-intensive involving complex treatment plans, most patients require assistance from caregivers in performing successful self-care.14 Heart failure patients rely on caregivers to facilitate their ongoing well-being by contributing to HF self-care through related tasks such as medication management,15 and dietary sodium adherence16 which is shown to improve self-care and HF readmissions.17,18 However, the current evidence related to caregiver influence on HF patient outcomes is lacking. The conceptual model influencing this dissertation is a combination of the Individual and Family Self-management theory,19 social cognitive theory (SCT),20 and social support theory (Figure 1.1).21 Social relationships have considerable influence on the health of individuals with HF. The conceptual framework for this dissertation (Figure 1.1) is influenced by the Individual and Family Self-Management framework,19 social cognitive theory (SCT) and social support theory.20,19,21 The concept of family and support from others is very significant to self-care. The Individual and Family Self-Management framework outlines the relationship between individual, family and clinical factors and self-care within a contextual environment.19 What makes this model unique is the integration of variables from family and other social resources within into the context in which self-care is performed, the home. This model identifies family and social structural factors that influence individual self-care behaviors as part of HF treatment adherence. Social cognitive theory (SCT) is also integrated into this conceptual model. Social cognitive theory suggests that encouragement, persuasion, role modeling, and ongoing support from a family or person in which the individual has a
close social relationship can positively influence the patients’ own efficacy judgments, thus improving their health behavior. Caregivers or others living with the patient who are confident in their patients’ ability to perform self-care are more likely to offer words of encouragement. Evidence supports that people tend to pursue the tasks they know they can accomplish and avoid the ones they know they cannot. Patients obtain normative guidance through comparison of similar behaviors within their social environment. This influence can occur through simple observations or the verbal persuasion of others. Since norms for health behavior are learned from the social environment, assistance and support from family members or close others can be very influential in changing or sustaining health behavior. Social support theory posits that social support is one of the major influences on health behaviors. The exchange of social support is the major basis of developing and maintaining social relationships. Support interventions often use existing social support, social exchange, and social influence processes such as modeling and verbal persuasion.

In this dissertation, it is hypothesized caregivers support patients with HF through direct social links such as those who assist in bedside self-care but also through indirect means such as those living in a household with the patient many tasks. Heart failure self-care education can optimize the caregiver role increasing their self-efficacy, perceived control and knowledge which is needed for successful patient self-care. The mechanisms by which caregivers influence patient outcomes of self-care, readmission and mortality has not been clearly defined. This dissertation will help to quantify some of their influence on the outcomes of HF self-care, readmissions and mortality.
The purposes of this dissertation were to: (1) to determine if caregiver depressive symptoms mediate the relationship between family functioning and caregiver quality of life, (2) to evaluate the association between living arrangements (living with someone vs. living alone) on all-cause death and rehospitalization in patients with HF (3) to evaluate the effectiveness of an in-hospital, three-session, interactive, caregiver only, educational intervention aimed at improving caregiver self-efficacy, HF knowledge, and perceived control thus improving patient self-care and readmission rate.

**Family Functioning, Caregiver Depressive Symptoms, and Quality of Life**

Caregiving for patients with HF exacts a massive toll on the well-being of caregivers with them frequently describing caregiving for HF patients as overwhelming. Caregivers suffer from depressive symptoms at four times the rate of non-caregivers. Depressive symptoms are common in HF caregivers with greater than 30% of caregivers experiencing depressive symptoms. Some studies report depressive symptoms among HF caregivers to be equal to or worse than depressive symptoms in patients with HF. Depressive symptoms in caregivers are associated with poor quality of life. For example, Pressler and colleagues, found depressive symptoms at baseline in caregivers of patients with HF to predict a worse caregiver quality of life at a 4-month follow-up. Depressive symptoms are a known predictor of poor caregiver quality of life.

Quality of life is defined in this study as the perceived quality of an individual's daily life, that is, an assessment of their well-being or lack thereof including all emotional, social and physical aspects of the individual’s life. Investigators also discovered poor caregiver quality of life to be associated with poor patient quality of life which is associated with an increase in patient readmissions and mortality.
other than depressive symptoms like family functioning can influence caregiver quality of life.\textsuperscript{37,38}

It is well known that a person who has a chronic illness can disorganize the life of the entire family and disrupt the family’s overall lifestyle.\textsuperscript{39} Caregivers often report insufficient support from family members with a lack of appreciation for their efforts.\textsuperscript{40-42} Caregivers report families as being neglectful to them as well as offering inadequate emotional, informational and tangible support for their caregiving activities.\textsuperscript{43-46} Caregiving for a patient with HF can be a very daunting task that carries with it stress directly related to caregiving activities involving the family environment.

Family functioning refers to the relationships and emotional connections between members within the family system.\textsuperscript{47} Poor family functioning can have negative effects on caregivers due to family conflict or lack of cohesion between patient, caregiver and family members.\textsuperscript{48} Conflictual or poor functioning families are apt to provide less assistance to caregivers causing them increased depressive symptoms leading to a poor quality of life.\textsuperscript{49} Prior studies suggest that family functioning plays an important role in determining caregiver quality of life; however, there is little evidence in the HF population and what is reported is conflictual.\textsuperscript{48,50-52} Two studies have examined the relationship between family functioning and HF caregiver quality of life with conflicting results.\textsuperscript{30,53} The association between family functioning and caregiver depressive symptoms has not yet been examined in the HF population, but research in other populations find poor family functioning to be a predictor of depressive symptoms.\textsuperscript{54,55} Considerable research has demonstrated that there is a strong association between depression and impaired family functioning.\textsuperscript{56,57,58,59} The relationship between poor
family functioning and depression is certainly present, but it is unclear if the family
dysfunction maintains the depression or if the depression maintains family dysfunction. It
is also unclear in the HF population the underlying mechanism between family
functioning and caregiver quality of life. Therefore, exploration and understanding of the
relationship between family functioning, caregiver quality of life, and depressive
symptoms are important in designing appropriate interventions to assist in improving
caregiver outcomes.53,60 Some patients do not self-report having caregiver support at
home, however they may report living arrangements indicative of support from someone
living in their household.

Living with Someone and Heart Failure Readmission and Mortality

Socioeconomic factors are implicated as impacting HF patient outcomes of
readmission and mortality.61,62 The social environment of a HF patient can inhibit or
promote the successful management of HF.63 Living arrangements of living with
someone or a having a partner is reported to be a high form of support, and those patients
with HF who are married are shown to have a lower readmission, and mortality rate and
even higher event-free survival.61,64 However, it is not known if living with someone is as
protective as being married against poor HF outcomes such as readmissions and mortality
in patients with HF. The term “being married” does not necessarily indicate whether a
person is actually living alone, or with others or in a collective household.61,64,65 It is
reported that the proportion of U.S. adults who are currently married are at a historic low.
66 Over the past quarter century, the share of men ages 50 years and older who are
married has declined from 78% in 1990 to 67.3% in 2015.67 Another big change in living
arrangements has to do with the increase in non-family households.68 More Americans
are living alone. In fact, the percent of households with only one person climbed from 17 percent in 1970 to 27 percent in 2012. In 2011, there were eleven million one-person households maintained by individuals 65 years and older. We have evidence available on the influence of marital status on patients with cardiovascular disease. In a recent review of 35 studies of the evidence related to the influence of marital status or being single on cardiovascular risk, investigators reported marital status to be associated with lower cardiovascular risk factors and better health status, including all-cause mortality. Heart failure patients who are married are shown to have less readmissions and better survival. However, few studies have examined the influence of living arrangements such as living with friends, a partner or a family member on HF patient outcomes of self-care, readmission and mortality. Therefore, in assessing the effects of potential support from living with someone on mortality and readmission risks, we need to look beyond the role of legal marital status and investigate living arrangements more directly.

Any individuals acting as support to patients at home may serve as a critical extension of the formal health care system, and supporting these individuals has recently emerged as a national public health priority. Recently, the American Heart Association released a statement emphasizing the need to focus on self-reported social determinants such as living arrangements when forming a treatment plan for patients with HF. Therefore, it is essential to determine if the same positive relationship for patient outcomes exists for those patients who do not have spouses, but who receive assistance from within their realm of social relationships i.e. their social network such as from partners, friends or family. Once individuals who provide support for patients are
identified, it is important to determine the resources needed for those living with them to continue their support. Identified support sources such as those living with the patient should be incorporated in HF self-care patient assessments and educational interventions as important sources of support in order to facilitate and enhance successful self-care.

**Caregiver Education and Patient Self-Care, and Readmission**

Readmission rates within 30-60 days of HF patients’ discharge is 15% and 30% respectively, with the highest rate among those patients admitted to the hospital over the age of 65. Heart failure self-care education has been the cornerstone for enhancing the 'patients' ability to perform HF self-care thus preventing readmissions. However, patients most often perform self-care with the assistance of others such as caregivers. Even though support from caregivers are essential to successful HF self-care, they are often not included in HF discharge education. Caregivers describe feeling overlooked, neglected and unprepared to assist the patient in self-care after discharge. Caregivers assist patients in self-care activities such as medication administration, dietary sodium restriction, symptom monitoring, and treatment decisions. Most patients experience at least two changes in their usual medications during hospitalization with modifications in diet and fluid restrictions, making self-care difficult after discharge. Caregivers can act as resources and proxies for self-care making it vital for their involvement in HF discharge education. If patients cannot participate in discharge education and caregivers are not included, patients are at higher risk for readmission and death post-discharge. Therefore, national guidelines recommend including caregivers in HF discharge education, yet this is not routinely practiced. Caregivers if
adequately educated, had the opportunity because of time spent with the patient to positively influence HF self-care and patient readmissions.\textsuperscript{20,93}

Self-efficacy, perceived control and HF knowledge are a few personal characteristics that are considered personal assets in providing resolve to manage chronic illness.\textsuperscript{94,95-97} Caregiver self-efficacy for HF patient self-care is the feeling of confidence the caregivers has in their ability to keep the patient free of HF symptoms.\textsuperscript{8,98} Recent evidence supports the importance of caregiver self-efficacy in HF patient self-care. One investigator reported results of the two hierarchical regression analyses suggested that caregiver confidence significantly affected caregiver’s contribution to both self-care maintenance and to self-care management.\textsuperscript{99} Caregiver perceived control can influence their perception of their ability to help the heart failure patient manage their illness. Research in HF and other chronic illness populations has suggested that caregiver perceived control is associated with better self-care.\textsuperscript{100-102} In order to be a competent resource for HF patient self-care, accurate HF knowledge is needed. Knowledge about the condition in which self-care is being performed has found to be a determinant for successful self-care.\textsuperscript{16} Evidence from other HF chronic illness populations have shown improving caregiver characteristics such as self-efficacy, perceived control and HF knowledge with education and training to have a positive influence on patients’ self-care thus improving patient outcomes.\textsuperscript{103-108}

Caregivers and patients share a relationship and social interaction over time. In this relationship, caregivers and patients can influence each other’s behaviors.\textsuperscript{109} For example, the problem-solving skills of HF caregivers are reported to be associated with levels of depression and satisfaction in patients,\textsuperscript{110} patients and caregivers with higher
depressive symptoms were reported to be more likely to report their own quality of life as poor\textsuperscript{28} and social factors, such as marital status and living alone, are shown to be associated with patient HF self-care, readmissions, and survival.

**Conclusion**

This dissertation will fill in some of the gaps with greater understanding and quantification of caregivers’ influence on HF caregiver and patient outcomes. Even though most HF patients have caregivers to assist them in self-care, caregiver characteristics, and their influence on patients’ outcomes is rarely included in interventions or measured. Therefore there are significant gaps in what is known about the influence of caregivers to heart failure patient outcomes of self-care, readmission, and mortality. Understanding the influence of HF caregivers on patients’ outcomes can help establish novel interventions targeting caregiver education and resources toward caregivers’ behaviors at improving patient self-care, readmissions, and mortality.

**Aims of the Dissertation**

Therefore the specific aims of this dissertation are to: (1) to determine if there is a relationship between family functioning, caregiver quality of life and depressive symptoms and if depressive symptoms mediate the relationship between family functioning and caregiver quality of life, (2) to determine efficacy of living with a family member, partner or friend on HF patients’ readmission and mortality, (3) and to determine the effect of an educational intervention aimed at caregivers of hospitalized HF patients on caregiver characteristics of self-efficacy, perceived control and knowledge on improving patient self-care and readmissions.
Summary of Subsequent Chapters

Chapter Two is a report of a secondary data analysis we conducted to determine the mediating effects of caregiver depressive symptoms on family functioning and caregiver quality of life. The sample was from an HF outpatient clinic at a tertiary care hospital. Depressive symptoms in HF caregivers are associated with poor health. Research regardless of gender, age, social participation and quality of social support received unhealthy lifestyles has shown that family functioning has a close relationship with depressive symptoms.\textsuperscript{39,111-115} However, the causal mechanisms between family functioning and caregiver quality of life has not been clearly understood. Mediation analysis will provide insight into the workings of the relationship between family functioning, caregiver depressive symptoms and caregiver quality of life so that appropriate interventions can be developed improving caregivers outcomes thus preventing poor patient outcomes.

Chapter Three is an analysis of the association between living with a family member, partner, or friend on and patient outcomes of readmission and mortality. This was a retrospective chart review. Data were collected from an electronic medical record. Being married and having social support is shown to provide some protection against readmission and mortality in the HF population.\textsuperscript{61,116} Living alone is a known risk factor for higher readmission rates and mortality.\textsuperscript{72,73} However, the influence of living with someone in the same household on HF patient outcomes of readmission and mortality is unclear. It is hypothesized that those HF patients living with someone with have better all-cause readmission and mortality rates than those living alone. Cox regression analysis was performed to determine the association between living with someone versus living alone on all-cause readmission and death. Identifying patients at high risk of readmission
and mortality can assist in the development of interventions to improve post-discharge outcomes of readmission and death.

Chapter Four is a randomized clinical trial of the influence of delivering an HF self-care educational intervention to caregivers of hospitalized HF patients on caregiver characteristics of self-efficacy, perceived control and HF knowledge on patient outcomes of self-care and 30-day readmissions. The sample consisted of 37 patient-caregiver dyads recruited while the patient was admitted to a tertiary care hospital. Education was given to caregivers only in three, in-hospital sessions with data being collected at baseline, after the intervention, before discharge and per telephone follow-up at 7 and 30-days after discharge. Univariate and Cox analysis was performed to determine the association between caregiver characteristics and patient outcomes of self-care and 30-day readmission. This chapter will provide insight into how educating caregivers of HF patients can influence patient outcomes of HF self-care and readmissions.

In Chapter Five, a summary, discussion, and conclusions are presented with implications from these studies and recommendation for future research to advance our understanding of the relationship of caregiver characteristics to patient outcomes.

Copyright © Linda Clements 2019
Figure 1.1 Conceptual framework
CHAPTER TWO

The Mediator Effects of Depressive Symptoms on the Relationship between Family Functioning and Quality of Life in Caregivers of Patients with Heart Failure
Abstract

**Background:** Caregivers of patients with heart failure (HF) commonly report depressive symptoms and poor quality of life (QOL) and these may be related to poor family functioning. Caregiver depressive symptoms and poor QOL are predictors of risk for poor caregiver health. Understanding the relationship between depressive symptoms, family functioning, and caregiver QOL is necessary for the development of successful interventions to improve caregiver health.

**Aim:** The aim of this study was to examine the mediator effect of depressive symptoms on the relationship between family functioning and QOL in the HF caregiver.

**Methods:** A secondary data analysis of 143 caregivers of patients with HF was conducted. Caregivers completed measures evaluating depressive symptoms (The Patient Health Questionnaire-9), family functioning (Family Assessment Device three subscales of general functioning, problem-solving and communication) and QOL (physical and mental health subscales of the Short Form-12).

**Results:** The three subscales scores of the Family Assessment Device, general, problem-solving and communication, predicted depressive symptoms ($p < 0.001$, $p < 0.001$, $p < 0.001$, respectively), as well as caregiver physical ($p = 0.002$, $p = 0.013$, $p = 0.002$, respectively) and mental quality of life ($p < 0.001$, $p < 0.001$, $p < 0.001$, respectively). Depressive symptoms predicted physical ($p < 0.001$) and mental ($p < 0.001$) QOL. The inclusion of depressive symptoms in the final model with each subscale of the Family Assessment Device decreased the significance of general ($p = 0.219$), problem-solving ($p = 0.387$) and communication ($p = 0.102$) family functioning as predictors of caregiver physical QOL. Similarly, the addition of depressive symptoms in the final model with
each subscale of the Family Assessment Device decreased the significance of general (p = 0.034), problem-solving (p = 0.046) and communication (p = 0.013) family functioning as predictors of mental QOL. These results indicate that depressive symptoms mediate the relationship of family functioning with caregiver physical and mental QOL.

**Conclusion:** The results of this study suggest that interventions targeting caregiver depression and family functioning could be effective in enhancing HF caregivers’ physical and mental QOL.
The Mediator Effects of Depressive Symptoms on the Relationship between Family Functioning and Quality of Life in Caregivers of Patients with Heart Failure

**Introduction**

There are approximately 6.5 million patients in the United States currently diagnosed with HF. In order to improve outcomes, HF patients must perform effective HF self-care.¹ As most management of HF occurs at home and most patients with HF are elderly with impaired functional status, caregivers typically assist patients with their complex self-care regimens, which can be rewarding to some.² There can, however, be negative consequences associated with caregiving.³ The purpose of this study was to determine if depressive symptoms mediate the relationship between family functioning and physical and mental quality of life of caregiver of patients with HF.

Depressive symptoms are a common source of psychological distress in caregivers of patients with HF.⁴⁻⁶ Previous investigators found that about 45% of spousal caregivers caring for end-stage HF patients report depressive symptoms,⁶ and that approximately 23–47% of all caregivers of those with HF report at least mild to moderate depressive symptoms.⁵,⁷ Depressive symptoms in caregivers of patients with HF can affect their risk for cardiovascular disease and mortality,⁸ and poor QOL.⁹,¹⁰

Thirty-two percent of HF caregivers are known to report poor QOL.¹¹⁻¹³ Caregivers of patients with HF who report depressive symptoms are more likely to report poor QOL.¹⁴⁻¹⁶ Caregivers often neglect their self-care in order to perform HF caregiving.¹⁷ They adjust their daily schedule, defaulting to the needs of the patient, leaving less time for their activities, self-care, and social relationships. Caregiver self-neglect causes psychological distress, leading to depressive symptoms.¹⁶,¹⁸
investigators have found that HF caregiver depressive symptoms are associated with poor caregiver QOL.\textsuperscript{5,7,14,18,19}

The family is a closely interconnected social unit, and illness in one family member is sure to affect the functioning of the family.\textsuperscript{20} Given that most HF care occurs in the home, and caregivers assist the vast majority of HF patients, it is essential to consider the role of the family in the caregiving experience.\textsuperscript{21} Heart failure self-care can disrupt pre-existing family relationships, communication, problem-solving, daily rituals, and routines.\textsuperscript{22} Yet, the research about the role of the family is limited in the HF caregiver population. There is, however, some evidence that family factors such as family functioning may influence caregiver depressive symptoms and QOL.\textsuperscript{23,24}

Poor family functioning can contribute to stress among caregivers.\textsuperscript{25} If functioning well, families can be an important source of support to caregivers, lending them respite, and time for self-care and leisure activities.\textsuperscript{26} Families with poor family functioning are disengaged, disrupted by conflict, exhibit disintegration, poor communication, and are less likely to assist in caregiving.\textsuperscript{5,7,27-32} Even though there is some evidence related to the relationship between family functioning, depressive symptoms, and caregiver QOL in other chronic illness populations, research in the HF population is very limited.\textsuperscript{25,33-36}

Two investigative groups have studied the relationship between family functioning and HF caregiver QOL with conflicting results. One group of investigators found caregiver depressive symptoms to be independently associated with poor family functioning and poor QOL, while the other study found no independent relationships among family functioning, depressive symptoms, and caregiver QOL.\textsuperscript{18,35} Because only
cross-sectional studies have been done, the direction of the relationship is unclear. Caregivers who perceived their family functioning to be poor may be more likely to report higher levels of depressive symptoms, while it is likely that caregiver with higher levels of depressive symptoms may report worse family functioning. In studies with caregivers of patients with stroke and mood disorder, poor family functioning independently predicted caregiver depressive symptoms. Based on this evidence, we hypothesized that caregiver depressive symptoms would mediate the relationship between family functioning and caregiver QOL.

Given the high prevalence of depressive symptoms and poor QOL in HF caregivers, as well as the importance of well-functioning families to caregiving, determining the mechanism by which depressive symptoms influence the relationship between family functioning and caregivers’ QOL is warranted. Understanding the mechanism for the relationship between family functioning and caregivers’ QOL is necessary for the development and successful implementation of interventions to improve both caregiver and HF patient outcomes. Therefore, we aimed to examine the mediator effect of depressive symptoms on the relationship between family functioning and QOL in caregivers of patients with HF.

**Methods**

**Design**

This study was a cross-sectional, secondary analysis using baseline data collected from HF caregivers who participated in a longitudinal observational study. Caregivers of patients with HF were recruited from outpatient clinics in an academic medical center.
Sample

Caregivers were eligible for the study if patients identified them as the primary caregiver who assisted them with HF self-care. Caregivers needed to be cognitively capable of providing informed consent and able to read and write English. Caregivers were excluded if they had major medical conditions, including HF, cancer, or other terminal illnesses. When caregivers met eligibility inclusion criteria, they were provided with information about the study, after which they gave informed, signed consent.

Measures

Sociodemographic data (i.e., gender, age, education, ethnicity, relationship with the patient, and days per week spent caregiving) and clinical (comorbidities) characteristics of caregivers were collected by interview and standardized questionnaire.

Family functioning. Family functioning was assessed using the Family Assessment Device (FAD),\textsuperscript{39} which is based on the McMasters family functioning model.\textsuperscript{33} Family functioning is the ability of the family to work together to satisfy the basic needs of its members.\textsuperscript{40} The FAD is a 27-item instrument used to evaluate family functioning in the context of a variety of physical and mental illnesses.\textsuperscript{41} The three subscales of the FAD were used in this study to measure caregivers’ perceptions of family functioning.\textsuperscript{42} These subscales are the following: (1) general family functioning subscale, which evaluates the overall level of family functioning; (2) problem-solving subscale, which evaluates the ability of the family to solve problems at a level that will maintain the overall effectiveness of family functioning; and (3) communication subscale, which evaluates the effectiveness of the exchange of information between family members. Participants rate how well each item depicts their family on a four-point
Likert scale. Each subscale score is calculated by averaging the items on each scale. Possible total scores range from one to four for each of the three subscales. Standard cut-off scores for each subscale (2.0 for family functioning and 2.2 for problem-solving and communication) were used to determine the poor versus healthy family functioning.\textsuperscript{35,43,44} Adequate validity and reliability of the scale are reported among healthy persons, psychiatric patients, and patients with HF.\textsuperscript{45,46} These scales have been used in other studies in HF populations with good reliability and sensitivity.\textsuperscript{47,48} The Cronbach’s alpha score in this study for general family functioning was 0.77, for problem-solving was 0.80 and for communication was 0.66.

**Depressive symptoms.** The Patient Health Questionnaire (PHQ-9) was used to measure caregiver depressive symptoms.\textsuperscript{49} The PHQ-9 is a nine-item, self-report screening questionnaire that measures the frequency of depressive symptoms over the past two weeks using a four-point Likert scale.\textsuperscript{41} Each item corresponds to one of the criteria for diagnosing depression from the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition.\textsuperscript{50} Scores can range from 0 to 27, with higher scores indicating more severe depressive symptoms. Individual scores of 1-4 indicate no depressive symptoms, 5-9 indicate mild depressive symptoms, 10-14 indicate moderate depressive symptoms, 15-19 indicate moderately severe depressive symptoms and a score of 20-27 indicates a level of severe depressive symptoms.\textsuperscript{51} A recent psychometric analysis in patients with HF showed good internal consistency reliability with a Cronbach alpha of 0.87, as well as good concurrent validity when compared to the Beck Depression Inventory-II ($r = 0.78$, $p < 0.01$).\textsuperscript{41} The Cronbach alpha coefficient for the PHQ-9 in this study was 0.91.
Quality of life. Quality of life was assessed using the twelve items derived from the Short Form -12 Health Survey Version 2 (SF-12v2). The SF-12 is composed of 12 items that are aggregated into two dimensions: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The PCS items address physical QOL as influenced by physical health, physical functioning, role limitations caused by physical health and bodily pain. The MCS items address mental QOL as influenced by mental health, vitality, and role limitations caused by mental health and social functioning. A standardized score ranging from 0 to 100 is obtained for each SF-12 scale, with higher scores indicating better QOL. Scores are calibrated as such that the national norm is a mean score of 50.0 and a standard deviation of 10.0. The SF-12 is demonstrated to be a valid and reliable instrument in HF patients and caregivers of patients with chronic conditions.

Procedure

The Institutional Review Board of the University of Kentucky approved the parent study and this secondary data analysis involving caregivers of patients with HF. Primary care providers referred participants to the study. Trained research nurses contacted caregivers during outpatient clinic visits for their family member with HF. Research nurses obtained informed consent from each eligible caregiver. Study questionnaires were given to each caregiver. Questionnaires were either given to participants at a clinic visit or mailed to their homes. Caregivers were asked to complete the questionnaires in their packets without discussing their answers with their ill family member. Completed questionnaires were returned to the research nurse using a stamped,
addressed envelope, or collected by the nurse during a home visit. Participants received reminder calls if the questionnaires were not returned on time.

**Data Analysis**

All data analyses were performed using IBM SPSS 21.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.). An alpha of <0.05 was used to determine significance. A series of multiple regression analyses were used to determine whether depressive symptoms mediated the relationship between the three FAD subscales and caregiver mental health QOL (Figure 2.1). The four necessary steps for establishing mediation were the following: (1) determine if the predictor variable in this case, family functioning is a significant predictor of the mediator variable (i.e. depressive symptoms), (2) determine if the predictor variable is a significant predictor of the outcome variable (i.e., caregiver physical and mental health QOL), (3) determine if the mediator is a significant predictor of the outcomes variable (i.e. caregiver physical and mental health QOL), and (4) when both the mediator and the predictor are included in the same regression as potential predictors of the outcomes, the latter becomes less significant or no longer significant at all.56

The Sobel test was performed to assess the statistical significance of the indirect effect (i.e., mediator effect) in each of the mediation models.57 This test determined the significance of the reduction in the impact of the predictor variables (general, problem-solving, communication family functioning) on the dependent variable (QOL) when depressive symptoms were included in the regression. Multiple regression standardized beta weights were used to summarize the direct effect of family function and indirect effects of the mediator, depressive symptoms, on caregiver QOL.56
Results

Caregiver Characteristics

The sociodemographic and clinical characteristics of the sample of caregivers are shown in Table 2.1. A total of 143 caregivers with a mean age of 56 ± 14 years were included in the analysis. Of the total participants, 90% were Caucasian, 68% were female, and 73% were spouses. Eighty-three percent of caregivers reported more than a high school education. Ninety-two percent of caregivers reported living with patients with HF for an average of 28 ± 17 years. One-fourth of caregivers (28%) worked full or part-time, and 9% reported that they quit a job or retired early to take care of patients. More than half of caregivers (69%) reported spending seven days per week caring for the HF patient. Half of the caregivers were healthy without any comorbidities, and the other half had at least 1-3 comorbidities. The most common occurring comorbidities were hypertension (45%) and diabetes (20%).

The mean PHQ-9 score for caregivers was 5 ± 6, and 23% had at least mild depressive symptoms (PHQ-9 score 5-9). The mean scores of 1.94 ± 0.43 for general family functioning, 1.98 ± 0.43 for problem-solving family functioning and 2.17 ± 0.44 indicating poor family functioning. Family functioning was reported to be poor by 36% of caregivers on the general family functioning subscale (score > 2.0), 20% on the problem-solving family functioning subscale and 52% on the communication subscale (score >2.2). The mean score for the mental health QOL subscale was 50 ± 10, and the mean score for the physical health QOL scale was 43 ± 11; 29% of caregivers reported poor physical QOL and 58% reported poor mental QOL.
Mediator Effect of Depressive Symptoms on the Association Between General Family Functioning and Physical and Mental QOL

As shown in Table 2.2 and Table 2.3, general family functioning was independently associated with depressive symptoms ($\beta = 0.468, p < 0.001$), and with caregiver physical QOL ($\beta = -0.314, p = 0.002$) and mental QOL ($\beta = -0.536, p < 0.001$) satisfying the first and second requirements for mediation. That is, poor family functioning was associated with higher levels of depressive symptoms, and poorer physical and mental QOL. Depressive symptoms were predictive of caregiver physical QOL ($p < 0.001$) and mental QOL ($p < 0.001$), satisfying the third requirement for mediation. Worse depressive symptoms were associated with poorer physical and mental QOL. The final requirement for mediation was met when depressive symptoms were added to the models that included physical and mental QOL as the outcome. With the addition of depressive symptoms to the model, general family functioning became non-significant as a predictor of caregiver physical QOL ($p = 0.219$), and of mental QOL ($p = 0.34$). The Sobel’s z-test for general family functioning and both physical ($z = -2.62, p = 0.008$) and mental ($z = -5.0, p < 0.001$) QOL indicated that depressive symptoms were a significant mediator in the relationship between general family function and caregiver QOL. The indirect/total ratio indicated that 48.8% of the variance in caregiver physical QOL and 62% of the variance in caregiver mental health QOL was explained by the mediator, depressive symptoms.
Mediator Effect of Depressive Symptoms on the Association Between Problem-Solving and Caregiver Physical and Mental QOL

As shown in Table 2.2 and Table 2.3, problem-solving family functioning was independently associated with depressive symptoms ($\beta = 0.415, p < 0.001$), and with caregiver physical ($\beta = -0.257, p = 0.013$) and mental QOL ($\beta = -0.475, p < 0.001$). That is, poor problem-solving was associated with higher levels of depressive symptoms, and poorer physical and mental QOL. In addition, depressive symptoms were predictive of caregiver physical QOL ($p < 0.001$) and mental QOL ($p < 0.001$). Worse depressive symptoms were associated with poorer physical and mental QOL. These steps demonstrated satisfaction of the first three requirements for mediation. The final requirement for mediation was met when depressive symptoms were added to the problem-solving family functioning model with physical and mental QOL. The significance of problem-solving family functioning decreased for physical QOL ($p = 0.387$) and mental QOL ($p = 0.046$), signifying mediation. The Sobel’s z-test indicated that depressive symptoms were a significant mediator in the relationship between problem-solving family functioning and physical QOL ($z = -2.82, p = 0.004$) and mental ($z =-4.8, p < 0.001$) QOL. The indirect/total ratio indicated that depressive symptoms explained 57.9% of the variance in caregiver physical QOL and 64% of the variance in caregiver mental health QOL.

Mediator Effect of Depressive Symptoms on the Association Between Communication and Caregiver QOL

As shown in Table 2.2 and Table 2.3, communication family functioning was independently associated with depressive symptoms ($\beta = 0.384, p <0.001$), caregiver
physical QOL ($\beta = -0.326, p = 0.002$) and mental ($\beta = -0.509, p = < 0.001$) QOL. Worse communication was associated with higher levels of depressive symptoms, and worse physical and mental QOL. Higher levels of depressive symptoms were predictive of worse caregiver physical QOL ($p < 0.001$) and mental QOL ($p < 0.001$), thus, satisfying the second and third requirement for mediation. The final requirement for mediation was met when depressive symptoms were added to the model with communication family functioning, and physical QOL, and the model then became nonsignificant ($p = 0.102$). The same occurred when depressive symptoms were added to the model with communication and mental QOL, and the model became less significant ($p = 0.013$). The Sobel’s z-test indicated that depressive symptoms were a significant mediator in the relationship between communication family function and physical QOL ($z = -2.53, p = 0.011$) and mental QOL ($z = -4.4, p < 0.001$). The indirect/total ratio indicated that depressive symptoms explained 37.5% of the variance in caregiver physical QOL and 53.9% of the variance in caregiver mental health QOL.

**Discussion**

This study provides a step toward gaining a more comprehensive understanding of how family functioning and depressive symptoms interact to contribute to HF caregiver physical and mental QOL. In this study, we found family functioning to predict caregiver depressive symptoms and caregiver physical and mental QOL, and that depressive symptoms mediated the relationship between family functioning measured by all three of the subscales (i.e., general, problem-solving and communication) and caregiver mental and physical QOL.
Consistent with previous studies, caregiver depressive symptoms and family functioning, predicted caregiver physical and mental QOL.\textsuperscript{5,7,14,35} Our results align with previous research in HF patients and other chronic illness populations that determined there was a negative relationship between family functioning and caregiver QOL\textsuperscript{24,35,58,59} and depressive symptoms and caregiver QOL.\textsuperscript{7,31,60} Findings from our study suggest that poor family functioning increases the incidence of caregiver depressive symptoms thus increasing the risk of poor caregiver QOL. The positive relationship between family functioning and depressive symptoms in our study is consistent with previous studies that suggested as family functioning worsens, so does caregiver depressive symptoms.\textsuperscript{37,61,62} The major finding in our study in that depressive symptoms mediated the relationship between family functioning and caregiver physical and mental QOL. Until this study, a mechanism for the association in the relationship between family functioning and caregiver physical and mental QOL had not been defined.

Families are an important source of support to their members as well as a potential source of stress.\textsuperscript{63} A family member’s chronic illness can disrupt existing family dynamics and can result in family dysfunction.\textsuperscript{64,65} Several investigators have examined the impact of family functioning on caregiver depression in caregivers of patients with HF\textsuperscript{24,35} and other chronic illness populations such as those with stroke, Alzheimer’s and dementia finding poor family functioning to influence caregiver depressive symptoms.\textsuperscript{25,33,35,36} Our findings demonstrate that poor family functioning in the areas of general functioning, problem-solving, and communication are predictive of caregiver depressive symptoms and poor physical and mental QOL.
Considerable research has documented the important role that general family functioning has in the development, course, and recurrence of caregiver depression.\(^{66-68}\) Unhealthy general family functioning has been reported to interfere with the caregivers' ability to regulate the emotional distress that frequently accompanies the care situation.\(^{69}\) Poor family problem-solving can also become challenging for caregivers.

There is increasing evidence that family problem-solving abilities are essential to the health of the caregiver.\(^{70}\) Poor family problem-solving is disruptive for caregivers of patients with chronic diseases such as HF.\(^{71}\) Effective problem-solving in family members in addressing HF-related problems set the stage for collaboration among those who live with the disease daily, the patient and the caregiver.\(^{72}\) Individuals or families who have poor problem-solving have difficulties regulating unpleasant moods, which in turn can exacerbate negative ruminations and pessimism interfering with family ability to assist caregivers in activities such as making decisions.\(^{72}\) Successful family problem-solving is important as a means of support for caregivers in making appropriate care-associated decisions each day. Effective family problem-solving is associated with lower levels of depression and higher QOL in caregivers.\(^{73,74}\) Communication between the caregiver and the family is also important to the health of the caregiver.\(^{75,76}\)

The ability to communicate effectively is a critical aspect of healthy functioning in families.\(^{34}\) Heart failure caregivers and those in other chronic illness populations report the communication with other family members to be difficult. Criticism of the caregiver and lack of communication between the family and the caregiver can influence caregiver depressive symptoms and poor QOL.\(^{77,78}\) Communication from family members such as criticism and negative comments concerning HF caregiving can cause caregiver
emotional distress, leading to depressive symptoms, and poor QOL. Investigators found support and encouragement from family members to lessen caregiver emotional distress associated with caregiving. The cessation of communication between family members and caregivers can also be stressful. Caregivers of HF patients report feeling frustrated, alone and isolated when family members cease communicating. For example, family members may become frustrated concerning the caregiving performance, and patient condition as HF progresses, leading them to become disengaged and less communicative with caregivers. Caregivers may then feel “socially isolated” contributing to depressive symptoms, placing them at risk for poor QOL.

Thus poor family functioning can impact caregiver depressive symptoms influence caregiver QOL. Depressive symptoms are a known contributor to poor QOL in caregivers of HF patients. In this study, we found slightly more than one quarter (28%) of caregivers to experience mild depressive symptoms. The prevalence of depressive symptoms of caregivers in this study was consistent with previous reports of caregivers of patients with HF. Depressive symptoms can cause a myriad of symptoms in caregivers of HF patients such as tiredness, difficulty concentrating and making decisions, and memory deficiencies that can influence their ability to perform their self-care and to assist the patient in HF self-care, which can influence caregiver QOL. It is well known that depressive symptoms frequently result in a decrease in caregiver QOL. Consistent with prior literature, in this study, depressive symptoms explained more of the variance in caregiver mental QOL than in physical QOL. In this study, as much as 64% of the variance for caregiver mental QOL was explained by depressive symptoms while depressive symptoms explained only as much as 54% of the variance in caregiver QOL.
Depressive symptoms are reported to have a strong relationship with mental QOL, because psychological distress can affect psychological well-being and sense of well-being and both are considered to be elements of mental QOL. Previous evidence shows that depressive symptoms can trigger the occurrence of physical symptoms such as fatigue and difficulty concentrating through the sharing of a common neurological pathway, thus influencing caregiver physical QOL. Therefore, interventions to improve family functioning and caregiver QOL must address caregiver depressive symptoms first in order for the intervention to be successful.

Caregiver depressive symptoms and QOL are commonly measured outcomes in HF caregiving research nonetheless, the literature related to interventions to improve HF caregiver depressive symptoms and QOL is limited. A recent integrated review reported four interventional studies aimed at improving HF caregiver depressive symptoms and QOL. Caregiver QOL was measured in three studies, but none reported significant beneficial effects from the intervention. Similarly, four studies measured caregiver depressive symptoms with three out of four studies demonstrating no significant changes in depressive symptoms except for one study. Characteristics of unsuccessful caregiver interventions found in the literature included a three-session, nurse-led, computer-based education intervention, a six-session multi-disciplinary lecture-type intervention, and one-on-one counseling intervention with written information and phone support. However, one group of investigators did have success in improving HF caregiver depressive symptoms. In that study, 369 caregivers were randomized to receive weekly automated self-care support calls for 12 months, and improvements in depressive symptoms were seen primarily among HF caregivers.
Authors of the study believe that the improvement in caregiver depressive symptoms received from the intervention is due to the receipt of information about the patient’s status and appropriately timed guidance about helping the patient with specific HF problems.

Our study is limited by its cross-sectional design, which does not permit causal conclusions. This study may have potential sampling bias related to the caregivers being recruited from a single academic center using convenience sampling. The caregiver sample was comprised of predominately Caucasian, and mostly female caregivers which limits generalizability.

**Conclusion**

Despite prior findings that depressive symptoms are common in caregivers of patients with HF and are associated with poor caregiver QOL, this is the first study with HF caregivers to demonstrate depressive symptoms to mediate the relationship between family functioning and caregiver QOL. These results suggest that the depressive symptoms of the caregiver must be addressed before attempting to successfully intervene on caregiver QOL or family functioning and that interventions to improve caregiver QOL and family functioning would only be successful when depressive symptoms are effectively treated.

This study has some implications for future practice and research. First, the findings provide preliminary evidence that caregiver depressive symptoms and family functioning are important modifiable factors associated with caregiver QOL. Prior research is limited to successful interventions related to the improvement in caregiver depressive symptoms and QOL. These results have the potential to guide the
development of successful interventions for improving caregiver depressive symptoms and QOL. Second, more research is needed to solidify these preliminary results, preferably longitudinal research as HF disease trajectory, family functioning, caregiver depressive symptoms, and QOL are fluid and change over time. Such a design would also solidify the direction of the examined relationships. Third, the possibility cannot be eliminated that the relationship between family functioning and depressive symptoms operate in a bidirectional manner. Therefore more investigation of the direction of the relationship between family functioning, depressive symptoms and caregiver QOL is needed.

If depressive symptoms could be replicated in future studies as a prevailing and vital link between family functioning and caregiver QOL, interventions targeting caregivers with a high risk of depressive symptoms or with family dysfunction could be beneficial for caregiver and patient outcomes. Incorporating strategies to nurture improved family functioning early in HF caregiving and providing the caregiver with interventions to prevent and treat depressive symptoms may help in further enhancing the effectiveness of depressive symptom treatment and thus improving caregiver QOL.
Table 2.1  Characteristics of caregivers of patients with heart failure

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total (n=143)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ±SD</td>
</tr>
<tr>
<td></td>
<td>N (%)</td>
</tr>
<tr>
<td>Age, years</td>
<td>56 ± 14</td>
</tr>
<tr>
<td>Female gender</td>
<td>105 (68%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt; High school graduate</td>
<td>26 (17%)</td>
</tr>
<tr>
<td>≥ High school graduate</td>
<td>114 (83%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>10 (7%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>129 (83%)</td>
</tr>
<tr>
<td>American Indian or Alaskan</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Caregiver relationship to patient</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>103 (73%)</td>
</tr>
<tr>
<td>Son or daughter</td>
<td>20 (14%)</td>
</tr>
<tr>
<td>Son or daughter-in-law</td>
<td>6 (4%)</td>
</tr>
<tr>
<td>Other relative</td>
<td>5 (4%)</td>
</tr>
<tr>
<td>Friend</td>
<td>7 (5%)</td>
</tr>
<tr>
<td>Lives with the patient</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>129 (92%)</td>
</tr>
<tr>
<td>No</td>
<td>11 (8%)</td>
</tr>
<tr>
<td>Years living with the patient</td>
<td>28 years ±17</td>
</tr>
<tr>
<td>Years living with patient</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>1-5 years</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>6-10 years</td>
<td>16 (14%)</td>
</tr>
<tr>
<td>11-15 years</td>
<td>12 (10%)</td>
</tr>
<tr>
<td>16-20 years</td>
<td>6 (5%)</td>
</tr>
<tr>
<td>&gt; 21 years</td>
<td>69 (61%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Days per week spent caregiving</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily 7 days per week</td>
<td>95 (69%)</td>
</tr>
<tr>
<td>5-6 days per week</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>3-4 days per week</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>1-2 days per week</td>
<td>11 (8%)</td>
</tr>
<tr>
<td>less than 1 day per week</td>
<td>25 (18%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full or part-time</td>
<td>44 (28%)</td>
</tr>
<tr>
<td>Unemployed by choice</td>
<td>11 (7%)</td>
</tr>
<tr>
<td>Disability</td>
<td>18 (11%)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>36 (23%)</td>
</tr>
<tr>
<td>Retired due to heart failure</td>
<td>15 (10%)</td>
</tr>
<tr>
<td>Retired not due to heart failure</td>
<td>17 (11%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quit job/early retirement to care for patients</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13 (9%)</td>
</tr>
<tr>
<td>No</td>
<td>127 (92%)</td>
</tr>
</tbody>
</table>
### Table 2.1 Continued

<table>
<thead>
<tr>
<th>Charlson comorbidity index score</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>56 (51%)</td>
</tr>
<tr>
<td>1-3</td>
<td>49 (44%)</td>
</tr>
<tr>
<td>&lt; 4</td>
<td>6 (5%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Most common caregiver comorbidities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>63 (41%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>29 (19%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver depressive symptoms (PHQ-9)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5 ± 6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of caregiver depressive symptoms (PHQ-9)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver PHQ-9 score 1-4 (no depressive symptoms)</td>
<td>73 (51%)</td>
</tr>
<tr>
<td>Caregiver PHQ-9 score 5-9 (mild depressive symptoms)</td>
<td>33 (23%)</td>
</tr>
<tr>
<td>Caregiver PHQ-9 score 10-14 (moderate depressive symptoms)</td>
<td>12 (8%)</td>
</tr>
<tr>
<td>Caregiver PHQ-9 score 15-19 (moderately severe depressive symptoms)</td>
<td>16 (11%)</td>
</tr>
<tr>
<td>Caregiver PHQ-9 score 20-27 (severe depressive symptoms)</td>
<td>9 (6%)</td>
</tr>
</tbody>
</table>

| Caregiver general family functioning score | 1.94 ± .4 |
| Caregiver problem-solving family functioning score | 1.98 ± .4 |
| Caregiver communication family functioning score | 2.17 ± .4 |

| Caregiver SF-12 mental QOL score | 50 ± 10 |
| Caregiver SF-12 physical QOL score | 43 ± 11 |
Table 2.2  The mediator effects of caregiver depressive symptoms on the relationship between family functioning and caregiver physical QOL

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Outcome</th>
<th>Standardized coefficient</th>
<th>95% CI</th>
<th>p-value</th>
<th>R2</th>
<th>Total effect (C)</th>
<th>Direct effect (C')</th>
<th>Indirect effect (a*b)</th>
<th>Indirect/total ratio (a*b/C)</th>
<th>Sobel z-Value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General family functioning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General family functioning</td>
<td>Physical quality of life</td>
<td>-0.314</td>
<td>[-1.0, -.22]</td>
<td>0.002</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General family functioning</td>
<td>Depressive symptoms</td>
<td>0.468</td>
<td>[.341, .656]</td>
<td>&lt;0.001</td>
<td>.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>Physical quality of life</td>
<td>-0.402</td>
<td>[-1.0, -.375]</td>
<td>&lt;0.001</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General family</td>
<td>Physical quality of life</td>
<td>-0.140</td>
<td>[-.722, .168]</td>
<td>0.219</td>
<td>.17</td>
<td>-0.31</td>
<td>-0.14</td>
<td>-0.15</td>
<td>.488</td>
<td>-2.62</td>
<td>0.008</td>
</tr>
<tr>
<td>Problem-solving family functioning</td>
<td>Physical quality of life</td>
<td>Depressive symptoms</td>
<td>0.257</td>
<td>[-2.0, -0.239]</td>
<td>0.013</td>
<td>0.06</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------------------</td>
<td>---------------------</td>
<td>-------</td>
<td>----------------</td>
<td>-------</td>
<td>------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-solving family functioning</td>
<td>Depressive symptoms</td>
<td>0.415</td>
<td>[0.600, 1.29]</td>
<td>&lt;0.001</td>
<td>0.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>Physical quality of life</td>
<td>-0.402</td>
<td>[-1.0, -0.375]</td>
<td>&lt;0.001</td>
<td>0.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-solving family functioning</td>
<td>Physical quality of life</td>
<td>-0.094</td>
<td>[1.3, 0.530]</td>
<td>0.387</td>
<td>0.16</td>
<td>-0.25</td>
<td>-0.09</td>
<td>-0.14</td>
<td>0.579</td>
<td>-2.82</td>
<td>0.004</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>Physical quality of life</td>
<td>-0.359</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2.2 Continued

<table>
<thead>
<tr>
<th>Communication family functioning</th>
<th>Physical quality of life</th>
<th>Depressive symptoms</th>
<th>Physical quality of life</th>
<th>Physical quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication family functioning</td>
<td>Physical quality of life</td>
<td>-0.326 [-1.4, -0.353]</td>
<td>0.002 .16</td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>Physical quality of life</td>
<td>0.384 [.344, .807]</td>
<td>&lt; 0.001 .14</td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>Physical quality of life</td>
<td>-0.402 [-1.0, -0.375]</td>
<td>&lt; 0.001 .16</td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>Physical quality of life</td>
<td>-0.178 [-1.0, 0.099]</td>
<td>0.102 .17 -.32 -.17 -.12 0.375 -2.53 0.011</td>
<td></td>
</tr>
</tbody>
</table>
Table 2.3  The mediator effects of caregiver depressive symptoms on the relationship between family functioning and caregiver mental QOL

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Outcome</th>
<th>Standardized coefficient</th>
<th>95% CI</th>
<th>p-value</th>
<th>R2</th>
<th>Total effect (C)</th>
<th>Direct effect (C')</th>
<th>Indirect effect (a*b)</th>
<th>Indirect/total effect ratio (a*b/C)</th>
<th>Sobel z-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>General family functioning</td>
<td>General family functioning</td>
<td>-0.536</td>
<td>[-1.38, 0.000]</td>
<td>.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental quality of life</td>
<td>-0.695</td>
<td>(.341, 0.000)</td>
<td>.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General family functioning</td>
<td>Depressive symptoms</td>
<td>0.468</td>
<td>[.341, 0.000]</td>
<td>.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental quality of life</td>
<td>-0.798</td>
<td>[-1.6, 0.000]</td>
<td>.63</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

40
<table>
<thead>
<tr>
<th></th>
<th>quality of life</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>General family functioning</td>
<td>Mental</td>
<td>-0.158</td>
<td>[-0.589, 0.034, 0.65, -0.47, -0.15, -0.33, 0.62, -4.8, &lt;0.001]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>quality of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive</td>
<td>Mental</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>symptom</td>
<td>quality of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Problem-solving family functioning**

<table>
<thead>
<tr>
<th>Problem-solving family functioning</th>
<th>Mental</th>
<th>-0.475</th>
<th>[-2.8, 0.000, 0.25]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-solving family</td>
<td>quality of life</td>
<td></td>
<td>-1.2</td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-solving family</td>
<td>Depressive</td>
<td>0.415</td>
<td>[0.600, 0.000, 0.17]</td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
<td></td>
<td>1.2</td>
</tr>
<tr>
<td>family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>--------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td><strong>Table 2.3 Continued</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental quality of life</td>
<td>-0.798</td>
<td></td>
<td>-1.1</td>
</tr>
<tr>
<td>Problem-solving family</td>
<td>-0.142</td>
<td>[-1.2, 0.046]</td>
<td></td>
</tr>
<tr>
<td>mental quality of life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>-0.733</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>-0.509</td>
<td>[-1.8, 0.000]</td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>0.384</td>
<td>[.344, 0.000]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental quality of life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>-0.798</td>
<td>[-1.6, 0.000 .63]</td>
<td></td>
</tr>
<tr>
<td>Communication family functioning</td>
<td>-0.715</td>
<td>[.851, .013 .66 -.50 -.17 -.27 .539 -4.43 &lt;0.001]</td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>-0.177</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Figure 2.1 Steps to test for direct and mediator effect

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Testing whether variation in levels of the independent variable significantly accounts for variation in the outcomes variable</th>
<th>Path A: $p&lt;.05$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td><strong>Model 1</strong></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>Testing variation in levels of the independent variable significantly accounts for variations in the presumed mediator</td>
<td>Path B: $p&lt;.05$</td>
</tr>
<tr>
<td>Model 2</td>
<td><strong>Model 2</strong></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td>Testing variation in the mediator significantly accounts for variation in the outcomes variable</td>
<td>Path C: $p&lt;.05$</td>
</tr>
<tr>
<td>Model 3</td>
<td><strong>Model 3</strong></td>
<td></td>
</tr>
<tr>
<td>Step 4</td>
<td>When the independent variable and mediator are entered into the model together, a previously significant relationship between the independent variable and outcome variable is no longer significant</td>
<td>Path A’: $p&lt;.05$</td>
</tr>
</tbody>
</table>
CHAPTER THREE

Living Arrangements, Readmission and Mortality in Patients with Heart Failure
Abstract

**Background:** Heart failure (HF) is a leading cause of readmission and death in the United States. Caregiver support from family members is associated with better outcomes, but what happens to those who live alone? Are they at higher risk by virtue of living alone and not having access to daily, in-home support?

**Objective:** The purpose of this study was to evaluate the association between living arrangements (living with someone vs. living alone) on all-cause readmission and death in patients with HF.

**Methods:** A retrospective electronic medical record review of patients admitted with a primary diagnosis of HF between January 1, 2013, and December 31, 2013, was performed. Sociodemographic data, clinical variables, length of stay, all-cause death, and rehospitalization were extracted from the electronic medical record. The independent association between living with someone and readmission and death was evaluated using Cox regression adjusting for covariates.

**Results:** Patients (n=398) were primarily male (57%), Caucasian (79%), and 63 ± 14 years of age. Sixty-seven percent of patients lived with someone, and less than half of those were spouses (49%). Heart failure patients living with someone experienced a significantly longer time to rehospitalization than those living alone (290 vs. 201 days, \( p=0.005 \)). In a Cox regression hazard regression model, adjusting for covariates, patients who lived alone were 1.42 times more likely to be readmitted one year after discharge (\( p=0.045 \)). The relationship between living alone and all-cause death was not significant after adjustment for covariates (\( p=0.660 \)).
Conclusion: Living alone is an independent predictor of hospital readmission in patients with HF up to one year after discharge. Clinicians should assess the living arrangements of HF patients, and work with family members outside the home, social workers, and other care providers to provide ongoing support for HF patients who live alone after discharge.
Living Arrangements, Readmission and Mortality in Patients with Heart Failure

Introduction

Approximately 6.5 million people in American are living with heart failure (HF), and that number is expected to increase by 46% from 2012 to 2030 resulting to over 8 million people living with HF over the age of 18 years. More than 5% of people age 60-69 years have HF, and HF annual incidence approaches 10 per 1,000 populations after 65 years of age.

Heart failure is the most common diagnosis in hospital patients age 65 years and older. From 2011-2014 nationally, HF readmissions were approximately 22%. Approximately 50% of patients die within 5 years of diagnosis. The majority of patients with HF are readmitted at least once after an index hospitalization, and more than half will be readmitted three or more times within 4-5 years of diagnosis. The American Heart Association estimates that the total direct costs (defined as medical spending) for treating CHF will rise to $53 billion in 2030, more than double the $21 billion in 2012.

Repeated readmissions of HF patients result in worse patient outcomes. Heart failure readmissions are associated with poor patient quality of life and increased patient mortality. Many factors are associated with HF readmission and mortality, but at least half of HF readmissions are believed to be preventable if pertinent risk factors can be identified. Multiple demographic, clinical, and psychosocial factors are reported as significant predictors of readmissions and mortality in patients with HF. Identified risk factors include clinical factors of blood pressure, heart rate, blood glucose, blood urea nitrogen level, comorbidities, psychological factors of depressive and anxiety, and social...
factors of age, race, and gender. There is now considerable interest in the role of social factors in predicting readmissions and mortality in patients with HF.

Heart failure patients are at high risk for readmission and mortality unless they follow their HF self-care treatment plan. Heart failure self-care is complex and is usually performed with the support of others, such as caregivers, family, partners, or friends living with the patient. The leading sources of support for patients with HF are their spouses (62%), then adult children (32%), and then friends and relatives (6%). Social support changes over the life course. The proportion of adults in the United States who are currently married are at an all-time low. As patients’ social demographics change it is important to consider patient living arrangements.

Considering whether a patient with HF lives in a shared household with another adult or lives alone can provide valuable information about available support for their self-care after discharge. Living arrangements are reported to be one of the most significant indicators of social support because living with someone provides multiple natural opportunities through which needed social support is provided. Little research exists in the HF population of the influence of living with someone versus living alone on HF readmission and mortality. Therefore, the purpose of this study was to evaluate the association of living arrangements (living with someone vs. living alone) with all-cause readmission or all-cause death in patients admitted with a primary diagnosis of HF.

Methods

Design and Sample

This study was a retrospective chart review that included all patients (> 20 years of age) admitted to the cardiology service at the University of Kentucky Chandler
Medical Center and the Good Samaritan Hospital with a primary diagnosis of heart failure (ICD-9 code 428.0) between January 1, 2013, and December 31, 2013. Patients were identified from the electronic medical record for inclusion in this study. Patients who were inmates, admitted from a nursing home or rehabilitation center were excluded given the focus on the post-discharge survival and readmission. Three hundred and ninety-eight patients met criteria for inclusion in the study.

Approval was obtained for the retrospective chart review from the Institutional Review Board at the University of Kentucky. All data were extracted from the electronic medical record by an advanced practice HF nurse trained in the use of the electronic medical record. Patients were followed for up to 12 months after hospital discharge to determine rehospitalization and mortality.

Measures

**Outcomes.** The outcomes measured in this study were time to all-cause death or time to all-cause rehospitalization during the follow-up period. Outcomes data were collected using the electronic medical record and the hospital administrative database by an advanced practice nurse with expertise in cardiac care and a health system informaticist. Data about hospitalization and death were collected for up to one year following patient discharge from the index hospitalization.

**Demographic and clinical variables.** Data about age, gender, educational level, employment status, ethnicity, living arrangement, marital status, comorbidities, smoking status, insurance status, length of stay, New York Heart Association (NYHA) functional class (on admission) and left ventricular ejection fraction were collected from the electronic medical record. New York Heart Association class (categorized as class I-II
and III-IV), educational level (≤ high school diploma and > high school), employment (employed and unemployed), insurance (has health insurance and no health insurance) and smoking (current/recent smoker and never smoker) were categorized into two groups for analysis. Living arrangement was defined as living with any other person regardless of whether they were a direct family member or living alone.

Comorbidities were assessed from data in the medical record, using the Charlson Comorbidity Index (CCI). In the current study, we used the revised version of the CCI which encompasses 23 medical conditions. Compared with the original version, the updated version was found to better predict health outcomes in previous analyses of data from national population health surveys. Using the CCI, weighted scores were assigned to comorbid conditions. Based on the CCI score, the severity of comorbidity burden is usually classified into three grades: mild (CCI score 1–2), moderate (CCI score 3–4) and severe (CCI score ≥5).

**Data analysis.** Data analysis was conducted using IBM SPSS 21.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.). A significance level of .05 was used throughout the study. Patient characteristics and clinical data were summarized using means and standard deviations, or frequencies and percentages depending on the level of measurement. The comparisons of demographic and clinical variables between those living with someone and those living alone were accomplished using the chi-square test of association and the independent samples t-test. Cox proportional hazards regression modeling was used to predict outcomes based on living with someone while adjusting for covariates of insurance.
status, smoking status, NYHA class, gender, and co-morbidities. Two separate models were run, one to predict all-cause death and one to predict all-cause rehospitalization.

Results

A total of 398 patients HF patients participated in this study. The mean age of patients was 63 ± 14 years, and 57% were male (Table 3.1). Most patients (79%) were white, and less than half of the patients were married (49%). Mean left ventricular ejection fraction was 39 ± 14 percent, and 60% of patients were classified as NYHA class III or IV. Seventy-eight percent of patients had a score on the CCI of 1-2, indicating a lower level of co-morbidities.

More than half (67%) of the patients were living with someone. Fifty-eight percent of patients living with someone were male with 78% of them having more than a high school education. Seventy-seven percent of patients living with someone had a lower level (CCI score of 1-2) of co-morbidities. Greater than ninety percent of patients living with someone had were unemployed (92%) and had health insurance (91%) More than half of patients living with someone (64%) were former/never smokers compared to thirty-six percent of those living alone. Days from discharge to readmission were significantly longer (290 vs. 201 days, \(p=0.003\)) and the frequency of patients readmission within a year was significantly more (61% vs. 39%, \(p=0.005\)) in patients living with someone than in those living alone. A total of 17 patients died (4%), and 204 (51%) patients were readmitted within one year of discharge.

In a Cox proportional hazard regression model (Figure 3.1), living alone predicted all-cause readmission within one year of discharge after controlling for insurance status, smoking, NYHA class, gender, age, and co-morbidities (Table 3.2). Compared with
patients who live with someone, those patients who live alone were 1.42 more likely to experience all-cause readmission within one year after discharge \((p=0.045)\). The results were also significant for patients living alone and cardiac readmission one year after discharge \((p=0.045)\). The relationship between living alone and all-cause death (Figure 3.2) was not significant after adjustment for covariates \((\chi^2=5.1, p=0.660, \text{Table 3.3})\). Variables controlled for that were found to be significant were insurance status and smoking. Patients with no health insurance were 36% or 0.567 times less likely to be readmitted within one year after discharge \((p=0.044)\) and patients who were former or recent smokers within the last year before hospitalization were 1.49 times more likely to be readmitted within one year of discharge than those who never smoked or stopped smoking 2 years before hospitalization \((p=0.007)\).

**Discussion**

The main finding of this study is that living alone was found to be an independent predictor of all-cause readmission one year after discharge in HF patients. This is one of the first studies to examine the influence of living with someone versus living alone on HF patient outcomes of readmission and mortality. This study is consistent with results from three studies in the HF population.\(^{24,12,30}\) Howie-Esquivel and others, in a sample of 809 HF patients, using multivariable analysis reported that patients younger than 65 years old and not partnered were at 1.8 times greater risk for being readmitted 90 days after discharge \((p =0.02; 95\% \text{CI,} 0.33-0.92)\) than those who were younger than 65 years and lived with partners.\(^{24}\) Lu and colleagues, in a sample of 611 African American patients with acute decompensated HF, found patients living with family members to have a significantly lower 30-day readmission \((21\% \text{ vs } 7\% \text{ } p < 0.0001)\) rate than those patients.
living alone. In a longitudinal observational study in 432 patients with chronic HF, investigators found compared to patients living alone, those patients who lived with family members were less likely to be readmitted within 6 months of discharge (OR = 0.361, \( p = 0.048 \)). The results of our study demonstrate that support from anyone living with the HF patient can assist HF patients in avoiding readmission within one year of discharge.

One way in which living with someone may influence HF readmissions is through influencing patient HF self-care behaviors. Successful self-care has been associated with HF readmissions. There may be a direct health promotion effect of the presence of another person acting through social influence by modeling and verbal persuasion. Support from others has been shown to improve patient medication and dietary adherence in patients with HF. Individuals obtain behavioral and verbal guidance through comparisons with similar others with whom they spend time. Visualizing individuals performing self-care behaviors such as choosing low sodium foods or increasing physical activity can raise the patient’s belief that they too possess the capabilities to succeed at performing these HF self-care behaviors. Using verbal persuasion individuals living with the patient can provide them with information and knowledge concerning the importance of HF self-care behaviors motivating them to perform the behavior. Individuals living with the patient in the household may act as a substitute or proxy for social support in modeling or discussing appropriate HF self-care behaviors. Social relationships and increased social contact could increase exposure to others who have participated in self-care behaviors or who have knowledge of concerning chronic
illnesses and are therefore aware of benefits of appropriate self-care behaviors. Evidence suggests engagement in preventative health behaviors increases among people with more social relationships, such as those living with someone, compared with those who are not socially connected.\textsuperscript{38-40} Chung et al, reported that compared to patients whose family did not followed a low sodium diet, patients whose family member followed a low sodium diet with the patient had lower average urinary sodium excretion (3651mg vs. 4280mg, \(p=0.003\)) and were 1.6 times more likely to be adherent to a low sodium diet (95\% CI: 1.03 - 2.4, \(p=0.035\)).\textsuperscript{32} In another study, investigators reported that elderly individuals who live with another person are more likely to be immunized against influenza than those who live alone.\textsuperscript{41} Support supplied by people living in the household with the patient may be able to contribute to the patients’ ability to engage in self-care behaviors assisting in preventing HF readmission.

Being a current smoker was found to be a significant contributor to HF patient all-cause rehospitalization in this sample. Compared to patients who had not smoked or quit one year before hospitalization, patients who currently smoke or are recent smokers within two years of hospitalization were 1.49 times more likely to be rehospitalized within one year of discharge \((p=0.007)\). While some factors related to HF readmission are not malleable, smoking is one such risk factor that can be changed. Many studies have linked smoking to poorer outcomes in patients with HF.\textsuperscript{42} For example, researchers have observed that patients with HF that continue to smoke are twice as likely to be readmitted than those patients who currently smoke or have never smoked.\textsuperscript{43}

Another significant contributor to HF patients’ all-cause readmission was insurance status. We found HF patients with no health insurance to have a 36\% less likely
chance of HF readmission one year after discharge. This finding was unexpected, the mechanism of which remains speculative. The vast majority of patients admitted to the hospital for HF decompensation are usually admitted through the emergency department. Prior data suggest that more than 80% of heart failure readmissions are admitted through the emergency department.\textsuperscript{44,45} Findings from our study are consistent with prior results from three studies finding patients without health insurance to be less likely to be admitted from the emergency department to the hospital.\textsuperscript{46-48} There may be several explanations for this. Perhaps a majority of HF patients may be using the emergency department for primary care purposes and thus maybe not as critically ill when they present to the emergency department.\textsuperscript{49,50} Alternatively, there also may be a concentrated effort to try to accomplish managing the uninsured patients as outpatients, saving cost as a result of an inpatient admission versus an emergency department discharge.\textsuperscript{49} Likewise, the emergency departing is increasingly being counted on triage, treat, and then release more critically ill patients due to the unavailability of hospital beds.

The results of this paper have significant implications that may affect readmission in HF patients. The social context formed by living arrangements, such as those of living with someone appears to be important to HF patient readmission. Therefore it is important to assess living arrangements early in the hospitalization of patients with HF in order to recognize those who are high risk for readmission. This will allow clinicians to designate resources to those who need them most. Therefore, it is important to assess the living arrangements of patients as these may be sources of potential support after discharge.
Limitations

This study must be interpreted in light of several limitations. First, the study was retrospective, and we had to depend on information documented in the electronic medical record by clinicians. Second, another limitation might be its cross-sectional design. We cannot conclude causality between living with someone and one year readmission for HF patients. Third, as this was an electronic medical record review, no information about household composition, perceived or received support was collected in this study which limits the understanding of the role of the individual living the in the household with the patients and HF readmission at one year. A longitudinal study with more detailed information related to perceived support, received support would provide more information and may clarify the causality and mechanisms of association between living with someone and HF readmission in one year. Fourth, this chart review was conducted in one academic medical center with little diverse ethnicity limiting its generalizability.

Conclusion

An emphasis on HF patient readmission increases due to its negative influence on HF patient mortality. The present study has identified living alone to be an independent predictor of HF readmission within one year of discharge and offers insight into an area of focus for prevention. Our findings suggest that the potential availability of being in a shared household may help negate the complex nature of HF self-care, making it less likely for the patient to be readmitted. This information could be used to focus on support interventions and follow-up efforts on those patients not living with someone who is maybe a high risk for readmission post-discharge.

Copyright © Linda Clements 2019
Table 3.1  Characteristics of heart failure patients in the total sample and compared between those living alone compared to living with someone

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean ± SD or N (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (N=398)</td>
<td>Living with someone (n=265)</td>
</tr>
<tr>
<td></td>
<td>Mean ± SD</td>
<td>N (%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>63 ± 14</td>
<td>63 ± 13</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>226 (57%)</td>
<td>153 (58%)</td>
</tr>
<tr>
<td>Charlson comorbidity index score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 (no co-morbidities)</td>
<td>2 (1%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>1-2 (mild)</td>
<td>311 (78%)</td>
<td>206 (77%)</td>
</tr>
<tr>
<td>3-4 (moderate)</td>
<td>56 (14%)</td>
<td>36 (14%)</td>
</tr>
<tr>
<td>≥5 (severe)</td>
<td>29 (7%)</td>
<td>21 (8%)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school education or &gt;</td>
<td>311 (78%)</td>
<td>207 (78%)</td>
</tr>
<tr>
<td>No education/≤ High school education</td>
<td>87 (22%)</td>
<td>58 (22%)</td>
</tr>
</tbody>
</table>
### Table 3.1 Continued

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>African American</th>
<th>Caucasian</th>
<th>American Indian</th>
<th>Native Hawaiian</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
<tr>
<td></td>
<td>314 (79%)</td>
<td>314 (79%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>82 (21%)</td>
<td>57 (22%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>57 (22%)</td>
<td>107 (80%)</td>
<td>1 (1%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>25 (19%)</td>
<td>207 (78%)</td>
<td>0</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Employed</th>
<th>Unemployed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>25 (6%)</td>
<td>363 (94%)</td>
</tr>
<tr>
<td></td>
<td>21 (8%)</td>
<td>237 (92%)</td>
</tr>
<tr>
<td></td>
<td>4 (3%)</td>
<td>126 (97%)</td>
</tr>
<tr>
<td></td>
<td>0.055</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Has insurance</th>
<th>No insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>359 (90%)</td>
<td>39 (10%)</td>
</tr>
<tr>
<td></td>
<td>240 (91%)</td>
<td>25 (9%)</td>
</tr>
<tr>
<td></td>
<td>119 (90%)</td>
<td>14 (10%)</td>
</tr>
<tr>
<td></td>
<td>0.730</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Married</th>
<th>Separated/divorced</th>
<th>Single/widowed</th>
<th>Cohabitate with partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>195 (49%)</td>
<td>53 (13%)</td>
<td>145 (36%)</td>
<td>5 (100%)</td>
</tr>
<tr>
<td></td>
<td>192 (73%)</td>
<td>22 (8%)</td>
<td>46 (17%)</td>
<td>5 (2%)</td>
</tr>
<tr>
<td></td>
<td>3 (2%)</td>
<td>31 (23%)</td>
<td>99 (74%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Smoking history</th>
<th>Current smoker/recent smoker</th>
<th>Former/never smoked</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>148 (37%)</td>
<td>250 (63%)</td>
</tr>
<tr>
<td></td>
<td>95 (36%)</td>
<td>170 (64%)</td>
</tr>
<tr>
<td></td>
<td>53 (40%)</td>
<td>80 (60%)</td>
</tr>
<tr>
<td></td>
<td>0.436</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hospital length of stay( days)</th>
<th>9 ± 14</th>
<th>8 ± 12</th>
<th>8 ± 12</th>
<th>0.989</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 3.1 Continued</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Days from discharge to readmission (days)</td>
<td>260 ± 301</td>
<td>290 ± 312</td>
<td>201 ± 268</td>
<td>0.003</td>
</tr>
<tr>
<td>Days from discharge to death (days)</td>
<td>358 ± 171</td>
<td>265 ± 358</td>
<td>133 ± 356</td>
<td>0.895</td>
</tr>
<tr>
<td>Ejection Fraction (%)</td>
<td>39 ± 14</td>
<td>37 ± 15</td>
<td>40 ± 16</td>
<td>0.155</td>
</tr>
<tr>
<td>Rehospitalized within 1 year of discharge (yes)</td>
<td>227 (57%)</td>
<td>138 (61%)</td>
<td>89 (39%)</td>
<td>0.005</td>
</tr>
<tr>
<td>Death within 1 year of discharge (yes)</td>
<td>50 (13%)</td>
<td>34 (68%)</td>
<td>16 (32%)</td>
<td>0.820</td>
</tr>
<tr>
<td>New York Heart Association Class</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I-II</td>
<td>151 (40%)</td>
<td>97 (39%)</td>
<td>54 (43%)</td>
<td>0.450</td>
</tr>
<tr>
<td>III-IV</td>
<td>228 (60%)</td>
<td>155 (62%)</td>
<td>73 (58%)</td>
<td></td>
</tr>
</tbody>
</table>


Table 3.2  Cox regression model showing the association between living with someone and all-cause readmission

<table>
<thead>
<tr>
<th>Variable</th>
<th>Hazard Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>1.43</td>
<td>[1.07, 1.91]</td>
<td>0.015</td>
</tr>
<tr>
<td>Insurance</td>
<td>0.569</td>
<td>[0.329, 0.984]</td>
<td>0.044</td>
</tr>
<tr>
<td>Smoking</td>
<td>1.49</td>
<td>[1.11, 1.99]</td>
<td>0.007</td>
</tr>
<tr>
<td>NYHA class</td>
<td>1.14</td>
<td>[0.857, 1.53]</td>
<td>0.357</td>
</tr>
<tr>
<td>Gender</td>
<td>1.10</td>
<td>[0.833, 1.47]</td>
<td>0.484</td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
<td>0.953</td>
<td>[0.866, 1.05]</td>
<td>0.332</td>
</tr>
<tr>
<td>Age</td>
<td>1.00</td>
<td>[0.992, 1.01]</td>
<td>0.676</td>
</tr>
</tbody>
</table>

*Cox regression full model ($x^2=19.8, p=0.003$)

Data presented as Odds Ratio (OR) and 95% Confidence intervals (CI) and p-value
Table 3.3  Cox regression model showing the association between living with someone and all-cause death

<table>
<thead>
<tr>
<th>Variable</th>
<th>Hazard Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>0.900</td>
<td>[0.301, 2.67]</td>
<td>0.850</td>
</tr>
<tr>
<td>Insurance</td>
<td>1.84</td>
<td>[0.503, 6.79]</td>
<td>0.355</td>
</tr>
<tr>
<td>Smoking</td>
<td>1.80</td>
<td>[0.649, 5.00]</td>
<td>0.259</td>
</tr>
<tr>
<td>NYHA class</td>
<td>0.431</td>
<td>[0.155, 1.20]</td>
<td>0.107</td>
</tr>
<tr>
<td>Gender</td>
<td>1.36</td>
<td>[0.490, 3.80]</td>
<td>0.551</td>
</tr>
<tr>
<td>Charlson co-morbidity index</td>
<td>1.09</td>
<td>[0.726, 1.43]</td>
<td>0.956</td>
</tr>
<tr>
<td>Age</td>
<td>1.03</td>
<td>[0.968, 1.04]</td>
<td>0.850</td>
</tr>
</tbody>
</table>

*Cox regression full model ($\chi^2$ 5.1, $p=0.660$)

Data presented as (OR) and 95% (CI) and p-value
Figure 3.1  Cox regression plot of living with someone and all-cause rehospitalization

[Graph showing percent survival over follow-up time for living with someone and living alone.]
Figure 3.2  Cox regression plot of living with someone and cardiac rehospitalization
CHAPTER FOUR

Improvement in Heart Failure Self-Care and Reduction in Patient Hospital Readmissions with Caregiver Education: A Randomized Controlled Trial
Abstract

Introduction: Heart failure (HF) readmissions continue to be a challenge in the care of HF patients with approximately 23% of patients greater than 65 years old readmitted to the hospital within 30-days of discharge. It is estimated that one-half to one-third of HF readmissions are preventable through successful self-care. Caregivers play an important role as a resource in supporting self-care. However, caregivers assist patients in HF self-care with little or no education or training, and it is not usual practice to provide caregivers with training to assist with HF self-care.

Aims: The aims of this study were (1) to determine the effect of an in-hospital, three-session, interactive, educational intervention with telephone follow-up for caregivers only in improving HF patients’ self-care, reducing 30-day cardiac readmission rates and (2) to evaluate the effect of the intervention on caregiver self-efficacy, perceived control, and HF knowledge.

Methods: In this randomized control trial (RCT), we enrolled 37 hospitalized HF patients and their caregivers. The intervention directed at caregivers alone consisted of three in-hospital, nurse-led, educational sessions with telephone follow-up. These educational sessions were designed to provide caregivers with the knowledge and skills to assist patients in engaging in successful HF self-care. Patient self-care, patient 30-day cardiac readmission rates, and caregiver self-efficacy perceived control, and HF knowledge was measured at baseline, discharge, 7-days, and 30-days post-discharge.

Results: Data from 37 patients and caregivers were analyzed. The patients with HF were 67% male and had a mean age of 59.14 ± 11.03 years. Forty-five percent of patients were New York Heart Association (NYHA) class IV with a mean ejection fraction of 27.0
±14.4%. The mean of age of caregiver was 49.0 ±10.7 years with 78% of them being female and 54% of them being spouses. A linear mixed-model analysis revealed that patients whose caregivers received the educational intervention had significantly better self-care maintenance (p<.001) and self-care management (p<.001) across time. Cox survival analysis demonstrated patients whose caregivers did not receive the educational intervention were 11 times more likely to experience cardiac readmission within 30 days after discharge than those patients whose caregivers received the intervention (HR=11.492, p=.003). Caregivers who received the educational intervention had higher perceived control [F (2/91) = 6.53, P < 0.001] for up to 30-days post-intervention versus the control group, however, there were no differences between caregiver groups in self-efficacy and HF knowledge.

**Conclusions:** Addressing a significant gap in HF management by including caregivers in inpatient education, this caregiver only educational intervention provided a template for in-hospital education that can improve caregiver perceived control, patient self-care, and 30-day cardiac readmissions. This intervention is ready for a rigorous test on a large scale, multicenter, randomized control trial. Delivering educational interventions for family caregivers in the hospital is feasible and has the potential to improve caregiver and patient outcomes.

**KEYWORDS:** caregiver education heart failure
Improvement in Heart Failure Self-Care and Reduction in Patient Hospital Readmissions with Caregiver Education: A Randomized Controlled Trial

**Introduction**

Heart failure has an enormous impact on individual health and the health care system in the United States. Heart failure afflicts ~6.5 million Americans and is the primary diagnosis in >1 million admissions yearly.\(^1,2\) Heart failure imposes a complex treatment plan, limitations on daily activities of patients, and changes in lifestyle. Compared to patients admitted for other diagnoses, HF patients have the highest 30-day\(^3\) readmission rates at 27% when compared with the overall rate of approximately 21%.\(^4\) In 2011 hospitalization accounted for approximately 70% of the total costs for HF.\(^5\) Approximately 27% of HF readmissions are thought to be preventable.\(^6,7,8\) Successful HF self-care is essential in preventing HF readmissions.\(^9\)

Self-care is defined as a process of maintaining health through the performance of health-promoting practices and managing illness.\(^10\) Effective HF self-care is critical in promoting optimal patient outcomes in illnesses such as HF.\(^3,11\) Heart failure self-care requires patients to follow a complicated treatment plan related to medication administration, diet modification, activity participation, and symptom monitoring.\(^12,13\) While self-care is an essential component of HF treatment; patients struggle to perform successful self-care.\(^14\)

Caregivers play an essential but often ignored part of HF patients’ self-care. Caregiver influences on HF patients’ self-care can range from being a resource on the performance of self-care to providing care when the patient is unable to perform self-care.\(^15,16\) Through communication, behaviors, and attitudes, caregivers often have a
significant impact on patients’ well-being, decisions to follow recommendations for
medication treatment, and abilities to initiate and maintain lifestyle changes.17,18
Therefore, national consensus guidelines from the American College of
Cardiology/American Heart Association (ACC/AHA) and the Heart Failure Society of
America (HFSA) for the management of chronic HF, recommend that all HF patients
along with their caregivers receive individualized education focused on self-care before
discharge.19-21 Yet, most discharge education is aimed at HF patients alone.22
Hospitalized patients may be anxious related to their condition, concerned about
performing self-care or be experiencing dyspnea or fatigue at the time of discharge,
making patient education difficult. Therefore, a caregiver may have to serve as a proxy
during educational interventions in order to provide a safe patient safe transition from
hospital to home. 23,24 Treatment management routines for patient self-care related to
chronic disease can be enhanced by increasing caregiver self-efficacy,25-29 perceived
control,30,31 and disease knowledge,32,33 through educational interventions. Caregivers
perform caregiving activities daily with almost exclusive access to HF patients, providing
a mechanism for which they can positively influence patient outcomes.

Caregiver characteristics such as self-efficacy, HF knowledge, and perceived
control can positively influence HF patient self-care.34-37 Most HF caregivers report little
self-efficacy (i.e., confidence in the ability to perform a task) in assisting the patient in
self-care.38-40 Caregiver self-efficacy improved through educational interventions is
associated with better patient and caregiver outcomes such as survival.28,41-43 With
increased self-efficacy, individuals have greater confidence in their ability and thus are
more likely to be motivated to engage in healthy behaviors.44 In addition to self-efficacy,
perceived control can also promote HF self-care.\textsuperscript{22} Improvements in spousal self-efficacy or confidence is shown to result in improvements in patient depressive symptoms,\textsuperscript{45} quality of life,\textsuperscript{46} and survival.\textsuperscript{28}

An individual’s higher perception of control is associated with improved patient outcomes.\textsuperscript{36,47} Health researchers report that an individual’s sense of perceived control influences how they perceive and manage their illness.\textsuperscript{48} Quantitative research in patients with asthma,\textsuperscript{48} diabetes,\textsuperscript{49} and HF \textsuperscript{50} has suggested that greater perceived control is associated with better outcomes such as improved self-care. The perception of control by caregivers is associated with improved patient outcomes.\textsuperscript{36} Chen and colleagues explored the relationships among HF knowledge, perceived control, social support, and family caregiver contribution to self-care of HF, based on the Information-Motivation-Behavioral Skills Model.\textsuperscript{42} They discovered that caregiver perceived control directly affected caregiver contribution to self-care maintenance and both directly and indirectly affected caregiver contribution to self-care management.\textsuperscript{42} Srisuk and colleagues\textsuperscript{50} reported that a patient-caregiver educational intervention d caregiver perceived control and patient self-care. Therefore, perceived control might have a significant role in initiating and sustaining health behavior change efforts like the performance of self-care.\textsuperscript{51} Another foundational precursor for HF self-care is HF knowledge.

The ability to act as a resource for HF patients or to assist in performing self-care requires knowledge about HF and its treatment, and accurate HF knowledge is one determinant of self-care behaviors.\textsuperscript{52-54} For example, Chung and others reported that 12 weeks of self-care education for HF patient-caregiver dyads, with two home visits and
telephone follow-up, resulted in a significant reduction in patient (p=0.02) and caregiver (p<0.01) dietary sodium consumption.54

Although the literature acknowledges that caregivers play an essential role in supporting HF patients and encourages their inclusion in HF education, there is a paucity of studies that have evaluated its effectiveness. In a recent systematic review55 of educational interventions involving caregivers of HF patients in HF education, only two studies were found measuring outcomes in both dyads56-58 In these studies caregiver knowledge was increased but quality of life, perceived control, anxiety, and depression did not improve. One study58 of the two noted a significant improvement in the patient outcome of perceived control after the educational intervention. However, no other significant changes between groups were reported. Therefore, evidence highlights a knowledge gap regarding the effectiveness of HF caregiver education on patient outcomes.

The purpose of this study was to evaluate the effectiveness of an in-hospital, three- session, interactive, caregiver only, educational intervention aimed at improving caregiver self-efficacy, HF knowledge, and perceived control thus improving patient self-care and cardiac readmission rates. Therefore, it is hypothesized that by improving these caregiver factors, patient self-care would be improved, and 30-day readmission rates decreased. The specific aims were the following: (1) to determine the effect of an in-hospital, three-session, an interactive, educational intervention for caregivers only in improving HF patients’ self-care, reducing 30-day cardiac readmission rates and (2) to evaluate the effect on caregiver self-efficacy, perceived control, and HF knowledge.
Methods

Design

This study was a two-group, prospective, repeated measures randomized controlled trial, using a caregiver only educational intervention versus usual patient education. The outcomes measured included patient self-care, patient 30-day cardiac readmission status, and caregiver self-efficacy, perceived control, and HF knowledge. Written and informed consent was obtained, then patients and caregivers were randomly assigned to groups based on a schedule derived from a computer-generated table of random numbers.

Sample

The sample of recruited patients and caregivers came from the inpatient progressive-care unit at the University of Kentucky Medical Center. Screening of inpatients with a secondary diagnosis of HF and their caregivers occurred for eligibility to participate in the study. Patients enrolled had (1) a diagnosis of chronic HF confirmed by their cardiologist and had an echocardiogram within the previous six months that supported the diagnosis, (2) were able to speak and write English, (3) had a phone in the home, and (4) had a caregiver living with them. Exclusion criteria for patients included receiving a heart transplantation, having a co-existing terminal illness or cognitive impairment per medical record. Patients identified eligible caregivers through self-report. Caregiving by definition is providing assistance that is more than the aid provided for a physically and psychologically healthy person. Caregivers of patients were eligible if the following were true: (1) primary caregiver living with the HF patient; (2) able to speak and understand English; (3) no self-reported history of cognitive impairment; (4) no co-existing terminal illness. The University of Kentucky Biomedical Institutional
Review Board approved the protocol and informed consent documents. Both patients and caregivers gave informed consent and signed separate consent forms.

**Procedure**

**Usual care.** At this hospital, bedside nurses are responsible for HF discharge education. Discharge education provided to HF patients include a booklet entitled “Caring for Your Heart: Living Well with Heart Failure,” a weight calendar, a 10-minute video entitled “What is Heart Failure” (Milner/Fenwick) and pill box for keeping track of their medications. The bedside nurses use the “teach-back” method of educational evaluation during their discharge session. There was no consistent intent to include caregivers in HF patient education at this facility. If caregivers happen to be present at the time of discharge education, then they are included.

**Intervention.** During the patient’s stay in the hospital, caregivers completed three educational sessions. Investigators in this study chose to use a hospital-based educational intervention over the outpatient setting because it is more practical, less costly for caregivers. Educational content of the sessions were based on the HF guidelines from the American College of Cardiology /American Heart Association/Heart Failure Society of America. The intervention consisted of three educational sessions lasting approximately 30 minutes using written material, videos, one-on-one discussion, the “teach-back method of learning evaluation, and skill building. Information using these teaching strategies are reported to assist in improving self-care. Bedside nurses were not enlisted to reinforce education presented by the study nurse. The intervention also consisted of two follow-up telephone calls at 7 and 30-days post-discharge. Telephone follow-up has shown to reduce 30-day readmissions in patients with HF.
An advanced practice nurse with expertise in HF presented content on HF self-care during each session. Nurses are well positioned to deliver health education because of their extensive contact with the patients of families. Educational sessions took place in patients’ room and lasted approximately 60 minutes. A minimum of 60 minutes of HF inpatient education is shown to reduce 30-day readmissions. At the beginning of each session, a sign was placed on the door, reading “education in progress”: and if the sessions were interrupted, the investigator rescheduled the session at another time.

In the first session, caregivers viewed two videos entitled “What is Heart Failure?” (Milner/Fenwick) and” Heart Failure Monitoring for Signs and Symptoms (Milner/Fenwick) with a discussion using the corresponding written information from the booklet. Strategies for symptom monitoring discussed with caregivers included obtaining accurate daily weights at home. Caregivers received a calendar in which to record the patient’s daily weight. Caregivers participated in decision-making activities related to scenarios based on current guidelines illustrating patient weight gain with several decision-making options such as calling the physician to notify them about weight gain.

In the second education session, caregivers viewed a video entitled “Understanding Heart Failure Medications” (Milner/Fenwick) combined with a discussion using the corresponding written information in their booklet. The study nurse used the patient’s medication list and a medication bottle as an adjunct teaching modality assisting in providing information on the reason for the medication, actions to take for a missed dose and how to obtain a refill from the physician. Across studies, caregivers report knowledge gaps related to assisting HF patients with medication administration.

39,70,71
In the third session, caregivers received their last educational intervention. Caregivers viewed the video entitled “Nutrition and Exercise” (Milner/Fenwick) combined with corresponding written information related to diet modification and exercise. Caregivers practiced reading sodium and fat content using food labels. Caregivers participated in decision-making activities related to current guidelines illustrating high sodium content foods. Discussions with caregivers included low sodium options, such as not adding salt to food or using other spices for flavoring foods. Evidence recommends instructing caregivers on reading food labels for sodium content, low-sodium diet cooking, and shopping to support patient adherence.72,73

Data collection took place at baseline (before the first educational session), before discharge (after the last educational session), and by phone at 7 and 30-days. Data collected at baseline were patient and caregiver sociodemographic characteristics, comorbidities, health literacy, and family functioning. Data collection for patient self-care and caregiver self-efficacy perceived control and HF knowledge also occurred at baseline, at discharge, 7 and 30-days post-discharge. Telephone follow-up with caregivers and patients occurred at 7 and 30-days after discharge. During the phone-call, remediation of caregivers occurred if caregiver gave incorrect responses related to the HF knowledge questionnaire. Cardiac readmission within thirty days was determined during the 30-phone call and using medical record review.

Measures

A standardized sociodemographic instrument developed for and used extensively in this population was completed by both caregivers and patients to gather data on age, gender, education level, race/ethnicity, marital status, financial status. The Charlson
Comorbidity Index (CCI) was used to measure comorbidity burden.\textsuperscript{74} Scores on the CCI can range from 0-34 with higher scores indicating a greater burden from comorbid conditions. The CCI has good reliability and validity in many populations, including HF. A trained research nurse determined the New York Heart Association functional classification by medical record review.

The Self-Care Heart Failure Index (SCHFI) v. 6.2 was used to collect data on patient self-care.\textsuperscript{23} The SCHFI v.6 is a self-report questionnaire comprised of 22 questions that capture self-care maintenance (daily routine behaviors), self-care management (symptom recognition and response behaviors), and confidence (confidence in the ability to engage effectively in self-care). Each sub-scale of the SCHFI is calculated (range 0-100) with higher scores indicating better self-care with a cut-point of 70, indicating adequate self-care. The Cronbach alpha coefficients for the three subscales of the SCHFI in this population were .71 for self-care maintenance, .72 for self-care management and .92 for self-care confidence.

The end-point of 30-day cardiac readmission was measured by self-report of the patient per telephone interview at 30-days post discharge and review of hospital electronic medical record using admission diagnosis.

The Revised Scale for Caregiver Self-Efficacy instrument was used to evaluate caregiver self-efficacy related to the caregiving role. The scale has three subscales (1) caregiver self-efficacy for obtaining respite from family and friends (5 items; e.g., asking a friend or family member to stay with your relative for a day to take a break), (2) caregiver self-efficacy for controlling disturbing thoughts (CGSE-DB) about the caregiver role (5 items; e.g., the unfairness of having to manage this caregiving situation),
and (3) caregiver self-efficacy responding to the relative’s disrupting behaviors (CGSE-UT; 5 items; e.g., responding without raising your voice when your relative interrupts your activities repeatedly).\textsuperscript{51} Using this scale, caregivers rate their degree of self-efficacy on an analog scale from 0 (absolutely incapable) to 100 (fully capable). The Cronbach alpha coefficients for this population for the self-efficacy respite scale were .67, disturbing behavior scale was .55, and the upsetting thoughts scale was .66.

Perceived control for caregivers over managing patients’ HF symptoms was assessed by the eight-item Control Attitudes Scale-Revised.\textsuperscript{52} In this study, perceived control is defined as an individual’s belief that he or she has the resources essential to cope with adverse events in a way that positively influences such events.\textsuperscript{75} The measure uses a 5-point Likert scale (1: totally disagree to 5: totally agree). The total score was calculated by adding the ratings of all items after reversing the ratings of two items. Possible scores range from eight (perception of no perceived control) to 40 (perception of the highest level of perceived control). Reliability has been supported in patients with coronary artery disease, cardiac disease, and HF.\textsuperscript{76} The Cronbach alpha coefficient for this study sample was .62.

Heart failure knowledge in this study was measured using the Dutch Heart Failure Knowledge Scale (DHFKS).\textsuperscript{53} This scale is a reliable, valid instrument to measure general HF knowledge, symptom recognition, and HF treatment consisting of 15 multiple-choice items (0-15). Higher scores on the scale indicate more HF knowledge.\textsuperscript{50,77,78} Cronbach alpha for the DHFKS in a study of 902 patients with HF from 19 hospitals located in the Netherlands was .62.\textsuperscript{79} The Cronbach alpha coefficient in this study sample is .84.
Patients with chronic diseases such as those suffering from health failure (HF) show low levels of health literacy (HL). We are measuring health literacy in this study as it may a confounding variable. Health literacy is “the degree to which individuals can obtain, process, and understand necessary health information and services needed to make appropriate health decisions.” Lower patient HL is consistently associated with decreased medication adherence, decreased the use of preventative services, greater difficulties participating in self-care, and more hospitalizations. Lower levels of caregiver HL are found to be associated with inadequate patient self-management behaviors and increased patient use of health services. The Newest Vital Sign was used to measure health literacy in this study. This is a sensitive, reliable, and valid instrument for the assessment of health literacy in screening individuals with low educational levels. The instrument is based on a 7th-grade reading level and is comprised of 6 questions based on reading a nutrition label. It requires about 3 minutes for administration. Scores can range from 0-6, and a cut point of three divides the scores into inadequate and adequate health literacy.

Most HF self-care occurs at home within the family environment, therefore family functioning maybe a confounding variable in this study. Families are a vital source of support for patients, and lack of support from families for patients and caregivers can result in poor self-care and increased patient readmissions. Poor HF self-care is associated with poor family functioning. The Family Assessment Device (FAD) was used to measure family functioning at baseline. The FAD measures structural, organizational, and transactional characteristics of families. It consists of 6 scales assessing the six dimensions of the McMaster Model of Family Functioning: affective
involvement, affective responsiveness, behavioral control, communication, problem-solving, and roles as well as a scale measuring general family functioning. The measure contains 60 statements about family interactions. Respondents are asked to rate how well each statement describes their own family. The range of possible scores is 1-4 with 1 indicating healthy family functioning and a score of 4 indicating unhealthy family functioning. The FAD is used widely in the HF population; internal consistency of the scale ranges between .86 and .92, and the test-retest reliability is reported to be .71.\textsuperscript{91,93,94} The Cronbach alpha for the FAD in this study is .72.

**Data Analysis**

Analysis of data was done with SPSS for Windows (version 22.0, SPSS Inc., Chicago, IL). Comparability of the groups on baseline measures was examined with Chi-square or independent t-tests, depending on the level of measurement. All analyses followed an intent-to-treat strategy, that is, the analyses included all patients in the groups to which they were randomly assigned, regardless of their level of adherence to the intervention or subsequent withdrawal from the study. Differences in patient self-care scores and caregiver self-efficacy perceived control, and HF knowledge between the groups over the study period were calculated with linear mixed-models analysis. Using these analyses, investigators examined the main effects by group, time, and a group-by-time interaction. The within patients covariance structures were set at unstructured. When the Mauchly’s test of sphericity was significant, univariate tests with the Greenhouse-Geisser epsilon correction factor were reported. When significant group-by-time interaction effects were found, mean pairwise comparisons using the Bonferroni correction for multiple comparisons were calculated. To compare times to the composite
endpoint of rehospitalizations, a log-rank test to compare the times to cardiac readmission between the intervention and control group was used. A Cox, proportional hazards model, was used to determine the effect of the intervention on time to the first cardiac readmission.

Results

Baseline Characteristics of Patients and Caregivers

A total of 37 HF patients and their caregivers completed baseline questionnaires (see Figure 4.1 for participant flow through the study). Two patients died after data collection but before discharge. No patients were lost to follow-up.

The mean age of patients was 59.14 ± 11.03 years (Table 4.1). The patients were predominantly white (86%), male (70%), and married or cohabitating (73%). Greater than 75% of patients had more than high school education, with 32% of patients being retired. Patients were distributed among New York Heart Association functional classes of II, III, and IV, with 53% of patients being class IV. The average ejection fraction among patients was 27.0 ± 14.4%. Greater than 25% of patients reported more than five comorbidities. The mean comorbidity score was 3.83 ± 2.61 Forty-three percent of patients reported their financial status as inadequate with “not enough to make ends meet.” Greater than 80% of patients had health literacy score of 4 ± 1 indicating adequate health literacy.

The mean age of caregivers was 49.0 ± 10.7 years (Table 4.2). The majority of caregivers were white (87%) and female (78%). More than half of the caregivers were married or cohabitating (59%) and spouses (54%). Forty-one percent of caregivers were employed full time outside the home with 79% reporting greater than a high school
education. The mean caregiver comorbidity score was low at 1.08 ± 1.89 with more than half of caregivers (57%) reporting no comorbidities. The mean caregiver health literacy score was 4.43 ± 1.14, indicating adequate health literacy. Thirty-nine percent of caregivers rated their quality of support as very good, while forty-nine percent of patients rated the quality of their support as only good (Table 4.2).

**Baseline Values of Patient and Caregiver Outcome Variables**

At baseline, the mean patient self-care maintenance score was 54.9 ± 18.2, self-care management score was 44.3 ± 23.1, and self-care confidence score was 46.1 ± 23.5. There were no significant differences in self-care measures between the intervention and control groups at baseline (Table 4.1).

At baseline (Table 4.2), the mean caregiver self-efficacy score for respite was 75.8 ± 32.6, for managing disturbing behavior was 64.5 ± 8.0, and for controlling upsetting thoughts was 73.5 ± 49.6. The mean score for caregivers’ perceived control was 27.0 ± 4.0, and for caregivers, HF knowledge was 7.3 ± 1.1. Although there are no published norms for perceived control, levels below 16 reflect a low level of perceived control. A score of 12 on the DHFKS indicates a high or adequate level of heart failure knowledge. There were no significant differences between the intervention and control groups at baseline in caregivers’ self-efficacy, perceived control, or HF knowledge.

**Impact of the Intervention**

The impact of the intervention on patient self-care can be seen in Table 4.3. The linear mixed-model analysis revealed a statistically significant group-by-time interaction effect for self-care maintenance (F (3, 96) = 5.76, p <0.001, ηp² 0.153) and self-care
management (F (3, 51) =4.826, p=0.005, \( \eta^2 \) 0.221) with a small to moderate effect size. There was no significant time or group by time interaction for self-care confidence (\( p=0.159 \)).

The analysis of caregiver perceived control revealed a significant group-by-time interaction effect (F (3, 81) =8.32, p<0.001, \( \eta^2 \) 0.236) with a moderate effect size (Table 4.4). Pairwise comparisons revealed significant differences in perceived control between intervention and control groups at discharge and 7-day (31 ± 3 vs. 31 ± 5, \( p=0.027 \)) and between 30-days (31 ± 3 vs. 31 ± 4, \( p=0.030 \)) post-discharge. There were no significant group-by-time interaction effects noted in caregiver self-efficacy and HF knowledge (Table 4.4).

The time to cardiac readmission was significantly longer in patients who received the educational intervention (28 ± 7 days, \( p=<0.004 \)) than in patients who did not receive the educational intervention (20 ± 11 days). Over the 30-day study period post-discharge, the proportion of patients who experienced cardiac readmission in the intervention group was significantly lower (5%, \( p=0.003 \)) when compared with the control group (42%). Two patients (5%) died from cardiac reasons after the intervention but before discharge. Cox hazards regression analysis (Figure 4.2) demonstrated that patients whose caregiver did not receive the educational intervention were 11.4 times more likely (\( p=0.002 \)) to experience cardiac readmission than those patients whose caregiver received the educational intervention.

**Discussion**

Heart failure education is recommended for all patients and their caregivers to achieve optimal HF self- care behaviors such as medication adherence, monitoring daily
weights, and dietary adherence. Self-care is fundamental to the success of HF treatment and has been shown to improve all-cause hospitalization. Caregivers play an essential role in supporting patients in HF self-care. However, caregivers are rarely included in HF education. The purpose of this study was to evaluate the effectiveness of an in-hospital, three-session, interactive, caregiver only, educational intervention aimed at improving caregiver self-efficacy, HF knowledge, and perceived control thus improving patient self-care and readmission rate. It was hypothesized that by improving these caregiver self-efficacy, perceived control and HF knowledge patient self-care would be improved, and 30-day readmission rates decreased.

The results of our study suggest that an in-hospital, innovative, three-session, caregiver only educational intervention is effective in improving HF patient self-care maintenance, self-care management, 30-day readmission, and caregiver perceived control. The intervention did not improve patient self-care confidence, caregiver self-efficacy or caregiver HF knowledge. This study is the first randomized control trial to determine that an in-hospital, three-session, innovative, caregiver only, HF educational intervention is effective in improving patient self-care maintenance, self-care management, 30-day readmission rates, and caregiver perceived control.

Our first aim was to determine the effect of an in-hospital, three-session, innovative, caregiver only educational intervention on patient self-care and 30-day readmission rates. In this study, patient self-care maintenance and self-management in the intervention group significantly increased from baseline to 30-days post-discharge. In this study, self-care maintenance and self-care management in the intervention group significantly increased by 62% and 97% respectively, from baseline to 30-days post-
discharge. However, there was no significant increase in self-care confidence. Prior literature related to the influence of caregiver education on patient self-care is limited. However, three randomized control trial were found, including caregivers in HF self-care education and testing patient outcomes.\textsuperscript{50,53,99}

The results of this study are consistent with the results from these three randomized control trials.\textsuperscript{50,53,99} In all three studies patients whose caregiver was included in the educational intervention reported significant improvements in self-care, self-care maintenance, and self-care management. Common educational strategies among these studies with this study include the use of a face to face individualized approach to education and varied modes of educational content delivery. They differed from this study in that only one study occurred in the hospital setting,\textsuperscript{99} one utilized the teach-back method of learning evaluation\textsuperscript{50} and only two utilized telephone follow-up\textsuperscript{50,53}

These results are consistent with previous studies demonstrating that educational interventions improve perceived control in caregivers of cardiac patients.\textsuperscript{36,50,100} However, the sustained effect of the educational intervention on caregiver perceived control seen in this study was only consistent with the study by Moser et al.\textsuperscript{36} The educational intervention from Moser and colleagues was similar to the one in this in that both interventions were individualized and used multi-media modes for educational delivery. Caregivers report the time of discharge to be a time of uncertainty which can cause feelings of a loss of control.\textsuperscript{40,101} Perceived control is a central concept in the caregiver and patients’ adjustment to chronic illness and is considered important to a positive perception of a stressful situation such as caregiving.\textsuperscript{96,102} Perceived control is one individual characteristic that is amendable to education. High levels of perceived
control are associated with better emotional well-being, successfulness at coping with stress and improved performance.\textsuperscript{75} It may be that individuals such as caregivers, who experience repeated success in a task can develop a generalized expectancy that they can influence the occurrence of positive outcomes in themselves and others such as the patients’ performance of successful self-care.\textsuperscript{103}

There were no significant differences found between the intervention and control group related to caregiver self-efficacy and heart failure knowledge. Patients and caregivers included in the study had been seen before by healthcare providers for their heart failure care. Knowledge and self-efficacy are amendable through education. It is possible that caregivers were exposed in previous medical encounters to heart failure education. This previous experience with education may have improved their sense of self-efficacy and HF knowledge accounting for the lack of improvement in self-efficacy and heart failure knowledge related to the caregiver educational intervention. Perceived control is defined and operationalized in ways that are similar to self-efficacy.\textsuperscript{104} Perceived control can also exert an independent effect or a mediator effect on health behaviors. According to some theorists, including Bandera, perceived control and self-efficacy could be used interchangeably both conceptually and operationally. Caregivers influenced by the educational intervention may have already felt prepared and confident in their ability to perform self-care form prior educational interventions but was still feeling overwhelmed with a loss of control. Once caregiver perceived control was improved, then those individuals with high self-efficacy may have performed better at assisting the patient in self-care. Evidence reports perceived control might only benefit those who are already confident their ability to perform self-care.
This study must be interpreted in light of several limitations. First, the generalizability of the results is limited by the sample, which was drawn from one hospital-based healthcare system, serving a patient population with a relatively little ethnic variation. Because patients were recruited from a university hospital with an active heart transplant program, they may be more impaired than HF patients in most community samples. Finally, our results cannot be extrapolated beyond 30-days and future studies should include longer follow-up periods.

Conclusion

This study provides sufficient evidence to suggest that this intervention could be feasibly implemented in other hospital settings. The findings are significant because they quantify the value of providing HF self-care education to caregivers, and the results help to fill the gap regarding the effectiveness of HF caregiver education in improving patient outcomes. A larger, multicenter, randomized controlled trial will help to validate these findings. It is recommended that patient characteristics of self-efficacy, perceived control and HF knowledge be measured in combination with caregiver characteristics. As self-efficacy and HF knowledge were not significant in this analysis, it is of our opinion that they are consistently important to the performance of successful HF self-care and thus may give more information on how better to use caregiver HF education to improve patient outcomes.\textsuperscript{105,106} Additionally, longer longitudinal studies could help determine if the positive influence of caregiver education is sustained after 30 days. The innovative approach of in-hospital, innovative, three-session, caregiver only education was found to be effective in improving patient outcomes. This educational intervention has the
potential to be successfully incorporated as an effective part of routine HF patient discharge and post-discharge care.
Table 4.1 Baseline Patient Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Total Sample (N=37)</th>
<th>Control (n=18)</th>
<th>Intervention (n=19)</th>
<th>( p )-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>59.14 ± 11.03</td>
<td>56.33 ± 9.71</td>
<td>61.8 ± 11.7</td>
<td>0.135</td>
</tr>
<tr>
<td>Male gender</td>
<td>26 (70%)</td>
<td>16 (32%)</td>
<td>14 (38%)</td>
<td>0.946</td>
</tr>
<tr>
<td>Caucasian ethnicity</td>
<td>32 (86%)</td>
<td>16 (50%)</td>
<td>16 (50%)</td>
<td>0.677</td>
</tr>
<tr>
<td>Education, years</td>
<td>12.5 ± 2.5</td>
<td>12.8 ± 3.0</td>
<td>12.2 ± 2.0</td>
<td>0.465</td>
</tr>
<tr>
<td>Married or cohabitating</td>
<td>27 (73%)</td>
<td>13 (35%)</td>
<td>14 (37%)</td>
<td>0.909</td>
</tr>
<tr>
<td>Quality of support</td>
<td></td>
<td></td>
<td></td>
<td>0.105</td>
</tr>
<tr>
<td>Satisfactory</td>
<td>2 (5.4%)</td>
<td>2 (5.4%)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>18 (48.6%)</td>
<td>6 (16.2%)</td>
<td>12 (32.4%)</td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>17 (45.9%)</td>
<td>10 (27%)</td>
<td>7 (18.9%)</td>
<td></td>
</tr>
<tr>
<td>NYHA Class</td>
<td></td>
<td></td>
<td></td>
<td>0.723</td>
</tr>
<tr>
<td>II</td>
<td>4(14%)</td>
<td>2(7%)</td>
<td>2(7%)</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>10(33%)</td>
<td>6(20%)</td>
<td>4(13%)</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>16(53%)</td>
<td>7(23%)</td>
<td>9(30%)</td>
<td></td>
</tr>
<tr>
<td>Financial stability</td>
<td></td>
<td></td>
<td></td>
<td>0.460</td>
</tr>
<tr>
<td>Comfortable, more than</td>
<td>8 (21.6%)</td>
<td>5(13.5%)</td>
<td>3 (8.0%)</td>
<td></td>
</tr>
<tr>
<td>enough to make ends meet</td>
<td></td>
<td></td>
<td></td>
<td>734</td>
</tr>
<tr>
<td>Enough to make ends meet</td>
<td>13 (35%)</td>
<td>7 (18.9%)</td>
<td>6 (16.2%)</td>
<td></td>
</tr>
<tr>
<td>Not enough to make ends meet</td>
<td>16 (43.2%)</td>
<td>6 (16.2%)</td>
<td>10 (27%)</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.1 Continued

<table>
<thead>
<tr>
<th>Heart failure medications</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Beta-blockers</td>
<td>37 (100%)</td>
<td>18 (48.6%)</td>
<td>19 (51.3%)</td>
</tr>
<tr>
<td>Angiotensin-converting-enzyme inhibitor</td>
<td>24 (64.9%)</td>
<td>10 (27.0%)</td>
<td>14 (37.8%)</td>
</tr>
<tr>
<td>Angiotensin receptor blockers</td>
<td>3 (8.1%)</td>
<td>3 (8.1%)</td>
<td>0</td>
</tr>
<tr>
<td>Diuretic</td>
<td>32 (86.5%)</td>
<td>16 (43.2%)</td>
<td>16 (43.2%)</td>
</tr>
<tr>
<td>Charlson comorbidity score</td>
<td>3.83 ± 2.61</td>
<td>4.44 ± 2.54</td>
<td>3.26 ± 2.62</td>
</tr>
<tr>
<td>Adequate health literacy</td>
<td>4.21 ± 1.08</td>
<td>4.16 ± 1.20</td>
<td>4.26 ± 0.991</td>
</tr>
<tr>
<td>Family functioning scores</td>
<td>1.68 ± 1.5</td>
<td>1.70 ± 3.6</td>
<td>1.65 ± 1.4</td>
</tr>
<tr>
<td>Self-care score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintenance</td>
<td>54.9 ± 18.2</td>
<td>56.6 ± 18.9</td>
<td>53.3 ± 17.8</td>
</tr>
<tr>
<td>Management</td>
<td>44.3 ± 23.1</td>
<td>47.3 ± 22.8</td>
<td>41.7 ± 23.8</td>
</tr>
<tr>
<td>Confidence</td>
<td>46.1 ± 23.5</td>
<td>42.6 ± 24.7</td>
<td>49.4 ± 22.3</td>
</tr>
</tbody>
</table>

*Pearson Chi-Square test used to determine differences between groups for categorical variables and independent samples t-test used to determine differences between groups for continuous variables. NHYA (New York Heart Association)
Table 4.2  Baseline Caregiver Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Total Sample (N=37)</th>
<th>Control (n=18)</th>
<th>Intervention (n=19)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%) or mean ± SD</td>
<td>N (%) or mean ± SD</td>
<td>N (%) or mean ± SD</td>
<td></td>
</tr>
<tr>
<td>Age, years</td>
<td>49 ± 10.7</td>
<td>47.3 ± 11.9</td>
<td>50.5 ± 2.2</td>
<td>0.376</td>
</tr>
<tr>
<td>Female gender</td>
<td>29 (78.4%)</td>
<td>14 (37.0%)</td>
<td>15 (40.0%)</td>
<td>0.931</td>
</tr>
<tr>
<td>Caucasian ethnicity</td>
<td>32 (86.5%)</td>
<td>15 (40.5%)</td>
<td>17 (45.9%)</td>
<td>0.585</td>
</tr>
<tr>
<td>Education, years</td>
<td>12.7 ± 3.44</td>
<td>12.8 ± 4.36</td>
<td>12.8 ± 2.38</td>
<td>0.824</td>
</tr>
<tr>
<td>Married or cohabitating</td>
<td>22 (59.4%)</td>
<td>10 (27.0%)</td>
<td>12 (32.4%)</td>
<td>0.638</td>
</tr>
<tr>
<td>Quality of support</td>
<td></td>
<td></td>
<td></td>
<td>0.803</td>
</tr>
<tr>
<td>Satisfactory</td>
<td>10 (27.0%)</td>
<td>4 (10.8%)</td>
<td>6 (16.2%)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>12 (32.4%)</td>
<td>6 (16.2%)</td>
<td>6 (16.2%)</td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>15 (40.5%)</td>
<td>8 (21.6%)</td>
<td>7 (18.9%)</td>
<td></td>
</tr>
<tr>
<td>Financial stability</td>
<td></td>
<td></td>
<td></td>
<td>0.116</td>
</tr>
<tr>
<td>Comfortable &gt; than enough to</td>
<td>6 (16.2%)</td>
<td>5 (13.5%)</td>
<td>1 (2.7%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Make ends meet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------</td>
<td>-----------------------------------</td>
<td>-----------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Have enough to make ends meet</td>
<td>15 (40.5%)</td>
<td>8 (21.6%)</td>
<td>8 (21.6%)</td>
</tr>
<tr>
<td></td>
<td>Not enough to make ends meet</td>
<td>15 (40.5%)</td>
<td>5 (13.5%)</td>
<td>10 (27.0%)</td>
</tr>
<tr>
<td>Employment status</td>
<td>Fulltime</td>
<td>12 (32.4%)</td>
<td>5 (13.5%)</td>
<td>7 (18.9%)</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>12 (32.4%)</td>
<td>5 (13.50%)</td>
<td>7 (18.9%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>13 (35.1%)</td>
<td>8 (21.6%)</td>
<td>5 (13.5%)</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>Spouse</td>
<td>20 (54.1%)</td>
<td>10 (27.0%)</td>
<td>10 (27.0%)</td>
</tr>
<tr>
<td></td>
<td>Child</td>
<td>9 (24.3%)</td>
<td>3 (8.1%)</td>
<td>6 (16.2%)</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
<td>1 (2.7%)</td>
<td>1 (2.7%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Parent</td>
<td>1 (2.7%)</td>
<td>0</td>
<td>1(2.7%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6 (16.2%)</td>
<td>4 (10.8%)</td>
<td>2 (5.4%)</td>
</tr>
<tr>
<td>Charlson comorbidity score</td>
<td></td>
<td>1.08 ± 1.89</td>
<td>1.11 ± 2.1</td>
<td>1.05 ± .37</td>
</tr>
<tr>
<td>Adequate health literacy</td>
<td></td>
<td>4.43 ± 1.14</td>
<td>4.05 ± .27</td>
<td>4.7 ± .23</td>
</tr>
<tr>
<td>Family functioning scores</td>
<td></td>
<td>1.71 ± 1.70</td>
<td>1.74 ± 15.5</td>
<td>1.68± 18.3</td>
</tr>
<tr>
<td>Caregiver self-efficacy</td>
<td>Self-efficacy obtaining-</td>
<td>75.8 ± 32.6</td>
<td>69.8 ± 14.9</td>
<td>81.5 ±42.9</td>
</tr>
<tr>
<td></td>
<td>respite(SE-OR)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-efficacy managing patient</td>
<td>64.5 ± 8.0</td>
<td>62.3 ± 7.6</td>
<td>6.7 ± 8.0</td>
</tr>
</tbody>
</table>
Table 4.2 Continued

<table>
<thead>
<tr>
<th></th>
<th>Group A (N=40)</th>
<th>Group B (N=57)</th>
<th>Group C (N=55)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disturbing behavior (SE-DB)</td>
<td>73.5 ± 49.6</td>
<td>80.6 ± 71.0</td>
<td>66.7 ± 8.2</td>
<td>0.401</td>
</tr>
<tr>
<td>Self-efficacy –controlling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>upsetting thoughts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver perceived control</td>
<td>27.0 ± 4.0</td>
<td>25.4 ± 5.7</td>
<td>28.2 ± 4.3</td>
<td>0.274</td>
</tr>
<tr>
<td>Caregiver heart failure knowledge</td>
<td>7.3 ± 1.1</td>
<td>7.2.9 ± 1.0</td>
<td>7.4.0 ± 1.3</td>
<td>0.787</td>
</tr>
</tbody>
</table>

*Pearson Chi-Square test used to determine differences between groups for categorical variables and independent samples t-test used to determine differences between groups for continuous variables.
Table 4.3  Comparison of Patient Outcomes Across Time Between Intervention and Usual Care Groups

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Groups</th>
<th>Baseline</th>
<th>Discharge</th>
<th>7-day</th>
<th>30-day</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Time/</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Time x</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Group</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>interaction</td>
</tr>
<tr>
<td>Self-care</td>
<td>Intervention</td>
<td>50.9 ± 16.4</td>
<td>73.3 ± 21.2</td>
<td>79.2 ± 21.2</td>
<td>82.7 ± 12.5</td>
<td>0.022</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Control</td>
<td>57.7 ± 19.4</td>
<td>51.3 ± 14.7</td>
<td>57.5 ± 24.3</td>
<td>52.4 ± 29.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Self-care</td>
<td>Intervention</td>
<td>41.5 ± 22.9</td>
<td>54.2 ± 22.6</td>
<td>85.7 ± 20.8</td>
<td>81.9 ± 15.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Management</td>
<td>Control</td>
<td>56.6 ± 23.1</td>
<td>48.3 ± 24.8</td>
<td>55.0 ± 8.3</td>
<td>63.3 ± 20.6</td>
<td>0.005</td>
</tr>
<tr>
<td>Self-care</td>
<td>Intervention</td>
<td>50.0 ± 22.8</td>
<td>57.7 ± 27.2</td>
<td>66.4 ± 28.2</td>
<td>76.2 ± 26.3</td>
<td>0.323</td>
</tr>
<tr>
<td>Confidence</td>
<td>Control</td>
<td>44.9 ± 24.5</td>
<td>41.9 ± 28.8</td>
<td>37.4 ± 26.4</td>
<td>42.9 ± 26.2</td>
<td>0.159</td>
</tr>
<tr>
<td>Caregiver Outcome</td>
<td>Groups</td>
<td>Baseline</td>
<td>Discharge</td>
<td>7-day</td>
<td>30-day</td>
<td>P</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-----------------</td>
<td>-----------</td>
<td>-----------</td>
<td>--------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Time x Group Interaction</td>
</tr>
<tr>
<td>Self-efficacy respite (SE-OR)</td>
<td>Intervention</td>
<td>74.4 ± 13.0</td>
<td>84.5 ± 6.8</td>
<td>93.5 ± 5.2</td>
<td>96.8 ± 3.2</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>69.1 ± 16.8</td>
<td>80.6 ± 7.8</td>
<td>92.3 ± 3.4</td>
<td>94.7 ± 5.7</td>
<td>0.675</td>
</tr>
<tr>
<td>Self-efficacy disturbing behavior (SE-DB)</td>
<td>Intervention</td>
<td>67.1 ± 6.55</td>
<td>89.9 ± 5.4</td>
<td>94.5 ± 5.9</td>
<td>97.7 ± 2.6</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>62.1 ± 7.7</td>
<td>86.8 ± 8.0</td>
<td>91.1 ± 7.3</td>
<td>93.1 ± 5.5</td>
<td>0.829</td>
</tr>
<tr>
<td>Self-efficacy upsetting thoughts (SE-UT)</td>
<td>Intervention</td>
<td>68.0 ± 8.3</td>
<td>91.1 ± 5.5</td>
<td>94.5 ± 4.4</td>
<td>95.9 ± 7</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>63.3 ± 15.3</td>
<td>90.2 ± 6.1</td>
<td>94.8 ± 4.8</td>
<td>95.8 ± 6.3</td>
<td>0.458</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Perceived control</td>
<td>28.2 ± 4.0</td>
<td>25.4 ± 4.3</td>
<td>28.2 ± 5.2</td>
<td>19.6 ± 6.4</td>
<td>20.9 ± 5.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>30.7 ± 3.3</td>
<td>28.2 ± 5.2</td>
<td>31.0 ± 5.4</td>
<td>19.6 ± 6.4</td>
<td>20.9 ± 5.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>31.0 ± 5.4</td>
<td>31.0 ± 5.4</td>
<td>30.9 ± 3.6</td>
<td>30.9 ± 3.6</td>
<td>0.125</td>
<td></td>
</tr>
<tr>
<td></td>
<td>30.9 ± 3.6</td>
<td>30.9 ± 3.6</td>
<td>30.9 ± 3.6</td>
<td>30.9 ± 3.6</td>
<td>0.125</td>
<td></td>
</tr>
<tr>
<td>Heart Failure</td>
<td>7.3 ± 1.4</td>
<td>7.3 ± 9.0</td>
<td>7.7 ± 1.7</td>
<td>6.9 ± 2.2</td>
<td>7.7 ± 1.7</td>
<td>0.157</td>
</tr>
<tr>
<td>Knowledge</td>
<td>8.2 ± 1.5</td>
<td>7.7 ± 1.7</td>
<td>9.4 ± 6.5</td>
<td>7.7 ± 1.7</td>
<td>0.055</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7.9 ± 2.1</td>
<td>7.9 ± 2.1</td>
<td>9.4 ± 5.4</td>
<td>7.7 ± 1.7</td>
<td>0.055</td>
<td></td>
</tr>
</tbody>
</table>

*Greenhouse-Geisser epsilon correction factor used.*
Figure 4.1  Participant Flow through the Study

Assessed for Eligibility, n=193

Eligible, n=93

Choose not to participate, n=54
1. Felt too SOA (n=15)
2. No time (n=25)
3. No reason given (n=14)

Participants Enrolled, n=39

Ineligible, n=100
1. Family not available
2. Heart failure as primary diagnosis
3. Patient listed for transplant

Randomized

Control group, n=18

Baseline data collection,

Discharge data collection, n=18

7-day data collection, n=18

30-day data collection, n=18

Intervention group, n=21

Baseline data collection, n=21

Discharge data collection, n=21

Died after data collection but before discharge n=2

7-day data collection, n=19

30-day data collection, n=19

Baseline data collection, n=21

Discharge data collection, n=21

Died after data collection but before discharge n=2

7-day data collection, n=19

30-day data collection, n=19
Figure 4.2  Cox regression plot for caregivers who received educational intervention versus the usual care group.
CHAPTER FIVE

Dissertation Conclusion
Dissertation Conclusion

Background and Purpose

Heart failure (HF) is increasing in prevalence due to the aging population and improvements in the treatment of coronary artery disease, which increase survival among those with myocardial damage.\textsuperscript{107} Heart failure is a major health problem worldwide with one of the highest readmission and mortality rates of all chronic diseases.\textsuperscript{108} Hospital readmission is the number one cost for HF patients.\textsuperscript{108,109}

Heart failure management is difficult and takes place at home usually with the patient requiring help from others such as caregivers.\textsuperscript{97} Caregiving for HF patients is complex, because patients are required to engage in multiple self-care behaviors that include adherence to pharmacological and non-pharmacological treatments. Caregiver support is essential in patients with HF for the successful performance of self-care.\textsuperscript{110} Self-care is the foundation for successful treatment adherence and poor self-care is believed to contribute to frequent readmissions of patients with HF.\textsuperscript{111,112} Support from others such as caregivers, spouses, family and friends has shown to be positively associated with HF patient outcomes such as medication adherence, dietary sodium management and weighing compliance impacting HF patient self-care, readmissions and mortality.\textsuperscript{99,111,113}

Caregiving for HF patients can be satisfying, but it also can yield unhealthy effects on caregivers, who often report depressive symptoms and poor quality of life as outcomes of HF caregiving. This is of serious concern because caregiver depressive symptoms are not only associated with negative outcomes for caregivers but also for patients with HF.\textsuperscript{114} National guidelines recommend involving family caregivers and
those in a close relationship with the patient in HF self-care education. However, this is not routinely done when discharging HF patients from the hospital.

The overall purpose of my dissertation was to determine the influence of HF caregivers on patient self-care, readmission and mortality. Family functioning and caregiver depressive symptoms can have a deleterious effect on caregiver quality of life thus influencing patient quality of life. To better understand this mechanism, the manuscript in Chapter Two was developed and is a mediation analysis of the effects of caregiver depressive symptoms on the relationship between family functioning and caregiver quality of life. We anticipated that depressive symptoms would mediate the relationship between family functioning and caregiver quality of life.

Caregiver support can come in many forms. Living with someone in a shared space can provide opportunities for support from family, partners and friends as well as spouses. We anticipated that living with someone would offer social ties that in turn would bring instrumental, information and emotional support, and that patients living with someone would be less likely to be readmitted or die within one year of readmission. To better understand the influence of caregivers on outcomes of rehospitalization and mortality of patients with HF, a retrospective electronic medical record review was completed on patients with a primary diagnosis of HF. Three hundred and ninety-eight patient charts were examined.

After this retrospective chart review, a randomized controlled trial of a caregiver only, three-session, in-hospital educational intervention was undertaken and reported in Chapter Four. Thirty-seven HF patients hospitalized with a secondary diagnosis of HF and their caregivers (19 receiving a caregiver only three-session educational intervention
and 18 caregivers receiving usual care) was conducted. The group of patients whose caregivers received the educational intervention were predicted to have better self-care and lower readmission rates, while caregivers were predicted to have better self-efficacy, perceived control and HF knowledge.

**Summary of Findings**

Chapter Two was a mediation analysis of the influence of caregiver depressive symptoms on the relationship between family functioning and caregiver quality of life. One hundred and forty-three caregivers of patients with HF completed measures on family functioning, depressive symptoms and quality of life. We found the three subscales of family functioning (general, problem-solving and communication) to be independent predictors of depressive symptoms, as well as physical and mental quality of life. Caregiver depressive symptoms predicted physical and mental quality of life. In determining if mediation occurred, depressive symptoms were added to the final model with each subscale of the Family Assessment Device. When depressive symptoms were added to the final model the significance of general, problem-solving and communication family functioning as predictors of caregiver physical quality of life decreased, demonstrating mediation. Likewise, the addition of depressive symptoms in the final model with each subscale of the Family Assessment Device decreased the significance of general, problem-solving and communication family functioning as predictors of mental quality of life.

Chapter Three was a retrospective chart review of influence of HF patients living with someone versus living alone on readmission and death one year post discharge. All patients (n = 398) admitted with a primary diagnosis of HF between January 1, 2013 and
December 31, 2013 were included in the study. Patients (n=398) were primarily male, Caucasian, and 63 ± 14 years of age. Sixty-seven percent of patients lived with someone, and less than half of those were spouses. Our findings demonstrated that HF patients living with someone experienced a significantly longer time to rehospitalization than those living alone. In a Cox regression hazard regression model, adjusting for covariates, patients who lived with someone were 1.42 times less likely to be rehospitalized one year after discharge than those who lived alone. The relationship between living with someone and all-cause death was not significant after adjustment for covariates.

Chapter Four was a randomized controlled trial in which I enrolled 37 HF inpatients and their caregivers for an in-hospital, three session, and caregiver only discharge educational intervention with telephone follow-up. A linear mixed model analysis was used to determine the effects of the caregiver only education. Patients whose caregiver was in the intervention group had better self-care maintenance (p<.001) and self-care management (p<.001) and among caregivers, perceived control was significantly improved. Kaplan Meier analysis revealed that time to cardiac readmission was significantly longer in patients whose caregiver received the educational intervention. Cox proportional hazard analysis revealed that patients whose caregiver did not receive the educational intervention were 11 times more likely to experience cardiac readmission than patients whose caregiver did receive the educational intervention.

**Impact of Dissertation on the State of Science**

This dissertation focuses on caregivers’ influence on HF patients’ self-care, readmission and mortality in order to provide insight to this under-researched area. The findings from this dissertation offers unique insights about how caregivers influence
patient outcomes. In this dissertation we found caregiver depressive symptoms to be a mediator between family functioning and caregiver quality of life. Until this study, a mechanism for the association of family functioning with caregiver quality of life had not yet been defined. Finding that depressive symptoms mediated the relationship between family functioning and caregiver quality of life will assist clinicians in their efforts to design and implement interventions at both the prevention and the early treatment stages for depressive symptoms in caregivers, thereby improving caregiver quality of life and helping to prevent poor quality of life in HF patients.

Current evidence about living arrangements and their effects on the health of an individual is in most cases confined to the health of those who are married and those who are living alone. The degree to which living arrangements contribute to or impede HF patients’ ability to avoid hospital readmission may be underestimated. Through the study in Chapter Three, it was shown that HF patients living with someone are far less likely to be readmitted one year after discharge from a HF hospitalization. This adds to the limited state of knowledge in the HF population that individuals living in a household with someone can share resources that can benefit the health status of its members. This study suggests that the social context formed by the household appears to be important to the individuals’ health, regardless of marital status. As the population of HF patients increases and the number of patients who need assistance at home with HF self-care increases, understanding the confluence of these trends or how an individual’s household can help them avoid risk or place them at risk for HF readmission will remain important.

In Chapter Four, the state of the science was advanced by evaluating the effectiveness of a caregiver only, in-hospital, multi-session, educational intervention
aimed at increasing caregiver knowledge of HF, improving caregiver self-efficacy and perceived control thereby, improving HF self-care and patient outcomes. This study demonstrated the participation of caregivers in a three-session, in hospital, educational intervention can significantly improve caregiver perceived control, patient self-care maintenance and management while reducing HF patient 30-day readmissions. This is important as it is the first study to show the benefit of educating caregivers only on HF patient outcomes of self-care and readmission. At times, patients may not be available for educational interventions in the hospital, this study indicates that if needed, caregivers may serve as suitable proxies for self-care education. The findings are significant because they quantify the value of providing HF self-care education to caregivers, and the results help to fill the gap regarding the effectiveness of HF caregiver education in improving patient outcomes. Also, this study contributes to the foundational research of the importance of caregiver support to positive HF patient outcomes of self-care and readmission.

**Recommendations for Nursing Practice and Research**

Bringing understanding to the everyday experience of HF patients and their partners who experience HF is particularly timely and urgent, given the fact that HF longevity has increased due to technology and pharmaceuticals, increasing the need for caregivers. The inclusion of caregivers in HF patients' outcome research is receiving greater consideration. An explanation for the increased recognition may be requests to integrate caregivers as collaborators and part of the healthcare team as we have come to recognize their importance in supporting self-care at home. Additionally, clinicians and
researchers have begun to acknowledge the positive influence of caregiver support on patients’ health outcomes such as readmission and mortality.

Depressive symptoms and poor quality of life are both common problems for caregivers and patients with HF.\textsuperscript{114} Almost 50\% of caregivers of patients with end-stage heart failure have depressive symptoms,\textsuperscript{115,116} while the prevalence of depressive symptoms in spousal caregivers is reported to be about 47\%.\textsuperscript{117} Caregivers who have depressive symptoms are less likely to participate in assisting patients in HF self-care and treatment adherence.\textsuperscript{118} The study in Chapter Two determined depressive symptoms to be a mediator of the relationship between family functioning and caregiver quality of life. Further investigation is needed to determine if there is an effect of marital quality and relationship quality on the relationship between family functioning, caregiver depressive symptoms and caregiver quality of life. Also, more research should be performed to determine if the role of depressive symptoms on family functioning and caregiver quality of life could be replicated in future studies. Because if depressive symptoms are an influential and an essential link between family functioning and caregiver quality of life, the therapeutic implications for interventions targeting HF caregivers with high risk of depression or with family dysfunction could be extensive. Depressive symptoms can interfere with the positive effects of self-care education in patients with heart failure.\textsuperscript{119} Therefore, before providing education for caregiver of HF patients, it is necessary to consider their psychological problems such as depression.

Social scientist concur that living arrangements of older patients such as those with HF may play a key role in their use of formal or informal healthcare.\textsuperscript{120} Heart failure patients in this study were found less likely to be readmitted within one year of discharge.
if they lived with someone versus living alone. Though living with a spouse seem to confer some protective effect, many older adults do not live with a spouse because they have outlived their spouse, they are divorced or they did not marry at all. Thus is very important to assess patient living arrangements in HF patients in addition to marital status. The diversity of living with someone versus living for HF patients reinforces the point that one-size-does-not-fit-all when it comes the household structure and health. Our results underscore the critical importance of some support within the household in patients with HF. The household in which the HF patient lives with someone seems to provide social integration and support for its members, who exchange resources. There is a lack of high quality longitudinal data illuminating the interacting nature between living arrangements and HF patient outcomes. Longitudinal data would helpful as considerable variations in the propensity of transitions in living arrangements could exist over time, such as the loss of a spouse or worsening of the patient’s HF. A lack of high quality longitudinal data with the HF population has inhibited progress in understanding the interplay between living arrangements and HF patient outcomes.

The study described in Chapter Four has an innovative approach for caregiver HF self-care discharge education. Research confirms that a traditional model of discharge education is not effective in positively influencing HF patient self-care, and has actually been associated with readmissions.\textsuperscript{121,122} Current guidelines recommend the inclusion of caregivers in HF discharge education however, this is seldom done.\textsuperscript{123} Certain caregiver characteristics such as self-efficacy, perceived control and heart failure knowledge may positively influence patient self-care.\textsuperscript{44,124} The purpose of this study was to evaluate the effectiveness of a caregiver only, in-hospital, multi-session, educational intervention
aimed at increasing caregiver knowledge of HF, improving caregiver self-efficacy and perceived control. We hypothesized that by improving these caregiver factors, patient self-care would be improved and 30-day readmission rates would be decreased. The intervention resulted in an improvement in caregiver perceived control, HF patient self-care maintenance and management and fewer HF patient readmission in 30-days.

This research will add to the evidence that including caregivers into HF self-care discharge education is beneficial to caregiver and patient outcomes. This study provides a structured outline for the effectiveness of a caregiver only education when patients’ are not able physically or mentally to participate in HF patient self-care education, however, further research is needed to solidify these results. Further investigation of this interventional model is needed with more intensive, longer periods of follow-up to ensure that the influence of the educational interventions persists after 30-days. In current practice, the results of this study suggests that there needs to be greater attention and deliberateness to consistently involve caregivers into HF discharge education. Using this type of educational intervention, nurses have the potential to improve patient outcomes using the caregiver as a resource for heart failure patient self-care thus decreasing HF readmissions.
References

Chapter One


Chapter Two


5. Pihl E, Jacobsson A, Fridlund B, Strömberg A, Måtensson J. Depression and health-related quality of life in elderly patients suffering from heart failure and


21. Yeh PM, Bull M. Use of the resiliency model of family stress, adjustment and adaptation in the analysis of family caregiver reaction among families of older


40. Mpofu E, Oakland TD. *Assessment in rehabilitation and health*. Pearson/Merrill; 2010.


51. Kroenke K, Spitzer R. Instruction manual: Instructions for patient health questionnaire (PHQ) and GAD-7 measures. 2010.


Chapter Three


Chapter Four


51. Williams SL, French DP. What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour—and are they the same? *Health education research*. 2011;26(2):308-322.


54. Chung ML, Moser DK, Lennie TA. Feasibility of Family Sodium Watcher Program to Improve Adherence to Low Sodium Diet in Patients with Heart Failure and Caregivers. *Am Heart Assoc*; 2014.


68. Jaarsma T, Nikolova-Simons M, van der Wal MH. Nurses’ strategies to address self-care aspects related to medication adherence and symptom recognition in


73. Lennie TA, Chung ML, Moser DK. What should we tell patients with heart failure about sodium restriction and how should we counsel them? *Current heart failure reports.* 2013;10(3):219-226.


Chapter Five


51. Williams SL, French DP. What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour—and are they the same? *Health education research.* 2011;26(2):308-322.


54. Chung ML, Moser DK, Lennie TA. Feasibility of Family Sodium Watcher Program to Improve Adherence to Low Sodium Diet in Patients with Heart Failure and Caregivers. *Am Heart Assoc; 2014.*


68. Jaarsma T, Nikolova-Simons M, van der Wal MH. Nurses’ strategies to address self-care aspects related to medication adherence and symptom recognition in


73. Lennie TA, Chung ML, Moser DK. What should we tell patients with heart failure about sodium restriction and how should we counsel them? *Current heart failure reports.* 2013;10(3):219-226.


hospitalized patients due to heart failure with and without depression. *PloS one.*

120. Russell D, Taylor J. Living alone and depressive symptoms: the influence of
gender, physical disability, and social support among Hispanic and non-Hispanic
older adults. *Journals of Gerontology Series B: Psychological Sciences and

121. Gheorghiade M, Vaduganathan M, Fonarow GC, Bonow RO. Rehospitalization
for heart failure: problems and perspectives. *Journal of the American College of

122. Fonarow GC, Abraham WT, Albert NM, et al. Factors identified as precipitating
hospital admissions for heart failure and clinical outcomes: findings from
OPTIMIZE-HF. *Archives of internal medicine.* 2008;168(8):847-854.

123. Albert NM, Fonarow GC, Abraham WT, et al. Predictors of delivery of hospital-
based heart failure patient education: a report from OPTIMIZE-HF. *Journal of
cardiac failure.* 2007;13(3):189-198.

124. Wallston BS, Alagna SW, DeVellis BM, DeVellis RF. Social support and
Vita

Education

<table>
<thead>
<tr>
<th>Institution</th>
<th>Degree</th>
<th>Date Conferred</th>
<th>Field of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prestonsburg Community College</td>
<td>ADN</td>
<td>1983</td>
<td>Nursing</td>
</tr>
<tr>
<td>University of Kentucky</td>
<td>BSN</td>
<td>1991</td>
<td>Nursing</td>
</tr>
<tr>
<td>University of Kentucky</td>
<td>MSN</td>
<td>2008</td>
<td>Nursing</td>
</tr>
</tbody>
</table>

Professional Experience

<table>
<thead>
<tr>
<th>Year</th>
<th>Employer</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-Present</td>
<td>University of Kentucky Medical Center</td>
<td>Clinical Nurse Specialist CCU/CTICU</td>
</tr>
<tr>
<td>2010-Present</td>
<td>Bluegrass Community &amp; Technical College</td>
<td>Clinical Nursing Instructor</td>
</tr>
<tr>
<td>2002-2010</td>
<td>University of Kentucky Medical Center</td>
<td>Cardiac Catheterization Recovery Unit Staff Nurse/Charge Nurse</td>
</tr>
<tr>
<td>2007-2008</td>
<td>University of Kentucky College of Nursing</td>
<td>Coronary Care Unit</td>
</tr>
</tbody>
</table>

Honors and Awards:

- Recipient of the 2019 Saha Awards for Cardiovascular Research and Education, Paula Fritz, RN Patient Education Award.

Publications:


________________________________________
Linda Clements
Signature