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THE RELATIONSHIP OF SOCIAL SUPPORT IN SELF-CARE, DEPRESSIVE SYMPTOMS,
AND QUALITY OF LIFE OUTCOMES IN PATIENTS WITH
HEART FAILURE

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Nursing
at the University of Kentucky

By
Shannon C. Shumaker

Lexington, Kentucky

Director: Dr. Susan Frazier, Professor of Nursing Science

Lexington, Kentucky

2016

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ABSTRACT OF DISSERTATION

THE RELATIONSHIP OF SOCIAL SUPPORT IN SELF-CARE, DEPRESSIVE SYMPTOMS, AND QUALITY OF LIFE OUTCOMES IN PATIENTS WITH HEART FAILURE

The purpose of this dissertation was to evaluate outcomes associated with social support in patients with heart failure and their caregivers. Specific aims were to: 1) examine the association of depressive symptoms with self-care in patients with HF; 2) evaluate the psychometrics properties of the Multidimensional Scale of Perceived Social Support (MSPSS) instrument as a measure of perceived social support in patients with heart failure; and 3) determine whether patient and caregiver perception of relationship quality measured at baseline upon enrollment predicted quality of life at baseline in both patient and caregiver using a multilevel dyadic analysis in patient and caregiver.

Specific aim one was addressed by secondary analysis data from patients with heart failure enrolled in the Rural Education to Improve Outcomes in Heart Failure (REMOTE-HF) clinical trial. Multiple linear regression was used to determine whether depressive symptoms were associated with self-care, while controlling for age, sex, ethnicity, education level, and New York Heart Association functional class. The presence of depressive symptoms predicted worse self-care in patients with heart failure. For the second specific aim, the psychometric properties of the Multidimensional Scale of Perceived Social Support (MSPSS) and its subscales were investigated. The MSPSS reliability and validity were supported by measures of internal consistency reliability, factor analysis, and hypothesis testing. The third specific aim was met with an investigation of the patient and caregiver to examine whether relationship quality measured at baseline influenced quality of life measured at baseline in patient-caregiver heart failure dyads. The Actor Partner Interdependence Model (APIM) demonstrated both actor and partner effects for the patient and caregiver. Relationship quality was associated with quality of life in patient-caregiver dyads.

KEYWORDS: *self-care, depressive symptoms, social support, quality of life, dyads*

Shannon C. Shumaker

8/4/2016

Dedication

This dissertation is dedicated to my nephews and nieces; Kristian, Brooklynn, Alivia, Mason, and Maddie. I hope that I have inspired your educational motivation and desire. You will do great things in life with passion and perseverance.

All my love, Aunt Shannon

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CHAPTER ONE

Introduction

Heart failure (HF) affects 5.7 million Americans and the prevalence is expected to increase.¹ Mortality remains high; 50% of those with heart failure will die within 5 years of diagnosis.² Costs of heart failure-related care include medications, healthcare services, and missed days of work, which total approximately 32 million dollars annually.³ Approximately 83% of patients with HF are hospitalized at least once, and 43% are hospitalized more than 4 times within 5 years.^{2,4} Physical, social, and psychological functioning of patients with HF is compromised; thus, patients with HF are at risk for poor self-care, depressive symptoms, and worse quality of life.⁵⁻⁹ Evidence suggests that these outcomes for patients with HF are associated with perceived social support and may be affected by the relationship quality of the patient-caregiver dyad.¹⁰⁻¹³

When social support was originally explored, researchers used concrete terms to describe a relationship or interaction.¹⁴ However, over time the concept of social support has expanded to embody perceptions of support, quality of support, anticipation of support among persons, behaviors, and social relationships.¹⁵ Social support is a multidimensional concept and is commonly defined as the resources provided by others.¹⁶ Measures of social support use descriptions of structure or function of the support.¹⁶ Structural support includes marital status; living arrangement, and frequency, intensity, and size of the available social network.¹⁷ Functional support is comprised of practical, emotional, and family connectedness.¹⁸ Functional social support occurs in the presence of a social network, social climate, and social embeddedness.^{10,19} Within a positive social climate there is a prevailing typology of four attributes of functional support; these are emotional, informational, instrumental, and appraisal.^{15,19,20} Emotional support refers to caring and empathy; informational support is

characterized by problem-solving during times of stress. Instrumental support occurs through tangible or physical assistance; appraisal support is the communication of information related to affirmations by others^{10,19} Within each attribute, it is theorized that reciprocity must be present for support to continue.¹⁹

Several social support theories that include social competence, social comparison, and social exchange propose that the process of social exchange (giving and receiving) requires social competence (ability to interact with the environment) for enhancement of psychological well-being and maintenance of social relationships.¹⁹ These social support theories validate the emotional contagion theory. The emotional contagion theory describes how others (the social network, partner, spouse, etc.) might influence an individual's emotional reactions.²¹ Schachter (1959) hypothesized that an individual's affiliation creates pressures to establish a shared social reality.²² Therefore, a social relationship between two individuals who share a common environment has the ability to influence each individual's emotions. Emotional involvement between two or more individuals who live in geographically close location comprises family care relationships.²³ The concept of family care relationships between the patient and the caregiver constitute a dyad.²⁴ The Actor-Partner Interdependence Model of Relationship Quality (Figure 1.) conceptualizes the interdependence of this relationship.

Self-care

Individuals with HF experience a range of physical symptoms including dyspnea, edema, functional impairment, difficulty sleeping and fatigue.^{8,25} The progressive nature of HF affects the individual's ability to perform self-care behaviors.²⁶ The management of HF symptoms with self-care strategies is necessary to manage symptoms and improve outcomes. However, successful self-care is hindered when depressive symptoms exist. Scientists previously found that

patients with HF who are nonadherent have more depressive symptoms.²⁷ Prior research evidence supports the association between worse depressive symptoms and poorer self-care in patients with HF.²⁸ Previously, scientists suggested that self-care behaviors were affected by social support. Patients with HF and a high level of social support had better self-care compared to patients with HF and low to moderate social support.²⁹ Although, the presence of a partner is not enough to impact self-care; the social support person must be involved and provide good quality of assistance that matches the patient's perception of support.²⁹

Depressive Symptoms

Depressive symptoms are highly prevalent among those with HF; 1 in 5 HF patients reported depression.³⁰ The presence of worse depressive symptoms is independently associated with higher mortality and increased readmission for HF.³¹⁻³³ The risk of developing depressive symptoms is greater in patients with HF with worse health status (symptoms, social functioning, physical functioning, self-efficacy, and quality of life), and worse New York Heart Association functional class (NYHA). When one of these (symptoms, social and physical functioning, self-efficacy, quality of life, and class III/IV functional class) is present, the incidence of depression is 15.5% in one year; when three are present the incidence increases to 69.2%.^{34,35} Overall, prior research evidence supported the hypothesis that depressive symptoms increased the risk for worse outcomes.

The perception of instrumental and emotional support, as well as an available social network, among those with HF decreased depressive symptoms.¹⁰ Heart failure patients with more physical symptoms had less social support, increased depressive symptoms, and poorer self-care behaviors.³⁶ However, additional research is needed to determine the particular

attributes of social support which may worsen or improve depressive symptoms in patients with HF.

Quality of Life

Scientists have measured the concept of quality of life among HF patients using quality of life instruments and health-related quality of life instruments. Quality of life (QOL) is an individual's subjective perception of their general life quality.³⁷ Health-related quality of life (HRQOL) is defined as the individual's perspective of life quality related to the illness experience.³⁸ Because these two concepts differ, it is important to distinguish between the two when evaluating the value of quality of life by the participant.

Outpatients with HF who were 55-years and older had worse quality of life compared to their healthy age-matched counterparts.³⁹ However, researchers who explored health-related quality of life have shown that HRQOL is best for those over 63-years old.⁴⁰ Further evidence suggests that worse NYHA class was associated with worse quality of life.⁴¹ Therefore, future research which includes these confounding variables that may impact quality of life is necessary.

There is evidence that poorer social support and the presence of depressive symptoms predicted poorer quality of life; this association was mediated by depressive symptoms.¹² Additional evidence demonstrated that physical symptoms (presence, frequency, distress, and severity) and depressive symptoms mediated the relationship between health-related quality of life and emotional support.⁴² Thus, social and emotional support have the potential to affect quality of life in those with HF when depressive and physical symptoms are also evaluated.

Summary of Subsequent Chapters

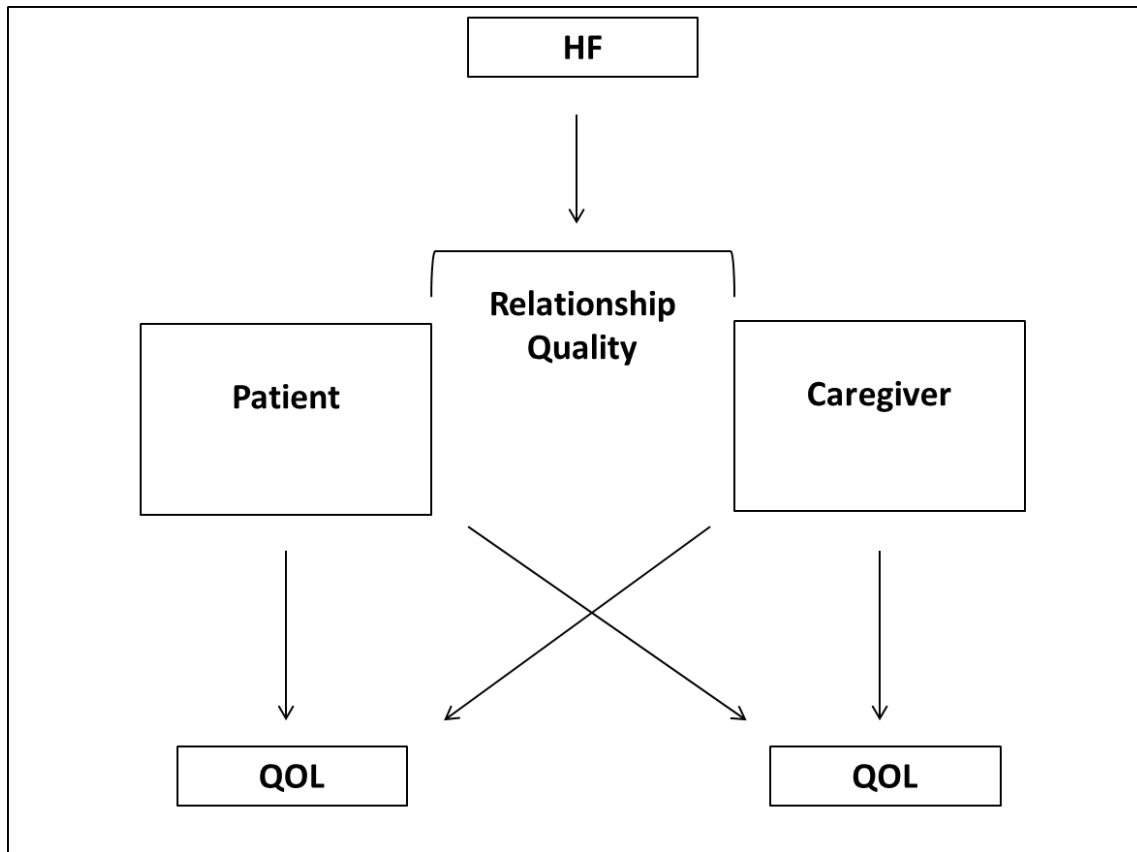
Chapter Two is a report of a secondary analysis of data focused on the association of self-care and depressive symptoms in patients with HF. We hypothesized that depressive symptoms

predicted worse self-care. A greater depressive symptoms score predicted worse self-care in patients with HF. Thus, self-care might be improved with effective assessment and management of depressive symptoms. Because evidence suggests that poor self-care is also associated with low perceived social support, the evaluation of a measure of perceived social support in the heart failure population was needed. Therefore, Chapter Three is a report of a psychometric evaluation of the Multidimensional Scale of Perceived Social Support (MSPSS) in patients with HF. This included evaluation of the reliability and validity; construct validity was further examined using hypothesis testing. We hypothesized that perceived social support predicted depressive symptoms, and that poorer perceived social support was associated with a higher degree of depressive symptoms. We found that the MSPSS was a reliable and valid instrument to measure perceived social support in patients with HF. Hypothesis testing demonstrated that perceived social support measured with the MSPSS was a predictor of depressive symptoms; higher perceived social support predicted fewer depressive symptoms. While the measurement of perceived social support was necessary to evaluate, attention to the unique relationship that may exist in the close family relationship of patient-caregiver dyads was performed to determine the quality of the relationship on outcomes. Chapter Four is a report from an original investigation about the association of relationship quality with quality of life in patients with HF and their caregivers. The purpose of this study was to examine whether relationship quality influenced quality of life in HF patient-caregiver dyads. We hypothesized that increased relationship quality was associated with increased quality of life in both members of the dyad using the Actor Partner Interdependence Model (APIM). The findings from this study demonstrated actor effects (the impact of the relationship quality on the person's own quality of life) and partner effects (the effect of each person's level of relationship quality on their partner's quality of life).^{43,44} Our

findings showed a patient actor effect; high dyadic strain was associated with the patient's own greater health-related quality of life. They also demonstrated a caregiver actor effect; high communication in caregivers was associated with their own greater health-related quality of life. Our findings also demonstrated two partner effects; higher decision-making by the caregiver was associated with poorer patient physical quality of life; and higher caregiver reciprocity was associated with poorer patient physical quality of life.

Chapter Five is a summary of findings from these dissertation manuscripts. Conclusions from these manuscript findings are presented. Future research and nursing implications for heart failure patients and their caregivers are presented in this chapter.

Figure 1. Actor-Partner Interdependence Model of Relationship Quality in Patient-Caregiver Dyads



HF, Heart Failure; QOL, Quality of Life

CHAPTER TWO

Depressive Symptoms Predict Poorer Self-care in Patients with Heart Failure

Abstract

Objective: We aimed to examine the association of depressive symptoms with self-care in patients with HF.

Background: Ineffective self-care is the most common reason for rehospitalization in patients with HF.

Methods: We performed a secondary analysis of data from the REMOTE-HF trial. Multiple linear regression determined whether depressive symptoms were associated with self-care, while controlling for age, sex, ethnicity, education level, and New York Heart Association functional class.

Results: Participants (n = 608) were primarily Caucasian (86%), males (59%), aged 66 ± 13 years with adequate self-care (score 20 ± 7). Nearly two thirds of participants (59%) reported depressive symptoms. Depressive symptoms were an independent predictor of worse self-care (B = 0.243, $p < 0.001$).

Conclusions: Depressive symptoms were prevalent in this group of HF patients, and were an independent predictor of self-care. Assessment for and effective treatment of depressive symptoms in patients with HF may improve self-care and subsequent patient outcomes.

Key words: *self-care, depressive symptoms, heart failure, predictors, rehospitalization*

Introduction

Heart failure (HF) affects more than 5.7 million Americans.⁴⁵ More than 1 million hospitalizations occur each year for HF,⁴⁵ and approximately 25% of those with HF are rehospitalized within 30 days of hospital discharge.⁴⁶ Hospitalization is an independent predictor of greater mortality in patients with HF.⁴⁷ However, more than 70% of hospitalizations are regarded as preventable when effective self-care strategies are implemented.^{48,49} Self-care is defined as the strategies and decisions which an individual uses to maintain healthy functioning, quality of life, and well-being.⁵⁰ These strategies and decisions result in behaviors such as adherence to medication, fluid and sodium restriction, and daily symptom monitoring.⁵⁰ According to Lee and colleagues, patients with HF who engaged in effective self-care management had a 56% decrease in hospitalization, emergency room visits, and all-cause mortality.⁵¹

Common symptoms of HF include dyspnea, edema, weight gain, and fatigue.^{49,52} Self-care strategies are important to manage symptoms, avoid HF exacerbation and subsequent hospitalization, improve functional ability, and decrease mortality.^{26,47,53,54} Expertise in self-care is the ability to demonstrate an understanding of the treatments for HF and describe HF symptoms in relation to HF etiology.²⁸ However, only 10.3% of patients with HF are classified as experts in self-care.²⁸

Self-care strategies include adherence to medication, low sodium diet, and daily symptom monitoring. Medication adherence is defined as the percentage of medication that is actually taken as prescribed.⁸ Reported adherence to medication prescription in patients with HF is poor; in one study only 34% reported taking all of the prescribed medications.⁵⁵ Another important self-care strategy is fluid and sodium restriction. A daily dietary intake of 2.3 g/day of sodium is

recommended for those with heart failure; however, 22% of patients with HF did not follow a sodium restricted diet which resulted in an acute exacerbation of HF.⁵⁴ Early symptom recognition is also poor in patients with HF; 40% exhibited aggravating symptoms of HF at least 2 weeks prior to hospitalization.⁵⁶ Thus, in a number of studies, patients with HF have demonstrated inadequate self-care strategies which impacted their outcomes.^{8,28,54} Determination of factors that influence self-care ability is vital to improvement of outcomes.

Risk factors for poorer self-care described in prior research have included age, sex, ethnicity, education level, and New York Heart Association (NYHA) functional class. Those who were older than 61 years of age had an increased risk of poor self-care.⁵⁷ Sex may also increase the risk of poorer self-care with men and women interpreting HF symptoms differently.⁵⁸ There is some evidence that women were less likely to recognize HF-related symptoms and seek treatment.⁵⁸ Poorer medication adherence has been reported in African-Americans as compared to Caucasian patients with HF; therefore, ethnicity may be a risk factor for poorer self-care.⁵⁹ Previous investigators also suggested that higher education level and increased symptom burden were predictive of better self-care behaviors.⁶⁰ Psychological states may also influence self-care ability.

Comorbid depressive symptoms may reduce self-care ability because of associated cognitive dysfunction,⁶¹ significant reduction in functional status which reduces the physical ability to enact self-care behaviors,⁶² poorer social support which is vital to development of self-care skills,⁴² and the use of ineffective coping mechanisms.⁸ The prevalence of depressive symptoms is high in patients with HF; investigators have reported that 73% of patients with HF compared to 59% of healthy individuals exhibited evidence of depressive symptoms.⁶³ Other

investigators found that the presence of depressive symptoms was an independent predictor of a decrease in physical function, hospital readmission, and death.^{32,64}

The synergistic effect of medication nonadherence and depressive symptoms resulted in a 5 times greater risk of hospitalization or death when compared with patients with HF who were medication adherent without depressive symptoms.⁶⁵ Nonadherence with a low sodium diet restriction and concurrent depressive symptoms was associated with a 3.7 times higher risk of cardiac hospitalization or death when compared to those without depressive symptoms.⁶⁶ Patients with HF and depressive symptoms also demonstrated a 1.5 times longer delay of more than 3 days between onset of symptoms of HF and seeking medical treatment.⁶⁷ Thus, there is evidence that concurrent depressive symptoms worsened patient outcomes.

The findings of previous investigators support the hypothesis that both depressive symptoms and self-care ability are associated with outcomes. Because depressive symptoms are highly prevalent in patients with HF, and provide several mechanisms that may reduce self-care ability, it is essential to better understand this relationship to improve patient outcomes. Thus, the aim of this study was to examine the association of depressive symptoms with self-care in patients with HF. We hypothesized that depressive symptoms were an independent predictor of worse self-care.

Materials and Methods

Design

This was a secondary analysis of data from patients with HF enrolled in the Rural Education to Improve Outcomes in Heart Failure (REMOTE-HF) randomized clinical trial.⁶⁸ The REMOTE-HF trial tested the effect of 2 levels of HF education on HF hospitalization or death for those in rural areas. Recruitment took place from 12 clinics or hospitals in Kentucky, Nevada,

and California. Institutional Review Board approval was obtained for each individual recruitment site. For the primary study, data were collected at baseline, 3, 12, and 24 months; we used baseline data for this secondary analysis. Only those participants (n = 608) with complete baseline data for age, sex, education level, ethnicity, New York Heart Association (NYHA) functional class and instruments for depressive symptoms, and self-care were included in this analysis.

Participants

Participants were eligible for the study when they had a cardiologist confirmed diagnosis of HF; were older than 18 years of age; were living in a rural area, metropolitan center or open country; had been hospitalized for HF within the past 6 months; were able to read and write in English; and were able to live independently.⁶⁸ Those who were participating in a heart failure disease management program, had a neurological disorder with impaired cognition, or with a complicated comorbidity (untreated malignancy, renal failure requiring dialysis, or psychiatric illness) were excluded.

Measures

Demographic and Clinical Variables

Demographics (age, sex, education level, and ethnicity) and the clinical variable NYHA functional class were obtained by medical record review and interview in the parent study.

Self-care

Self-care is defined as the strategies and decisions an individual uses to maintain healthy functioning, quality of life, and well-being.⁵⁰ The European Heart Failure Self-care Behavior Scale-9 (EHFScBS-9) is a nine-item self-report instrument used to measure self-care behaviors.⁶⁹ For example, “I weigh myself every day” and “If leg/feet swollen, I contact my doctor or nurse”.

The instrument uses a 5-point Likert scale with responses ranging from 1 (completely agree) to 5 (completely disagree). Total scores range from 9 to 45; higher scores indicate worse self-care.⁶⁹ The internal consistency reliability is good with Cronbach's alpha of 0.80. The instrument has established convergent and discriminant validity with quality of life and adherence in patients with heart failure.⁶⁹

Depressive Symptoms

Depressive symptoms are a disorder of mood that results in low mood combined with negative physical symptoms related to sleep, activity, and appetite. Depressive symptoms may occur in the presence or absence of clinical depression.⁷⁰ The Patient Health Questionnaire-9 (PHQ-9) is a nine-item self-report instrument used to evaluate depressive symptoms. The instrument is based on the Primary Care Evaluation of Mental Disorders (PRIME-MD) developed to screen for depressive symptoms.⁷¹ The PHQ-9 was created from the nine diagnostic criteria for major depressive disorder in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).⁷² The diagnostic criteria include depressed mood, feeling tired, anhedonia, difficulty sleeping, feelings of guilt or worthlessness, change in appetite, restless feelings, difficulty concentrating, and suicidal thoughts.⁷² Items are rated with a Likert scale; each item is rated from 0 (not at all) to 3 (nearly daily). The responses are totaled to form a total score of 0 to 27; the higher the score, the greater the level of depressive symptoms. Severity of depressive symptoms is determined by scores; 0-4 none, 5-9 mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe; scores 10 or more are suggestive of clinical depression.⁷¹ The instrument demonstrates good internal consistency with Cronbach's alpha of 0.83.⁷³ Concurrent validity has been established; the PHQ-9 is strongly correlated with the Beck Depression Inventory-II in patients with heart failure.⁷⁴

Procedure

The study was approved by individual Institutional Review Boards in the parent study. Following informed consent, sociodemographic data were collected using structured questionnaires. Clinical data were collected using a standardized form; this information was collected from hospital medical records by trained research personnel. Participants who did not have an echocardiogram in the medical record within the past 6 months had one performed. NYHA class was determined by the physician or research nurse. All other data were obtained at baseline from medical record review, interview, or completion of instruments. For this secondary analysis, baseline data were chosen for analysis. Baseline data included sociodemographic variables (age, sex, ethnicity, and education level); clinical variables (New York Heart Association class); and depressive symptoms using the PHQ-9 instrument; the EHFSBS-9 was used to measure self-care. The original dataset was filtered to obtain these data for analysis.

Data Analysis

All analyses were performed using SPSS version 22.0 (IBM, Amonk, NY). An a priori significance level of 0.05 was used to determine significance. Descriptive statistics were used to characterize the participants in our secondary analysis. Participants were categorized as those with none, mild, moderate, and those with moderate and severe depressive symptoms using the standard PHQ-9 cut points.⁷¹ Demographic and clinical variables were compared between these four groups using Chi-square analyses and multiple comparisons one-way analysis of variance (ANOVA) with Tukey post-hoc test based on the level of measurement of each variable. Multiple linear regression was used to determine predictors of self-care from demographic (age, sex, ethnicity) and clinical variables (NYHA class, self-care score, depressive symptoms score). Prior to regression analysis, tests of normality assumptions were conducted. Investigation of

residual plots versus predicted values indicated that linearity and normality of error distribution, and homoscedasticity were supported; the tolerance and variance inflation factor (VIF) values in the final model were satisfactory (Tolerance > 0.1 and VIF < 10); and Durbin-Watson statistic of 1.9 supported independence; thus, regression assumptions were met. All variables were entered into the regression in one block using the enter method.

Results

Characteristics of the Participants

Participants were primarily Caucasian (86%), males (59%), aged 66 ± 13 years (Table 2.1.). Two thirds of participants (67%) had less than a high school education. The majority (65%) of the participants were in NYHA class I/II, which indicated that these participants experienced minimal to no physical limitations with activity. The mean self-care score reflected adequate self-care in these participants. Depressive symptoms were reported by 59% of participants; 27% reported mild, 17% reported moderate, and 15% reported moderate and severe depressive symptoms.

A significantly greater proportion of women than predicted reported moderate/severe depressive symptoms compared with men (male 48%, female 52%, $p = 0.022$), and those in NYHA classification III/IV exhibited a significantly higher proportion of moderate/severe depressive symptoms compared with those in NYHA class I/II (NYHA I/II 45%, NYHA III/IV 55%, $p < 0.001$). The Tukey post hoc test determined those with no depressive symptoms were older than those with moderate (no depressive symptoms age 69 ± 12 ; moderate age 63 ± 13 , $p = 0.001$); and moderate/severe (moderate/severe age 61 ± 12 , $p < 0.001$) depressive symptoms. Those with mild depressive symptoms were also significantly older than those with

moderate/severe depressive symptoms (mild age 66 ± 13 ; moderate/severe age 61 ± 12 , $p = 0.007$).

Those patients in the without depressive symptoms group had lower self-care scores (19 ± 6) when compared to patients with moderate (21 ± 7 , $p = 0.015$) and moderate/severe (23 ± 8 , $p < 0.001$) depressive symptoms groups. Those with mild depressive symptoms had lower self-care scores (20 ± 7) than those with moderate/severe depressive symptoms (23 ± 8 , $p = 0.010$). Mean self-care score was significantly higher in those with moderate/severe depressive symptoms; higher scores indicated worse self-care; however, scores in all groups demonstrated adequate self-care.

Predictors of self-care

We used multiple linear regression to test the hypothesis that depressive symptoms were an independent predictor of self-care after controlling for age, sex, ethnicity, education level, and NYHA class. All variables were entered into the regression model in one block. The overall model explained 6% of the variance in self-care and was significant ($p < 0.001$) (Table 2.2.). Depressive symptoms were the only independent predictor of self-care in these participants ($B = 0.243$, $p < 0.001$) (Table 2.2.). For each one unit increase in PHQ-9 score, there was a subsequent 0.243 unit increase in self-care score; thus, those with more depressive symptoms had worse self-care.

Discussion

In this secondary analysis, we examined the association of depressive symptoms with self-care in patients with HF. Depressive symptoms were an independent predictor of self-care. As the severity of depressive symptoms increased, self-care became worse. To our knowledge, this is one of the first studies to find that depressive symptoms predicted worse self-care.

We found a high prevalence of depressive symptoms reported by our participants; 27% reported mild, 17% reported moderate, and 15% reported moderate/severe depressive symptoms. Previous investigators also found that the prevalence of depressive symptoms was high among those with HF.⁷⁵ Freedland⁷⁶ and colleagues investigated the prevalence of depression in hospitalized patients and found that 51% of participants reported depression. Lesman-Leegte³² and colleagues investigated the prognostic value of depressive symptoms in patients with HF who were hospitalized; 39% of their participants had depressive symptoms and 21% of those had severe depressive symptoms. Thus, the prevalence of depressive symptoms in our participants is consistent with other investigations.^{32,77}

Our findings supported the hypothesis that depressive symptoms predicted poorer self-care. Other investigators have examined predictors of self-care. Cameron and colleagues⁷⁸ found that depressive symptoms were a predictor of self-care management (defined as decision-making of HF symptoms⁵²), but not self-care maintenance (defined as treatment adherence⁵²) in outpatients with HF. Chriss and colleagues⁷⁹ evaluated predictors of self-care at baseline and 3 months following hospitalization, and determined that predictors of successful self-care over time was predicted by male sex and fewer comorbid conditions. Alternatively, Rockwell and colleagues⁶⁰ found that higher education and more symptoms predicted better engagement in self-care. Our findings may have been different as our study was cross sectional and one fifth of our participants earned a bachelor's degree or higher, in contrast with Chriss and colleagues⁷⁹ whose study was longitudinal in design, and Rockwell and colleagues⁶⁰ whose participants primarily earned a high school degree.

Self-care was adequate in these patients with HF based on their self-care scores. Our findings were similar to those seen by Vellone⁸⁰ and colleagues who used cluster analysis to

examine differences in adherence and consulting self-care behaviors. Those with adequate self-care scores had more consistent adherence and better consulting behaviors; adequate self-care represented the largest majority among the groups.⁸⁰ However, other investigators have found that patients with HF have less than adequate self-care. Carlson²⁶ and colleagues compared self-care abilities between those newly diagnosed with those who were experienced in HF self-care. Overall, both groups of participants demonstrated poor self-care, and those with more experience in self-care management revealed better self-care behaviors; 75% experienced with HF limited sodium intake when weight gain occurred as compared to 45% of those newly diagnosed. Our participants were overall in a lower NYHA functional class and reported fewer symptoms that interfered with their activities of daily living; this may have influenced self-care in these participants.

The association of depressive symptom severity with self-care scores in our participants demonstrated a linear relationship; as depressive symptoms worsened from mild to severe, self-care scores increased. Dickson⁸¹ and colleagues also found that those with depressive symptoms had worse self-care. However, other investigators found no direct relationship between depressive symptoms and self-care.³⁶ Graven³⁶ and colleagues examined the relationships among physical symptoms, depressive symptoms, self-care, social support, and social problem-solving, and found that depressive symptoms did not predict self-care behavior. However, they found that those with greater social support had fewer depressive symptoms and better self-care scores; thus, a mediator relationship may have been present. In addition, their participants had a lower prevalence of depressive symptoms compared with our participants with only 22% reporting depressive symptoms. Thus, the high prevalence of those with depressive symptoms in our study may have contributed to our findings.

Limitations

We acknowledge that our study contained limitations. The REMOTE-HF data set provided prospective data; we were limited to the variables in the data set. Thus, we were unable to include variables such as perceived social support which is known to have an association with self-care.⁸² The cross-sectional design of this study precludes an examination of causation. The primary variables of interest, self-care and depressive symptoms were measured with self-report instruments; thus, some degree of social desirability bias may be present in these data. However, self-report is the gold standard measure of these variables. Our identification of depressive symptoms as an independent predictor of self-care provides a greater understanding of this relationship.

Conclusions

Depressive symptoms were prevalent in this group of participants with HF, and depressive symptoms predicted worse self-care. A clear understanding of this association may support the development of targeted interventions that reduce depressive symptoms, improve self-care ability and practices, and subsequently improve patient quality of life and outcomes.

Table 2.1. Characteristics of the Participants Divided by Depressive Symptoms Severity
(n = 608)

Variable	Total (n = 608)	None (n = 250)	Mild (n = 166)	Moderate (n = 101)	Moderate/Severe (n = 91)	P value
Age	66 ± 13	69 ± 12	66 ± 13	63 ± 13 ^a	61 ± 12 ^{ab}	< 0.001
Sex						
Female	250 (41%)	86 (34%)	72 (43%)	45 (45%)	47 (52%)	0.022
Ethnicity						
Caucasian	520 (86%)	216 (86%)	142 (86%)	89 (89%)	73 (80%)	0.428
Education						
High School or less	407 (67%)	163 (65%)	110 (66%)	69 (68%)	65 (71%)	0.548
Some College	81 (13%)	32 (13%)	25 (15%)	10 (10%)	14 (16%)	
Bachelor's or higher	120 (20%)	55 (22%)	31 (19%)	22 (22%)	12 (13%)	
NYHA class						
I/II	393 (65%)	191 (76%)	103 (62%)	58 (57%)	41 (45%)	< 0.001
III/IV	215 (35%)	59 (29%)	63 (38%)	43 (43%)	50 (55%)	

Variable	Total (n = 608)	None (n = 250)	Mild (n = 166)	Moderate (n = 101)	Moderate/Severe (n = 91)	P value
Self-care scores	20 ± 7	19 ± 6	20 ± 7	21 ± 7 ^a	23 ± 8 ^{ab}	< 0.001

Values are mean ± SD or f (%); NYHA = New York Heart Association functional class; Superscript a is significantly different from none and b is significantly different from mild

Table 2.2. Predictors of self-care in patients with HF (n = 608)

Variable	B	SE(B)	β	P value
Age	.011	.022	.02	0.633
Sex	.512	.572	.036	0.372
Ethnicity	1.420	.791	.072	0.073
Education	.263	.348	.03	0.450
NYHA class	.522	.599	.036	0.384
PHQ-9	1.315	.243	.229	< 0.001

NYHA = New York Heart Association functional class, PHQ-9 = Patient Health Questionnaire

R² = 0.062, Adjusted R² = 0.053, df = 6, Model F statistic = 6.632, p < 0.001

CHAPTER THREE

Psychometric Properties of the Multidimensional Scale of Perceived Social Support in Patients with Heart Failure

Abstract

Background and Purpose: Low social support is associated with worse outcomes in patients with heart failure. Thus, the purpose of this study was to examine the reliability and validity of the Multidimensional Scale of Perceived Social Support (MSPSS).

Methods: We performed a secondary analysis of registry data from patients (n = 475) with confirmed heart failure.

Results: The MSPSS demonstrated excellent internal consistency reliability. Factor analysis yielded three factors that explained 83% of the variance in perceived social support. More than half of the sample had depressive symptoms (56%). Hypothesis testing demonstrated that worse perceived social support was a predictor of depressive symptoms.

Conclusion: The MSPSS is a reliable and valid instrument to measure perceived social support in patients with heart failure.

Key words: heart failure, perceived social support, depressive symptoms, psychometrics

Introduction

Heart failure (HF) is a progressive chronic syndrome which affects more than 5.7 million Americans who are over 20 years of.^{1,83} Mortality rates within 5 years of initial diagnosis of HF are 58.2% and 41.8% respectively, for males and females.² Multiple hospitalizations are common after diagnosis, and 83% of those with HF are hospitalized at least once; while 43% of those with HF are hospitalized at least 4 times within 4.7 years.^{2,4} The complexity of HF management requires daily adherence to medications, daily weights, continuous symptom monitoring, frequent interaction with healthcare providers, low sodium diet, ongoing systematic heart failure education, and maintenance of physical activity to prevent exacerbations.⁸

Patients need the support of family, friends, and significant others to optimally manage heart failure; thus, the perception of social support is a vital component to successful management of this complex syndrome.^{8,18,83} In patients with HF, better perceived social support was associated with less psychological distress, enhanced quality of life, better medication adherence, longer event-free survival, reduced hospitalizations, and lower mortality.^{10-12,84-87} Patients with HF and low perceived social support had a 50% greater risk of hospitalization or death than those with higher perceived social support.¹¹ Thus, sufficient perceived social support is essential to optimal patient outcomes. Systematic evaluation of perceived social support may support targeted interventions that promote better patient outcomes.

Older adult patients with HF experienced more depressive symptoms when compared to healthy older adults.⁶³ Perceived social support has previously been determined to be an independent predictor of depression in patients with HF; lack of satisfaction with social support increased the risk of depression by 48%.⁸⁸ However, there is conflicting evidence about this association due to the use of a variety of instruments, and differences in conceptual definitions of

social support.²⁰ For example, Klein et al. found that social support measured as emotional support as a coping mechanism was not influenced by depressive symptoms.⁸⁹ Therefore, continued research in this area is needed.

Zimet and colleagues (1988) introduced the Multidimensional Scale of Perceived Social Support (MSPSS) to measure the subjective perception of support using a collective approach of the differing social support definitions and theories. A specific theoretical or conceptual model was not used in the development of this instrument. The MSPSS is a 12-item, brief, self-administered questionnaire. Items in the instrument are suited for a fourth-grade reading level.⁹⁰ The MSPSS measures the perceived availability and sufficiency of social support across 3 sources of support: family, friends, and significant others.⁹¹ The MSPSS has been used extensively in populations that include urban adolescents, pregnant women, pediatric residents, and undergraduate students.⁹⁰⁻⁹³ The MSPSS has also been used in adult patients with diabetes and end-stage renal disease (ESRD).⁹⁴ The MSPSS instrument has shown good internal consistency and strong factorial validity in these populations.⁹⁰⁻⁹³ Although researchers have performed psychometric testing of the MSPSS in various populations, there is very little support for the validity of the MSPSS in the HF population; however, the MSPSS is commonly used in HF studies. Only one other psychometric evaluation of the MSPSS has been published; this study included Danish and Dutch cardiac patients, less than half with HF, and the majority with an implanted cardioverter defibrillator.⁹⁵ Although this instrument demonstrated reliability and validity in other patients populations, those findings do not ensure that this instrument performs as well in patients with HF.

Thus, the purpose of this secondary analysis was to evaluate the psychometric properties of the MSPSS instrument as a measure of perceived social support in patients with HF. The

specific aims of the study were to examine the internal consistency reliability and the construct validity. The construct validity was examined using two approaches; we determined the factor structure of the MSPSS, and evaluated the hypothesized relationship between perceived social support and depressive symptoms. We hypothesized that perceived social support predicted depressive symptoms, and that poorer perceived social support was associated with a higher degree of depressive symptoms.

Conceptual Framework

For over 40 years, researchers have demonstrated an interest in the role of social support in health and illness. Social support is a complex concept which encompasses the emotional and physical support, and quality of relationships.⁹⁶ The concept of social support has been studied extensively; however, there is no consensus definition.^{15,97,98} Social support has been described as functional support when it serves to provide emotional support, social companionship, appraisal support, instrumental support, and informational support within the interpersonal relationship.⁹⁹ Heo and colleagues defined social support as the subjective perception of assistance from social relationships or significant others¹⁰⁰; and according to Haber et al. (2007), social support is actual or perceived. Although these scientists have diverse perspectives about social support, research evidence suggests a greater consensus of social support as actual or perceived. Actual support is provided by the social network of an individual¹⁹; whereas, perceived support is the subjective perceptions of support.⁹⁸

Social support is conceptualized as a contributor to health maintenance and disease management.^{91,101} Social support may improve health by its impact on affective states, its action as a buffer for stress, and by modifying health behaviors.¹⁰¹ There are four types of functional social support; these are emotional, informational, instrumental, and appraisal. Functional social

support occurs in the presence of the social network, social climate, and social embeddedness.^{10,19} Emotional support refers to love, caring, and empathy; informational support represents problem solving during times of stress. Instrumental support occurs through tangible goods and assistance; appraisal support denotes the communication of information related to self-evaluation and affirmations by others.^{10,19} Within each type, it is theorized that reciprocity must be present for support to continue.¹⁹

Methods

Design and Sample

Data for this secondary analysis came from a large multicenter heart failure registry of inpatients and outpatients maintained at the University of Kentucky College of Nursing.^{11,12,53,68,86,102-104} Participants (n = 4076) included in this registry were recruited when they had a cardiologist confirmed diagnosis of heart failure with preserved or non-preserved systolic function, had not experienced a myocardial infarction within the past 3 months, had no terminal illness including end-stage liver or renal disease, and were older than 18 years of age. This registry contains data from numerous studies conducted in patients with HF performed over the past 2 decades. In this secondary analysis, we selected patients (n = 475) who had completed data for demographic (age, sex, ethnicity, marital status, education, and financial status) and clinical variables (diagnosis of heart failure and comorbidities), as well as concurrent scores for perceived social support and depressive symptoms.

Demographic and Clinical Characteristics

Clinical and demographic variables were collected by patient interview and medical record review. Demographic variables included age, sex, ethnicity, marital status, education

level, and financial status. Clinical variables included current diagnosis of hypertension and diabetes mellitus comorbidities.

Perceived social support

Perceived social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS is a 12-item, self-report measure, which consists of 3 subscales that evaluate support from family, friends, and significant others (4 items each). The instrument uses a Likert scale which ranges from 1 (very strongly disagree) to 7 (very strongly agree). Scores for the 12 items are summed for a total score, which ranges from 12 to 84; higher scores indicate more perceived support.⁹² The Cronbach's alpha for this instrument from previous studies ranged from 0.85 to 0.94.^{11,65} Discriminant validity was previously demonstrated in another population using the Adolescent Family Caring Scale to evaluate the Family subscale of the MSPSS. The Adolescent Family Caring Scale is a 44-item instrument that measures an adolescent's perception of caring by family members.⁹⁰ Strong factorial validity and construct validity has been previously established in urban adolescents, pregnant women, pediatric residents, undergraduate students, and patients with ESRD.⁹⁰⁻⁹⁴ However, validity has not been previously evaluated in patients with HF.

Depressive symptoms

We measured depressive symptoms with the Brief Symptom Inventory-Depression Subscale (BSI-DS), which contains six items evaluated on a 5-point Likert scale. The scale ranges from 0 - 4; 0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, and 4 = extremely. Loneliness, feeling blue, loss of interest, hopelessness about the future, suicidal thoughts, and feelings of worthlessness are rated according to the degree of symptom experience over the past 2 weeks. The item scores are totaled and divided by six to obtain an average rating.

The subscale cut-point of 0.28 or higher indicates the presence of depressive symptoms^{105,106}.

The BSI-DS psychometric properties have been evaluated in patients with heart failure with and without comorbid renal dysfunction.^{105,106} The instrument has good internal consistency with a Cronbach's alpha that ranged from 0.82 - 0.88 for the BSI-DS. Construct validity for this instrument was previously established in patients with HF and normal renal function.¹⁰⁵

Procedure

Institutional review board approval was obtained prior to recruitment. A large HF registry was used for secondary data analysis. The registry consisted of data from numerous studies performed in patients with a cardiologist confirmed diagnosis of HF with preserved or non-preserved systolic function.^{11,12,53,68} All participants signed approved informed consent documents. All nurse researchers were trained to perform all study procedures and were evaluated for fidelity prior to and during data collection. Nurse researchers were present during all data collection and provided assistance to participants as needed. All data were double entered in SPSS version 22.0, (IBM, Armonk, NY) spreadsheet and evaluated for accuracy prior to analysis. For this study, data were de-identified, examined, and cleaned before psychometric analyses were performed. All analyses were performed with SPSS version 22.0 (IBM, Armonk, NY).

Approaches to Reliability and Validity Assessments

Descriptive statistics, including means with standard deviations and frequencies with percentages were used to characterize demographic and clinical variables. The internal consistency of the 12-item MSPSS and its subscales was assessed with Cronbach's alpha, and item analyses included item-total correlations and Cronbach's alpha with item deletion. The construct validity was examined by evaluation of the factor structure of the MSPSS. Suitability

for factor analysis was confirmed by evaluating sample adequacy and the correlation matrix. Kaiser-Meyer-Olkin (KMO) was used to evaluate matrix sample adequacy. The KMO index was considered acceptable when the values were greater than 0.7. Bartlett's test of sphericity was used to evaluate the correlation matrix, and the value of the Bartlett's test of sphericity was set at significance < 0.05 .¹⁰⁷ Principal component analysis extraction with varimax rotation was used to examine dimensionality of the MSPSS. Eigenvalues of greater than one were retained, and a scree plot was used to confirm eigenvalues of the factors. We accepted item loading greater than .40 for factors.¹⁰⁷ We examined cross-loaded items, those that loaded on more than one factor, with a difference of less than .20. Hypothesis testing was performed using multiple linear regression to determine whether social support was a significant predictor of depressive symptoms after controlling for age, sex, ethnicity, marital status, education level, financial status and comorbidities, potential confounding variables. All variables were entered simultaneously into the regression. An a priori α level was set at 0.05 to determine significance.

Results

Characteristics of the Participants

Participants ($n = 475$) were primarily married (54%), Caucasian (72%), men (69%) aged 61 ± 12 years (Table 3.1). Slightly more than half of participants (51%) had high school or less education, and one fifth (21%) reported that they did not have enough money to make ends meet. A diagnosis of hypertension (66%) was reported for two thirds of the sample, and a diabetes diagnosis (40%) was present for nearly half of patients. Perceived social support was moderately high with the MSPSS mean score of 67 ± 17 (median = 72). The proportion of participants categorized as depressed using the established cut point¹⁰⁵ was 59% with a mean BSI-DS score of 0.68 ± 0.82 .

Internal Consistency Reliability

We determined that the internal consistency reliability for the MSPSS was excellent with a Cronbach's alpha of 0.94 for the total instrument. The three subscales, family support, friend support, and significant other support, also exhibited excellent internal consistency reliability with Cronbach's alpha values of 0.94, 0.94, and 0.94 respectively. Item-total correlations ranged from 0.71 to 0.78, and correlation coefficients were greater than 0.30 for all of the items (Table 3.2), which indicated adequate contribution of all items to the measure without redundancy. The Cronbach's alpha did not increase with removal of each item from the instrument; thus, all items were maintained in the instrument. Inter-item covariance demonstrated a positive correlation among items which indicated similarity of the items of the MSPSS.

Construct Validity

In principal component analysis, the high KMO index (0.90) and significant Bartlett's test ($p < 0.001$) denoted adequacy for analysis.¹⁰⁸ In the initial factor extraction, we found that 3 factors were retained as eigenvalues were greater than one. The first factor had an eigenvalue of 7.414 and explained 61.8% of the total variance. Two other factors explained an additional 11.5% (eigenvalue = 1.383) and 9.8% of the variance (eigenvalue = 1.173). The scree plot demonstrated 3 factors. Thus, this instrument exhibited 3 factors which corresponded to family, friends, and significant other support.

To maximize the loading of each factor, we performed varimax rotation of these three factors. All items loaded strongly on the three subscales, family support, friends support, and significant other support (Table 3.2). None of the items cross-loaded among factors; all items loaded exclusively to one of the three factors with factor loadings greater than .70.

We used multiple linear regression to test the hypothesis that perceived social support was an independent predictor of depressive symptoms after controlling for age, sex, ethnicity, marital status, education level, financial status, and diagnosis of hypertension and diabetes. Regression assumptions were tested prior to the analysis; a Durbin-Watson statistic of 1.96 supported independence. Examination of normality residual plots, and a plot of residuals versus predicted values indicated that linearity and normality of error distribution, and constant variance of errors (homoscedasticity) were also supported; thus, regression assumptions were met. All variables were entered in the regression in one block. The overall model explained 21% of the variance and was significant ($p < 0.001$) (Table 3.3.). We found that financial status ($B = 0.224$, $p < 0.001$), ethnicity ($B = 0.303$, $p = 0.001$), age ($B = - 0.014$, $p < 0.001$), and perceived social support ($B = - 0.012$, $p < 0.001$) were significant predictors of depressive symptoms. Income perceived as not meeting household needs (compared to comfortable or more income than needed) was associated with higher risk for depressive symptoms. Minorities were at greater risk for depression compared with Caucasians. Younger age was associated with more depressive symptoms; for each one year increase in age, there was a 0.014 decrease in depressive symptoms score. Higher perceived social support was predictive of lower depressive symptoms score (i.e. A one unit higher score on the MSPSS was associated with a 0.12 unit decrease in depressive symptoms score). None of the other variables were predictors of depressive symptoms.

Discussion

Perceived social support is vital for patients with HF; self-care is essential, and requires some degree of social support from family, friends, and significant others for optimal patient outcomes. Lower social support from family, friends, and significant others is associated with an increased mortality, decreased quality of life, increased hospitalizations, shorter cardiac event-

free survival, and lower medication adherence.^{11,12,109} Regular evaluation of perceived social support would provide important clinical data and support the development of tailored interventions to improve outcomes. Thus, a reliable and valid measure of perceived social support is needed. We tested the psychometric properties of the Multidimensional Scale of Perceived Social Support, and found that this instrument was reliable and valid in patients with heart failure. This is the first systematic evaluation of the psychometric properties of this instrument in patients with HF, even though this instrument has been previously used in studies of patients with HF and their caregivers.^{42,95}

Our results demonstrated that among patients with HF, the MSPSS exhibited excellent internal consistency reliability. In previous studies, similar internal consistency reliability of the MSPSS was reported in other populations. In 3 groups of participants, who included pregnant women, adolescents, and pediatric residents, internal consistency reliability for the MSPSS as a whole was 0.84 - 0.92. The Cronbach's alpha for the subscales were: family support 0.81 - 0.90, friends support 0.90 - 0.94, and significant others support 0.83 - 0.98.⁹² Internal consistency reliability among urban adolescent participants showed excellent internal consistency reliability with a Cronbach's alpha of 0.93 with subscales for family, friends, and significant others of 0.91, 0.89, and 0.91, respectively.⁹⁰

Factor analysis with varimax rotation in this study revealed a 3 factor structure, which corresponded with family support, friends support, and significant others support dimensions of the MSPSS. This factorial validity is consistent with previous studies in other populations which have shown a 3-factor structure corresponding to the dimensions of family, friends, and significant others.⁹⁰⁻⁹³ Thus, our findings support the 3 dimensions of the MSPSS in patients with HF.

Our results also supported construct validity of the MSPSS in patients with HF through hypothesis testing. We demonstrated that perceived social support measured with the MSPSS was a predictor of depressive symptoms; higher perceived social support predicted fewer depressive symptoms. Perceived social support has previously been identified as an independent predictor of depression, and lack of satisfaction with social support increased the risk of depression by 48%.⁸⁸ Researchers have also found that depressive symptoms were an independent predictor of event-free survival, and higher depressive symptoms were associated with lower perceived social support.¹¹

We also observed that financial status was a predictor of depressive symptoms. When patients do not have enough finances to make ends meet, their illness results in an economic burden. Medical care of HF that is perceived by patients as an economic burden is a predictor of depressive symptoms.³⁴ Economic burden due to having a lower income has also been found to be an independent predictor of hospital readmission.¹¹⁰ Poorer adherence to treatment regimens increases symptoms, reduces quality of life, and worsens survival. Younger age and minority status were also independent predictors of depressive symptoms in this sample of patients. These findings support those of other investigators. Age has been shown to be negatively associated with depressive symptoms in previous studies.^{31,35,76} The rationale for this finding may be that younger patients with heart failure experience greater life stress in work, health, and family management. Minorities have previously been found to have more depressive symptoms.¹¹¹ Perhaps, this finding is due to cultural differences in coping mechanisms among different ethnicities.

Limitations

We used registry data for this psychometric evaluation. Consequently, we did not control data collection, variable selection, or fidelity to the data collection procedures. For example, New York Heart Association functional class data were not present for all those who completed both the MSPSS and the BSI depression subscales. Therefore, we could not include NYHA functional class as a control variable, and could not determine whether it predicted depressive symptoms. Data were collected using several self-report instruments; self-report instruments may be subject to social desirability bias.¹¹² Strategies for minimizing socially desirable responses include avoiding yes/no and agree/disagree responses within the instrument and addressing multiple dimensions rather than only one dimension of a construct. These strategies were all included in the collection of the original data.

Relevance to Nursing Practice, Education or Research

Our study provided rigorous psychometric support for the MSPSS in the HF population. Thus, this 12-item measure can be used to determine perceived social support from family, friends, and significant others in this population. Our findings suggested that researchers and clinicians can use the MSPSS measure with confidence of its reliability and validity in patients with HF. Because the MSPSS may or may not be adequately sensitive to monitor clinically important changes in perceived social support, further studies are needed to determine the degree of change that can be captured by the instrument.

Table 3.1. Sample Characteristics (n = 475)

Characteristics	Mean \pm SD or n (%)
Age in years	61 \pm 12
Male gender	326 (69%)
Caucasian	340 (72%)
Non-Caucasian	135 (28%)
Marital Status	
Single	68 (14%)
Married	255 (54%)
Divorced	94 (20%)
Widowed	58 (12%)
Education Level	
High school or less	243 (51%)
Some college or associate degree	111 (23%)
Bachelor degree or higher	121 (26%)
Financial Status	
More than enough to make ends meet	134 (28%)

Have enough to make ends meet	239 (50%)
Do not have enough to make ends meet	100 (21%)
Hypertension Diagnosis	314 (66%)
Diabetes Diagnosis	192 (40%)
Perceived Social Support (MSPSS)	67 ± 17
Depression (BSI subscale)	0.68 ± 0.82

Table 3.2. Item analysis and rotated matrix for the Multidimensional Scale of Perceived Social Support (n = 475)

	Item-total correlation	Cronbach's alpha if item deleted	Factor 1	Factor 2	Factor 3
Family support					
#3 My family really tries to help me	0.71	0.940	0.233	0.846	0.241
#4 I get the emotional help and support I need from my family	0.78	0.937	0.281	0.840	0.309
#8 I can talk about my problems with my family	0.73	0.939	0.278	0.791	0.277
#11 My family is willing to help me make decisions	0.78	0.937	0.328	0.801	0.297
Friends support					
#6 My friends really try to help me	0.76	0.938	0.820	0.296	0.258
#7 I can count on my friends when things go wrong	0.77	0.938	0.847	0.291	0.247

#9 I have friends with whom I can share my joys and sorrows	0.75	0.938	0.855	0.250	0.247
#12 I can talk about my problems with my friends	0.74	0.939	0.865	0.245	0.237
Significant Others support					
#1 There is a special person who is around when I am in need	0.66	0.941	0.157	0.287	0.813
#2 There is a special person with whom I can share my joys and sorrow	0.71	0.94	0.231	0.245	0.853
#5 I have a special person who is a real source of comfort to me	0.77	0.938	0.310	0.273	0.827
#10 There is a special person in my life who cares about my feelings	0.72	0.939	0.303	0.263	0.781

Table 3.3. Multiple Linear Regression Variables Predicting Depressive Symptoms (n = 475)

Model Variable	Unstandardized coefficient	Standardized Coefficient	p-value
Age	-0.014	-0.206	< 0.001
Gender	0.112	0.064	0.161
Ethnicity	0.303	0.157	0.001
Financial Status	0.224	0.194	< 0.001
Marital Status	0.034	0.036	0.450
Education	0.016	0.017	0.711
Hypertension	0.61	0.034	0.442
Diabetes	0.034	0.020	0.644
Perceived Social Support (MSPSS)	-0.012	-0.265	< 0.001

R² = 0.213, Adjusted R² = 0.197, df = 9, Model F statistic = 12.605, p < 0.001

CHAPTER FOUR

The Association between Relationship Quality and Quality of Life in Heart Failure Patient-Caregiver Dyads

Abstract

Objective: To determine whether patient and primary caregiver relationship quality predicted quality of life in HF dyads using a multilevel dyadic analysis.

Background: Patients with HF and their caregivers have an interdependent relationship. The quality of this relationship may impact the quality of life in both members of the dyad.

Methods: We performed a secondary analysis of baseline data in dyads; 45 patients with HF and their primary caregiver provided demographic and clinical variables; relationship quality and quality of life were measured at baseline using the Shared Care Instrument-Revised, Dyadic Relationship Scale, Minnesota Living with Heart Failure Questionnaire, and the Medical Outcomes Trust Short Form-36 version 2.0. Actor Partner Interdependence Modeling determined actor (relationship quality influences on their own quality of life) and partner (relationship quality influences other dyad member) effects as predictors of quality of life.

Results: A total of 45 patients (78% Caucasian, 51% female; mean age 58 ± 16 years) and 45 caregivers (76% Caucasian, 67% female; mean age 53 ± 17 years) participated. Patients and caregivers reported similar relationship quality; and poor physical and mental quality life.

Patients had worse health-related quality of life (HRQOL) than their primary caregiver ($p < 0.001$). There was a patient actor effect in relationship quality dyadic strain on patient HRQOL ($\beta = -3.38, p = 0.017$), a caregiver actor effect in communication on caregiver HRQOL ($\beta = -1.98, p = 0.006$), patient partner effect in decision-making on patient physical QOL ($\beta = -3.80, p = 0.029$), and a patient partner effect in reciprocity on patient physical QOL ($\beta = -2.88, p = 0.047$).

Conclusion: Relationship quality influenced both members of the dyad. Dyads may benefit from tailored/targeted interventions to improve relationship quality and quality of life in both members of the dyad.

Keywords: *Relationship quality, quality of life, heart failure, dyad, APIM*

Introduction

Heart failure (HF) affects more than 5.7 million persons, and the prevalence is expected to increase as the population ages.¹ In 2013, the estimated total cost for diagnosis and management of heart failure was \$32 billion; costs are expected to reach \$70 billion by 2030.² Thirty-day readmissions for patients with heart failure are approximately 25%, and readmission contributes significantly to the total cost of care.^{46,113} Hospital readmissions for heart failure are associated with a lack of social support; lower perceived social support increased the risk of hospitalization or death by 50% compared to those with higher perceived social support.^{11,114} Adequate social support has also been identified as an important contributor to quality of life in patients with heart failure.^{12,87,100,115,116} Worse quality of life and inadequate social support from primary caregivers are associated with an increased likelihood of rehospitalization and mortality.^{117,118}

Approximately 45%-70% of patients with heart failure have partners, spouses, or family members who participate in providing their care and social interaction.^{60,119,120} These partners, spouses, or family members who provide unpaid assistance are classified as a caregiver.¹²¹ The relationship of the patient with heart failure and their respective caregiver can be defined as a HF dyad. The patient-caregiver relationship provides the environment for exchange of support for one another.¹²² However, not all dyadic relationships are supportive.¹²³ The quality of support within the relationship between both members of the dyad is critical to the disease management of heart failure as a progressive and complex syndrome.^{124,125} It has been suggested that relationship quality and positive dyadic interaction may influence outcomes in dyads.²⁴

Previous investigators did not examine the interdependence that existed within the dyad, nor relationship quality as a potential influence for quality of life. Therefore, the purpose of this study was to examine the influence of relationship quality on quality of life in heart failure

patients and their caregivers. The specific aim of this study was to determine whether the patient perception, as well as caregiver perception, of relationship quality measured at baseline upon enrollment predicted quality of life at baseline in both patient and caregiver using a multilevel dyadic analysis. Our hypothesis was that better relationship quality would be associated with higher quality of life in both members of the dyad.

Background

Relationship Quality

Marital status has often been used as a proxy for measuring relationship quality.¹²⁶ In fact, measures of marital functioning predicted all-cause patient mortality; worse marital functioning was associated with increased mortality.¹²⁶ Multiple scientists have reported improved patient outcomes associated with perceived higher marital functioning and better emotional support.^{20,85,102,127} Relationship quality includes negative and positive interactions from the patient and caregiver perspective.²⁴ Higher marital quality was associated with more positive and less negative dyadic coping over time;¹²⁸ in fact relationships can and do change over time.²⁴ Caregivers have been shown to have improved perceived relationship quality, compared to patients with heart failure after a 12-week Shared Care intervention.¹²⁹ However, there are insufficient investigations focused on the association of perceived relationship quality in patient caregiver dyads and related outcomes.

Quality of life

Health-related quality of life is defined as the functional effect of the illness experience from a subjective perspective.¹³⁰ Patients with heart failure have poorer health-related quality of life, and perceived quality of social support has been associated with quality of life.¹⁰⁰ Living alone increased the risk of poorer quality of life.⁹ In addition, changes in social support predicted

changes in health-related quality of life. Specifically, an increase in social support was associated with an increase in health-related quality of life.¹³¹ However, research findings about the association of social support with health-related quality of life in patients with heart failure have been inconsistent.²⁰ This inconsistency is likely due to the complex nature of social support. Caring for those with heart failure may affect the health of caregivers as well.¹³² Thus, the caregivers of patients with heart failure also demonstrated poorer quality of life.¹³³ Caregivers of patients with heart failure who exhibited multiple, frequent physical and emotional symptoms have poorer quality of life when compared with caregivers of patients with fewer symptoms.¹³⁴ In summary, evidence suggests that perceived quality of the relationship within the dyad may influence quality of life for patients with heart failure and their caregiver.

Design

This was a cross-sectional investigation which used baseline data obtained upon enrollment from a larger longitudinal clinical trial which aimed to test the effects of a 16-week low sodium dietary intervention for patients with heart failure and their caregiver. This investigation included both heart failure patients and their caregiver. Demographic variables (age, sex, ethnicity, marital status, education years, and comorbidities) were collected from both patients and caregiver. Clinical variables were collected for patients (medical history, medications, left ventricular ejection fraction, and New York Heart Association functional class), measures of communication, decision-making, reciprocity, positive interaction and dyadic strain, quality of life and health-related quality of life were measured in both patient and caregiver.

Sample/Setting

Patients with heart failure and their primary caregiver were referred by the physician or nurse practitioner from a regional tertiary medical center outpatient clinic; we aimed for equal

male and female recipients of care. Previous studies have enrolled more female caregiver participants within the dyad relationship; therefore, we anticipated more female caregivers than male caregivers.¹²⁹ Multilevel modeling using The Actor-Partner Interdependence Model (APIM) was used in dyadic statistical analysis.

Inclusion/Exclusion criteria

Patients eligible for the study had a diagnosis of heart failure with preserved or non-preserved systolic function, were able to read and speak English, and lived with a spouse, partner, or significant other primary caregiver. Exclusion criteria for patients included the lack of a primary dedicated caregiver, documented cognitive impairment in the patient (i.e. Alzheimer's disease or dementia), co-existing terminal illness (active treatment for cancer, end-stage kidney or liver disease), those who had a referral for heart transplantation or left ventricular assist device, those who had a major psychiatric disorder diagnosed other than depression, and a current dietary prescription from their healthcare provider which precluded following a 2-3 gram sodium diet (requirement for the parent study).

Inclusion criteria for caregivers included individuals with age > 20 years, who were the designated caregiver living with the patient, were able to read and speak English, who had no known cognitive impairment, and also had no major comorbidities (i.e. heart failure, cancer, kidney or liver failure, or self-reported uncontrolled diabetes).

Measures

Sociodemographic variables measured in both members of the dyads included age, sex, ethnicity, marital status, education level, and diagnosed comorbidities. Clinical variables for patients included their medical history, current medication prescriptions, left ventricular ejection

fraction, and New York Heart Association functional class. Relationship quality was measured using two different instruments.

Relationship Quality

Communication, decision-making, and reciprocity

We measured communication, decision-making, and reciprocity with the Shared Care Instrument-Revised (SCI-R).¹²¹ This instrument measures the pattern of relationship processes based on the needs of each partner in a dyad.¹²⁹ This instrument has both patient and caregiver versions. Communication was operationalized as the exchange of information. Decision-making was operationalized as making care decisions, and reciprocity was operationalized as giving/receipt of a partnership, listening, and empathy.¹³⁵ The instrument is a 19-item (5-communication, 6-decision-making, and 8-reciprocity) instrument with three subscales; each item uses a 6-point Likert scale with responses ranging from 0 (completely disagree) to 5 (completely agree). The decision-making and reciprocity subscales contain positively worded items. However, the communication subscale has negatively worded items which require reverse coding. The scores are not combined for a total score; rather each subscale is scored separately. Higher scores on each subscale signify better communication, decision-making, and reciprocity. Both the patient and caregiver versions have good internal consistency reliability with Cronbach's alpha of 0.74-0.76 and 0.72-0.78 respectively.¹²¹ Construct validity was established using hypothesis testing where shared care was associated with relationship quality in patients and caregiver home health family dyads.¹²¹

Positive Interaction and Dyadic Strain

We also measure relationship quality using the Dyadic Relationship Scale that had two subscales, positive interaction and dyadic strain.²⁴ Relationship quality is the positive and

negative dyadic interactions from the perspectives of both patient and caregiver. Relationship quality has a two-factor structure; positive interactions and dyadic strain.²⁴ Positive interactions occur within the dyad when the patient/caregiver report having patience and feeling close to their partner.²⁴ Dyadic strain occurs when the patient/caregiver reports resentment and feeling strained by their partner.²⁴ Both patient (10-item) and caregiver (11-item) versions were administered. This instrument uses a 4-point Likert scale with responses ranging from 1 (strongly disagree) to 4 (strongly agree). Items are summed for each subscale. Higher scores on each of the subscales indicate higher levels of dyadic strain and greater positive interaction. Internal consistency reliability is good with Cronbach's alpha of 0.86 for patient positive interaction and 0.84 for patient dyadic strain. The Cronbach's alpha for caregivers is 0.85 for positive interaction and 0.89 for caregiver strain.²⁴ Concurrent validity was established for dyadic strain and depressive symptoms in a study of home healthcare dyads.²⁴

Health-related Quality of Life and Quality of Life

Health-related quality of life is the perceived physical, social, psychological, and functional status impact of heart failure.¹³⁶; quality of life is a subjective perception of satisfaction with aspirations and needs in life.¹³⁷ A health-related quality of life instrument and a generic quality of life instrument were administered to both patient and caregiver. Health-related quality of life was measured using the Minnesota Living with Heart Failure Questionnaire.¹³⁸ This instrument has 21-items which assess the impact heart failure has on daily life for patients with heart failure. Responses are rated from 0 (no impact on health related quality of life) to 5 (most negative impact on quality of life) on the physical and emotional categories. The total score range is 0-105.¹³⁸ Higher scores indicate worse health-related quality of life. Cronbach's alpha internal consistency reliability of this instrument is 0.85-0.91.¹³⁹ Construct validity of the

instrument was supported by associations with New York Heart Association functional class, and health perception in a study of patients with heart failure.¹³⁹

Generic quality of life was measured in dyads using the Medical Outcomes Trust Short Form-36 Health Survey version 2.0.¹⁴⁰ This is a 36-item instrument and total score is 0-100; higher scores indicate greater quality of life. Internal consistency reliability has been established with Cronbach's alpha of 0.75. Construct validity of the instrument has been supported previously in the outpatient population.¹⁴⁰

Procedures

Institutional Review Board (IRB) approval was received prior to the initiation of recruitment. Patients with heart failure and their caregivers were screened using inclusion/exclusion criteria. Dyad participants were approached following referral from a physician or nurse practitioner in the tertiary medical center outpatient cardiology clinic. Following a full explanation of the study purpose, requirements for participation and risks versus benefits, both members of the dyad were invited to participate. If the patient and caregiver agreed to participate, informed consent was obtained. The informed consent was read aloud to the participants and questions about the study were answered at that time. A (Health Insurance Portability and Accountability Act) HIPPA Authorization form was also read aloud to the participants at that time. Copies of the informed consent and HIPPA forms were provided to the dyad.

Baseline data collection followed enrollment. Participants received the questionnaires upon enrollment and they returned them by mail or they were retrieved by a member of the research team who traveled to the home. Patients and their caregiver were asked to avoid discussing questions and answers with each other; to complete questionnaires separately.

Baseline questionnaires were completed using paper versions of the instruments. Both patients and caregivers completed a form for demographic and clinical characteristics, the Minnesota Living with Heart Failure Questionnaire, the Short Form-36, the Shared Care Instrument-Revised, and the Dyadic Relationship Scale in this order. The data from the completed instruments were then manually entered by a trained member of the research team. Subsequent medical record review affirmed patient comorbidities and medications. A trained data manager monitored data collection and accuracy of data entry.

Data analysis

Data analysis was conducted using IBM SPSS (version 21, Armonk, NY). An a priori α level of ≤ 0.05 indicated significance. Descriptive statistics, including means with standard deviations and frequencies and percentages were used to characterize demographic and clinical variables for participants. Paired t-test and Chi-square test were used to compare patient and caregiver variables to further describe the participants. A power analysis algorithm had not been developed yet using the APIM, therefore a sample size of 40 dyads was selected based on previous research demonstrating adequacy of this sample size with an alpha of 0.05. For the 40 dyads, a medium effect size yields a prediction model for quality of life of 82% power for the regression F test.^{141,142} To determine the effect relationship quality in dyads, a standard dyadic design was used. The Actor-Partner Interdependence Model (APIM) was chosen based on the concept of interdependence between the patient and the caregiver.⁴⁴ The actor effect was the impact of the relationship quality on the person's own quality of life, and the partner effect was the effect of each person's level of relationship quality on their partner's quality of life.^{43,44} The patient and the caregiver constituted a distinguishable dyad and multilevel modeling (MLM) regression was used.⁴⁴ To conduct APIM analysis, a pairwise data structure with grand mean

scores were used.⁴⁴ For the APIM regression, a single regression model was used for the patient and caregiver predictor variables (relationship quality) which were regressed on the patient and caregiver outcome variables (quality of life and health-related quality of life) while controlling for age and education.

Results

Sample Characteristics of Patient and Caregiver Participants

Patient Characteristics

A total of 45 dyads participated to form the unit of analysis. Patient participants were primarily Caucasian (78%) women (51%) aged 58 ± 16 years who were married (71%) and had completed 12.9 ± 2.8 years of education (Table 4.1.). A majority of these participants were classified as NYHA class III/IV (58%); LVEF averaged $32 \pm 15\%$. Patient participants were prescribed ACE-Inhibitor (ACEI) (51%), Angiotensin receptor blocker (ARB) (18%), beta antagonists (82%), and at least one diuretic (76%). Common comorbidities included hypertension (71%), diabetes (44%), and chronic lung disease (29%).

Caregiver Characteristics

Caregiver participants were also primarily Caucasian (76%), women (67%) aged 53 ± 17 years of age who were married (71%). Although caregivers also reported comorbid conditions that included hypertension (24%), diabetes (10%), and chronic lung disease (5%), caregivers reported significantly less comorbidities compared with patients ($p < 0.01$). Caregivers reported their relation with the patient as spouse (64%), son/daughter (11%), another relative (7%), and other relative (boyfriend, fiancée, mother, partner, and sister; 18%).

Patient and Caregiver Characteristics Compared

When patient and caregiver participants were compared, patients were on average 5 years older than caregivers ($p = 0.029$), more caregivers were female ($p < 0.001$), and patients reported more comorbid conditions ($p < 0.01$). There were no other significant characteristic differences between patient and caregiver participants (Table 4.1.)

Patient Relationship Quality and Quality of Life Scores

Patient scores for relationship quality (Table 4.2.) indicated that on average patients reported adequate relationship quality. The mean health-related quality of life score demonstrated poor health-related quality of life in patients. The mental and physical quality of life scores were poor.

Caregiver Relationship Quality and Quality of Life Scores

Caregiver scores for relationship quality (Table 4.2.) also indicated that on average, caregivers reported adequate relationship quality. The mean health-related quality of life scores for caregivers demonstrated adequate health-related quality of life. The mental and physical quality of life scores were both poor.

Comparison of Relationship Quality and Quality of Life Between Patients and Caregivers

There were no differences in scores for communication, decision-making, reciprocity, positive interaction, and dyadic strain between the dyad members. When quality of life scores were compared between patients and caregivers, caregivers reported better physical quality of life ($p < 0.001$). There were no differences between mental quality of life scores, however, patients and caregivers scored below the median for both physical and mental components indicating poor quality of life for both. Patient scores for health related quality of life were significantly higher compared to caregivers ($p < 0.001$), which indicated worse health-related quality of life in patients (Table 4.2).

Association between relationship quality and health-related quality of life in patient and caregivers

The APIM regression demonstrated an actor effect between relationship quality dyadic strain and health-related quality of life in patients, but not the caregivers (patient $B = -3.36$, $p = 0.0171$; caregivers $B = -1.37$, $p = 0.354$). Thus, high dyadic strain was associated with the patient's own greater health-related quality of life (Table 4.4, Figure 4.1).

The APIM regression demonstrated an actor effect between communication and health-related quality of life in caregivers, but not in patients (caregiver $B = -1.98$, $p = 0.006$; patients $B = -0.99$, $p = 0.084$) (Table 4.4, Figure 4.2). Thus, high communication in caregivers was associated with their own greater health-related quality of life.

Association between relationship quality and quality of life (mental and physical) in patients and caregivers

There were partner effects demonstrated for decision-making and reciprocity on physical quality of life (Table 4.6). The APIM regression determined there was a partner effect between decision-making and physical quality of life in patients, but not in caregivers (patients $B = -0.380$, $p = 0.029$; caregivers $B = 0.055$, $p = 0.79$). Thus, increased decision-making by the caregiver was associated with poorer patient physical quality of life (Table 4.6, Figure 4.3). The APIM regression also demonstrated a partner effect between reciprocity and physical quality of life in patients, but not in caregivers (patients $B = -0.288$, $p = 0.047$; caregivers $B = -0.205$, $p = 0.45$). This demonstrated that greater caregiver reciprocity was associated with poorer patient physical quality of life (Table 4.6, Figure 4.4). Thus, relationship quality was associated with quality of life in both patients and caregivers. However, there were no actor or partner effects seen in the mental quality of life outcome (Table 4.5).

Discussion

In this interdependent dyadic analysis, we examined the association between relationship quality on quality of life in patients with HF and their caregivers. This study was the first to examine whether patient perception, as well as caregiver perception of relationship quality, predicted quality of life in the patient-caregiver dyad using a multilevel dyadic analysis. Our hypothesis was partially supported by actor and partner effects detected for relationship quality on the outcome of quality of life in both members of the dyad. We used the APIM in these dyads to determine the influence of relationship quality on each person's own and their partner's quality of life. However, we did not find an actor or partner effect for mental quality of life in this analysis.

First, we found that our patients and caregivers reported similar relationship quality, which is dissimilar to findings by other scientists. Sebern¹³⁵ and colleagues found that caregivers reported lower communication and decision-making, but greater reciprocity than patients.¹³⁵ The patient sample in their study was homebound, which may have contributed to this difference. Bidwell and colleagues¹⁴³ caregivers reported worse relationship quality than patients. However, those investigators used a one-item question to measure relationship quality in their patient-caregiver dyads, while we used several variables to measure relationship quality. Thus, our evaluation of relationship quality was more rigorous and systematic.

Actor effects occurred when a measured variable was associated with their own health related quality of life outcome, whether patient or caregiver. When evaluated as a dyad with the APIM model, two actor effects were seen in these participants on health-related quality of life. First in patients, there was an actor effect for dyadic strain on their own health-related quality of life; this indicated that a high level of dyadic strain predicted their own greater health-related

quality of life. Although other investigators have evaluated the association of a variety of variables related to relationship quality, none have previously included dyadic strain. Hooker¹⁴⁴ and colleagues evaluated relationship quality and health outcomes in HF dyads and determined that both patients and caregivers with better relationship quality had greater well-being.¹⁴⁴ However, in another study, Krause¹⁴⁵ and colleagues evaluated negative interactions on heart disease outcomes and found that it may take time for the effects of those negative interactions to affect outcomes. However, there are no studies that included measures of relationship quality like dyadic strain; thus, no direct comparison can be made, and differences in findings between our study and others could be due to differences in the measures of relationship quality. Our study also used baseline data to evaluate dyadic strain and health-related quality of life; a longitudinal evaluation of how dyadic strain affects health-related quality of life in patients over time may provide valuable information regarding this association. We also used a specific dyadic analysis technique which may have also contributed to our different findings, but also added significant credibility to our results.

Second, we found a caregiver actor effect for caregiver communication on health-related quality of life; higher communication predicted the caregiver's own greater health-related quality of life. Fried¹⁴⁶ and colleagues found that approximately 67% of caregivers were content with their level of communication; those who were not had greater caregiver role strain. Pressler¹³⁴ and colleagues examined family functioning, which included a dimension of communication in caregivers, and found that those who cared for more symptomatic patients with HF had poorer health-related quality of life.¹³⁴ In our participants, those who reported high communication may have experienced less role strain, thus contributing to their own higher health-related quality of life.

Partner effects occur when a measured variable was associated with the health related quality of life outcome of their partner in the dyad, either patient or caregiver. We found two partner effects for the physical quality of life outcome. There was a patient partner effect for decision-making and physical quality of life; greater decision-making by the caregiver predicted poorer patient physical quality of life. Clark¹⁴⁷ and colleagues found that caregivers decision-making ability in self-care behaviors was poor and mirrored those of the patient.¹⁴⁷ Although our participants exhibited greater decision-making; those decisions by the caregiver may not have equated to the appropriate decision for the patient's physical concern leading to worse physical quality of life for the patient.

Our second partner effect demonstrated that higher caregiver reciprocity predicted poorer patient physical quality of life. Liang¹⁴⁸ and colleagues examined social exchange reciprocity and psychological well-being in older Medicare recipients and found that reciprocity was correlated with psychological well-being; over benefiting (receiving more than given) was associated with increased distress, whereas under benefiting (receiving less than was given) was associated with less distress. Sebern¹⁴⁹ and colleagues described relationship quality reciprocity outcomes in nurses as caregivers and patients with cardiac disease; they found that as caregiver reciprocity increased patient's mental quality of life increased.¹⁴⁹ Our findings were dissimilar to these investigators, perhaps our patients perceived less benefit from the reciprocity that caregivers provided which contributed to poorer physical quality of life in these patients.

Limitations

There are a few limitations to this study. First, this was a secondary analysis using cross-sectional data. Second, we measured relationship quality at one point in time and perceptions of the relationship could change over time. Third, other characteristics in patients and caregivers

such as length of time in the relationship, marital quality, and caregiving length of time may have associations with QOL and HRQOL were not available and could not be controlled in this analysis. However, our findings do provide substantive information about the importance of relationship quality on quality of life.

Implications

The findings of our study provide evidence that relationship quality in patients with heart failure and their caregiver has an interdependent relationship which influences both members of the dyad. Therefore, healthcare professionals should include data about relationship quality in interventions developed for both patients with HF and their caregivers. The findings in this study also provide evidence upon which to base future research. The influence of the relationship quality dyadic strain in patients with HF and their caregivers provided further evidence for the importance for health outcomes. Further research focused on the quality of caregiving relationships over time is vital for those with chronic diseases who require extensive self-care management; these data would be useful in the development of interventions that could improve patient and caregiver health outcomes.

Conclusion

Relationship quality variables were predictors of quality of life in our patient-caregiver dyads. Dyad members may benefit from interventions focused on improvement of relationship quality, to improve quality of life in both members of the dyad.

Table 4.1. Characteristics of Patients (N=45) and Caregivers (N = 45)

Characteristics	Patient (n = 45)	Caregiver (n = 45)	p-value
Age in years	58 ± 16	53 ± 17	0.29
Sex, Female	23 (51%)	30 (67%)	< 0.001
Ethnicity, Caucasian	35 (78%)	34 (76%)	0.99
Education Level in years	12.9 ± 2.8	13.7 ± 2.5	0.195
Marital Status			
Married/Cohabiting	32 (71%)	32 (71%)	0.99
Single/Divorced/Widowed	13 (29%)	13 (29%)	
Comorbidities			
Diabetes Mellitus	18 (44%)	4 (10%)	0.003
Chronic Lung Disease	12 (29%)	2 (5%)	0.013
Hypertension	29 (71%)	10 (24%)	< 0.001
History of Stroke/TIA	3 (7%)	4 (10%)	0.99
Medications prescribed			
ACE-I	23 (51%)	--	--
ARB	8 (18%)	--	--
Beta-Blocker	37 (82%)	--	--
Diuretic	34 (76%)	--	--
LVEF	32 ± 15	--	--

Characteristics	Patient (n = 45)	Caregiver (n = 45)	p-value
NYHA			
I/II	19 (42%)	--	--
III/IV	26 (58%)	--	--
Relation to Patient			
Spouse		29 (64%)	--
Son/daughter		5 (11%)	--
Another relative		3 (7%)	--
Boyfriend, fiancée, mother, partner, or sister		8 (18%)	--

Mean \pm SD or n (%); comparisons between patient and caregiver used paired t test or Chi square analyses based on the level of measurement; S.D., Standard Deviation; ACE-I = angiotensin converting enzyme inhibitor; ARB = Angiotensin Receptor Blocker; LVEF =Left Ventricular Ejection Fraction; NYHA = New York Heart Association functional class

Table 4.2. Relationship Quality, Quality of Life, and Health-related Quality of Life Score Comparisons for Patients and Caregivers (N = 45)

Characteristics	Patient (n = 45)	Caregiver (n = 45)	p-value
Communication	21 ± 6	19 ± 6	0.32
Decision-making	29 ± 7	27 ± 7	0.19
Reciprocity	42 ± 5	41 ± 8	0.76
Positive Interaction	12 ± 3	12 ± 3	0.80
Dyadic Strain	13 ± 3	13 ± 3	0.59
Quality of Life			
Physical	36 ± 8	45 ± 9	< 0.001
Mental	39 ± 10	41 ± 9	0.41
Health-related Quality of Life	61 ± 23	32 ± 26	< 0.001

Comparisons between patient and caregiver used paired t-test

Table 4.3. The Actor–Partner Independence Model Demonstrating the Actor and Partner Relationship Quality to Health-related Quality of Life

Effect	Patients			Caregivers		
	B	<i>t</i>	p-value	B	<i>t</i>	p-value
Communication						
Actor	-0.99	-1.77	0.084	-1.98	-2.88	0.006
Partner	-1.08	-1.74	0.089	-0.63	-1.03	0.309
Patient Decision-making						
Actor	-0.84	-1.58	0.12	0.677	1.15	0.25
Partner	0.507	0.98	0.33	-0.144	-0.23	0.81
Patient Reciprocity						
Actor	-0.95	-1.39	0.17	0.55	1.13	0.266
Partner	0.44	1.04	0.305	-0.476	-0.061	0.546
Positive Interaction						
Actor	1.51	1.38	0.17	-1.59	-1.17	0.247
Partner	-0.77	-0.67	0.51	1.28	1.03	0.31
Dyadic Strain						
Actor	-3.36	-2.48	0.017	-1.37	-0.94	0.354
Partner	-0.873	0.69	0.492	-3.08	-2.00	0.052

B = unstandardized coefficient

Table 4.4. The Actor–Partner Independence Model Demonstrating the Actor and Partner Relationship Quality to Mental Quality of Life

Effect	Patients			Caregivers		
	B	<i>t</i>	p-value	B	<i>t</i>	p-value
Communication						
Actor	0.029	0.12	0.91	0.097	0.35	0.72
Partner	0.37	1.31	0.19	0.015	0.06	0.95
Patient Decision-making						
Actor	0.164	0.72	0.47	0.289	1.39	0.17
Partner	0.193	0.86	0.39	-0.146	-0.67	0.51
Patient Reciprocity						
Actor	0.27	0.90	0.37	0.28	1.68	0.10
Partner	-0.040	-0.22	0.83	0.01	0.05	0.96
Positive Interaction						
Actor	-0.57	-1.24	0.22	0.734	1.52	0.14
Partner	0.463	0.94	0.35	0.38	0.87	0.38
Dyadic Strain						
Actor	1.08	1.83	0.07	0.245	0.43	0.66
Partner	0.352	0.63	0.52	-0.06	-0.11	0.91

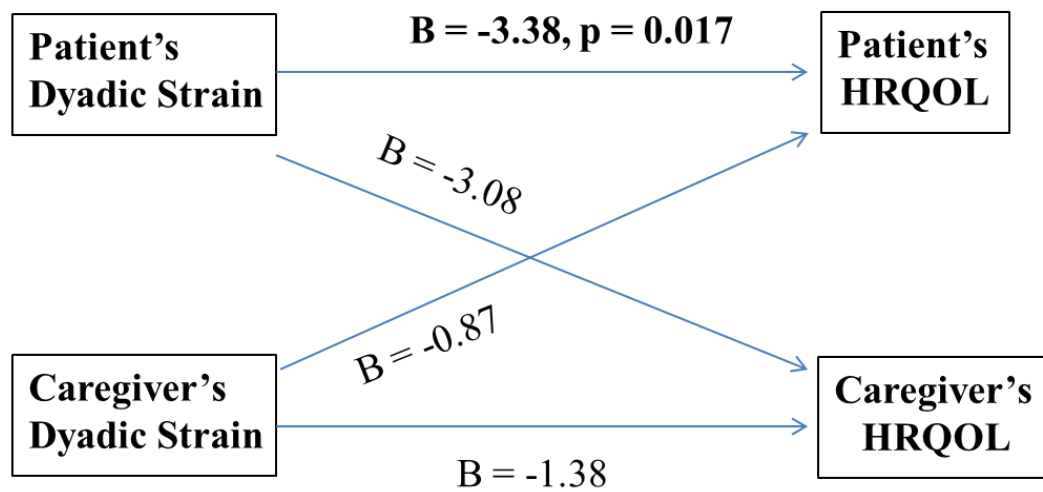
B = unstandardized coefficient

Table 4.5. The Actor–Partner Independence Model Demonstrating the Actor and Partner Relationship Quality to Physical Quality of Life

Effect	Patients			Caregivers		
	B	<i>t</i>	p-value	B	<i>t</i>	p-value
Communication						
Actor	0.179	0.88	0.38	0.030	0.12	0.90
Partner	0.084	0.37	0.71	0.103	0.45	0.66
Patient Decision-making						
Actor	0.199	1.16	0.25	0.276	1.38	0.17
Partner	-0.380	-2.27	0.029	0.055	0.26	0.79
Patient Reciprocity						
Actor	0.040	0.18	0.86	0.14	0.85	0.40
Partner	-0.288	-2.05	0.047	-0.205	-0.76	0.45
Positive Interaction						
Actor	-0.082	-0.22	0.83	-.054	-1.18	0.25
Partner	0.015	0.04	0.97	0.27	0.65	0.51
Dyadic Strain						
Actor	-0.046	-0.09	0.92	-0.096	-0.18	0.86
Partner	-0.315	-0.68	0.49	-0.07	-0.13	0.89

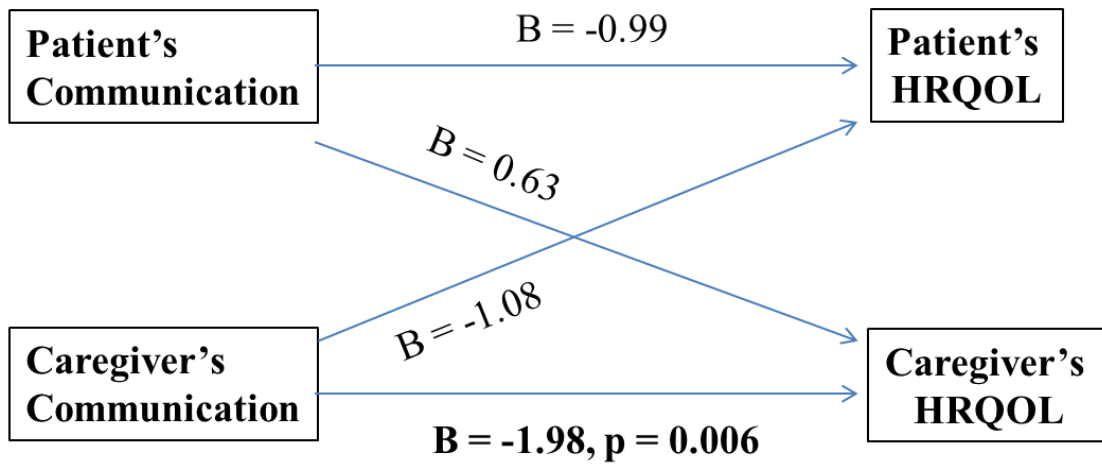
B = unstandardized coefficient

Figure 4.1. The Actor Partner Interdependence Model: Dyadic Strain. Actor Partner Effects as Predictors of Health-related Quality of Life



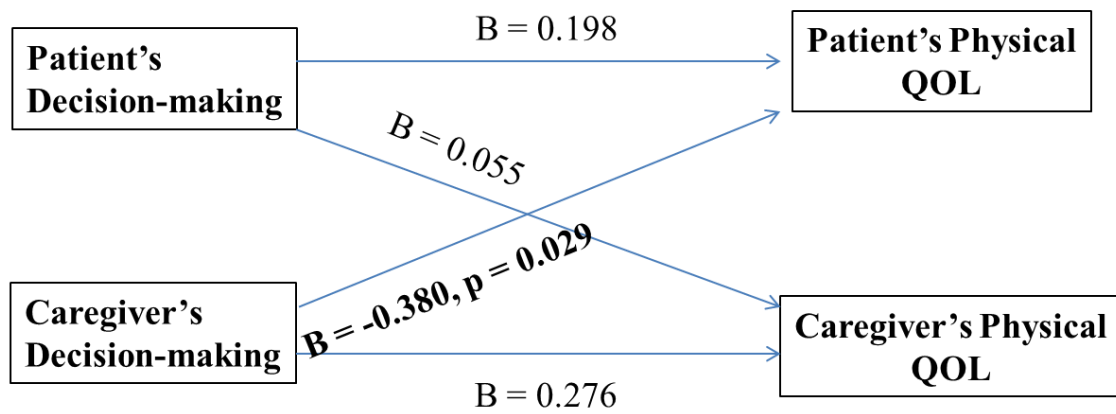
HRQOL = Health-related Quality of Life, B = unstandardized coefficient

Figure 4.2. The Actor Partner Interdependence Model: Communication. Actor Partner Effects as Predictors of Health-related Quality of Life



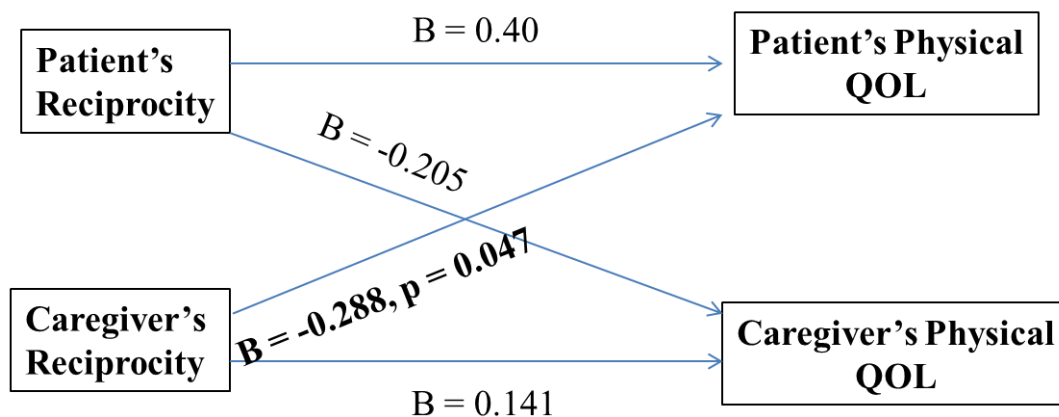
HRQOL = Health-related Quality of Life, B = unstandardized coefficient

Figure 4.3. The Actor Partner Interdependence Model. Decision-making: The Actor Partner Effects as Predictors of Physical Quality of Life



QOL = Quality of Life, B = unstandardized coefficient

Figure 4.4. The Actor Partner Interdependence Model. Reciprocity: The Actor Partner Effects as Predictors of Physical Quality of Life



QOL = Quality of Life, B = unstandardized coefficient

CHAPTER FIVE

Conclusion and Implications

Nearly 6 million adults in the United States and more than 23 million worldwide have heart failure (HF).^{1,150} Each year, there are 915,000 new cases of HF.¹ The average incidence of HF related hospitalization for those ≥ 55 years-old was 11.6 per 1,000 people per year with recurrent hospitalization incidence of 6.6 per 1,000 people per year.¹ One in 9 deaths has been attributed to HF.¹ Greater than 1 million physician office visits occurred over one year with a primary diagnosis of HF.¹ Hospitalizations are common and 83% of those with HF are hospitalized at least once; 43% more than 4 times over a 5 year time span.⁴ HF has become an epidemic due to the rising incidence rates and increase in mortality.¹⁵⁰ The direct medical costs associated with HF are approximately 21 billion, with the expectation to increase 127% by the year 2030.¹⁵¹ The management of HF is complex and patients with HF are at risk for poor self-care, depressive symptoms, and worse quality of life.⁵⁻⁹ Evidence suggests that these outcomes are associated with social support and the relationship quality of the patient-caregiver dyad.^{20,29,109} Therefore, the purpose of this dissertation was to 1) examine the association of depressive symptoms with self-care; 2) examine the reliability and validity of the Multidimensional Scale of Perceived Social Support; and 3) determine the influence of relationship quality on quality of life in patient-caregiver dyads.

Self-care is essential to the management of HF.^{125,152} In one study, 82% of patients with HF and poor self-care had at least one hospital readmission or death over one year; poor self-care was also associated with increased cost of care.¹⁵³ Patients with HF who reported greater self-care confidence had better health-related quality of life than those who reported less self-care confidence.¹⁵⁴ Thus, this evidence suggests that poor self-care is associated with worse health outcomes. Risk factors for poor self-care described by previous investigators included age, sex,

ethnicity, education level, and New York Heart Association (NYHA) functional class. Poor self-care was seen in those older than 61 years of age; in both men and women who interpreted symptoms differently; in medication adherence of African-Americans compared to Caucasians; those with lower education level; and those with worse NYHA class.⁵⁷⁻⁶⁰ Depressive symptoms have been suggested as a contributor which may influence self-care ability.⁸ Depressive symptoms were associated with nearly 12% greater hospital readmission and death than those without depressive symptoms;³² as well as worse prognosis.³³ Because poor self-care and depressive symptoms contribute to worse health outcomes for patients with HF, it is critical to understand this association. In this dissertation, chapter two reported a secondary analysis from a large HF clinical trial; depressive symptoms were prevalent among patients with HF and were an independent predictor of self-care. In addition to being one of the first to investigate this association, our findings filled a gap of previous works by determining the predictive influence depressive symptoms have on self-care when controlling for age, sex, ethnicity, education, and New York Heart Association (NYHA) class. Our findings accentuate how understanding the association between depressive symptoms and self-care may support the development of targeted interventions that reduce depressive symptoms, improve self-care ability and practices, and subsequently improve outcomes.

Perceived social support demonstrated a positive influence on self-care behaviors in previous studies; when there was greater perception of social support, self-care behaviors were better.^{13,82} Lack of social support was also associated with the development of depressive symptoms.⁸⁸ Patients with HF who reported poor social support and depressive symptoms had a 2.1 times greater risk of death and hospitalization compared to those without depressive symptoms and high social support.¹¹ However, Klein⁸⁹ and colleagues found no influence of

depressive symptoms by social support measured as emotional support. Thus, this evidence suggests that there may be an association between social support and outcomes in patients with HF. The Multidimensional Scale of Perceived Social Support (MSPSS) has been used to measure perceived social support in previous studies in the HF population.^{12,109,155} However, its psychometric properties have only been evaluated in one other study by Pedersen⁹⁵ and colleagues using a Danish population with ICD implantation who also had HF. Therefore, an examination of the reliability and validity of the MSPSS in patients with HF was needed. In chapter three of this dissertation, we rigorously evaluated the psychometric properties of the MSPSS in the HF population. Our findings supported that this 12-item measure can be used to determine perceived social support from family, friends, and significant others in this population. Our findings also suggested that researchers and clinicians can use the MSPSS measure with confidence of its reliability and validity in patients with HF.

While social support encompasses the social relationships of family; friends; and spouses who provide levels of resources to an individual¹⁶, HF management often requires the assistance of a caregiver to provide social support within a close relationship between two people.^{20,82,125} The close relationship of the patient and their primary caregiver function as a dyad in the management of HF.^{24,123} In one study, caregivers exhibited behaviors such as yelling, swearing, insulting, withholding food and threatening care recipients when care recipients had greater caregiving needs and more physical symptoms.¹⁵⁶ Another investigator reported that patient's lack of satisfaction with intimate support was associated with 6% greater mortality.¹⁵⁷ However, Trivedi¹⁵⁸ and colleagues found that patients and their spousal caregiver were satisfied with their relationship. Thus, relationship quality may impact subsequent outcomes.

Quality of life in outpatients with HF was poorer than their healthy age-matched counterparts.³⁹ Wu¹⁵⁹ and colleagues found that health-related quality of life in patients with HF was associated with 2.3 times greater risk of a cardiac event.¹⁵⁹ In another study by Pressler¹³⁴ and colleagues which included patient-caregiver dyads, caregivers of patients with greater symptom burden reported worse physical health-related quality of life.¹³⁴ However, little is known about how quality of life may be affected by influences from both members of the dyad. Therefore, the purpose of the study in chapter four was to determine whether the patient perception, as well as caregiver perception, of relationship quality measured at baseline upon enrollment predicted quality of life at baseline in both patient and caregiver using a multilevel dyadic analysis. Our findings demonstrated that on average, patients and caregivers reported similar relationship quality. Lum¹⁶⁰ and colleagues found that caregivers on average had adequate relationship quality; however, they did not measure the relationship quality in patients in their study. Similar to other investigators, we found that patients and caregivers reported poor quality of life.^{5,117} We used the Actor Partner Interdependence Model (APIM) to determine the interdependence between the patient and the caregiver. The actor effect was the impact of the relationship quality on the person's own quality of life, and the partner effect was the effect of each person's level of relationship quality on their partner's quality of life.^{43,44} Our findings demonstrated two actor effects; high dyadic strain was associated with the patient's greater poor health-related quality of life; and high communication in caregivers was associated with their own greater health-related quality of life. Our findings also showed two partner effects; greater decision-making by the caregiver was associated with poorer patient physical quality of life; and greater caregiver reciprocity was associated with poorer patient physical quality of life. To our knowledge, this is the first study to report this association between relationship quality and

quality of life in HF patient-caregiver dyads; thus, this study fills a gap in our understanding of the influence of relationship quality on quality of life in dyads.

Implications

We found that depressive symptoms were prevalent in patients with HF, and depressive symptoms predicted worse self-care. Future research should extend on this association which may support the development of targeted interventions that reduce depressive symptoms, improve self-care, and outcomes.

Our findings suggest that the MSPSS is a reliable and valid instrument to measure perceived social support in patients with HF. However, it may or may not be adequately sensitive to monitor clinically important changes in perceived social support. Therefore, further studies are needed to determine the degree of change that can be captured by the instrument.

Finally, our findings also suggest that relationship quality in patients with heart failure and their caregiver has an interdependent relationship which influences both members of the dyad. Relationship quality variables were predictors of quality of life in our patient-caregiver dyads. Therefore, healthcare professionals should include data about relationship quality in interventions developed for both patients with HF and their caregivers. Future research should focus on the longitudinal influence of relationship quality as it is vital for those with chronic diseases who require extensive self-care management. Dyad members may benefit from interventions focused on improvement of relationship quality, to improve quality of life in both members of the dyad.

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CHAPTER ONE

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Vita
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Education

<u>Institution</u>	<u>Degree</u>	<u>Date Conferred</u>	<u>Field(s) of Study</u>
University of Kentucky Lexington, KY	PhD	2012-expected 2016	PhD in Nursing
University of Kentucky Lexington, KY	Certificate	2016	Clinical Research Skills
University of Kentucky Lexington, KY	MSN	2007-2010	Acute Care NP, MSN
Eastern Kentucky University Richmond, KY	BSN	1996-2000	Nursing

Certifications and Licensure

Advanced Practice Registered Nurse, American Nurses Credentialing Center,
 #3006601, 2010- present

Registered Nurse, Kentucky Board of Nursing, #1094447, 2000-present

Professional Experience

Dates	Institution and Location	Academic Position
2016-present	Eastern Kentucky University Richmond, KY	Assistant Professor
2015-2016	Eastern Kentucky University Richmond, KY	Part-time Clinical Faculty
2011-2012	University of Kentucky College of Nursing, Lexington, KY	Part-time Clinical Faculty
2014-2016	University of Kentucky College of Nursing, Lexington, KY	Research Assistant
2010-2014	University of Kentucky Chandler Medical Center, Lexington	Acute Care Nurse Practitioner

2006-2010	University of Kentucky Chandler Medical Center, Gill Heart Institute Cardiac Catheterization Laboratory, Lexington, KY	Registered Nurse
2002-2004	N. Thannoli, M.D., PSC, Private Cardiology Practice, Somerset, KY	Registered Nurse
2000-2006	Lake Cumberland Regional Hospital, Intensive Care Unit and Cardiac Catheterization Laboratory, Somerset, KY	Registered Nurse

Awards and Honors

- 2014 Kentucky Fellowship Scholarship, University of Kentucky, Lexington, KY
- 2009 Best MSN Student Poster Presentation Award, “Pulmonary Arterial Hypertension: Evaluation of the Six-Minute Walk Distance Test for Predicting Disease Severity”. University of Kentucky, Lexington, KY
- 1999 Most Energetic Leadership Award, Eastern Kentucky University, Richmond, KY

Teaching Experience

- 2016 Eastern Kentucky University, Richmond, KY
Assistant Professor
Second-degree, Baccalaureate, and DNP Nursing Students
- 2015 University of Kentucky, Lexington, KY
Visiting Lecture, Theoretical & Conceptual Framework: A System of Concepts for Shared Care
PhD Nursing Students
- 2011-2012 University of Kentucky, Lexington, KY
Visiting Lecture, Cardiovascular System
Second-degree Nursing Students

Research Presentations

Date of presentation	Title of presentation, type of presentation (poster, paper), Program title, organization sponsoring program, location of program.
2015	Depressive Symptoms Predict Self-Care in Patients with Heart Failure, Poster Presentation. SNRS 29 th Annual Conference, Tampa, FL
2013	Pulmonary Arterial Hypertension: Evaluation of the Six-Minute Walk Distance Test for Predicting Disease Severity, Oral Presentation. University of Kentucky Advanced Practice Conference-Emerging Evidence for Acute and Primary Care, Lexington, KY
2010	Does This Evidence Make the Grade for Clinical Practice? Oral Presentation. University of Kentucky Chandler Medical Center, Nursing Grand Rounds, Lexington, KY
2009	Pulmonary Arterial Hypertension: Evaluation of the Six-Minute Walk Distance Test for Predicting Disease Severity, Poster Presentation. University of Kentucky Nursing Research Day, Lexington, KY

Publications

Published Manuscripts

Shumaker, S.C., Frazier, S.K., Moser, D.K., & Chung, M.L. (Accepted for publication March 28, 2016). Psychometric Properties of the Multidimensional Scale of Perceived Social Support in Patients with Heart Failure, *Journal of Nursing Measurement*.

Published Abstracts

Seratnaehai, A., Cummings, M.S., Leung, S.W., Shumaker, S., & Smith, M.D. (2011). Infective Endocarditis: A Plague for the 21st Century? *Journal of the American College of Cardiology*, 57, 1390.

Editorial Service

2015 Mentored Student Manuscript Reviewer

Professional Memberships

2014-present Southern Nursing Research Society
2010-present American Academy of Nurse Practitioners
2009-present Sigma Theta Tau International Nursing Honor Society, Delta Psi Chapter
2003-present American Association of Critical Care Nurse
2003-present American Heart Association
2007-2009 University of Kentucky Gill Heart Institute Cardiac Catheterization
Laboratory Nursing Council

Professional Service

Date(s)	Service provided, organization served
2012-2014	Secretary Board Member, Sigma Theta Tau Delta Psi Chapter
2009-2011	Finance Chairperson, Sigma Theta Tau Delta Psi Chapter