

# Role of Shared Care in the Relationship between Depressive Symptoms and Self-Care in Patients with Heart Failure

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ROLE OF SHARED CARE IN THE RELATIONSHIP BETWEEN DEPRESSIVE  
SYMPTOMS AND SELF-CARE IN PATIENTS WITH HEART FAILURE

by

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ABSTRACT  
ROLE OF SHARED CARE IN THE RELATIONSHIP BETWEEN DEPRESSIVE  
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Susan M. Cole, MSN, PhD(c), MSN, RN

Marquette University, 2015

Heart failure (HF) is a chronic condition affecting over 5 million Americans. Heart failure accounts for over 32 billion dollars in total cost each year, and is the most common cause of hospitalization for persons 65 years of age or older. Patients with HF experience poor self-care, are at risk for depressive symptoms, and have high rates of 30-day hospital readmissions. Social support influences depressive symptoms, self-care, and hospital readmissions. Shared care was used to operationalize social support. Shared care is a system of three relationship processes communication, decision making, and reciprocity, used to exchange social support. The purpose of this study was to determine if shared care moderated the relationship between depressive symptoms and self-care in community dwelling HF patients.

A cross-sectional study was conducted with 89 patients receiving care from a HF clinic. The Stress-Buffering Model was used to guide the study. The Theory of Self-Care of Chronic Illness and the Processes of Self-Management were used to operationalize the definition of self-care and describe relationships between variables. Study variables of depressive symptoms, shared care, and HF self-care were assessed. Qualitative questions assessed subjective patient experiences related to study variables. Descriptive, correlation, and regression analysis were used to analyze quantitative data. Content analysis was used for qualitative data analysis.

An association of shared care to depressive symptoms was supported by a significant inverse association between shared care communication and reciprocity and depressive symptoms. Partial correlation coefficients of shared care communication and reciprocity to depressive symptoms while controlling for HF severity were ( $r_{ab.c} = -.33$ ) and ( $r_{ab.c} = -.20$ ), respectively. Increased HF severity was associated with increased depressive symptoms. Older patients reported better self-care. The study supported prior research related to the role of social support in attenuating depressive symptoms, and the association between depressive symptoms and HF severity. Themes in qualitative data supported the difficulties patients experience and the importance of support from family caregivers.

Patient's perception of shared care with their caregiver is important to their psychological health. The development and testing of interventions to mobilize family caregiver support are essential for improving mental health in HF patients.

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## CHAPTER ONE

### **Introduction**

Heart failure (HF) is a significant chronic condition affecting over 5 million Americans (Roger et al., 2012) and is the primary cause of more than 56,000 deaths each year. A person's risk of developing heart failure in their lifetime is 1 in 5, with a 5-year mortality rate of 50% after diagnosis (Roger et al., 2012). Self-care is an essential component in care and management of patients with HF and has been advocated as a strategy to improve patient outcomes (Riegel et al., 2009b). Self-care for patients with HF involves management of complex medication regimens and lifestyle changes (Riegel et al., 2009b). Factors such as depressive symptoms and social support have been found to impact self-care (Riegel et al., 2009b). However, the specific interrelationships between depressive symptoms, social support, and self-care in patients are unclear (Rutledge, Reis, Linke, Greenberg, & Mills, 2006). This study explored the relationship between depressive symptoms and self-care in patients with HF and the potential moderating role of social support in this relationship.

In this chapter, the scope and significance of HF and the associated costs and challenges will be described. Background information regarding self-care, depressive symptoms, and social support will be discussed; supporting a need for the study and the significance to nursing practice, nursing education, and health systems. Lastly, the purpose of the study and research hypotheses will be described.

## Scope and Significance

Heart Failure has become a public health problem accounting for significant costs and healthcare expenditures (Roger et al., 2012; Liao, Allen, & Whellan, 2008). Heart failure costs in the United States totals over 32 billion dollars each year and are projected to double by the year 2030 (Go et al., 2013). These costs include health services, medications, and lost productivity. Heart failure also requires a significant amount of informal care by family members. In 2010 the estimated annual cost of informal care for HF patients was 3 billion dollars (Joo, Fang, Losby, & Wang, 2015). Additionally, HF is the most common cause of hospitalization for persons 65 years of age or older (Hall, DeFrances, Williams, Golosinskiy, & Schwartzman, 2010) and is the most frequent cause of unplanned hospital readmission contributing to an overall annual Medicare readmission cost of 17.4 billion dollars with approximately 27% of patients being readmitted within 30 days (Jencks, Williams, & Coleman, 2009).

Major emphases in HF management are prevention of hospital readmission, decreasing cost, improving quality of care (Hines, Yu, & Randall, 2010), self-care, and quality of life (Ditewig, Blok, Havers, & van Veenendaal, 2010; Gardetto, 2011). To improve quality of care and contain cost U.S. policy-makers have focused on the reduction of 30-day readmission rates of Medicare patients with HF. Under the 2010 Affordable Care Act (ACA), changes in Medicare and Medicaid reimbursement have been instituted and hospitals with higher than expected 30-day readmission rates for HF patients are held financially accountable (Centers for Medicare & Medicaid Services, 2012). Despite advances in the treatment and management of HF, hospital readmission rates remain high (Gheorghiadu, Vaduganathan, Fonarow, & Bonow, 2013).

Another important emphasis in HF management is improvement in quality of life. Heart failure patients report that quality of life is significantly more impaired than those with other chronic conditions (Bennett et al., 2001). Quality of life is an important indicator of how patients live with and manage their HF (Liu, Wang, Huang, Cherng, & Wang, 2014).

To decrease hospital readmission rates and improve quality of life, HF programs have focused on an educational person-centered approach to promote self-care (Ditewig et al., 2010). Heart failure self-care has potential to positively affect readmission rates and quality of life (Ditewig et al., 2010). Self-care in HF patients has been found to be less than optimal (Jaarsma et al., 2013; van der Wal & Jaarsma, 2008). Insufficient self-care, the presence of depressive symptoms, and inadequate social support are factors that have been found to contribute to hospital readmission (Moser, Doering, Chung, & Lexington, 2005) and reduced quality of life (Chung, Moser, Lennie, & Frazier, 2013; Ditewig et al., 2010) in patients with HF. Therefore, further research is warranted to better understand self-care and factors that influence patient self-care abilities.

## **Background**

### **Self-Care**

A patient's ability to engage in self-care is crucial in the management of chronic illness such as HF (Riegel et al., 2009b) contributing to a reduction in HF hospitalizations (McAlister, Stewart, Ferrua, & McMurray, 2004) and improved quality of life (Britz & Dunn, 2010; Buck et al., 2012; Seto et al., 2011). Self-care involves engagement in behaviors to maintain health, observe for symptom changes, and respond to symptoms

when they occur (Riegel, Jaarsma, & Stromberg, 2012). Studies support that for various reasons patients have difficulties engaging in self-care. Patients with poor self-care experience difficulties in following treatment recommendations such as taking medications (Riegel et al., 2009b; van der Wal, Jaarsma, & Van Veldhuisen, 2005; Wu, Moser, Lennie, & Burkhart, 2008b), following a sodium restricted diet, and engaging in regular exercise (Riegel et al., 2009b). Psychological factors such as depressive symptoms and social support from family or friends can influence a patient's ability to engage in self-care (Riegel et al., 2009b), however findings have been inconsistent. Some studies have found an association between depressive symptoms and HF self-care (Bauer et al., 2012; Holzapfel et al., 2009) and social support and HF self-care (Dunbar et al., 2013; Gallagher, Luttk, & Jaarsma, 2011). While, in other prior studies depressive symptoms and social support were not related to HF self-care (Heo, Moser, Lennie, Riegel, & Chung, 2008). Therefore, further study was warranted. The primary focus of this study was the impact of depressive symptoms on self-care in HF patients and factors that moderate the effect.

### **Depressive Symptoms**

Depressive symptoms in HF patients have been associated with worsening HF symptoms, functional status, quality of life (Rumsfeld et al., 2003), and increased morbidity (Rutledge et al., 2006). These worsening symptoms and outcomes in part are due to the negative impact of depressive symptoms on HF self-care (Cameron, Worrall-Carter, Riegel, Lo, & Stewart, 2009; Dickson, McCarthy, & Katz, 2013; Holzapfel et al.,

2009; Riegel, Dickson, Goldberg, & Deatrck, 2007). Depressive symptoms are common in HF patients with an average prevalence rate of 21% (Rutledge et al., 2006).

A significant number of patients with HF have difficulty recognizing symptoms of their HF (Moser & Watkins, 2008). The presence of depressive symptoms such as fatigue, loss of energy, and weight gain may make it even more difficult for patients to distinguish the source of their symptoms and worsening HF. Self-care and management of HF can prove challenging for patients and depressive symptoms can further complicate patients' self-care abilities and contribute to adverse outcomes (Riegel et al., 2009b). A more complete understanding of how depressive symptoms influence HF self-care can contribute to development of interventions to improve self-care and patient outcomes.

### **Social Support and Shared Care**

Social support is an important factor in the health of persons with chronic illness (Tay, Tan, Diener, & Gonzalez, 2013). The benefits of social support have been found to prevent and decrease depressive symptoms (Graven & Grant, 2013), predict faster remission from depression (Koenig, 1998), and improve medication adherence in patients with HF (Wu et al., 2008b). Social support has been defined as the exchange of emotional, instrumental, and informational support for a person in need of assistance (Cohen, Gottlieb, & Underwood, 2000). Patients obtain and utilize social support in the self-management of their chronic illness (Schulman-Green et al., 2012).

For this study the construct of shared care was used to operationally define social support. Shared care is comprised of three critical components; communication, decision making, and reciprocity used to exchange support. Shared care takes place between two



people in a dyadic relationship, usually a close family caregiver and the person with the chronic illness (Sebern, 2005). Based on the literature to date, there is a gap examining the moderating effects of shared care on the relationship between depressive symptoms and self-care.

## **Significance to Nursing**

### **Nursing Practice**

Understanding the relationships between depressive symptoms, social support, and HF self-care are important to nursing practice and can be linked to patient outcomes (Riegel et al., 2009b). Patients with chronic illness such as HF are faced with challenges of learning new knowledge, acquiring new skills, understanding the complexities of their disease, accessing resources, processing emotions, and adjusting to illness (Riegel et al., 2009b; Schulman-Green et al., 2012). Nurses are in an optimal position to collaborate with HF patients and their families in developing and optimizing self-care to promote patient outcomes. Assessment and early identification of factors that may affect a patient's self-care abilities, such as depressive symptoms and social support is important in maintaining health and managing illness. Identification of these factors can guide the development of a plan of care tailored to the needs of the patient. The findings from this study may contribute to a better understanding of the relationships between social support, depressive symptoms, and self-care and the development of practices and interventions to improve patient outcomes.

## **Nursing Education**

The development of knowledge of chronic illness and factors that may influence patient outcomes such as depressive symptoms, social support, and self-care are important in the education of nursing students. With an increasingly diverse and aging population it is important that students at the undergraduate level are taught about the complexities and challenges faced by patients with chronic illness. Additionally, it is essential that students develop the knowledge and sensitivity to address disparities that can contribute to poor patient outcomes. Learning how to recognize patients at risk for poor self-care is crucial to maintain health and improve outcomes. Findings from this study can contribute to curriculum and course development at the undergraduate level about the relationships between depressive symptoms, social support, and self-care in the management of a diverse HF population. Educating students about the complexity of self-care and challenges HF patients and their family experience can provide new nurses with the knowledge and skills to develop plans of care tailored to the needs of patients and their families.

## **Health Systems**

To reduce hospitalizations it is important to understand factors that may contribute to worsening HF and hospitalization such as self-care, depressive symptoms, and social support. Many healthcare systems have implemented strategies to reduce HF readmissions and improve quality of care. Strategies include coordination of care, proper transition to home, multidisciplinary follow-up, home health programs, remote monitoring, and HF clinics (Hines et al., 2010). An underlying premise of many of these

approaches is the promotion of wellness and self-care through care coordination and active involvement of patients and families, nurses, and advanced practice nurses (Hines et al., 2010). Findings from this current study may add to what is known about self-care and could be used in the evaluation and modification of strategies to decrease readmissions. To better understand factors that may influence self-care in patients with HF the following study hypotheses were explored.

### **Purpose**

The purpose of this study was to determine if shared care moderated the relationship between depressive symptoms and self-care in community dwelling HF patients.

### **Hypotheses**

To address the purpose of the study, the following hypotheses were addressed:

1. Depressive symptoms will have an inverse relationship with self-care in community dwelling patients with HF.
2. Shared care will have a positive relationship with self-care in community dwelling patients with HF.
3. Shared care will have a moderating effect on the relationship between depressive symptoms and self-care in community dwelling patients with HF.

The hypotheses were analyzed using a cross-sectional, descriptive design. Details regarding study design, methods, instruments, and data analysis are presented in Chapter

Three. Chapter Two provides an in-depth review of the literature, and describes the theoretical framework and underlying philosophical basis for the study.

### **Chapter One Summary**

In this chapter, the scope and significance of HF and associated costs and challenges were presented. Background information about self-care, depressive symptoms, and social support were discussed. The cornerstone of HF management is engagement in self-care (Riegel et al., 2009b). Depressive symptoms in HF patients are associated with worsening symptoms and negatively impact self-care (Riegel et al., 2009b). Shared care a form of social support is positively associated with self-care in patient with HF (Sebern & Riegel, 2009), but there is a lack of research exploring the effects of shared care on the relationship between depressive symptoms and self-care. The aim of this study was to address gaps in the literature describing shared care and effects on depressive symptoms and self-care in patients with HF.

## CHAPTER TWO

### **Review of the Literature**

In this chapter, the Stress-Buffering Model (Cohen et al., 2000), the Theory of Self-Care of Chronic Illness (Riegel et al., 2012), and the Processes of Self-Management in Chronic Illness (Schulman-Green et al., 2012), will be discussed, along with the philosophical underpinnings, and vulnerabilities of individuals who have HF. A review of literature will be presented addressing variables that may influence depressive symptoms and relationships among the concepts of depressive symptoms, self-care, and social support. Next a summary of the gaps in literature will be discussed and how these gaps are addressed by the research study. Lastly, assumptions and research hypotheses for this study are presented.

### **Theoretical Framework for the Research**

The Stress-Buffering Model (Cohen et al., 2000) was selected to guide the study and provided a theoretical and visual understanding of study variables and relationships between variables. The Theory of Self-Care of Chronic Illness (Riegel et al., 2012) was used to operationalize the definition of self-care and the Processes of Self-Management of Chronic Illness (Schulman-Green et al., 2012) provided an understanding of the patient role in activating social support resources in the management of chronic illness. The Stress-Buffering Model was used to describe relationships between depressive symptoms and self-care and social support and self-care.

## **Stress-Buffering Model**

The Stress-Buffering Model was used to conceptualize relationships between study variables (see Conceptual Model, Figure 1). In the Stress-Buffering Model Cohen and colleagues (2000) propose that stressful events can lead to adverse health effects and illness. Social support buffers or prevents adverse stress responses which may impact health. Additionally, social support may influence stress and stress responses at various points throughout the stress illness pathway. In persons who encounter or experience stress, those with high social support may appraise stress as benign, making the experience less stressful.

In the Stress-Buffering Model social support is defined as the exchange of emotional, instrumental, and informational support for a person in need of assistance, or the perception of assistance available in a stressful situation (Cohen et al., 2000). Social support can be categorized as structural support and functional support. Structural support refers to the structure of a supportive relationship such as social network or marital status, whereas, functional support refers to the quality of the relationship (House, Umberson, & Landis, 1988). Characteristics of functional social support include quality of the relationship, emotional support, instrumental support, and informational support. Emotional support is the perception of support through the provision of caring, empathy, love, and trust (Langford, Bowsher, Maloney, & Lillis, 1997). Instrumental support is the provision of tangible aid and services such as financial assistance or some type of work for others. Informational support is the provision of information during stressful times (Langford et al., 1997).

For this study shared care was used to operationally define social support. Shared care is comprised of three critical components; communication, decision making, and reciprocity used to exchange support. Shared care takes place between two people in a dyadic relationship, usually a close family caregiver and the person with the chronic illness (Sebern, 2005).

The Stress-Buffering Model has been used as the theoretical foundation for many research studies examining moderating effects of perceived social support on health and illness. Research provided support for the stress-buffering or moderating effects of social support in patients with chronic illness. One study found that in older adults the association between chronic illness and depressive symptoms was weakened with greater levels of social support (Beekman et al., 1997). Other studies found that social support moderated relationships between the burden of diabetes and emotional distress (Baek, Tanenbaum, & Gonzalez, 2014), and chronic illness and depressive symptoms and anxiety (Thomas, Jones, Scarinci, & Brantley, 2007). Another study of women with breast cancer found that higher satisfaction with spousal support moderated the effects of social concerns (reactions of friends and family about illness) (Gremore et al., 2011).

Social support has been shown to have direct effects on self-care and depressive symptoms in patients with HF. Higher levels of perceived social support are associated with better self-care (Gallagher et al., 2011; Friedman & Quinn, 2008; Sebern & Riegel, 2009) and less depressive symptoms (Heo, Lennie, Moser, & Kennedy, 2014; Sebern, 2008; Trivedi et al., 2009). Researchers in previous studies have investigated the stress-buffering effects of social support in persons with chronic illnesses. The Stress-Buffering Model is relevant to HF patients because social support attenuates depressive symptoms

(Heo, Lennie, Moser, & Kennedy, 2014; Sebern, 2008; Trivedi et al., 2009) and improves self-care (Gallagher et al., 2011; Friedman & Quinn, 2008; Sebern & Riegel, 2009).

### **Theory of Self-Care of Chronic Illness**

The Theory of Self-Care of Chronic Illness was used to define and measure self-care. According to Riegel et al. (2012), self-care is defined as a naturalistic decision making process, requiring patients to engage in essential behaviors of self-care maintenance, monitoring, and management.

Self-care maintenance involves patient engagement in behaviors that promote and maintain health (Riegel et al., 2012). Self-care maintenance behaviors include following a healthy diet, smoking cessation, taking medications, keeping appointments, and following prescribed treatments (Riegel et al., 2012). Patients may need to modify behaviors to adjust to changes in health. To modify behavior and adjust to changes, patients must engage in self-care monitoring (Riegel et al., 2012).

In patients with chronic illness self-care monitoring refers to behaviors directed toward recognizing physical and emotional changes due to chronic illness (Riegel et al., 2012). For example, patients with HF are encouraged to engage in monitoring activities such as weighing themselves daily to detect weight gain, monitoring for shortness of breath, lower extremity swelling, and increased fatigue (Riegel et al., 2009b). Regular and routine monitoring by patients can promote better outcomes. Early recognition of symptoms and understanding the significance of symptoms can preempt worsening HF (Riegel et al., 2012). Once symptoms are recognized patients make decisions to determine a course of action. The decision making process begins self-care management.



Self-care management involves patient self-assessment of physical and emotional change, decision making on a course of action, implementation of the action, and evaluation of the outcomes based on the action taken (Riegel et al., 2012). For example, weight gain of a couple of pounds or more in a day or two requires the patient to call their healthcare provider or follow through with a pre-prescribed treatment plan. Once patients have implemented the treatment plan they will need to evaluate the outcomes and effectiveness of the treatment and reflect on whether or not it should be used again in the future (Riegel et al., 2012). These processes of decision making and reflection are important aspects of self-care in patients with chronic illness.

The Theory of Self-Care of Chronic Illness identifies several factors that may hinder or contribute to a patient's self-care (Riegel et al., 2012). Major factors affecting self-care include experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, and access to care (Riegel et al., 2012). An important factor affecting self-care that warrants further discussion is that of patient confidence. In earlier work, the Theory of Heart Failure Self-Care (Riegel & Dickson, 2008) confidence was identified as a self-care component, but as the concept of self-care evolved, patient confidence to perform self-care was found to mediate and/or moderate relationships between self-care and patient outcomes. While confidence is no longer a core component of self-care it is thought to be an important influence on each aspect of the self-care process; helping to explain why some patients are better at self-care than others (Riegel & Dickson, 2008). Additionally, situational factors such as emotional stress or lack of sleep may impede patients' attention and memory and negatively affect self-care.

The Theory of Self-Care of Chronic Illness evolved from previous work including the Theory of Heart Failure Self-Care and the development of the Self-Care Heart Failure Index (SCHFI), a measure of self-care (Riegel & Dickson, 2008). The Theory of Heart Failure Self-Care and SCHFI have been used extensively in research and support to the relationships between the variables and hypotheses of this study. Studies using the Heart Failure Self-Care Theory supported an association between depressive symptoms and self-care. Depressive symptoms in patients with HF have been associated with poor self-care maintenance (Riegel et al., 2007), self-care management (Cameron et al., 2009; Dickson et al., 2013; Riegel et al., 2007), and self-care confidence (Cameron et al., 2009; Cameron et al., 2010). Studies utilizing the Heart Failure Self-Care Theory supported a relationship between social support and self-care in HF patients. Social support has been positively associated with self-care maintenance (Cene et al., 2013; Salyer, Schubert, & Chiaranai, 2012; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008), self-care management (Riegel & Carlson, 2004), and self-care confidence (Riegel & Carlson, 2004; Salyer et al., 2012).

Sebern and Riegel (2009) used the shared care construct and SCHFI to examine the relationship between shared care and self-care. A strong positive relationship was found between patient shared care decision making and self-care maintenance and confidence. Patient shared care communication and reciprocity was moderately associated with self-care confidence. A strong positive relationship was found between caregiver shared cared decision making and patient self-care maintenance and confidence.

Mental health illness such as anxiety or depressive symptoms can affect patients' self-care abilities by hampering the ability to recognize symptoms and make decisions (Riegel et al., 2009b). Patients with HF and depressive symptoms may require support from others to assist in self-care management (Riegel et al., 2012). Given that patients experience depressive symptoms at a rate 2 to 3 times that of the general population (Rutledge et al., 2006), research evaluating the role of depressive symptoms in self-care and the influence of social support on that relationship is important in improving self-care.

### **Processes of Self-Management of Chronic Illness**

The Processes of Self-Management of Chronic Illness was used to enhance the Stress-Buffering Model to provide an understanding of the patient role in activating social support resources in the management of chronic illness. A qualitative metasynthesis was used to conceptualize self-management processes in patients living with chronic illness (Schulman-Green et al., 2012). Three self-management processes emerged from the analysis. The processes were categorized as focusing on illness needs, activating resources, and living with a chronic illness. These categories provide a holistic view of chronic illness self-management that includes physical, psychological, social, spiritual, existential, and system-related processes. The category of activating resources, specifically, psychological and social resources require patients use skills such as advocating for self, maintaining a positive outlook, and seeking support from family and friends. Although skills and tasks are viewed as distinct, the processes of self-management are by no means linear, but dynamic and shifting, dependent upon

progression and variability of illness and life circumstances for the individual. The Processes of Self-Management of focusing on illness needs, activating resources, and living with chronic illness are relevant to optimal self-management.

The Processes of Self-Management of Chronic Illness, in particular, activation of psychological and social resources was used to describe the processes patients use to seek social support and engage in HF self-care. The processes of activating resources support the relationship between shared care and HF self-care.

### **Theoretical and Conceptual Similarities**

The conceptual definitions of self-care and activation of social support derived from the Theory of Self-Care of Chronic Illness (Riegel et al., 2012), and the Processes of Self-Management in Chronic Illness (Schulman-Green et al., 2012) provides support for the Stress-Buffering Model (Cohen et al., 2000) and theoretical framework used in this study. Although, the terms self-care and self-care management have often been used interchangeably in the literature, overlap exists between the concepts of self-care and self-management. Self-care is a broad concept, encompassing healthy life-style behaviors that patients engage in to promote and maintain health as well as manage illness (Riegel & Dickson, 2008). Whereas, self-management processes for patients are focused on illness needs, activating resources, and living with chronic illness (Schulman-Green et al., 2012). For this study the term self-care was used to operationalize self-care and behaviors patients engage in to maintain health and manage chronic illness.

A common theme in the Stress Buffering Model, Theory of Self-Care of Chronic Illness, and Processes of Self-Management of Chronic Illness is the influence of social

support on health and illness of individuals. According to the Stress-Buffering Model stress arises when the situation is appraised by the patient as demanding. The availability of social support can lead to appraising stress as less demanding, buffering the impact of stress. The Theory of Self-Care of Chronic Illness and Processes of Self-Management of Chronic Illness support the concept of social support and the need to seek support from others (Riegel et al., 2012) and the activation of social resources in the management of chronic illness (Schulman-Green et al., 2012). Riegel's et al. (2012) theory and Schulman-Green's et al. (2012) processes model supports Cohen's et al. (2000) Stress-Buffering Model and the important role social support plays in preventing or buffering stress that may impact health.

### **Conceptual Model**

It has been established that social support operationalized in the study as shared care plays a role in buffering stress and stress responses for patients living with chronic illnesses, such as HF. Cohen's et al. (2000) Stress-Buffering Model was adapted to guide the study in the examination of relationships between depressive symptoms, HF self-care, and shared care (see Figure 1. Conceptual Model).

Cohen and colleagues (2000) propose that stressful events can lead to adverse health effects and illness; stressful events were operationalized as HF severity. Social support operationalized as shared care may moderate patients' responses along various points of the stress-illness pathway. In response to the stressful event of HF severity, patients who perceive or activate social support (shared care) may not appraise HF severity as stressful because they perceive they have adequate resources. This perceived

social support (shared care) could decrease or prevent emotional responses such as depressive symptoms which could contribute to insufficient self-care. Second, perceived or received social support (shared care) may encourage self-care responses. Third, perceived or received social support (shared care) may provide assistance in engaging in sufficient self-care. Inadequate perceived social support (shared care) can lead to adverse health effects.

Inadequate perceived or received social support (shared care) can cause progression of stress responses through the stress-illness pathway, which may result in worsening HF, exacerbations, and continued or worsening depressive symptoms. Insufficient self-care can lead to worsening HF symptoms and psychological health. For example, insufficient self-care such as not taking medications as prescribed may cause adverse physiological responses (Riegel et al., 2009b). Perceived or received social support (shared care) at various points in the pathway may intercede to buffer or alleviate the impact of stress (HF severity). The Stress-Buffering Model was used to organize the relationships being tested in this dissertation study.

The Stress-Buffering Model and components of the Theory of Self-Care of Chronic Illness and the Processes of Self-Management of Chronic Illness were used to guide this study. This study examined relationships between depressive symptoms and self-care and potential moderating effects of shared care. The Theory of Self-Care of Chronic Illness provided the operational definition of self-care for this study. The Processes of Self-Management of Chronic Illness provided an understanding of the patient role in activating resources such as social support which was operationalized as shared care. The conceptual model for this study provided a theoretical and visual

understanding of study variables and relationships between depressive symptoms, self-care, and shared care in response to the stress of HF severity. Additionally, the theoretical framework guided data collection and analysis, interpretation of findings, and recommendations for future research and practice.

Figure 1. Conceptual Model

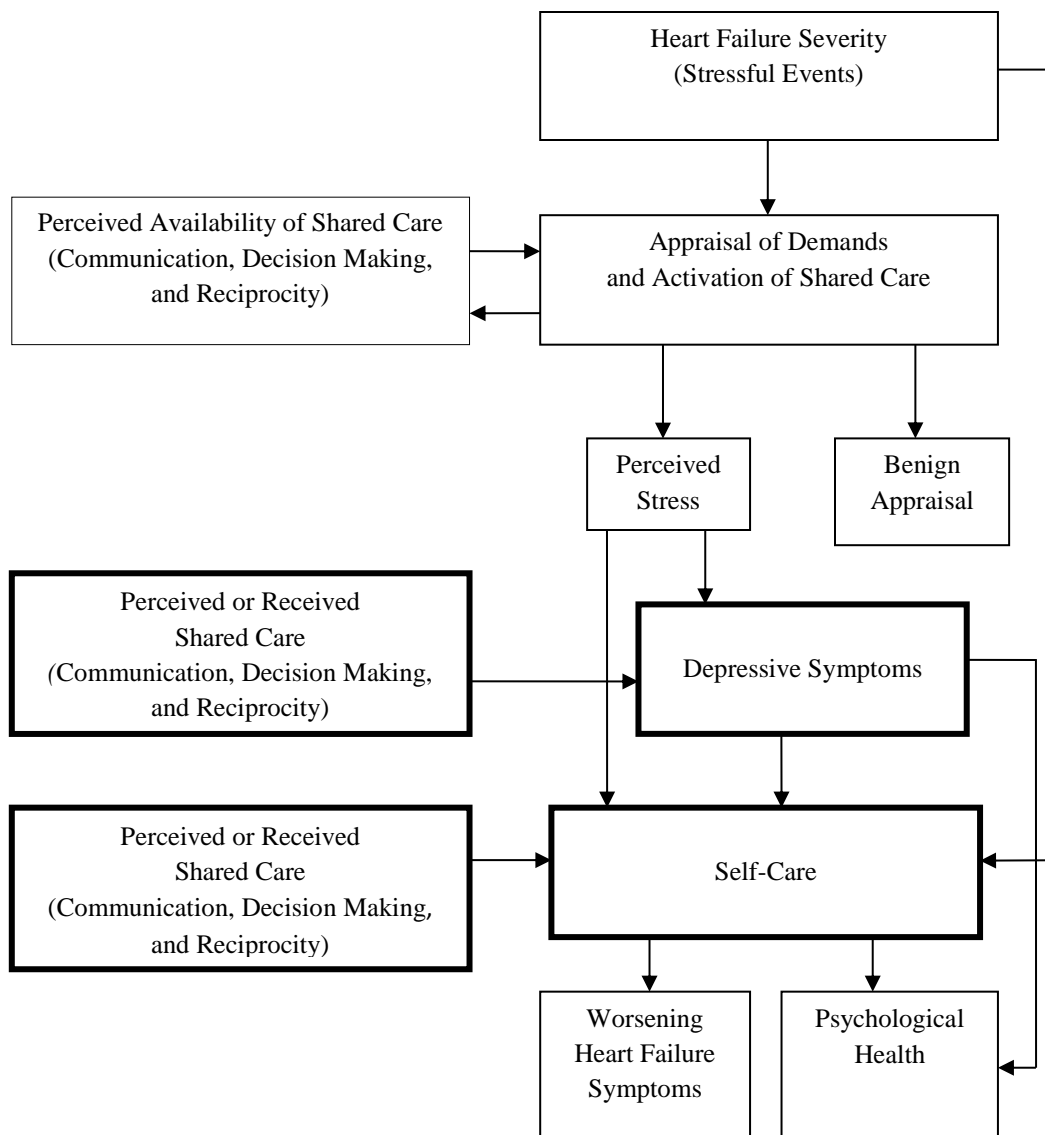


Figure 1. Is an adaptation of the Stress-Buffering Model to examine relationships among study variables. Pathways through which social support (shared care) influences or moderates the constructs of depressive symptoms and self-care and the interrelationships between the constructs in response to the stressful events HF severity). Boxes/arrows in bold indicate concepts or relationships addressed in this study: Social support was operationalized as shared care for the study. Adapted from Cohen, S., Gottlieb, B., & Underwood, L. (2000). Social relationships and health In S. Cohen, Underwood, Gottlieb, B. (Ed.), *Social Support Measurement and Intervention: A Guide of Health and Social Science* (pp. 13). Oxford: University Press.



## **Philosophical Underpinnings**

The advancement of nursing knowledge through research is underpinned by varying philosophies of scientific inquiry. A researcher's underlying philosophical perspective helps to define the study design, methods, and assumptions. This section will present an overview of post-positivism, the underlying philosophy that guided the study.

Guba (1991) describes the post-positivists view of the world from a critical realist's perspective. Reality exists but the absolute truth often cannot be found; research findings are imperfect and fallible (Guba, 1991). Because of research imperfection and human frailties, researchers need to be critical of their work and claims must be subject to empirical examination. While objectivity can never be fully attained, the researcher strives for objectivity by maintaining neutrality when identifying predispositions and assumptions. The post-positivist relies on multiple sources of data to decrease the likelihood of distorted interpretation. While post-positivism still reflects aspects of positivism such as well-defined concepts and variables and use of quantitative instruments and empirical testing, the post-positivist tries to find balance with the use of qualitative methods. These qualitative methods serve to enrich the study and gain insight into subjective experiences of study participants (Guba, 1991).

The post-positivist perspective is reflected in various aspects of this research study. Concepts and variables used in this study were clearly defined and based in theory. The research hypotheses were established prior to initiating the study. Recruitment and data collection took place in a HF clinic, a natural setting for many patients with HF, opposed to a laboratory setting. Both quantitative and qualitative methods were used for collection of data and provided multiple perspectives in data

analysis and decreased likelihood of distorted interpretation. In addition self-report instruments were used to collect quantitative and qualitative data. Qualitative questions were developed to assess subjective perspective regarding depressive symptoms, social support, and self-care for patients.

The post-positivist perspective was used to guide the study. The collection, analysis, and interpretation of both quantitative and qualitative data provided an enriched multi-method complementary approach.

### **Vulnerability**

According to Aday (2001), vulnerable populations are persons at-risk for poor physical, psychological, or social health because of social, political, and economic conditions that put them at risk. All persons at one time or another throughout their life may be at risk of poor physical and psychological health. Having a chronic illness can contribute to poor physical health making one more vulnerable to poor psychological health such as depressive symptoms or social health due to lack of social resources (Aday, 2001). Potential debilitating effects of chronic illness can contribute to limitations in daily activities and loss of income (Aday, 2001). The progressive nature of HF and associated physical limitations, along with an increased prevalence of depressive symptoms can contribute to individual vulnerability among patients with HF. In addition, populations who are marginalized due to demographic characteristics such as age, race, gender, and socioeconomic status are at greater risk for health problems and increased vulnerability (Aday, 2001). Disparities in age, race, gender, and socioeconomic status

(SES) have been associated with increased incidence of HF, hospitalization, and readmission (Giamouzis et al., 2011; Husaini et al., 2011; Joynt, Orav, & Jha, 2011).

Heart failure occurs predominately in the elderly, with an annual incidence rate of approximately 10 in 1,000 populations over the age of 65 years, and increases with each subsequent decade (Roger et al., 2012). While HF is more common in men, older patients with HF are more frequently women (Stein et al., 2012). The annual incidence rate of newly diagnosed HF varies across age, race, and gender (see Table 1). Ethnically diverse persons have a higher risk of HF. Heart Failure incident rates per 1000 are highest among blacks (4.6), followed by Hispanics (3.5), whites (2.4), and Chinese Americans (1.0) (Bahrami et al., 2008). Furthermore, the incidence of HF before the age of 50 years is considerably more common in blacks than whites (Bibbins-Domingo et al., 2009). Given the chronic nature of HF and risk for health disparities, research is important to better understand and best meet the needs of this vulnerable population.

Table 1. Annual Heart Failure Incidence

Race/Gender	65-74 years of age	75-84 years of age	85 years of age or older
White men	15.2	31.7	65.2
White women	8.2	19.8	45.6
Black men	16.9	25.5	50.6
Black women	14.2	25.5	44.0

Note: Annual rates per 1000 population of new HF events (Roger et al., 2012).

## Outline of Literature for Review

A comprehensive and critical review of literature relevant to this study is reported below. A review of the literature examining the relationships between study variables will be discussed. Study variable relationships include; depressive symptoms and self-care, social support and depressive symptoms, and social support and self-care. Additionally, covariates of age, gender, and HF severity and their impact on depressive symptoms will be reviewed. Description of search strategies for each section can be found in Appendix A. A table summarizing studies supporting the relationships between depressive symptoms and self-care can be found in Table 2B (see Appendix B). Studies supporting the relationship between social support and depressive symptoms can be found in Table 3C (see Appendix C). Lastly, a table summarizing studies supporting the relationship between social support and self-care can be found in Table 4D (see Appendix D). The quality and level of evidence of each study was rated according to the Strength of Recommendation Taxonomy (SORT) developed by Ebell and colleagues (2004). Using sort quality of studies can range from 1 to 3. Level 1 are good quality studies based on meta-analysis or high-quality random control trials (RCT). Level 2 are limited-quality studies, lower quality clinical trials or non-RCT studies. Level 3 are considered other evidence such as consensus guidelines, usual practice, or opinions. For purposes of clarity in this review of the literature the term social support will be used unless the study specifically utilized the term shared care.

### **Covariates of Age, Gender, and Heart Failure Severity**

In the HF population age, gender, and HF severity have been found to impact depressive symptoms (Eastwood et al., 2012; Gottlieb et al., 2004). Studies have reported that younger patients with HF have a greater incidence of depressive symptoms (Eastwood et al., 2012; Gottlieb et al., 2004; Lesman-Leegte, Jaarsma, Sanderma, Hillege, & van Veldhuisen, 2008; Rohyans & Pressler, 2009), which may be attributed to difficulties in adapting to HF and the associated emotional and physical limitations (Gottlieb et al., 2004).

Gender has been linked to depressive symptoms in HF patients. Similar to the general population (Kessler, 2003), some studies report women with HF have a greater prevalence of depressive symptoms than men (Eastwood et al., 2012; Gottlieb et al., 2004; Lesman-Leegte et al., 2008; Rohyans & Pressler, 2009). However, other studies have reported no differences in the incidence of depressive symptoms between men and women with HF (Friedman, 2003; Heo et al., 2008).

Higher prevalence rates of depressive symptoms were found to be associated with worse New York Heart Association (NYHA) classification (Gottlieb et al., 2004; Lesman-Leegte et al., 2008; Rohyans & Pressler, 2009). New York Heart Association classification is a measure of severity of HF symptoms and functional ability. However, these findings are not consistent between men and women, with one study reporting that NYHA classification was associated with depressive symptoms in men, but not in women (Eastwood et al., 2012). Although inconsistent, the above research supports an association between age, gender, and HF severity and depressive symptoms. These variables were examined and controlled for in the study.

## **Depressive Symptoms and Self-Care**

In this review of the relationship between depressive symptoms and self-care, six studies were identified. The majority of studies were cross-sectional, correlational studies (Cameron et al., 2009; Dickson et al., 2013; Holzapfel et al., 2009; Johansson, Nieuwenhuis, Lesman-Leegte, van Veldhuisen, & Jaarsma, 2011; van der Wal, Jaarsma, Moser, van Gilst, & van Veldhuisen, 2007), and one was a secondary analysis of a prospective randomized control trial (Bauer et al., 2012). Only one of the six studies reported race (Dickson et al., 2013).

The mean age of patients in the studies ranged from 59 to 73 years, and included mostly men. In the majority of studies women were represented in the sample at 40% or less with the exception of one study, where women represented 52% of the sample (Bauer et al., 2012). The rate of depressive symptoms in patients in five studies ranged from 16.7% to 52% (Cameron et al., 2009; Dickson et al., 2013; Holzapfel et al., 2009; Johansson et al., 2011; van der Wal et al., 2007). In one study only patients with depressive symptoms were recruited (Bauer et al., 2012). These rates of depressive symptoms are consistent with findings from a meta-analysis examining the prevalence of depressive symptoms in HF patients, with rates ranging from 9% to 60%; higher than those found in the general population (Rutledge et al., 2006). The remaining section of this review will be organized according to the influence of depressive symptoms on overall self-care, self-care maintenance, management, and confidence.

Depressive symptoms negatively affect overall self-care (Holzapfel et al., 2009) and aspects of self-care such as self-care maintenance, monitoring, and management (Bauer et al., 2012; Cameron et al., 2009; Dickson et al., 2013; Johansson et al., 2011;

van der Wal et al., 2007). Varying levels of depression have been found to affect self-care differently (Holzapfel et al., 2009). Patients with minor depression reported lower levels of self-care than those with major depression, or no depression (Holzapfel et al., 2009). Patients with major depression had similar levels of self-care as those with no depression. Holzapfel et al. (2009) proposed the following explanations for the lack of significant findings between major depression and self-care. Patients with major depression may interpret feelings and thoughts as part of their HF and not a depressive disorder. This could contribute to a heightened awareness of the seriousness of their HF and illness, prompting an increased diligence in self-care activities, similar to patients with no depression (Holzapfel et al., 2009). Another explanation could be the use of self-report to measure self-care. Self-reporting can result in a social desirability bias, where patients with major depression may be inclined to respond as they know they should versus reporting actual self-care behaviors (Holzapfel et al., 2009).

Patients with depressive symptoms have been reported to have lower levels of self-care maintenance behaviors (Bauer et al., 2012). They perceived more barriers to taking medications, following diet, and fewer benefits to medications than those without depressive symptoms (van derWal et al., 2007). In an intervention study in cardiac patients that included HF patients, improvement in depressive symptoms over time was associated with better self-care maintenance behaviors related to adherence to a healthy diet, exercise, stress reduction, and medications (Bauer et al., 2012).

Patients with depressive symptoms had lower levels of self-care management compared to those without depressive symptoms (Cameron et al., 2009; Dickson, et al., 2013). An important aspect of self-care management is the recognition of HF symptoms

and action in response to symptoms. Patients with depressive symptoms delay longer between onset of HF symptoms and hospitalization than patients without depressive symptoms (Johansson et al., 2011). Median time delay between worsening HF symptoms and hospital admission in patients with depressive symptoms was 120 hours, significantly higher than the median time delay of 54 hours seen in patients without depressive symptoms (Johansson et al., 2011).

Only one study examined the relationship between depressive symptoms and self-care confidence in Black patients (Dickson et al., 2013). In general self-care was poor, with women reporting better self-care maintenance than men. No association was found between depressive symptoms and self-care confidence or management.

**Summary of depressive symptoms and self-care.** The majority of studies were cross-sectional with one secondary analysis of patients from a previous randomized control trial. A patient's depressive symptoms can vary over time; studies examining differences in depressive symptoms over time would be helpful in evaluating changes and trends. Women were underrepresented in the studies. The underrepresentation of women in studies limits the generalizability of findings. There is a need for greater inclusion of women in future studies. The findings from this review showed a negative relationship between depressive symptoms and aspects of self-care, self-care maintenance, self-care monitoring, and self-care management. The association of increased depressive symptoms and poor self-care in patients with HF supports the need for further research in identifying factors that may influence or moderate this relationship such as social support.



## **Social Support and Depressive Symptoms**

In this review of social support and depressive symptoms ten studies were identified. Racial diversity of samples varied across studies. Two studies did not report race (Frasure-Smith et al., 2000; Dekker, Peden, Lennie, Schooler, & Moser, 2009). White patients represented 47.4% to 98% of study participants in eight of the ten studies (Bean, Gibson, Flattery, Duncan, & Hess, 2009; Evangelista, Ter-Galstanyan, Moughrabi, & Moser, 2009; Friedmann, Son, Thomas, Chapa, & Lee, 2014; Paukert, LeMarie, & Cully, 2009; Sebern, 2008; Thornhill, Lyons, Nouwen, & Lip, 2008; Trivedi et al., 2009; Vollman, La Montagne, & Hepworth, 2007). Six studies reported that blacks made up 1% to 49.5% of study participants (Bean et al., 2009; Evangelista et al., 2009; Paukert et al., 2009; Sebern, 2008; Trivedi et al., 2009; Vollman et al., 2007). Hispanic patients were represented in five studies ranging from 1% to 22.8% (Bean et al., 2009; Evangelista et al., 2009; Paukert et al., 2009; Sebern, 2008; Vollman et al., 2007). The mean age of patients in the studies ranged from 53 to 71.1 years, and included mostly men. Women represented 1% to 44% of study participants. The majority of studies included in this review were cross-sectional, correlational studies (Bean et al., 2009; Evangelista et al., 2008; Paukert et al., 2009; Sebern, 2008; Trivedi et al., 2009; Vollman et al., 2007). There was one prospective study (Frasure-Smith et al., 2000). Three of the studies did not report rates of depressive symptoms (Dekker et al., 2009; Thornhill et al., 2008; Vollman et al., 2007). Of the ten studies reviewed nine studies reported an association between social support and depressive symptoms. Only one study reported non-significant results (Paukert et al., 2009).

**Quantitative studies.** Social support, particularly emotional support may be a suitable resource for patients in dealing with depressive symptoms. The presence of social support was associated with less depressive symptoms in patients with HF (Trivedi et al., 2009; Vollman et al., 2007). The use of emotional support as a resource was found to be positively associated with less depressive symptoms (Trivedi et al., 2009; Vollman et al., 2007).

Four studies (Frasure-Smith et al., 2000; Friedmann et al., 2014; Paukert et al., 2009; Sebern, 2008) examined both functional and structural support with two studies examining the association between social support and depressive symptoms in cardiac patients at different points in time (Frasure-Smith et al., 2000; Friedmann et al., 2014). Frasure-Smith and colleagues (2000) found an association between social support and depressive symptoms in patients following a myocardial infarction. After one year, higher baseline depressive symptoms and higher baseline social support was found to be associated with improvement in depressive symptoms. Both functional and structural support were related to improvements in depressive symptoms. Additionally, the relationship between depressive symptoms and cardiac mortality decreased with increased social support. Although Frasure-Smith's et al. (2000) study did not include HF patients, seminal work in this area can contribute to a better understanding of the impact of social support and depressive symptoms in patients with HF. Similarly, Friedmann and colleagues (2014) found that over a two year period lower social support at baseline in patients with HF was associated with increases in depressive symptoms over time. This evidence suggests that the amount of social support over time may

change depressive symptoms and that higher levels of social support may buffer depressive symptoms in patients with HF.

Sebern (2008) studied relationships between shared care and depressive symptoms in patient and caregiver dyads. An inverse correlation was found between patient shared care communication and patient depressive symptoms. Caregiver depressive symptoms inversely correlated with caregiver shared care communication and reciprocity. All three components of the caregivers' and the patients' shared care were inversely associated with dyadic relationship strain. These findings suggest that shared care components may contribute to less depressive symptoms and dyadic strain between the patient and caregiver.

Lastly, Paukert and colleagues (2009) investigated functional and structural support as a predictor of depressive symptoms in patients with HF. The Multidimensional Scale of Perceived Social Support was used to measure functional support. Functional and structural social support were not related to depressive symptoms; there were no differences in living status (lived alone/or lived with someone) between depressed and non-depressed patients.

The relationship between social support and depressive symptoms was examined in different ethnic groups (Bean et al., 2009; Evangelista et al., 2009). Evangelista and colleagues (2009) examined structural support (the availability of someone to confide in) and depressive symptoms in non-Hispanic black (n = 18), Hispanic (n = 55), and non-Hispanic white (n = 168) HF patients. Compared to non-Hispanic blacks and non-Hispanic whites, Hispanic patients reported higher levels of social support and lower levels of depressive symptoms. In contrast, Bean and colleagues (2009) found no ethnic

differences between social support and depressive symptoms, although, less social support was associated with increased levels of depressive symptoms. The sample consisted of African American (n = 48), Hispanic (n = 3), and white (n = 46) HF patients. Based on the findings of these two studies it is difficult to draw any conclusions about ethnic differences between depressive symptoms and social support.

**Qualitative studies.** Two qualitative studies reviewed found family and friends to be an important source of social support to patients living with HF (Dekker et al., 2009; Thornhill et al., 2008). Support from family and friends in the form of emotional, physical, and financial support was crucial to HF patients in managing their depressive symptoms (Thornhill et al., 2008). Patients used family and friends as a means to ease their depressive symptoms by "taking my mind off of it" (Dekker et al., 2009, p. 310). In addition, family members provided support by helping patients keep their spirits up and being available when needed (Thornhill et al., 2008).

**Summary social support and depressive symptoms.** This review of the research suggests that social support may buffer depressive symptoms and moderate the relationship between depressive symptoms and self-care in patients with HF. Social support may influence HF patients' psychological well-being and physical health.

The majority of studies reviewed were cross-sectional, with one prospective and one longitudinal study. Depressive symptoms can change over time and the use of more longitudinal studies would be beneficial to identifying changes and trends. Of the 2,011 total patients who participated in the studies reviewed only 35% were women. This low

representation of women limits generalizability of findings and suggests the need to include more women in future studies. In addition, some samples were limited in representation of racial diversity (Dekker et al., 2009; Friedmann et al., 2014; Sebern, 2008, Thornhill, et al., 2008; Vollman et al., 2007). While various aspects of structural and functional support were examined only one study (Sebern, 2008) evaluated the quality of the relationship between the patient and the caregiver. Therefore, further research examining relationship quality of social support operationalized as shared care with depressive symptoms is warranted.

### **Social Support and Self-Care**

In this review of social support and self-care nine studies were identified. The majority of studies were cross-sectional, correlational studies (Cene et al., 2013; Friedman & Quinn, 2008; Gallagher et al., 2011; Salyer et al., 2012; Sayers et al., 2008; Sebern & Riegel, 2009). Additionally, one longitudinal (Wu, Moser, Chung, & Lennie, 2008a), one randomized control trial (Dunbar et al., 2013), and one qualitative study (Tierney et al., 2011) were included in this review. Representation of white patients in seven of the nine studies ranged from 40.5% to 96%. Two of the nine studies did not report race (Gallagher et al., 2011; Tierney et al., 2011). Black representation was reported in six of the studies ranging from 2.7% to 58% (Cene et al., 2013; Dunbar et al., 2013; Salyer et al., 2012; Sayers et al., 2008; Sebern & Riegel, 2009; Wu et al., 2008a). One study reported 1% Hispanic representation (Wu et al., 2008a) and two studies reported Native American representation of 1.3% to 1.4% (Sayers et al., 2008; Sebern & Riegel, 2009). The mean age of patients in the studies ranged from 56.3 to 72.5 years.

Women represented 4% to 51% of patients participating in the studies. The remaining section of this review will be organized according to the influence of social support on concepts of self-care maintenance and self-care management.

In this review a positive association was found between social support and self-care maintenance in seven of the studies. Support from families can be especially beneficial in assisting with medication and dietary adherence. Emotional and instrumental support was found to be significantly related to dietary and medication adherence (Sayers et al., 2008). Furthermore, perceived support was significantly associated with adherence to medication regimens as measured by dose-count and dose-time (Wu et al., 2008a). Similarly, high levels of social support were significantly associated with self-care behaviors of limiting fluids, taking medications, monitoring weight, and exercising regularly (Gallagher et al., 2011). In a qualitative study encouragement from family helped patients to be more active and engage in regular exercise (Tierney et al., 2011).

Two studies examined social support and self-care maintenance in patient and caregiver dyads; one randomized control trial, and one correlational (Dunbar et al., 2013; Sebern & Riegel, 2009). Sebern & Riegel (2009) explored shared care and self-care. Shared care (communication, decision making, and reciprocity) was used to measure supportive relationships. The process of patient shared care decision making was related to self-care maintenance and self-care confidence. Patient shared care communication and reciprocity were related to their self-care confidence. Caregiver decision making contributed to the patient's self-care maintenance; and caregiver decision making and

reciprocity contributed to the patient's self-care confidence. Sebern and Riegel's findings support the importance of both patient and caregiver contributions to HF self-care.

Dunbar and colleagues (2013) also examined self-care maintenance (dietary sodium intake and medication adherence) with patient and caregiver dyads. In an intervention study, patients were randomized to an educational group (usual care) or one of two intervention groups; Patient-Family Education (PFE), or Family Partnership Intervention (FPI). Participants in the PFE group received education and follow-up regarding dietary sodium and medication-taking behaviors. In addition to dietary sodium and medication-taking education, participants in the FPI group received education and counseling to enhance supportive family partnerships. Both intervention groups were found to have decreases in diet and urinary sodium from baseline to four months, lower than the usual care group. No improvements in medication adherence were found. However, baseline medication adherence levels were high for all groups (80%), potentially limiting improvement.

In this review only one study exclusively examined social support and self-care management (Friedman & Quinn, 2008). Self-care management requires symptom recognition, decision-making, and action. Symptoms, actions, and the time before admission to the hospital were examined in newly diagnosed HF patients and chronic HF patients. Symptoms of shortness of breath on exertion, orthopnea, weakness, edema, and cough were similarly reported by both groups, with a greater percentage of patients with chronic HF reporting fatigue. The amount of time spent from symptom onset to notifying family members, notifying their physician, and hospital admission were comparable between the groups. Family members, most commonly a spouse, were consulted about

symptoms and decision-making prior to seeking treatment from their physician. These findings reveal family members play an important role in decision-making related to seeking treatment.

Two studies supported positive direct effects of social support on HF self-care and the mediation effects of self-care confidence on that relationship (Cene et al., 2013; Salyer et al., 2012). When self-care confidence was added to the analysis, the relationship between social support and self-care was no longer significant. Therefore, self-care confidence indicated a significant mediator effect in the relationship between social support and self-care. These studies show that perceived social support is important in the engagement of self-care and that other factors such as self-care confidence may mediate that relationship.

**Summary of social support and self-care.** Social support has a positive association with self-care maintenance, self-care monitoring, and self-care management behaviors. Self-care confidence mediated the relationship between social support and self-care maintenance and management. Social support plays an integral role in adherence to medication and dietary regimens, engaging in regular exercise, symptom monitoring, and decision-making in the management of HF. Family members, particularly spouses are the primary resource in providing support and assistance to patients in the management of HF and engagement in self-care behaviors. Only one study (Sebern & Riegel, 2009) examined shared care between patients and spouses or close family caregivers and the influence on self-care. The findings from this review on the relationship between social support and self-care provide support for the hypothesis



that social support, operationalized as shared care will have a positive relationship with HF self-care.

### **Gaps in the Literature**

Findings from this review draw attention to the importance of the relationships between social support, depressive symptoms, and self-care. While studies have examined contributions of structural and functional support to depressive symptoms and self-care no studies have examined the moderating effects of social support on the relationship between depressive symptoms and self-care in patients with HF. Furthermore, no studies have investigated the moderator effects of social support operationalized as shared care on the relationship between depressive symptoms and self-care in patients with HF. Therefore due to gaps in the literature an exploration of the relationship between depressive symptoms, self-care, and shared care was warranted to understand the effects of shared care on the relationship between depressive symptoms and self-care in HF patients.

### **Research Purpose and Hypotheses**

The purpose of this study was to determine if shared care moderated the relationship between depressive symptoms and self-care in community dwelling HF patients.

To address the purpose of the study, the following hypotheses were addressed:

1. Depressive symptoms will have an inverse relationship with self-care in community dwelling patients with HF.
2. Shared care will have a positive relationship with self-care in community dwelling patients with HF.

3. Shared care will have a moderating effect on the relationship between depressive symptoms and self-care in community dwelling patients with HF.

### **Assumptions of the Study**

The assumptions of the study are based upon Riegel's et al. (2012) theory and Schulman-Green's et al. (2012) conceptual model, and review of the literature.

1. Self-care is a complex naturalistic decision making process.
2. The ability to engage in sufficient self-care is influenced by psychosocial factors.
3. Patients with HF activate psychological and social resources in order to engage in self-care.
4. Nurses play an important role in promoting social support (shared care) and self-care between HF patients and family caregivers.

### **Chapter Two Summary**

In this chapter, an overview of the Stress-Buffering Model and the Theory of Self-Care and Chronic Illness and the Processes of Self-Management in Chronic Illness were discussed, along with a discussion of post-positivism as the underlying philosophical underpinning of the study. The conceptual model developed for this study using Cohen's et al. (2000) Stress-Buffering Model was presented describing the relationships among the variables of depressive symptoms, self-care, and shared care. A critical review of the literature was undertaken describing the disparities and vulnerabilities of HF patients. Findings from this review provided important insight regarding the complexities and

challenges that patients face and the integral role social support plays in assisting with self-care behaviors. Gaps in the literature have been identified pertaining to the relationship between depressive symptoms, self-care, and social support, warranting further investigation. A better understanding of the relationship among these variables can contribute to the development of interventions to promote social support operationalized as shared care and improved self-care and patient outcomes.

## CHAPTER THREE

### **Research Design and Methods**

This chapter describes the research design and methods for this study. The purpose of the study was to determine if shared care moderated the relationship between depressive symptoms and self-care in community dwelling HF patients. A comprehensive description of the design, methods, procedure, and rationale will be presented. Threats to internal and external validity will be described and strategies used to control for these threats will be discussed.

### **Research Design**

#### **Description of Design**

A cross-sectional, descriptive design was used for the study. This descriptive design was appropriate for the exploration of the relationships between depressive symptoms, self-care, and shared care in patients with HF. The quantitative research design was enhanced with the inclusion of a qualitative component. The quantitative design was the primary research method. The study was conducted in a HF outpatient clinic.

The study variables were depressive symptoms, self-care, and shared care and were measured using valid and reliable self-report instruments. The incidence of depressive symptoms were measured using the Patient Health Questionnaire-8 (PHQ-8), self-care behaviors were measured with the European Heart Failure Self-Care Behavior Scale (EHFScB-9), and patient's perception of shared care was measured using the

Shared Care Instrument-3 (SCI-3). In addition, demographic data was collected from patients to describe sample characteristics.

### **Rationale for Design**

A descriptive design was appropriate to explore and understand relationships between variables. Descriptive research is considered a non-experimental design where the phenomena are studied without the manipulation of variables by the researcher. While non-experimental research designs do not provide the level of evidence an experimental design would, non-experimental research can help us understand relationships among variables, answer research questions, and provide for lower level evidence-based practice (LoBiondo-Wood & Haber, 2010). The inclusion of a qualitative component provided for greater understanding of subjective patient experiences.

There are various strengths in this type of research design. Results of this type of study can provide evidence about relationships between variables that can be tested in intervention studies. Descriptive research designs are both practical and economical. Researcher bias may be minimized with the use of standardized questions for all subjects. And lastly, with a cross-sectional design there is no loss of subjects due to attrition (Houser, 2012).

There also are limitations to this type of research design. Because of the non-experimental design casual claims cannot be made. Many times self-report instruments are used and subjects may misinterpret questions or choose socially acceptable responses leading to under reporting or over reporting of measured responses. And lastly, because

of the cross-sectional methodology, one cannot make conclusions regarding changes and trends over time (Houser, 2012).

## **Sample and Setting**

### **Description of Sample and Setting**

A convenience sample of patients was recruited for the study. Based on a linear regression model and three predictors a sample size of 77 patients allowed for detection of a moderate effect size ( $f^2 = .15$ ) with a significance level of .05 and power of .80. A moderate effect size was chosen based upon a previously conducted meta-analyses which indicated a small to moderate effect size of studies examining depression (Rutledge et al., 2006) and social support (DiMatteo, 2004). The sample was comprised of patients recruited from a HF clinic in Southeastern Wisconsin. The clinic provided multidisciplinary care and management of patients with HF. Patients were invited to participate if they were diagnosed with HF, spoke English, able to read and write, over the age of 21 years, and had no dementia. The clinic staff screened medical records of patients to determine eligibility.

The clinic was established in 2005, and is affiliated with a major healthcare system in Southeastern Wisconsin. The overall goals of the HF clinic are to manage disease symptoms and disease progression, promote HF self-care, and improve patient outcomes, and decrease readmissions and hospitalizations. Approximately 8 to 9 HF patients are seen at the clinic daily, Monday through Friday. Referrals to the clinic are made primarily while patients are hospitalized for HF or other causes. Once discharged from the hospital patients are usually seen at the clinic within three to five days, then

three times a month, and subsequent appointments are scheduled based upon patient status. According to clinic staff approximately 60% of patients seen at the clinic are over the age of 65 years. Although, they do not have exact numbers, staff estimate that the clinic serves a racially and ethnically diverse population of patients; African American, Hispanic, and whites. Based on the number of patients seen each day at the clinic, and taking into account patients who may not be interested in participating, it was anticipated that it would take 4 to 6 months to recruit subjects. Actual recruitment took approximately 4 months.

### **Rationale for Sample and Setting**

The recruitment of HF patients for research studies can be challenging. Studies have shown that HF patients decline to participate because they are not interested, they don't have the time or are too busy, are too sick, or feel overwhelmed (Kossmann et al., 2011; Pressler et al., 2008). Because of these challenges in recruiting patients a convenience sample was determined to be appropriate for this descriptive study.

Rationale for inclusion and exclusion criteria was based on the following. The inclusion of patients 21 years of age or older was used to capture younger HF patients and to allow for recruitment of patients within a reasonable time frame. Heart failure is more common in persons age 65 years or older, but studies have shown that younger HF patients have an increased prevalence of depressive symptoms (Gottlieb et al., 2004). The ability to read, write and speak English was important so that patients could adequately complete study instruments. Patients with a diagnosis of dementia were excluded due to inability to complete study instruments appropriately or provide consent.

There are multiple reasons that the HF clinic in Southeastern Wisconsin was selected for the study. A primary reason for selection was the emphasis on patient self-care, a major variable in this study. Another reason was access to HF patients with diverse racial and ethnic backgrounds, thereby decreasing threats to external validity. Lastly, the volume of patients seen at the clinic allowed for reasonable time frame for data collection.

## **Procedure**

### **Institutional Review Board Approval**

To ensure protection of human subjects approval from the Institutional Review Board (IRB) at Marquette University (Appendix E) was obtained. The director of the Human Research Protection Program of the healthcare organization where subjects were recruited reviewed and accepted Marquette University IRB approval (Appendix F). Marquette University IRB provided oversight of the research study. The study used surveys which involved no more than minimal risk. No patient names, medical record numbers, birthdates, or social security numbers were collected. Completion and return of the survey packet which included a letter describing the research study, indicated that patients had read the information and voluntarily agreed to participate, implying consent (see Consent to Participate in a Research Study, Appendix G). Based on these factors and the Code of Federal Regulations, Title 45, Part 46 (U.S. Department of Health and Human Services, 2010) the study qualified for exempt status-category two. Exempt status – category two was approved by Marquette University IRB.



In compliance with the Health Insurance Portability Accountability Act (HIPAA) initial patient contact regarding potential study participation was made by clinic staff (US Department of Health and Human Services, n.d.). To avoid coercion, potential and actual study participants were assured that their decision to participate or not participate in the study would not affect the care they received at the clinic which was included on the consent form.

Throughout the study, steps were taken to protect the confidentiality of data. No patient names, medical record numbers, birthdates, or social security numbers were collected. All data collected was stored in a password protected computer and in a locked cabinet in the office of the PI. Results of the study will be used for scholarly purposes and only aggregate data will be used in presentations and/or publications.

### **Description of Recruitment and Data Collection**

The following method was used for the recruitment plan. The PI made personal contact with clinic staff and explained the purpose of the study and inclusion and exclusion criteria. Clinic staff identified patients who meet eligibility criteria. The PI developed a check list of inclusion and exclusion criteria that clinic staff used to screen patients. Patients who met eligibility criteria were asked by clinic staff if they were interested in learning more about a research study. If the patient was interested and the PI was on site that day, the patient was approached by the PI who explained the study and invited them to participate. If the patient was interested and the PI was not on site the staff explained the study and invited eligible patients to participate. Patient autonomy

was respected and those who declined to participate were assured that their decision did not in any way affect the care they received at the clinic.

Patients who agreed to participate were given a survey packet. The packet contained a letter describing the research study, Demographic Data Form, Kansas City Cardiomyopathy Questionnaire (KCCQ), PHQ-8, EHFS<sub>c</sub>B-9, SCI-3, and two dollars as a token of appreciation. Those who agreed to participate had the option to complete the survey packet in a private space at the clinic or take it home to complete and return by mail. Survey packets completed at the clinic were placed in an envelope and returned to clinic staff. Patients who chose to complete the survey at home were provided with a postage-paid, addressed envelope. The surveys were addressed to a post-office box secured by the PI.

### **Rationale for Recruitment and Data Collection**

The establishment of a trusting effective relationship between the PI and clinic staff was important in the identification and recruitment of study participants. Data was collected using survey questionnaires and involved no more than minimal risk. No patient identifiers were linked to patient responses.

### **Study Variables and Instruments**

The variables of study included depressive symptoms, HF self-care, shared care, and covariates of age, gender, and HF severity. Information also was collected to describe sample characteristics and demographics. Descriptive data was collected

through the use of a self-report demographic form and the KCCQ which determined HF severity. Study variables were measured using the following instruments.

### **Demographic Information**

Information was collected on the self-report form (see Patient Demographic Survey, Appendix H). General information obtained included age, gender, ethnicity, marital status, caregiver relationship, level of education, perception of adequacy of income, and comorbidities.

### **Heart Failure Severity**

The KCCQ was used to determine HF severity for each patient. The KCCQ is a self-administered disease-specific health status instrument that measures physical limitations, symptoms, social limitations, self-efficacy, and quality of life (Green, Porter, Bresnahan, & Spertus, 2000). The KCCQ has two summary scales, the clinical summary and overall summary scale. The clinical summary scale of the KCCQ is a composite score of the physical function and total symptoms scale. The clinical summary score replicates NYHA classification and is used to measure HF severity. The overall summary scale score is an overall measure of health status; the mean of physical function, total symptoms, social limitations, and quality of life subscales.

### **Depressive Symptoms – Independent Variable**

Depressive symptoms were measured using the PHQ-8. The PHQ-8 was adapted from the Patient Health Questionnaire-9 (PHQ-9). The PHQ-9 was developed using the

nine criteria established for a diagnosis of depressive disorders, as defined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (Kroenke & Spitzer, 2002). In the PHQ-8 the final question assessing thoughts of self-harm or suicidal ideation is excluded. Kroenke & Spitzer (2002) note that the exclusion of this item is appropriate in the assessment of depressive symptoms in medical or non-psychiatric patients, as the thoughts of self-harm are less common in depressed primary care populations than those referred for mental health services. In addition, the authors recommend the use of PHQ-8 for research studies in which one or more of the following circumstances are present: the risk of suicidal ideations is low; depression is a secondary outcome in studies of other medical conditions; or data is collected using a self-administered questionnaire and there is no option of interview or follow-up regarding thoughts of self-harm or suicidal ideation (Kroenke & Spitzer, 2002). For this study there were no patient identifiers, excluding the ability to follow-up.

The PHQ-8 is an eight item self-report instrument that includes both emotional and somatic dimensions of depression. Patients are asked to rate on a scale of 0 to 3, (0) indicating not at all and (3) indicating nearly every day, how often during the previous two weeks they have been bothered by specific depressive symptoms. One example would include little interest or pleasure in doing things (Kroenke & Spitzer, 2002). The scores on the PHQ-8 range from 0 to 24 with higher scores denoting higher measures of depressive symptoms or severity of depressive symptoms. Scores less than 5 indicate no depressive symptoms, scores 5-9 indicate mild depressive symptoms, scores 10-14 indicate moderate depressive symptoms, scores 15-19 indicate moderately severe depressive symptoms, and score greater than 20 indicate severe depressive symptoms.

The PHQ-8 has operating characteristics similar to the PHQ-9 and scores are highly correlated, making it an acceptable alternative to the PHQ-9 (Kroenke & Spitzer, 2002).

**Validity and reliability.** Validity of the PHQ-8 and PHQ-9 was established in two large studies comprised of 6000 patients in primary care clinics and obstetrics-gynecology clinics (Kroenke & Spitzer, 2002; Kroenke, Spitzer, & Williams, 2001; Spitzer, Williams, Kroenke, Hornayk, & McMurray, 2000). Construct validity of the PHQ-9 was determined using the Medical Outcomes Study Short-Form General Health Survey (SF-20), disability days, symptom-related difficulty, and clinic visits. The SF-20 consists of 20 items assessing the constructs of physical functioning, role functioning, social functioning, mental health, current health perceptions, and pain (Rand Health, n.d.). There was found to be a strong association between PHQ-9 scores and SF-20 scores, disability days, and symptom-related difficulty. Criterion validity of the PHQ-9 was determined through the use of interviews by mental health professionals. A PHQ-9 and PHQ-8 score of  $\geq 10$  had a sensitivity of 88% and a specificity of 88% for major depressive symptoms. Reported Cronbach's alpha was 0.89 (Kroenke et al., 2001). In a study comprised of 249 HF patients Pressler et al. (2011) evaluated the validity and reliability of the PHQ-8 as a measure of depressive symptoms. Their findings support the construct validity of the PHQ-8 and scores on the PHQ-8 significantly correlated with scores on the living with Heart Failure Questionnaire. Pressler et al. (2011) reported the Cronbach's alpha was 0.82.

The PHQ-8 is a valid and reliable measure of depressive symptoms in patients with HF. Advantages of the PHQ-8 include: focus on the diagnostic criteria for DSM-IV depressive disorders; appropriate for studies when follow up is not possible; and it can be

self-administered in a short period of time. Although not measured, the authors estimate that patient self-administration would take approximately one minute to complete (Kroenke et al., 2001).

### **Heart Failure Self-Care-Dependent Variable**

Self-care behaviors were measured using the EHFS<sub>c</sub>B-9. The EHFS<sub>c</sub>B-9 was adapted in 2009 from the EHFS<sub>c</sub>B-12 and is a nine item self-report instrument used to measure self-care behaviors in patients with HF (Jaarsma, Arestedt, Martensson, Dracup, & Stromberg, 2009). It has been translated in several languages and has recently been validated in 200 symptomatic HF patients in the United States (Lee et al., 2013). The nine items on the EHFS<sub>c</sub>B-9 assesses self-care behaviors such as monitoring weight, diet and exercise recommendations, and consulting healthcare providers when symptoms worsen. Four of the nine items make up a consulting behavior subscale. The four consulting behavior items address behaviors in response to signs and symptoms of congestion (Lee et al., 2013). In addition to consulting behaviors, diet, exercise, and daily weighing are assessed. Items on the instrument are each rated ranging from, “I completely agree” (1) to, “I don’t agree at all” (5). Scores range from 9 to 45 with lower scores indicating better self-care and higher scores indicating poor self-care (Jaarsma, et al., 2009).

For this study some modifications were made to the instrument. First, for better understanding and data interpretation instrument ratings were reversed, with higher scores indicating higher levels of self-care. Second, to decrease the likelihood of central tendency bias a sixth column was added to the instrument. And third, to provide clarity and improve patient understanding the following adjectives were added to the instrument

“I completely disagree” (1), “I mostly disagree” (2), “I slightly disagree” (3), “I slightly agree” (4), “I mostly agree” (5), and “I completely agree” (6). Permission was obtained from Dr. Jaarsma (personal communication, June 6, 2013) one of the primary authors of the instrument to add adjectives to the response options. With instrument modification scores ranged from 9 to 54 with higher scores indicating better self-care. There is no cut-score for the EHFS<sub>c</sub>B-9. Determination of poor self-care and better self-care were based on data collected.

**Validity and reliability.** Lee and colleagues (2013) evaluated the validity of the EHFS<sub>c</sub>B-9 by comparing it to another well used instrument to measure self-care. The Self-Care Heart Failure Index (SCHFI) is a self-report instrument used to measure the concepts of self-care maintenance, self-care management, and self-care confidence. Analysis supported moderate to strong correlations between the EHFS<sub>c</sub>B-9 and self-care maintenance ( $r = -0.594$ ) and management ( $r = -0.424$ ) scores of the SCHFI. Item-total correlation of the EHFS<sub>c</sub>B-9, specifically, taking medications as prescribed ( $r = 0.246$ ) was low and was not a good discriminator between patients with better self-care and those with poor self-care. Lee and colleagues (2013) note that it has been found that HF patients may overestimate medication adherence in self-report compared to more direct measures of medication adherence. They determined that removal of the item "taking medications" would not significantly improve internal consistency. The reported Chronbach's alpha was .80.

### **Shared Care – Independent Variable**

Shared care was measured using the 19 item SCI-3. The SCI-3 is an instrument developed to measure the construct of shared care (Sebern, 2008). There are two versions of the SCI-3; patient version and caregiver version. The patient version of the SCI-3 was used for this study. The three shared care scales are; communication (5 items), decision making (6 items), and reciprocity (8 items). Communication items of the SCI-3 are negatively worded and reverse coded. An example of a communication questions is, “There is no one to talk with about how I am feeling.” An example of decision making is “When there is something wrong with me, I do what I can to relieve symptoms.” And, an example of a reciprocity item is “We have a partnership.” On the patient version of the SCI-3 patients are asked to rate their agreement with items ranging from completely disagree (1) to completely agree (6). There is not a total shared care score. Each subscale is scored individually with higher scores indicating better communication, decision making, and reciprocity. The SCI-3 takes approximately 5 minutes to complete and is written at a seventh grade reading level.

**Validity and reliability.** Validity of the SCI-3 was established in a study of 223 patients and 220 family caregivers (Sebern, 2008). Construct validity was supported by correlations in the hypothesized direction between the components of shared care and relationship quality, strain, and depressive symptoms. Data supported the three factor structure for the SCI-3 scale. The SCI-3 has adequate internal consistency for patient subscales of communication, decision-making, and reciprocity, with a reported



Cronbach's alpha of .75, .74, and .76, respectively. The SCI-3 a valid and reliable instrument was used to measure patient shared care in the study.

### **Qualitative Questions**

To enrich quantitative data and gain insight regarding patient's subjective perceptions three qualitative questions were used. The question, "How does your mood affect your ability to take care of yourself" was added at the end of the PHQ-8 instrument. The question, "How does your spouse or close caregiver help you manage your heart failure" was added at the end of the SCI-3. And, the question "What do you find most difficult about your heart failure self-care" was added at the end of the EHFSb-9.

### **Data Analysis**

Prior to analysis, data were screened for errors, missing data, and outliers. Mean values were imputed for missing data points for survey instruments with 20% or less missing data. Survey instruments in which means were imputed for missing data included four data points on the PHQ-8, four data points on the EHFSb-9, one data point on the SCI-3 decision making scale, and two data points on the SCI-3 reciprocity scale. Survey instruments with 20% or more missing data were not used in the analysis. Surveys excluded from analysis due to missing data included two PHQ-8 surveys, five KCCQ surveys, three SCI-3 communication scales, one SCI-3 decision making scale, and five SCI-3 reciprocity scales. In the screening process two extreme outliers were identified. Two participants, one on the EHFSb-9 and both on the SCI-3 instruments

had selected “I completely disagree” for all items, indicating they may not have read the questions on the instruments. Therefore, the data from these instruments were not used in the analysis. Other outliers were identified and examined; those determined to be genuine and within the range of possibilities were kept in the analysis. Examination of data and Cook’s Distance revealed no leverage points or influential observations.

### **Quantitative Analysis**

Prior to testing the research hypotheses correlation analysis using SPSS 22 was conducted to explore associations between variables of depressive symptoms, age, gender, HF severity, HF self-care, share care communication, decision making, and reciprocity. Regression analysis was employed to examine association of covariates of age, gender, and HF severity on depressive symptoms. Based on data analysis, the planned testing of the moderator effect of shared care on the relationship between depressive symptoms and self-care was not warranted.

Regression also was used in post-hoc analysis of the relationship between shared care and depressive symptoms. Results of evaluation of statistical assumptions led to transformation of the variables to reduce skewness and improve normality, linearity, and homoscedasticity. The variable depressive symptom was moderately positively skewed and a square root transformation was used. The variable HF self-care was negatively skewed, therefore, it was transformed (reflect and square root) to represent a more normal distribution.

## **Qualitative Analysis**

Three qualitative questions were analyzed. Content analysis of the qualitative responses was conducted by the PI and two other persons, a PhD candidate and a PhD nurse researcher experienced in qualitative analysis. Through an intensive process of coding, recoding and discussion, emerging themes and subthemes were identified for each qualitative question.

## **Internal and External Validity**

### **Threats to Internal Validity**

Internal validity refers to the extent in which study findings are the result of study procedure or intervention, and not that of extraneous factors. In addressing threats to internal validity the intent is to minimize extraneous factors that may hinder interpretation of study results (Groves, Burns, & Gray, 2013). Threats to interval validity include history, maturation, mortality, testing, instrumentation, and selection bias. The potential threats to internal validity in the study are discussed below.

History refers to factors or events that take place during the time of the study that may influence patient responses (Tappen, 2011). Although one cannot fully anticipate future events that may influence patient responses, the threat of history to validity is low. Due to the cross-sectional design of the study the influence of current events would occur to everyone who participated. During the time of the study there were no events identified that may have influenced study findings.

Maturation and mortality are factors that may threaten the validity of a study. Maturation is the developmental, biological, or psychological processes or changes that occur over time in individuals that could influence study results (LoBiondo-Wood & Haber, 2010). Mortality refers to the loss of study subject from one point of time to another. Because of the cross-sectional design of the study, threats of maturation and mortality were not applicable.

Testing refers to the use of the same pretest and post-test in a study. In general participants score higher on the post-test, because they are taking it for the second time. The increase in scores is usually unrelated to study interventions. (LoBiondo-Wood & Haber, 2010). Since data was only collected at one time the threat of testing was not applicable.

Instrumentation refers to the impact of outcomes directly related to instruments used in the study, regardless of the intervention (LoBiondo-Wood & Haber, 2010). Examples of instrument effect may be seen with the use of Likert-type scale and self-report instruments. A Likert-type scale instrument usually asks the participant to rate the strength of their beliefs or attitudes toward various statements. An example of rating options may range from “strongly agree” to “strongly disagree” (Thorndike & Thorndike-Christ, 2010). A participant’s response to this type of scale may not always be consistent with actual behavior. A problem that can occur is that participants may select middle-range or neutral responses, because they are unsure or want to avoid extreme responses. This is known as central tendency bias (Dawis, 2000). One way to force participants to select a response is to use even number response Likert-type scales, thereby eliminating the middle-range neutral option (Thorndike & Thorndike-Christ, 2010). Two of the

instruments used in the study were Likert-type instruments; the EHFScB-9 and the SCI-3. Of these two instruments the EHFScB-9 is an odd numbered Likert-type scale and could be subject to central tendency bias. To avoid central tendency bias a sixth column was added to the instrument.

Another instrument effect that may occur is related to the use of self-report instruments. When completing self-report instruments respondents may choose to answer questions in a way that would be seen as favorable by others, potentially influencing study results. This is known as social desirability response (SDR) bias (van de Mortel, 2008). In a review of the literature van de Mortel (2008) identified strategies used to address SDR which include discarding the data of those with high SDR; identifying the impact of SDR; correcting data of those with high SDR scores; and using statistical analysis to control for SDR. All of the instruments in this study were self-report. Outliers were identified and examined; those determined to be genuine and within the range of possibilities were kept in the analysis. Examination of data and Cook's Distance revealed no leverage points or influential observations.

The last potential threat to internal validity was selection bias. Selection bias refers to threats or problems that are the result of how subjects are chosen for the study (LoBiondo-Wood & Haber, 2010). Although selection bias is a greater threat in experimental studies, the voluntary nature of subject recruitment is biased in that there may be differences between those who choose to participate and those who do not. To address the overall selection process, all patients who met eligibility criteria during recruitment were invited to participate in the study.

## **Threats to External Validity**

External validity refers to the ability to generalize study findings across populations (Groves et al., 2013). Threats to external validity include selection effects, reactive effects, and measurement effects.

Selection effects refer to the ability to generalize study findings to other populations based upon the how the sample was selected (LoBiondo-Wood & Haber, 2010). The use of a convenience sample posed a threat to the study. To address this threat demographic data was collected to understand sample characteristics to allow for generalization to similar populations.

The next threat to external validity was reactive effect. A reactive effect refers to changes in behaviors or outcomes that are a result of how a subject responds to being studied, independent of study procedures or interventions. This is also known as the Hawthorne effect (LoBiondo-Wood & Haber, 2010). To minimize this threat a statement was included with the instrument instructions (PHQ-8, EHFSB-9, and SCI-3) that the PI was interested in their real life experiences with HF.

A final threat to external validity can be measurement effect. Measurement effect refers to studies that use pretests and post-tests. The pretest may have an effect on post-test results, impacting ability to generalize findings to other circumstances or conditions (LoBiondo-Wood & Haber, 2010). Pretests and post-tests were not used in the study; therefore measurement effects were not applicable.

## **Limitations**

Although measures had been put in place to promote methodological rigor and internal and external validity, limitations of the study remained. The sampling procedure and setting used for recruitment may contribute to study limitations. For this study the use of a convenience sample and voluntary participation of subjects may limit generalization of findings. In addition, the experiences of patients recruited from a clinic that specializes in HF may not be generalizable to other general medical clinic populations. Lastly, the use of self-report instruments may pose limitations for the study. The self-reporting of depressive symptoms, self-care, and shared care may not be a true reflection of actual everyday life.

## **Chapter Three Summary**

This chapter provided a description of the research design and methods, sample and setting, study variables and instruments, procedures for data collection and data analysis, threats and limitations of the study. A cross-sectional, descriptive design was used to describe the relationship between depressive symptoms, self-care, and shared care in study participants. A convenience sample of HF patients was recruited from a HF clinic in Southeastern Wisconsin. The variables of depressive symptoms, self-care, and shared care were measured using valid and reliable instruments; PHQ-8, EHFScB-9, and SCI-3, respectively. Descriptive analysis was used to describe sample characteristics and a linear regression model was used to control for the covariates of age, gender, and severity of HF. Correlation and linear regression were used to answer the study hypotheses and conduct post hoc analysis. Lastly, the chapter concluded with a

discussion of threats to internal and external validity, study limitations, and strategies used to control potential threats.



## CHAPTER FOUR

### **Results**

The purpose of this study was to determine if shared care moderated the relationship between depressive symptoms and self-care in community dwelling HF patients. To address this purpose, a mixed methods design was used consisting of a quantitative survey and qualitative questions. Study findings will be presented in the following sections: (1) sample demographics; (2) scale results; (3) quantitative results; (4) association between shared care and depressive symptoms and; (5) qualitative results.

### **Research Hypotheses**

1. Depressive symptoms will have an inverse relationship with self-care in community dwelling patients with HF.
2. Shared care will have a positive relationship with self-care in community dwelling patients with HF.
3. Shared care will have a moderating effect on the relationship between depressive symptoms and self-care in community dwelling patients with HF.

### **Sample Demographics**

Heart failure patients from a HF clinic in Southeastern Wisconsin were invited to participate in the study. One hundred and twenty five survey packets were distributed with a return rate of 73.6% (91). Of the 91 surveys that were returned, two were excluded because surveys were completed by family after the death of the HF participant.

The final sample included 89 participants. Demographic data used to describe sample characteristics included age, gender, ethnicity, level of education, perception of adequacy of income, marital status, caregiver relationship, and co-morbidities (see Table 5). Study participants were mostly white (73%) followed by Black/African American (22.5%), and Hispanic/Latino (4.5%). Women represented 38.2% of the participants. Participants ranged in age from 39 to 97 years ( $M = 70.15$ ;  $SD = 13.19$ ). Participants age 65 years or greater comprised 65.2% of the sample.

Half (50.6%) of the participants either attended college or had a college degree. Less than half (48.6%) of the participants in the study reported they were comfortable with their income, whereas others reported having just enough to make ends meet (30.3%) or not enough to make ends meet (20.2%). Thirty percent of Black/African American, 25% Hispanic/Latino, and 17% white study participants reported not having enough to make ends meet. Sixty five percent of participants were either married or in a committed relationship. The majority of participant (95.5%) had someone who helped them with their HF, either, spouse (43.8%), partner (3.4%), friend (13.5%), sibling (5.3), or others (29.2%). Multiple co-morbidities were seen in study participants, with hypertension (70.8%) most prevalent followed by arthritis (52.8%) and diabetes (51.7%). Please refer to Table 5 for complete list of co-morbidities.

Table 5

*Demographics of Study Participants*

<u>Demographics</u>	<u>N</u>	<u>(%)</u>	<u>M</u>	<u>(SD)</u>	<u>Range<sup>a</sup></u>
Age	88	(98.9)	70.15	(13.19)	39-97
Heart failure severity					
KCCQ clinical summary score	84	(94.4)	60.23	(24.28)	9.38-100
Gender					
Male	54	(60.7)			
Female	34	(38.2)			
Ethnicity					
Black/African American	20	(22.5)			
Hispanic/Latino	4	(4.5)			
White	65	(73)			
Education					
Less than high school	19	(21.3)			
High school graduate/GED	25	(28.1)			
Some college/college graduate	45	(50.6)			
Income					
Comfortable with income	43	(48.3)			
Just enough to make ends meet	27	(30.3)			
Not enough to make ends meet	18	(20.2)			
Living arrangements					
Married	37	(41.6)			
Widowed	19	(21.3)			
Not married: not in a relationship	10	(11.2)			
Not married: in a relationship, not living together	11	(12.4)			
Not married: in a relationship, living together	2	(2.2)			
Divorced/separated	9	(10.1)			
Relationship/person who help them with their HF					
Spouse	39	(43.8)			
Other	26	(29.2)			
Friend	12	(13.5)			
Sibling	5	(5.6)			
Partner	3	(3.4)			
Diseases/co-morbidities					
Heart disease	74	(83.1)			
Hypertension	63	(70.8)			
Arthritis	47	(52.8)			
Diabetes	46	(51.7)			
Kidney disease	17	(19.1)			
Other	17	(19.1)			
Cancer	16	(18.0)			
Stroke	8	(9.0)			
None	3	(3.4)			

Note. <sup>a</sup> Scale range of sample

## Scale Results

Variables explored in this study included depressive symptoms, self-care, and social support. The PHQ-8, EHFS<sub>c</sub>B-9, and SCI-3 were used to measure study variables. The reliability of these scales was adequate (see Table 6). The PHQ-8 was used to measure both emotional and somatic dimensions of depressive symptoms. In the current study, the PHQ-8 Cronbach's alpha coefficient was .86, exceeding desirable levels (Polit, 2010). The mean of depressive symptoms scores for the group was  $6.83 \pm 5.84$  (range 0-22). Higher scores denote higher measures of depressive symptoms. Depressive symptoms reported by participants ranged from none/minimal to mild (71.9%) and moderate to severe (25.1%).

Heart failure self-care was measured using the EHFS<sub>c</sub>B-9. This scale is a nine item instrument; due to a transcription error only 8 EHFS<sub>c</sub>B-9 items were included in the survey. Scale items included self-care behaviors of monitoring weight and exercise recommendations, and consulting healthcare providers when symptoms worsen; diet behavior was the omitted item. The EHFS<sub>c</sub>B-9 Cronbach's alpha coefficient in the current study was .79. The mean of self-care behavior scores for the group was  $36.23 \pm 8.64$  (range 12-48). Higher scores indicate better HF self-care.

Social support was measured using the patient version of the SCI-3. Shared care communication, decision making, and reciprocity were measured. The Cronbach's alpha coefficients for each subscale were .76 (communication), .84 (decision making), and .86 (reciprocity). These subscale reliability coefficients approached or exceeded desirable levels (Polit, 2010). Mean scale scores ranging from 1 to 6 were calculated for each shared care subscale. Shared care communication mean was  $3.94 \pm 1.38$ , decision making

mean  $5.10 \pm 0.998$ , and reciprocity mean  $4.84 \pm 1.13$ . Higher scores denote better shared care.

Table 6

*Scale Results*

Scale	N	Cronbach's Alpha	Median	Mean (SD)	Range
PHQ-8	87	.86	5	$6.83^a \pm 5.84$	0-22
EHFScB (8-item)	88	.79	38	$36.23^a \pm 8.64$	12-48
SCI Communication	84	.76	4.0	$3.94^b \pm 1.38$	1-6
SCI Decision Making	86	.84	5.0	$5.10^b \pm .998$	1-6
SCI Reciprocity	82	.86	5.0	$4.84^b \pm 1.13$	1-6

*Note.* <sup>a</sup> Mean sum of score; <sup>b</sup> mean scale score

## Quantitative Results

Associations between variables were explored; research hypotheses and an alternative hypothesis were tested. The results of this quantitative analysis will be discussed.

### Association between Variables

Associations between depressive symptoms, age, gender, HF severity, self-care, shared care communication, decision making, and reciprocity were examined.

Correlation analysis identified a significant negative correlation between depressive

symptoms and HF severity ( $r = -.53, n = 82, p < .0005$ ); worse HF severity indicated more depressive symptoms. A significant negative correlations was also found between shared care communication ( $r = -.31, n = 82, p < .004$ ), and depressive symptoms and shared care reciprocity ( $r = -.25, n = 81, p < .02$ ) and depressive symptoms; patients who perceived better shared care communication and reciprocity reported less depressive symptoms. A significant positive correlation was found between self-care and age ( $r = .26, n = 87, p < .02$ ); older patients reported better self-care.

No significant correlations were identified between depressive symptoms and self-care and depressive symptoms and shared care decision making. Shared care was not correlated with self-care. Point-Biserial correlations were conducted between gender and age, HF severity, self-care, shared care communication, decision making, and reciprocity. No significant correlations were identified between gender and variables tested.

In an examination of relationships among shared care processes, correlation analysis identified a positive association between share care communication and reciprocity ( $r = .28, n = 82, p < .01$ ); and shared care reciprocity and decision making ( $r = .51, n = 82, p < .0005$ ). See Table 7 for all correlation findings except gender.

Table 7

*Pearson's Product-Moment Correlations*

Variable	1	2	3	4	5	6	7
1. Depressive symptoms	-	-.20	-.53**	-.04	-.31**	-.15	-.25*
2. Age	-	-	.10	.26*	.07	.08	.13
3. HF severity	-	-	-	.15	.06	.08	.19
4. HF self-care	-	-	-	-	-.01	.10	.15
5. Shared care communication	-	-	-	-	-	-.02	.28*
6. Shared care decision making	-	-	-	-	-	-	.51**
7. Shared care reciprocity	-	-	-	-	-	-	-

\* $p < .05$  (2-tailed); \*\* $p < .01$  (2-tailed)

**Covariates of Age, Gender, and HF Severity**

Analysis was conducted to determine the effect of age, gender, and HF severity on depressive symptoms. Controlling for age and gender, only HF severity was related to depressive symptoms (Beta =  $-.52$ ,  $P = .0005$ ), ( $R^2 = .31$ ) (see Table 8).

Table 8

*Regression Model for Depressive Symptoms*

Independent Variables	Beta <sup>a</sup>	Partial Correlations	Sig. <sup>b</sup>	F	P	R <sup>2</sup>
Age	-.20			3.64	.06	.04
Gender	-.07			0.458	.50	.01
Heart failure severity	-.53			31.67	.0005	.28
Combined variables				11.53	.0005	.31
Age	-.15	-.18	.13			
Gender	.01	.02	.89			
Heart failure severity	-.52	-.52	.0005			

*Note.* <sup>a</sup> Standardized coefficients, <sup>b</sup> unique contribution of each independent variable to the equation

### Analysis of Hypotheses

No correlations were found between depressive symptoms and self-care and shared care and self-care; regression analysis was not conducted. Additionally, based on this analysis the planned testing of the moderator effect of shared care on the relationship between depressive symptoms and self-care was not warranted.

### Association between Shared Care and Depressive Symptoms

In a post hoc analysis an alternative hypothesis from the conceptual model was proposed and tested. It was hypothesized that shared care would have a significant relationship with depressive symptoms in community dwelling HF patients. Due to hypothesis generation in the exploration of a relationship between shared care and



depressive symptoms significance level of less than .10 was set. Three linear regression models were generated to determine the relationship between the hypothesized predictors shared care communication, decision making, and reciprocity and depressive symptoms while controlling for HF severity.

A significant relationship between shared care communication and depressive symptoms and shared care reciprocity and depressive symptoms was identified (see Table 9). Regression of shared care communication on depressive symptoms while controlling for HF severity explained 36% ( $F [2, 77] = 21.88, P = .0005$ ) of the variance in depressive symptoms scores. The contribution of shared care communication to depressive symptoms score was partial correlation ( $r_{ab.c} = -.33$ ).

Regression of shared care reciprocity on depressive symptoms while controlling for HF severity explained 31% ( $F [2, 77] = 17.11, P = .0005$ ) of the variance in depressive symptoms scores. The contribution of shared care reciprocity to depressive symptoms score was partial correlation ( $r_{ab.c} = -.20$ ). No significant relationship was identified between shared care decision making and depressive symptoms.

Table 9

*Alternative Hypothesis: Regression Model for Depressive Symptoms*

Independent Variables	Beta <sup>a</sup>	Partial Correlations	Sig. <sup>b</sup>	F	P	R <sup>2</sup>
Shared care communication	-.28	-.33	.003	21.88	.0005	.36
Heart failure severity	-.52	-.54	.0005			
Shared care decision making	-.06	-.07	.529	15.92	.0005	.29
Heart failure severity	-.52	-.52	.0005			
Shared care reciprocity	-.18	-.20	.076	17.11	.0005	.31
Heart failure severity	-.50	-.51	.0005			

Note. <sup>a</sup> Standardized coefficients, <sup>b</sup> unique contribution of each independent variable to the equation

### Qualitative Results

Three qualitative questions were analyzed to gain insight into the study concepts of depressive symptoms, shared care, and self-care. Seventy one (80.7%) participants responded to at least one of the qualitative questions, with 50 (56.8%) participants providing responses to all three questions. The themes and subthemes, of each question will be discussed. See Table 10I (Appendix I) for examples of responses supporting themes and subthemes.

## Depressive Symptoms and Self-Care

Three themes emerged from narrative analysis of responses to how mood affected their ability to take care of themselves. Themes identified as to how mood affected their self-care were (1) everyday activities; (2) strategies to manage mood; and (3) not aware/no effect. Subthemes of *keeping a positive attitude and activating social resources* were identified within the theme of strategies to manage mood. In this study participants most commonly described how their mood affected their ability to engage in *everyday activities* such as “I have to push myself to get out of bed,” “some days I just let things go undone” and “sometimes it will keep me from doing what I need to.” They described their mood as feeling down, feeling tired, moving slowly, or having little energy or interest.

While a participant’s mood affected their ability to engage in everyday activities, participants also identified strategies used in response to adverse moods such as *keeping a positive attitude and activating social resources*. In the theme of *keeping a positive attitude* participants described strategies that included the use of prayer, having faith in God, staying positive, and keeping a positive attitude.

Another strategy used by participants was that of *activating social resources*. Participants engaged in seeking support from others mainly family and friends, but also healthcare providers in caring for themselves. The activation of social resources was described as “What I can’t do, I just ask for help” and “If I am struggling with something, I ask someone to assist me.” Lastly, 33 participants reported that their mood did not affect their ability to care for themselves; *not aware/no effect* such as “not at all, no problems.”

## Heart Failure Self-Care Difficulties

Analysis of narrative responses related to HF and self-care difficulties identified two themes. The most difficult aspects of self-care were (1) functional status changes and (2) lifestyle changes. The theme of *functional status changes* was the most common in response to this question. Participants identified self-care difficulties with everyday activities and personal care because of functional changes and limitations associated with HF. *Functional status changes* that contributed to self-care difficulties were described as “lack of stamina,” “trying to exercise,” and “the ability to shower walk and breathe during activity.” These *functional status changes* made it difficult to carryout and manage personal care, and everyday life.

The second theme associated with self-care difficulties was *lifestyle changes*. Participants identified difficulties with making lifestyle changes to engage in self-care behaviors of maintenance, monitoring, and management. Participant examples include “having to take medication,” “monitoring of sodium is annoying,” “remembering to weigh daily,” and “recognizing I need to contact nurse or doctor when even slight problems occur.”

## Shared Care and Self-Care

Analysis of narrative responses related to caregiver help and HF self-care identified the theme of *informal support*. *Informal support* was defined as supportive relationships between participants and family or friends in the management of their self-care and HF. Subthemes of *communication*, *decision making*, and *reciprocity* were identified within the theme of *informal support*. The definitions of shared care

communication, decision making, and reciprocity were used to organize subthemes of *informal support*.

Shared care communication takes place between patient and caregiver and involves communication of symptoms, feelings, advice, and information which shape the meaning of the situation for the dyad. The subtheme of *communication* in this study was characterized by talking about HF with their caregiver, caregiver making suggestions, offering encouragement, and reminders related to self-care. The participant and caregiver talked about HF self-care, with the caregiver offering encouragement to “eat right and exercise,” providing reminders to “take medications,” and “keep doctor appointments.”

Shared care decision making is the patient’s ability to seek information and make decisions about their care (Sebern, 2008). The *decision making* subtheme was described as “my partner is in the medical field, so he is very helpful and knowledgeable” and “by showing interest and concern, it make me think about my condition and helps me do what’s right for myself.”

The final subtheme, shared care reciprocity was characterized by a patient and a caregiver engaging in mutual behaviors such as exchanging empathy, listening, and partnership in managing the illness (Sebern, 2008; Sebern & Riegel, 2009). The *reciprocity subtheme* in this study was described by participants as “by always being there for me,” “keeps me on track,” and “he is very supportive mentally and physically.”

Lastly, five participants responded that they did not seek or have support from others and managed their HF on their own. These responses were characterized by participants as “doing it alone”, “it is all me”, and “I live alone.” Analysis of the five individuals did not distinguish any patterns among characteristics of age, gender, income,

living situation, relationships, HF severity, depressive symptoms, self-care, and shared care. This group included three women (3-white) and two men (1-white and 1-Black/African American).

### Chapter Four Summary

The original hypotheses were not supported. No correlations were found between depressive symptoms and self-care, and shared care and self-care. Therefore, moderation analysis was not warranted. However, post hoc analysis did support an alternative hypothesis derived from the conceptual model examining the effects of shared care on depressive symptoms of HF participants. A significant relationship between shared care communication and reciprocity and depressive symptoms was identified. Regression analysis revealed shared care communication and heart failure severity explained 36% ( $F [2, 77] = 21.88, P = .0005$ ) of the variance in depressive symptoms scores. The contribution of shared care communication to depressive symptoms score was partial correlation ( $r_{ab.c} = -.33$ ). Analysis also revealed shared care reciprocity and HF severity explained 31% ( $F [2, 77] = 17.11, P = .0005$ ) of the variance in depressive symptoms scores. The contribution of shared care reciprocity to depressive symptoms score was partial correlation ( $r_{ab.c} = -.20$ ). Findings indicate that better communication and reciprocity was associated with less depressive symptoms.

Examination of the shared care processes of communication, decision making, and reciprocity identified an association between the variables. Correlation analysis identified a positive significant association between share care communication and shared

care reciprocity, and shared care reciprocity and decision making. No correlation was identified between shared care communication and decision making.

Although, the original hypotheses were not supported, the alternative hypothesis provided support for relationship between shared care and depressive symptoms identified in the conceptual model. Qualitative responses corroborated the impact of depressive symptoms and HF related functional status changes on every day activities, self-care behaviors, and the important role caregivers play in providing informal support in HF self-care. Social support as measured by shared care communication and reciprocity may decrease depressive symptoms.

## CHAPTER FIVE

### **Discussion**

This study examined the relationship between depressive symptoms and self-care and potential moderating effects of social support. Social support was operationalized as shared care. No correlations were found between depressive symptoms and self-care. Therefore, moderation models were not run. In a post hoc analysis an alternative hypothesis from the conceptual model was proposed and tested. It was hypothesized that shared care would have a significant relationship with depressive symptoms in community dwelling HF patients. Due to the hypothesis generating nature of post hoc analysis the significance level of less than .10 was set. Post hoc analysis supported significant associations between shared care communication and depressive symptoms and shared care reciprocity and depressive symptoms. This chapter presents a discussion of study findings which includes interpretation of finding and comparison to previous research, organized by research hypotheses. Next, theoretical implications, clinical significance of findings, implications for nursing practice, education, research, and vulnerable populations are presented. Lastly, strength and limitations, and suggestions for future research also are described.

### **Interpretation of Findings**

#### **Quantitative Data Results**

**Depressive symptoms and self-care.** Findings from the current study did not support a relationship between depressive symptom and self-care. Previous studies have



reported an association between depressive symptoms and self-care, but findings have been inconsistent. In some studies depressive symptoms were found to negatively affect overall self-care (Hjelm, Brostrom, Riegel, Arestedt, & Stromberg, 2015; Holzapfel et al., 2009; Kessing, Pelle, Kupper, Szabo, & Denollet, 2014), and aspects of self-care maintenance, monitoring, and management (Bauer et al., 2012; Cameron et al., 2009; Dickson et al., 2013; Johansson et al., 2011; van der Wal et al., 2007). Whereas, in other studies depressive symptoms were not related to self-care (Graven et al., 2015; Heo et al., 2008; Schweitzer, Head, & Dwyer, 2007). Heo et al. (2008) and Schweitzer et al. (2007) examined factors related to self-care or treatment adherence behaviors in patients with HF. Similar to current study findings the majority of participants in these two studies reported minimal to mild depressive symptoms. In the study conducted by Heo et al. (2008) mean depressive symptom scores for participants indicated mild depressive symptoms. Schweitzer and colleagues (2007) found that only 12.8% of participants reported moderate to severe depressive symptoms. In the current study only 25.1% of participants reported moderate to severe depressive symptoms.

Although, only a small percentage of participants reported moderate to severe depressive symptoms, HF severity was significantly associated with depressive symptoms. Current study participants with greater HF severity reported more depressive symptoms. These results are consistent with prior research identifying an association between HF severity and depressive symptoms (Graven et al., 2015; Paukert et al., 2009; Rohyans & Pressler, 2009; Rutledge et al., 2006).

The low prevalence of moderate to severe depressive symptoms in the current study may partially explain the lack of relationship between depressive symptoms and

self-care. The representation of participants experiencing depressive symptoms may have been inadequate to support the hypothesis, resulting in a possible Type II error.

The majority of participants in this study reported high levels of self-care; with a mean score of 36.23 out of 48. The high levels of reported self-care may have contributed to a lack of variance in the relationship between depressive symptoms and self-care. One possible explanation for high levels of self-care may be related to age. The mean age of participants was 70.2 years with 65.2% of participants 65 years of age or older. In the current study age was found to be significantly associated with self-care. Older participants reported better self-care. These findings are similar to other studies identifying a link between increased age and better self-care (Cameron et al., 2009; Chriss, Sheposh, Carlson, & Riegel 2004; Heo et al., 2008; Holzapfel et al., 2009; Schweitzer et al., 2007). Research has shown that experience and knowledge contribute to expertise in self-care (Riegel et al., 2007). The current study findings may be attributed to the possibility that older patients may have more experience with their HF and self-care behaviors.

Another possible explanation for participant high self-care ratings was that during each clinic appointment participant understanding of self-care was evaluated, followed by teaching, and reinforcement of self-care behaviors. This formal teaching and reinforcement of self-care behaviors may have contributed to higher levels of actual or perceived self-care.

High self-care ratings by participants also may have been due to the use of a self-report instrument to measure self-care and the potential for social desirability response bias. Self-reporting may differ from actual behavior with participants choosing to answer

as they know they should instead of what they actually do (van de Mortel, 2008).

Although measures were put in place to try and control and correct for this bias, the potential threat to internal validity exists.

**Shared care and self-care.** Findings from this study did not support a relationship between shared care and self-care. In contrast, prior research has demonstrated an association between shared care and self-care (Sebern & Riegel, 2009). Sebern & Riegel (2009) explored supportive relationships (shared care) and self-care in patient and caregiver dyads. Patient shared care decision making was related to self-care maintenance and self-care confidence, with patient shared care communication and reciprocity being related to self-care confidence. Caregiver decision making contributed to patient self-care maintenance; and caregiver decision making and reciprocity contributed to patient self-care confidence. Sebern & Woda (2012) in a pilot study evaluated the feasibility of an intervention to strengthen shared care processes. Findings identified improvement in patient self-care and caregiver relationship quality and health. These studies operationalized social support as shared care; shared care is similar to previous definitions of emotional, informational, and instrumental support.

Previous studies have found a positive association between social support and self-care maintenance (Cene et al., 2013; Dunbar et al., 2013; Gallagher et al., 2011; Salyer et al., 2012; Sayers et al., 2008; Tierney et al., 2011; Wu et al., 2008a), self-care monitoring (Gallagher et al., 2011), and self-care management (Friedman & Quinn, 2008). For example, emotional and instrumental support was significantly related to dietary and medication adherence (Sayers et al., 2008). High levels of social support were significantly associated with self-care behaviors of limiting fluids, taking

medications, monitoring weight, and exercising regularly (Gallagher et al., 2011). While these studies support a relationship between social support and self-care, other findings have not been consistent as to whether or not social support predicts self-care (Cameron et al., 2009; Chriss et al., 2004; Heo et al., 2008).

Other prior research that examined various aspects of structural and functional support did not support a relationship between social support and self-care. Structural support such as social situation/living with support was not associated with self-care (Cameron et al., 2009). Similarly, studies that examined functional support such as emotional, informational, and instrumental support were not associated with self-care in patients with HF (Chriss et al., 2004; Heo et al., 2008).

The lack of significant findings between shared care and self-care may be attributed to the fact that the majority of participants rated their shared care and self-care as good. The majority of participants tended to rate their shared care on the high-end of the scale, indicating better shared care. Most participants (95.5%) in the current study had someone who helped them with their HF such as a spouse, partner, friend, sibling, or others. In comparison to other research, participants in this study reported a high rate of caregiver assistance. Whereas, in Joo et al. (2015) only 33% of HF patients reported receiving assistance from informal caregivers. This wide discrepancy in rate of caregiver assistance may be attributed to different study methods and possible underreporting of HF and caregiver assistance. All participants in the current study had a diagnosis of HF. In Joo et al. (2015) participants self-identified as having HF, self-report could have resulted in underreporting of HF. In the current study each participant was asked about their relationship with the person (caregiver) who helped them with their HF. In contrast

participants in the Joo et al. (2015) study were prompted about caregiver relationships only when they reported a functional disability due to health or memory problems that required the assistance of others. These factors may have contributed to variance in reported caregiver assistance between studies. In the current study, the high levels of caregiver assistance, shared care, and self-care, and a small sample size may have contributed to a lack of power to detect significant associations.

Another explanation for lack of significant findings may be that the study only measured patient perceptions of shared care and couldn't capture mutual influences of caregivers. Shared care is a relationship processes between two people, further studies involving both the patient and caregiver would be recommended.

**Depressive symptoms and shared care.** Findings from the current study supported a significant relationship between shared care communication and depressive symptoms. Likewise, in a prior study Sebern (2008) found an inverse correlation between shared care communication and depressive symptoms. Better shared care communication between a HF patient and caregiver was associated with less depressive symptoms.

Shared care communication takes place between patient and caregiver involving communication of symptoms, feelings, advice, and information which is similar to exchanging emotional and informational support. The significant relationship between shared care communication and depressive symptoms corroborate prior work supporting a relationship between emotional support and depressive symptoms (Heo et al., 2014; Trivedi et al., 2009). For example, Heo and colleagues (2014) examined marital status and emotional support, only emotional support was significantly associated with

depressive symptoms in patients with HF. Whereas, in the study conducted by Trivedi and colleagues (2009) structural, emotional, and instrumental support were found to be associated with depressive symptoms.

Another important process of shared care is reciprocity. In the current study shared care reciprocity was associated with depressive symptoms. Participants who perceived better shared care reciprocity reported less depressive symptoms. Similarly, Sebern (2008) reported an association between shared care reciprocity and depressive symptoms; HF patients who perceived less shared care reciprocity had more depressive symptoms.

Shared care reciprocity is the exchange of empathy, listening, and partnership in management of illness between patient and caregiver, similar to the exchange of emotional support. Current study findings of an association between shared care reciprocity and depressive symptoms support prior research identifying an association between emotional support and depressive symptoms (Heo et al., 2014; Trivedi et al., 2009).

Lastly, no relationship was identified between shared care decision making and depressive symptoms. Shared care decision making measures a person's capacity to make decisions. Participants in the current study were not greatly depressed and reported high levels of shared care decision making. It is unclear why this association was not substantiated in the data. The lack of an association between shared care decision making and depressive symptoms may be reflective of limited sample size or use of convenience sample.

Prior research has demonstrated that structural, emotional, and instrumental support is associated with depressive symptoms (Heo et al., 2014; Trivedi et al., 2009). Current study findings suggest that improving shared care communication and reciprocity may contribute to improvement in depressive symptoms. Further examination of the nature of the relationships among depressive symptoms, shared care, and self-care in HF patients with depressive symptoms is warranted. Specifically, examine the direct effects of shared care and depressive symptoms on self-care; test both mediator and moderator effects of both shared care and depressive symptoms on self-care. Findings can be used to develop interventions to improve depressive symptom in patients with HF.

### **Qualitative Data Results**

The results of the qualitative analysis provided additional insight into the complexity and challenges HF patients experience. Three short open-ended questions were asked to gain perspective about depressive symptoms, social support, and self-care. The results of this qualitative analysis are discussed.

**Depressive symptoms and self-care.** Participants in the study described how their mood affected their ability to take care of themselves. One of themes that emerged from the study was the use of strategies to manage their mood such as keeping a positive attitude and activating social resources. Prior studies report that HF patients may rely on a sense of positivity (Bosworth et al., 2004; Dekker et al., 2009) and spirituality (Dekker et al., 2009; Dickson et al., 2013) to manage depressive symptoms. In the subtheme of keeping a positive attitude participants described strategies such as staying positive, keeping a positive attitude, prayer, and having faith in God.

Another strategy identified by participants was the activation of social resources, asking for help and assistance when needed. These findings corroborate prior qualitative work in which HF patients seek physical and emotional support from family and friends to help manage depressive symptoms. (Dekker, 2014; Schulman-Green et al., 2012). In the last theme in response to how mood affects ability to care for themselves some participants reported not aware/no effect between mood and ability to take care of themselves. It is not clear why some participants were not aware of mood effects. These findings could possibly be linked to pharmacological treatment of depressive symptoms, although, information regarding treatment of depressive symptoms was not collected.

**Heart failure self-care difficulties.** Two themes were identified in response to most difficult aspects of HF self-care they were difficulties with functional status changes and lifestyle changes. Consistent with prior research functional status and symptoms of HF pose challenges for patients in completing everyday tasks (Falk, Wahn, & Lidell, 2007; Jeon, Kraus, Jowsey, & Glasgow, 2010). For example in the study by Falk and colleagues (2007) participants reported that the management of personal cares and everyday activities took longer, and that they needed to make adjustments depending on their strength and energy. Participants in the current study reported that lack of stamina and energy, slowness, and shortness of breath contributed to difficulties in managing personal care and everyday activities such as housework and shopping.

In the second theme difficulties with life-style changes, the ability to make life-style changes and engage in self-care proved to be difficult and challenging for participants. Prior research has identified HF self-care difficulties such as remembering self-care behaviors, understanding importance of self-care behaviors, and associated links



between symptoms and worsening HF (Clark et al., 2014; Riegel et al., 2009b). Study participants identified self-care difficulties such as remembering to take medications, watching their salt intake, and recognizing the need to contact the nurse or doctor when even slight problems occurred.

**Shared care and self-care.** Shared care is important to self-care in patients with HF. Caregivers such as family and friends provide support through shared care communication, decision making, and reciprocity. The theme of informal support emerged from analysis of the narrative data. Within the theme of informal support subthemes of communication, decision making, and reciprocity between patient and caregiver were identified. Evidence of shared care processes described by study participants included talking about their HF (communication), caregiver shows concern which helps them to do what is right (decision making), and being there for them supporting them mentally and physically (reciprocity).

In prior studies family and friends were found to play an important role in helping patients manage their HF self-care (Strachan, Currie, Harkness, Spaling, & Clark, 2014). Strachan and colleagues (2014) in a meta-synthesis of qualitative studies examined contextual factors and processes that influenced patients HF self-care. Finding showed that caregivers were frequently considered as positive influences on self-care. The exchange of social support that patients received occurred in various forms such as emotional support, someone to listen to their concerns, informational support, daily reminders, instrumental support, physical assistance, and everyday needs.

Lastly, five participants reported that they had no support from others. Participants described taking care of themselves, doing it all alone, or living alone.

Further analysis of these five individuals did not identify any patterns related to age, gender, income, living situation, relationships, HF severity, depressive symptoms, self-care, and shared care. This group included three women (3-white) and two men (1-white and 1- Black/African American). No conclusions can be drawn about these results at this time.

The results of these qualitative findings support the difficulties and challenges HF patients experience in everyday life and the contributions and support of family caregivers. Participant's mood influenced their everyday activities requiring the development of strategies such as keeping a positive attitude and activating social resources to manage mood and its effects. Also reported in this study were the self-care difficulties and associated functional status changes and lifestyle changes that take place. While quantitative analysis in this study did not support a relationship between shared care and self-care, qualitative data revealed the importance of informal support and the contributions of caregivers in HF self-care.

### **Theoretical and Practical Implications**

The Stress-Buffering Model in conjunction with aspects of the Theory of Self-Care of Chronic Illness and the Processes of Self-Management of Chronic Illness was used to guide this study. The conceptual model developed for the study provided an over-arching structure to examine the relationships between depressive symptoms, self-care, and shared care in community dwelling HF patients (Cohen et al., 2000; Riegel et al., 2012; Schulman- Green et al., 2012). Cohen's et al. (2000) Stress-Buffering Model was used to organize and test relationships between variables. The study results did not

support the original hypothesized relationships proposed in the model. No relationships were found between depressive symptoms and self-care, and shared care and self-care.

A post-hoc alternative hypothesis derived from the conceptual model was also tested. A significant inverse relationship was found between shared care communication and depressive symptoms and shared care reciprocity and depressive symptoms.

Findings related to shared care communication and reciprocity supports the Stress-Buffering Model. Patient perceived shared care communication and reciprocity can influence or buffer a patient's appraisal of stressful events, leading to decreased perceived stress and emotional response of depressive symptoms. Study findings supported a relationship between shared care communication and depressive symptoms and shared care reciprocity and depressive symptoms. As with any chronic illness an individual's stressors, emotional responses, and available resources varies according to the trajectory of the illness and related concerns. Practical implications would include further testing of concepts and relationships identified in the Stress-Buffering model in a longitudinal study with adequate power. Specifically testing, (a) direct effect of depressive symptoms and shared care on self-care in HF patients with depressive symptoms, (b) moderator effects of both depressive symptoms and shared care on self-care in patients with HF, (c) mediator effects of both depressive symptoms and shared care on self-care in patients with HF.

### **Clinical Significance**

HF patient's perception of communication and reciprocity with their caregiver is important to their psychological health. Evaluation of communication between patients

and their caregiver and the quality of their relationship is important in improving depressive symptoms and promoting psychological health. Support of caregivers and the development of strategies to enhance shared care may lead to improvement in depressive symptoms in patients with HF.

Additionally, study findings indicated that individuals who experienced increased levels of HF severity reported more depressive symptoms. These findings emphasize the potential for psychological distress and the need for screening and management of depressive symptoms in patients with HF.

While patients with HF experience physical and psychological symptoms they also encounter difficulties and challenges incorporating necessary self-care behaviors into their daily lives. Sufficient self-care is difficult and requires the application of knowledge and skills on a daily basis (Riegel et al., 2009b). The qualitative findings of this study described the difficulties participants experienced in incorporating self-care into their everyday lives. Based on qualitative content analysis, patients rely on their caregiver to assist them in managing their HF and to engage in self-care behaviors. Assessment of both patient and caregiver HF self-care knowledge and understanding and providing education in areas of difficulty is important to improving self-care.

Self-care is also a learned process and occurs with personal experience or experience of caring for someone else (Riegel et al., 2012). In the current study older participants reported better self-care. Older patients may have more experience with their HF and self-care behaviors, suggesting that sufficient self-care develops over time as a person gains knowledge and experience (Dickson, Deatrck, & Riegel, 2008). Ongoing

assessment and evaluation of patient and caregiver self-care knowledge and skill is important in promoting sufficient self-care.

### **Implications for Nursing Practice**

This study supports previous findings of an association between social support operationalized as shared care and depressive symptoms. A significant inverse association was supported between shared care communication and depressive symptoms, and reciprocity and depressive symptoms. Practice guidelines direct nurses to screen for the presence of depressive symptoms and refer for further evaluation and treatment. Of equal importance, nurses should assess the quality and exchange of support between patients and their caregiver and identify any difficulties with communication, decision making, or reciprocity. The nurse could work with the patient and caregiver to promote shared care, such as encouraging open communication about symptoms and feeling and encourage a partnership to manage depressive symptoms.

Self-care is important in the maintenance and management of HF (Riegel et al., 2009b). In most instances patients require the assistance of family or friends to manage their HF self-care. Qualitative findings from this study support the literature related to self-care difficulties HF patients' encounter and the types of support they receive from their caregivers. Assessment and educational interventions directed at improving self-care could be based on both patient and caregiver needs to promote optimal outcomes.

### **Implications for Nursing Education**

The results of this study support the literature related to the complexities and challenges patients with chronic illness face. Qualitative findings support the important role caregivers have in HF self-care. These important study findings could be incorporated into nursing program curriculum and course development. Nursing graduates should be prepared to understand associated health problems and self-care challenges encountered by HF patients and their caregiver and use evidence-based practice to guide their care. Evidence supports the importance of assessing both patient and caregiver shared care and relationship quality in promoting mental health.

### **Implications for Nursing Research**

This descriptive study was a step in understanding the relations between depressive symptoms, shared care, and self-care in patients with HF. The results of this study adds to the body of evidence that social support, in particular, shared care communication and reciprocity is associated with depressive symptoms in patients with HF (Sebern, 2008). The influence of shared care communication, decision making, and reciprocity on self-care and well-being of HF patients and their caregiver warrants further attention and exploration. The theoretical framework and model used for this study provided structure and guidance and should be further tested in patient with HF and other chronic illnesses. Most importantly, this framework and model could be used to guide and test interventions and approaches to improve psychological health in patients with chronic illness.

### **Implications for Vulnerable Populations**

All participants in the study were diagnosed with HF. The chronic progressive nature of HF and associated health problem contributed to individual vulnerability. In addition to chronic illness, study participants were older with a mean age of 70 years, and had multiple co-morbidities such as hypertension, arthritis, or diabetes. Over half (71.9%) of the participants reported none/minimal to mild depressive symptoms with 25.1% reporting moderate to severe depressive symptoms.

Race and socioeconomic status also contributes to a person's health and vulnerability. Race and socioeconomic status has been found to be associated with increased incidence of HF, hospitalization, and decreased survival (Hawkins, Jhund, McMurray, & Capewell, 2012; Husaini et al., 2011). African Americans (22%) were well represented in this study, exceeding that of the general population. African Americans have been underrepresented in research studies. A systematic review of cardiovascular clinical trials found that the median rate of enrollment of African Americans was 7% (Zhang, Tsang, Wijesundera, & Ko, 2013). This underrepresentation is in contrast to the high incidence and burden of cardiovascular disease in African Americans. African Americans have the highest risk for developing HF and have a greater risk of death after hospitalization, as compared to whites (Roger et al., 2012). To better understand risk and vulnerability adequate representation of African American populations in research is important.

In this study, approximately 50% of participants reported having just enough or not enough income to make ends meet. African American (30%) participants reported not having sufficient income to "make ends meet." Race and socioeconomic status such

as being African American and having insufficient income can contribute to increased vulnerability in persons with HF.

In practice nurses need to be aware of health disparities encountered by vulnerable patients and treat all individuals with respect regardless of race, age, or economic status. To address the needs of this vulnerable group nurses should assess for depressive symptoms, HF associated symptoms, and co-morbidities. Additionally, patient and caregiver relationship and relationship quality should be assessed to promote exchange of support.

Based on the qualitative analysis HF patients experience difficulties and challenges with self-care and rely on caregivers to assist in managing their HF. Vulnerable patients may have limited access and/or resources to engage in self-care. Nurses in conjunction with patients and caregivers should assess healthcare needs and identify availability of resources. Resources may include the need for self-care education, prescription subsidies, medication management strategies, a scale for symptom monitoring, or transportation for healthcare services. For example, educating patients and caregivers about the importance of daily weight monitoring, how to obtain a scale if needed, and encouraging open communication between the patient and caregiver on how they can work together to monitor and report fluid changes. Engaging patients and their caregiver to partner in HF self-care is one way that nurses can provide care to vulnerable populations.



## Strengths and Limitations

Strengths of this study included the use of valid and reliable tools. The PHQ-8 and SCI-3 have established validity and reliability in the HF population. Another strength of the study was the strategies used to ensure validity of qualitative content analysis. The data was analyzed through an intensive process of coding, recoding, and discussion. Additionally, two other persons experienced in qualitative analysis also analyzed the data.

The representation of African Americans was a study strength. African Americans (22%) were well represented in the current study, exceeding that of the general population. Of the 22% of African American participants in this study 63.2% were men and 36.8% were women. In the United States African Americans represent 13% of the total population (Rastogi, Johnson, Hoeffel, & Drewey, 2011, September).

There were a number of study limitations. First, the cross-sectional design of this study only allowed for collection of data at one point in time, therefore causality cannot be inferred. Second, use of a convenience sample may be a source of potential bias; participants were recruited from a HF specialty clinic. Results may not be generalizable to hospitalized or general-medical clinic patients.

Third, women in this study were underrepresented making up 38.2% of participants. An explanation for underrepresentation in the current study may be attributed to age related factors. Women develop cardiovascular disease at an older age than men, generally 10 or more years older (McSweeney, Pettey, Lefler, & Heo, 2012). While the prevalence rate of HF in men ages 40 to 79 years is nearly twice that of women, the rate of HF in women age 80 years or older (11.5%), exceeds that of men

(8.6%) (Go, 2013). The mean age of women, particularly in this study was 71.76 years, with only 26.6% of women 80 years of age or older. Strategies to recruit older patients may contribute to greater representation of women in studies (Tsang, Wijeyesundra, Zhang, & Ko, 2012).

Fourth, modifications were made to the EHFScB-9 which may have influenced reliability of the instrument. To reduce central tendency bias a sixth column was added. Descriptive adjectives were added to numerical ratings to clarify meaning and improve participant understanding. An unintentional modification due to a transcription error occurred which led to the omission of the diet behavior scale item; this resulted in an eight item instrument instead of nine items. Cronbach's alpha coefficient in the current study was .79, which approached desirable levels (Polit, 2010). Another limitation associated with the EHFScB-9 was lack of recommended cut-scores to determine sufficient self-care. Most participants reported high levels of self-care behaviors which may be a result of self-reporting rather than actual self-care. The omission of the diet behavior item could have also contributed to the high self-care ratings. Most HF patients report difficulties in following a low-sodium diet (Riegel et al., 2009b).

Lastly, the low rate of moderate to severe depressive symptoms in study participants may have been inadequate to support the hypotheses, resulting in a possible Type II error. Further testing with adequate representation of participants with depressive symptoms is warranted.

## Suggestions for Future Research

Study finding point to the need for future research studies. Suggestions for future research include the need for longitudinal studies to establish causality for the variables of depressive symptoms, shared care, and self-care. A better understanding of causality can support the development of interventions to promote patient outcomes.

It is recommended that future studies include a larger sample to ensure adequate power and increase efforts to recruit women. When determining sample size researchers should be cognizant that the average prevalence rate of depressive symptoms in patient with HF is 21% (Rutledge et al., 2006), so a larger sample may be necessary for adequate power. The recruitment of older patients with HF may increase representation of women. Older HF patients are more commonly women (Stein et al., 2012). One strategy to address adequate representation of women 80 years of age or older is recruitment from senior housing, community centers, or home care agencies, which serve elderly populations. Another strategy could be the use of stratified random sampling with subjects grouped according to age, gender, or both.

Because of measurement concerns with the EHFScB-9 it is recommended that future studies use another measure of self-care. The Self-Care of Heart Failure Index (SCHFI) is a valid and reliable measure providing a more expansive examination of self-care concepts. The SCHFI measures self-care maintenance and management behaviors and patient confidence in self-care abilities (Riegel, Lee, Dickson, & Carlson, 2009a). Each scale is scored separately and a score of 70 or greater on a 0 to 100 range is used as the cut-point for evaluating self-care adequacy. This allows for more valid interpretation of self-care behaviors based on research.

Lastly, only the patient version of the SCI-3 was used to measure shared care. To better understand the shared care processes and relationship quality future studies need to measure both patient and caregiver shared care perspectives. A more complete understanding of how shared care processes influence depressive symptoms and self-care can contribute to intervention development and testing. Future research is needed to better understand the relationships between depressive symptoms, shared care, and self-care. Specifically testing, (a) direct effect of depressive symptoms and shared care on self-care in HF patients with depressive symptoms, (b) moderator effects of both depressive symptoms and shared care on self-care in patients with HF, (c) mediator effects of both depressive symptoms and shared care on self-care in patients with HF. Results of these future studies can be used in the development and testing of interventions to improve outcome for HF patients and their caregivers.

### **Chapter Five Summary**

The findings of this study adds to the understanding of shared care processes used by patients and their caregivers to exchange social support and its' contributions to depressive symptoms. A significant relationship was supported between shared care communication and depressive symptoms, and reciprocity and depressive symptoms. Participants who reported better shared care communication and reciprocity had less depressive symptoms. These significant relationships provide support for the need for further testing of the theoretical framework and conceptual model.

Qualitative analysis supported the difficulties and challenges persons with HF experience in their everyday lives. Future research is needed to better understand the

relationships between depressive symptoms, shared care, and self-care for the development of interventions to improve patient outcomes.

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## Appendix A

### Search Strategies

To better understand the relationships among constructs of depressive symptoms, social support, and self-care a search of CINAHL and PubMed databases were performed to identify relevant publications. The searches were limited to the English language and a time frame of 5 years. Once each search was completed non-research publications were removed, abstracts and reference lists were reviewed, and publications for review were identified. To examine the relationship depressive symptoms and self-care the following key words were used for the search which included: heart failure, depressive symptoms or depression, and self-care. Other search terms used in the place of self-care were self-management, adherence, and compliance. The initial search yielded 92 publications and subsequently six publications were identified for review. Key words of heart failure, depressive symptoms, depression, and social support were used to examine social support and depressive symptoms. Initial search identified 95 publications which resulted in ten relevant publications for review. Lastly, a search was conducted to examine the relationship of social support and self-care using key words heart failure, social support, self-care and self-management. Initially, 85 publications were identified with nine relevant publications for review.

## Appendix B

Table 2B

*Depressive Symptoms and Self-Care Evidence Table*

Author	Purpose	Methods	Findings/level of evidence
Category: Depressive symptoms and overall self-care (ordered by year)			
Holzappel et al. (2009)	Examine self-care in HF patients with different levels of depression.	<p>Sample: <math>n = 287</math>, HF outpatients, mean age <math>63 \pm 11.8</math> years, 26.3% women, race not reported, 45.1% NYHA class III-IV, non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive – correlational</p> <p>Measures:            Depression: PHQ-9 &amp; Structured Clinical Interview for DSM-IV (SCID)            Self-care: EHFSBS</p>	<p>Findings: 16.7% of patients had depression (10.4% major depression and 6.3% minor depression). Patients with minor depression reported significantly lower levels of self-care than those with major depression (<math>p &lt; .03</math>), or no depression (<math>p &lt; .001</math>).</p> <p>Level of evidence: 2</p>
Category: Depressive symptoms and self-care maintenance, and/or self-care management, and or self-care confidence (ordered by year)			
van der Wal et al. (2007)	Identify perceived barriers and benefits of self-care. Determine association between beliefs about compliance and demographic variables, depressive symptoms, NYHA, HF knowledge and experience, rate of compliance, and beliefs of compliance and self-care.	<p>Sample: <math>n = 954</math>, hospitalized HF patients, mean age <math>71 \pm 11</math> years, 38% women, race not reported, 49% NYHA class III-IV, 40% lived alone, non-random sample</p> <p>Design: Cross-sectional, descriptive study, part of a larger multi-center study (COACH).</p> <p>Measures:            Depressive symptoms: Center for Epidemiology Surveys-Depression scale            Self-care: Heart Failure Belief scale, Revised Heart Failure Compliance scale</p>	<p>Findings: Patients with depressive symptoms (40%) perceived significantly more barriers to taking medications and diet and fewer benefits to medications.</p> <p>Level of evidence: 2</p>

Author	Purpose	Methods	Findings/level of evidence
Category: Depressive symptoms and self-care maintenance, and/or self-care management, and/or self-care confidence (continued)			
Cameron et al. (2009)	Examine potential determinants of self-care in HF patients.	<p>Sample: <math>n = 50</math>, hospitalized HF patients, mean age <math>73 \pm 11</math> years, 24% women, race not reported, 50% NYHA class III-IV, 28% lived alone, non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive</p> <p>Measures:            Depression: Cardiac Depression Scale            Self-care: Self-Care of Heart Failure Index (SCHFI)</p>	<p>Findings: 53% reported depressive symptom, overall self-care low, 52% adequate self-care maintenance, 12% adequate self-care management. Depressive symptoms (<math>p &lt; .05</math>), gender (<math>p &lt; .05</math>), moderate-to severe comorbidity (<math>p &lt; .05</math>), and self-care confidence (<math>p &lt; .01</math>) significantly contributed to variance in self-care management. Patients with depressive symptoms had poorer self-care than those without depressive symptoms..</p> <p>Level of evidence: 2</p>
Johansson et al. (2011)	Examine the association between depressive symptoms and treatment seeking delay from onset of symptoms of worsening HF to hospitalization.	<p>Sample: <math>n = 958</math>, hospitalized HF patients, mean age <math>71 \pm 11</math> years, 37% women, race not reported, 95% NYHA class III-IV, non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive study part of a larger multi-center study (COACH)</p> <p>Measures:            Depressive symptoms: CES-D            Self-care: EHFS<sub>c</sub>B-9; interview questions to determine delay time</p>	<p>Findings: 39% of patients had depressive symptoms. Median time delay in patients with depressive symptoms was 120 hours, significantly higher (<math>p = .001</math>) than the median time delay of 54 hours in patients without depressive symptoms. Patients with depressive symptoms had 1.5 times higher risk for delay <math>\geq 72</math> hours independent of demographic and clinical variables (<math>p &lt; .008</math>).</p> <p>Level of evidence: 2</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Depressive symptoms and self-care maintenance, and/or self-care management, and/or self-care confidence (continued)			
Bauer et al. (2012)	Examine the association between improvement in depression and anxiety and adherence to self-care behaviors in depressed cardiac patients 6 months following hospitalization.	<p>Sample: <math>n = 134</math>, patients hospitalized with acute coronary syndrome, HF, or arrhythmias, mean age <math>61.49 \pm 11.8</math> years, 52% women, race not reported</p> <p>Design: Secondary data analysis of patients from a previous randomized intervention control trial</p> <p>Measures:            Depression: PHQ-9            Self-care: Medical Outcomes Study Specific Adherence Scale (MOS-SAS)</p>	<p>Findings: At all points in time improvement in depressive symptoms was significantly and independently associated with adherence to self-care maintenance behaviors, 6 month (<math>\beta 0.263, p &lt; .001</math>).</p> <p>Level of evidence: 2</p>
Dickson et al. (2013)	Describe depressive symptoms and self-care in black patients with HF and explore the meaning of depression in this population.	<p>Sample: <math>n = 30</math>, black HF outpatients, mean age <math>59.63 \pm 15.19</math>, 40% women, 40% married or cohabitating, NYHA class II (33.3%) and class III (66.6%), purposive sample</p> <p>Design: Mixed method</p> <p>Measures:            Depressive symptoms: PHQ-9, semi-structured interviews            Self-care: SCHFI</p>	<p>Findings: 40% of patients had depressive symptoms. Overall self-care very poor, less than 25% engaged in adequate self-care. Patients with depressive symptoms reported poorer self-care management (<math>p = .029</math>), described “feeling blue” or “waiting it out” rather than acting on worsening HF symptoms.</p> <p>Level of evidence: 2</p>

## Appendix C

Table 3C

*Social Support and Depressive Symptoms Evidence Table*

Author	Purpose	Methods	Findings/level of evidence
Category: Quantitative studies (ordered by year)			
Frasure-Smith et al. (2000)	Explore relationship between social support, depression, and prognosis the first year following an MI.	<p>Sample: <math>n = 887</math>, post-MI patients, mean age <math>59.3 \pm 11.2</math> years, 31.5% women, 19% lived alone, race not reported</p> <p>Design: Secondary data analysis from 2 separate projects; Montreal Heart Attack Readjustment Trial (M-HART)- a randomized controlled trial and Emotions and Prognosis Post-Infarct (EPPI)- a prospective study</p> <p>Measures:            Social support: Perceived Social Support Scale (PSSS), number of close friends and relative in regular contact (monthly), number of close friends and relatives, marital status, and living status (alone or with someone)            Depression: Beck Depression Inventory (BDI)</p>	<p>Findings: 32% of patients had mild to moderate depression at baseline. Depressed patients compared to non-depressed patients had significantly lower PSSS scores (<math>p &lt; .0001</math>), were less likely to have <math>\geq 1</math> close friend (<math>p &lt; .018</math>), less likely to be married (<math>p &lt; .001</math>), and less likely to be living with <math>\geq 1</math> others (<math>p &lt; .039</math>). At one year 89% of surviving patients were assessed, 26% were depressed, and of those who were depressed 52.7% had been depressed at baseline, and 14.9% who had not been depressed at baseline.</p> <p>Depressed patients had a significantly increased risk of 1-year cardiac mortality (<math>p &lt; .0006</math>). There was a significant interaction between depression and PSSS (<math>p &lt; .016</math>). Baseline depression and higher baseline social support was related to improved depressive symptoms.</p> <p>Level of evidence: 2</p>

Author	Purpose	Methods	Findings/level of evidence
Category: Quantitative studies (continued)			
Vollman et al. (2007)	Examine the use of social support as a resource for patients in dealing with their HF and depressive symptoms.	<p>Sample: <math>n = 75</math>, HF outpatients, mean age <math>54.6 \pm 13.1</math>, 31% women, 81.3% white, 17.3% African American, 1.3% Hispanic, 59% married/partnered, 57.3% NYHA class III-IV, non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive-correlational</p> <p>Measures:            Social support: Ways of Coping Questionnaire (WCQ); subscale measures seeking social support in response to stressful situations            Depressive symptoms: BDI</p>	<p>Findings: Patients who sought out social support had less depressive symptoms (<math>r = -0.23</math>, <math>p = .04</math>).</p> <p>Level of evidence: 2</p>
Sebern (2008)	Evaluated psychometric properties of the Shared Care Instrument and correlation between shared care components and depressive symptoms in patient and caregiver dyads.	<p>Sample: <math>n = 223</math> patients, 220 caregivers, homecare setting, patient mean age <math>66.6 \pm 14.3</math> years, caregiver mean age <math>64 \pm 15</math> years, 44% women patients, 64 women caregivers, patients = 98% white, 1% black and Hispanic, caregivers = 96% white, 2% black, 1.4% Hispanic, random selection</p> <p>Design: Cross-sectional</p> <p>Measures:            Shared care: Shared Care Instrument-Revised            Relationship: Dyadic Relationship Scale            Depressive symptoms: Center for Epidemiologic Studies Depression Scale</p>	<p>Findings: An inverse correlation was found between patient shared care communication and depressive symptoms (<math>r = -0.27</math>, <math>p &lt; .001</math>) and caregiver shared care communication (<math>r = -0.27</math>, <math>p &lt; .001</math>) and reciprocity (<math>r = -0.20</math>, <math>p &lt; .001</math>) and depressive symptoms. All components of patients' and caregivers' shared care were inversely associated with relationship strain. Patient shared care communication (<math>r = -0.35</math>, <math>p &lt; .001</math>), decision making (<math>r = -0.17</math>, <math>p &lt; .05</math>), and reciprocity (<math>r = -0.30</math>, <math>p &lt; .001</math>). Caregiver shared care communication (<math>r = -0.26</math>, <math>p &lt; .001</math>), decision making (<math>r = -0.28</math>, <math>p &lt; .001</math>), and reciprocity (<math>r = -0.39</math>, <math>p &lt; .001</math>).</p> <p>Level of evidence: 2</p>

Author	Purpose	Methods	Findings/level of evidence
Category: Quantitative studies (continued)			
Bean et al. (2009)	Investigate differences in social support, coping, spirituality, and health-related quality of life and relationship to depression and quality of life in patients with HF.	<p>Sample: <math>n = 97</math>, HF outpatients, mean age <math>53 \pm 14</math> years, 33% women, 49.5% African American, 47.4% white, 3.1% Hispanic, 45.4% NYHA class III-IV, non-random, convenience sample</p> <p>Design: Cross-Sectional, correlational</p> <p>Measures:            Social support: Interpersonal Support Evaluation List-Short Form (ISEL-SF) included esteem, belonging, tangible, and emotional support; Social Network Index which measured number of people in their support system, amount or regular social contact to estimate network size            Depression: Hospital Anxiety and Depression Scale (HADS)</p>	<p>Findings: Less social support was associated with increased levels of depression (<math>r = -0.66, p &lt; .01</math>), there were no differences in ethnicity between social support and depression.</p> <p>Level of evidence: 2</p>
Evangelista et al. (2009)	Examine and compare the incidence of anxiety and depression among groups of non-Hispanic black, Hispanic, and non-Hispanic white patients with HF.	<p>Sample: <math>n = 241</math>, HF outpatients, mean age <math>56.7 \pm 13.0</math>, 30% women, 7% non-Hispanic black, 22.8% Hispanic, 69.7% non-Hispanic white, non-random, convenience sample</p> <p>Design: Cross-sectional, correlational</p> <p>Measures:            Social support: Presence of a confidant-someone to confide in            Depression: PHQ-9</p>	<p>Findings: 20% of patients were depressed, Hispanics had lower levels of depression and higher social support (<math>r = -0.163, p &lt; .05</math>) compared to non-Hispanic blacks, and non-Hispanic whites.</p> <p>Level of evidence: 2</p>



Author	Purpose	Method	Findings/level of evidence
Category: Quantitative studies (continued)			
Paukert et al. (2009)	Investigate social support as a predictor of depressive symptoms in HF patients.	<p>Sample: <math>n = 104</math>, HF outpatients (veterans), mean age <math>71.1 \pm 7.7</math>, 1% women, 72% white, 22.5% African American, 7% Hispanic, 27% lived alone, non-random, convenience sample</p> <p>Design: Cross-sectional, correlational</p> <p>Measures:            Social support: Multidimensional Scale of Perceived Social Support (MSPSS) and living status (living alone or living with someone)            Depression: Geriatric Depression Scale (GDS)</p>	<p>Findings: 50% of patients were depressed, there were no difference in living status between depressed and non-depressed veterans (<math>\chi^2 = 2.30</math>, <math>p = .51</math>). Social support was not significantly related to depressive symptoms (<math>r = -.09</math>).</p> <p>Level of evidence: 2</p>
Trivedi et al. (2009)	Examine patients use of social support in dealing with HF.	<p>Sample: <math>n = 222</math>, stable HF outpatients, mean age <math>57.3 \pm 12.5</math> years, 33.75% women, 45.5% black, 49% white, 98% NYHA class II-III, non-random, convenience sample</p> <p>Design: Cross-sectional</p> <p>Measures:            Social support: PSSS, ENRICHD Social Support Inventory (ESSI), COPE measured seeking emotional and instrumental support            Depressive symptoms: BDI</p>	<p>Findings: Depressive symptoms were present (<math>BDI \geq 10</math>) in 42% of patients. Higher depressive symptom scores were associated with lower perceived social support (<math>p &lt; .001</math>). Patients who sought emotional support had decreased depressive symptoms (<math>p &lt; .05</math>).</p> <p>Level of evidence: 2</p>

Author	Purpose	Method	Findings/level of evidence
Quantitative studies (continued)			
Friedman et al. (2014)	Examine the contributions of social support and disease severity to changes in depression and anxiety over a 2 year period.	<p>Sample: <math>n = 108</math>, HF outpatients, mean age <math>60.5 \pm 11.2</math>, 18.5% women, 13% non-white, 87% white, 73.1% NYHA class II, randomized sample</p> <p>Design: Ancillary study to the Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT)-randomized clinical trial ( implanted cardioverter defibrillator or placebo), longitudinal</p> <p>Measures:            Social support: Social Support Questionnaire-6 (SSQ-6) quantifies the amount and satisfaction of social support            Depressive symptoms: BDI</p>	<p>Findings: At baseline 30% of patients were depressed, social support was not significantly correlated with depression. Over time the amount of social support contributed to changes in depression (<math>p = .04</math>). Depression increased overtime for patients who had lower amount of social support at baseline. Depression and anxiety was not related to heart failure severity (NYHA classification), or groups.</p> <p>Level of evidence: 2</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Qualitative studies (ordered by year)			
Thornhill et al. (2008)	Explore the experiences of persons living with HF.	<p>Sample: <math>n = 25</math>, HF inpatients and outpatients, age range 35 to 83 years, 16% women, 88% white, non-random, purposive sample</p> <p>Design: Qualitative</p> <p>Measures: One-time semi-structured interviews</p>	<p>Findings: Emotional and instrumental support by family member helped to deal with physical and psychological challenges of HF. Such as “helping me to keep my spirits up” and “they’re there when I want them. I only got to ask” (p. 165).</p> <p>Level of evidence: 2</p>
Dekker et al. (2009)	Describe experiences of persons living with HF.	<p>Sample: <math>n = 10</math>, HF outpatients, mean age <math>63 \pm 13</math> years, 50% women, race not reported, 70% married, purposive sample</p> <p>Design: Qualitative</p> <p>Measures: One-time semi-structured interviews</p>	<p>Findings: Patients used family and friend to ease depressive symptoms such as “taking my mind off of it” (p. 310). Patients who were married used positive descriptions to discuss their spouse and marriage.</p> <p>Level of evidence: 2</p>

## Appendix D

Table 4D

*Social Support and Self-Care Evidence Table*

Authors	Purpose	Methods	Findings/level of evidence
Category: Social support and self-care maintenance (ordered by year)			
Sayers et al. (2008)	Investigate effects of social support on self-care behaviors of medication and dietary adherence and symptom monitoring.	<p>Sample: <math>n = 74</math>, HF outpatients, mean age <math>63.2 \pm 11.9</math>, 4% women, 55.4% African American, 40.5% white, 2.7% Native American, 1.4% other, 43.2% married/partner, non-random, convenience sample</p> <p>Design: Cross-sectional, correlational</p> <p>Measures:            Social support: MSPSS            Self-care: SCHFI, medication non-adherence and dietary adherence</p>	<p>Findings: Family, usually spouses (69.9%) assisted in care and decision-making (<math>p &lt; .001</math>) related to self-care. Support from friends was positively associated with self-care confidence, whereas, support from family was negatively associated with self-care confidence. Emotional and instrumental support was related to dietary (<math>F = 3.41, p &lt; .05</math>) and medication adherence (<math>F = 3.71, p &lt; .05</math>).</p> <p>Level of evidence: 2</p>
Wu et al. (2008a)	Examine factors contributing to medication adherence.	<p>Sample: <math>n = 134</math>, HF outpatients, mean age <math>61.2 \pm 11.5</math>, 30% women, 88% white, 11% African American, 1% Hispanic, 61% married/cohabitating, 61% NYHA class III-IV, non-random, convenience sample</p> <p>Design: longitudinal, correlational</p> <p>Measures:            Social support: PSSS            Self-care: Medication adherence measured using microelectronic monitoring device in cap of medication bottle, record date and time when each bottle is opened</p>	<p>Findings: Perceived social support was significantly associated with medication adherence, dose-count (<math>F = 7.253, p &lt; .001</math>) and dose-time (<math>F = 6.293, p &lt; .001</math>).</p> <p>Level of evidence: 2</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Social support and self-care maintenance (continued)			
Sebern & Riegel (2009)	Examine background characteristics associated with supportive relationships and the contribution of supportive relationships (shared care) to HF self-care.	<p>Sample: <math>n = 75</math>, outpatient HF dyads, patient mean age <math>71 \pm 10</math> years, caregiver mean age <math>68 \pm 12</math> years, 27% of HF patients were women, patients were 96% white, 2.7% black, and 1.3% American Indian, 73% of patients identified spouse or partner as caregiver, non-random, convenience sample</p> <p>Design: Cross-sectional</p> <p>Measures:            Social support: Shared Care Instrument-3 (SCI-3), measures shared care communication, decision making, and reciprocity            Self-care: SCHFI</p>	<p>Findings: Patient shared care decision making related to HF self-care maintenance (<math>r = 0.65, p = .000</math>) and self-care confidence (<math>r = 0.52, p = .000</math>), patient communication (<math>r = 0.24, p = .023</math>) and reciprocity (<math>r = 0.41, p = .000</math>) were related to self-care confidence. Caregiver decision making (<math>r = 0.29, p = .014</math>) contributed to self-care maintenance, and caregiver decision making (<math>r = 0.37, p = .000</math>) and reciprocity (<math>r = 0.35, p = .001</math>) contributed to self-care confidence.</p> <p>Level of evidence: 2</p>
Gallagher et al. (2011)	Examine the types and levels of social support and the effects on HF self-care	<p>Sample: <math>n = 333</math>, hospitalized HF patients, mean age <math>72 \pm 11</math> years, 34% women, race not reported, 56% married/partner, 93% NYHA class III-IV, non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive, secondary analysis of a subgroup of patients from COACH study</p> <p>Measures:            Social support: Study developed instrument measuring level of support (having a partner, emotional support, instrumental support, and quality of the relationship)            Self-care: EHFScBS (12 item scale)</p>	<p>Findings: Better self-care reported in patients with high levels of social support (<math>p = .003</math>). High level of social support was a significant predictor of HF self-care maintenance behaviors (<math>p &lt; .05</math>). High levels of social support were significantly related to self-care behaviors of contacting healthcare professional for weight gain (<math>p = .02</math>), limit fluids (<math>p = .02</math>), exercise regularly (<math>p = .01</math>), take medications (<math>p = .04</math>), and get a flu shot (<math>p = .01</math>).</p> <p>Level of evidence: 2</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Social support and self-care maintenance (continued)			
Tierney et al. (2011)	Explore why patients with HF participate and don't participate in regular physical activity.	<p>Sample: <math>n = 22</math>, HF outpatients, mean age <math>68.9 \pm 8.1</math>, 31.8% women, race not reported, 81% NYHA class II, non-random, purposive sample</p> <p>Design: Qualitative</p> <p>Measures: People's readiness to be active survey (PACE), one-time semi-structured interviews</p>	<p>Findings: Family support, encouragement, and family member participation in exercise were helpful in promoting and maintaining regular exercise.</p> <p>Level of evidence: 2</p>
Dunbar et al. (2013)	Test patient-family partnership intervention in comparison to patient-family educations and usual care to reduce dietary sodium and improve medication adherence.	<p>Sample: <math>n = 117</math> dyads, HF outpatients, intervention groups, patient mean age <math>55.9 \pm 10.5</math>, caregiver mean age <math>52.3 \pm 33.3</math>, 37% women patients, 42% white, 58% black, 72.6% NYHA class II, 27.4% NYHA class III, random, purposive sample</p> <p>Design: Experimental, three-group, randomized Interventions: 1) Family Partnership Intervention (FPI); 2) Patient –Family Education Intervention (PFE); Usual Care (UC)</p> <p>Measures: Social Support: Patient-Perceived Autonomy Support, Perceived Family Criticism Self-care: Self-report dietary sodium, urine sodium levels; medication adherence- Medication Events Monitoring System, Morisky Medication Adherence Scale</p>	<p>Findings: Urinary Na decreased at 4 months for FPI and PFE groups, with FPI different than UC at 8 months (<math>p = .016</math>). Dietary Na decreased at 4 months for PFE (<math>p = .04</math>) and FPI (<math>p = .018</math>), which were lower than UC. Participants in the PFE and FPI groups were more adherent to Na intake than UC group (<math>p = .029</math>). No difference or improvement in medication adherence among groups; high level baseline medication adherence across groups 80%.</p> <p>Level of evidence: 1</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Social support and self-care management			
Friedman & Quinn (2008)	<p>Compare presenting symptoms and treatment time delay of patients admitted for first HF admission with patients admitted for previous HF hospital admissions. Examine difference between groups on whom they notified, when, and what advice they received after symptom onset, and examine differences in patients' actions taken before admission.</p>	<p>Sample: <math>n = 212</math>, hospitalized HF patients, mean age 72.5 years, 42% women, 83.6% white, non-random, convenience sample</p> <p>Design: correlational</p> <p>Measures: Social support/self-care: Researcher adapted Preadmission Illness Behavior Questionnaire to measure symptom experiences, actions, and healthcare seeking behaviors for HF participants.</p> <p>Number and types of symptoms experienced were also measured.</p>	<p>Findings: Most patients (89.2%) consulted family members about symptoms and decision making. Most often a spouse (77%) was consulted, followed by children (55%) for patients who were not married.</p> <p>Level of evidence: 2</p>

Authors	Purpose	Methods	Findings/level of evidence
Category: Self-care maintenance, self-care monitoring, and self-care management (ordered by year)			
Salyer et al. (2012)	Examine the effects of supportive relationships on self-care and to what extent are these relationships mediated by self-care confidence in HF patients.	<p>Sample: <math>n = 97</math>, HF outpatients, mean age <math>56.33 \pm 13.73</math>, 43% women, 48% white, 45.9% African American, 5.1% other, 54.6% married, NYHA class II (57.7%) and class III (20.6%), non-random, convenience sample</p> <p>Design: Cross-sectional, secondary analysis of subgroup of patients from a previous study on self-care and QOL</p> <p>Measures: Social support: The Social Support Study Self-care: SCHFI</p>	<p>Findings: Perceived social support had a positive direct effect on self-care maintenance (<math>\beta = .27, p = .003</math>) and a positive indirect relationship through self-care confidence on self-care maintenance (<math>\beta = .37, p = .0002</math>). Perceived social support had a positive effect on self-care confidence (<math>\beta = .37, p = .0002</math>) and indirect effect on self-care management, with self-care confidence mediating this effect. There were no direct effects of social support on self-care management. Structural support (social network size) had negative effect on self-care confidence (<math>\beta = -.22, p = .0145</math>) and self-care management (<math>\beta = -.23, p = .007</math>).</p> <p>Level of evidence: 2</p>
Cene et al. (2013)	Examine the relationship of perceived social support and self-care, and potential mediating effects of self-care confidence on the relationship in patients with HF.	<p>Sample: <math>n = 150</math>, HF outpatients, mean age <math>61 \pm 12</math> years, 51% women, 44% blacks, 39% married, NYHA class II (54%) and class III (20%), non-random, convenience sample</p> <p>Design: Cross-sectional, descriptive</p> <p>Measures: Social support: Medical Outcomes Study social support survey Self-care: SCHFI</p>	<p>Findings: Higher perceived emotional and informational support was significantly associated with better self-care maintenance (<math>\beta = .14, p = .03</math>). The relationship between perceived support and self-care maintenance and perceived support and self-care management were mediated by self-care confidence.</p> <p>Level of evidence: 2</p>



## Appendix E



Office of Research Compliance  
 Schroeder Complex, 102  
 P.O. Box 1881  
 Milwaukee, Wisconsin 53201-1881  
 P 414.288.7570  
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 W [marquette.edu/researchcompliance](http://marquette.edu/researchcompliance)

January 7, 2014

Ms. Susan Coles  
 Nursing

Dear Ms. Coles:

Thank you for submitting your protocol number HR-2717 titled, "*Role of Shared Care in the Relationship of Depressive Symptoms and Heart Failure Self-Care*" to the Office of Research Compliance (ORC). On January 3, 2014, a determination of exempt status was made under the following category or categories:

Category #2: Educational Tests, Surveys, Interviews, or Observations

You may proceed with your research. Your protocol has been granted exempt status as submitted. Documents submitted with your protocol (consent, flyer, etc.) may be used but do not receive formal IRB approval.

Minor changes to the project may be emailed to [orc@mu.edu](mailto:orc@mu.edu). Major changes, or changes affecting participant risk, require submission of a Protocol Amendment Form which can be found on the ORC web site.

Please submit an IRB Final Report Form once this research project is complete. Submitting this form allows the ORC to close your file.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Sincerely,

Benjamin Kennedy

Research Compliance Officer-Human Subjects & Radiation Safety

cc: Dr. Christopher Okunseri, IRB Chair  
 Dr. Margaret Sebern  
 Ms. Sherri Lex, Graduate School

BK/jn

## Appendix F

**Wheaton Franciscan Healthcare***In Partnership with the Felician Sisters*400 W. River Woods Parkway  
Glendale, WI 53212

October 21, 2013

To: Susan Cole, MSN, RN - Marquette University

Cc: Lisa Guerrero, WFH All Saints  
Karen Murillo, WFH All Saints

Re: Exempt study

Dear Susan,

Thank you for the email describing your research proposal. This research involves distributing anonymous surveys to patients at the Wheaton Franciscan Healthcare All Saints Heart Failure Clinic. Since WFH will not be “engaged” in conducting the research, WFH IRB approval is not needed. We understand that the Marquette IRB will be providing oversight for this minimal risk study.

Administrative approval in the form of a written letter of support from All Saints Heart Failure Clinic leadership is required. Please keep this letter in your research files.

If the scope or intent of this project changes, please contact me to see if it impacts this determination.

Sincerely,

Julia Kennedy, MPA, CIP  
Director, Human Research Protection Program  
Wheaton Franciscan Healthcare  
400 W River Woods Parkway  
Milwaukee, WI 53212  
Phone: 414-465-3134 / Fax: 414-465-3001  
Email: [julia.kennedy@wfhc.org](mailto:julia.kennedy@wfhc.org)  
IRB Website: <http://www.mywheaton.org/programs/irb/index.asp>

## Appendix G

IRB HR#: 2717

**MARQUETTE UNIVERSITY**  
**CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

This is a research project being conducted by Susan Cole at Marquette University. The purpose of this research project is to learn more about how persons with heart failure feel and manage their illness, and the role their close family members play in assisting them with this process. You will be one of approximately 77 participants. You are invited to participate in this research project because you are a person with heart failure.

Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may stop your participation at any time. Your decision to participate or not participate in the study will in no way affect the care you receive at the clinic.

You will be asked to complete five brief survey questionnaires that will take approximately 15 minutes. The first questionnaire is a form asking information about you, the second questionnaire (Kansas City Cardiomyopathy Questionnaire) asks about your heart failure and how it may affect your life. The third questionnaire (Patient Health Questionnaire) is a survey asking you about how you have been feeling. The fourth questionnaire is a survey asking about how you manage your heart failure (European Heart Failure Self-Care Behavior Scale). And, the fifth questionnaire is a survey asking about how your spouse or close caregiver helps you with your heart failure (Shared Care Instrument). Additionally, the third, fourth, and fifth questionnaire each have one question asking you to write a short response.

If you are completing the survey at the clinic today, please place the surveys in the enclosed envelope and return it to clinic staff. If you will be completing the surveys at home please return the completed surveys by mail using the addressed, postage-paid envelope included in this packet.

Your responses will be confidential and we will not be collecting any identifying information such as your name or address. To help protect your confidentiality, all data is stored in a password protected electronic format. The results of this study will be used for scholarly purposes only and may be shared with Marquette University representatives.

There are no foreseeable risks for your participation. As a token of our appreciation, two dollars has been included.

If you have any questions about the research study, please contact Susan Cole [susan.cole@mu.edu](mailto:susan.cole@mu.edu). This research has been reviewed according to Marquette University IRB procedures for research involving human subjects.

Completing the survey indicates that you have read the above information; you voluntarily agree to participate; and you are at least 18 years of age.

## Appendix H

## Patient Demographic Survey

The following questions are used to gather general information about the people who are in this study. There is no right or wrong answers.

Age: \_\_\_\_\_

Gender:

- Female
- Male

Indicate your ethnic identity:

- American Indian/Alaskan Native
- Asian
- Black/African American
- Hispanic/Latino
- Not Hispanic/Latino
- Native Hawaiian or Other Pacific Islander
- Other, \_\_\_\_\_

What is your highest level of education?

- 8<sup>th</sup> grade or less
- Some high school
- High school/GED graduate
- Some College
- College Degree

- Graduate Professional Degree

Do you have sufficient income?

- I am comfortable with my income
- I have just enough to make ends meet
- I do not have enough to make ends meet

Read the following options carefully. How would you describe your current living situation?

- Not married: not currently in a committed relationship
- Not married: in a committed relationship, but not living together
- Not married: living with a partner in a committed relationship as if married
- Married
- Divorced/separated from a spouse or partner with whom you lived as married
- Widowed by a spouse or partner with whom you live as married
- Other, \_\_\_\_\_

As the patient with heart failure, how do you describe your relationship with the person who helps you with your heart failure? I am their:

- Spouse
- Partner
- Parent
- Friend
- Son
- Daughter
- Other, \_\_\_\_\_

## Appendix I

Table 10I Qualitative Themes and Examples

*Question 1: How does your mood affect your ability to take care of yourself?*

Theme	Subtheme	Selected Responses
Everyday activities		<p>When it happens I don't want to take a shower and change my clothes.</p> <p>I am a little slower now days, but I take my time doing my chores or house work or washing dishes. Some days I just let things go undone.</p> <p>Sometimes I have to "Push" myself to get out of bed. Take a shower.</p> <p>Just too tired most of the time. Often, I'll stay in my PJ's all day. Little ambition.</p>
Strategies to manage mood	Keeping a positive attitude	<p>I pray every morning to try and stay positive. I make an effort every day to keep the house clean and I shower, no matter how much of a struggle it is. I always believe that I can get better, and do better. I get depressed when I can't take on larger projects and I feel overwhelmed by them. Overall, I try to be grateful for all that I can do.</p> <p>I try to keep a positive attitude with all the health problems that I have. What-ever I feel like doing for that day, whatever it is, whether it's reading, listening to music, watching T.V., play games, cards or just sitting quietly, I try to stay relaxed and stress free. It helps, to keep things in perspective. Keeping a positive attitude is key.</p>
	Activating social resources	<p>I really don't give it much thought. If I am struggling with something, I ask someone to assist me.</p> <p>What I can't do, I just ask for help.</p> <p>I'm usually in a pretty good mood and can take care of myself. My children help with housework and snow shoveling – things like that.</p>
Not aware/no effect		Does not affect my ability to take care of myself.

*Question 2: In relation to your heart failure what do you find most difficult about your self-care?*

Theme	Subtheme	Selected Responses
Functional status changes		<p>Being able to do what I want I.e. going out with friends, shopping etc.            Going for a long walk.            Getting dressed in AM!</p> <p>Hair washing, shampooing and rinse off.</p> <p>House work, getting in and out of my apartment, no railings on the steps</p> <p>Walking up stairs.</p> <p>Trying to exercise!</p> <p>The ability to shower walk and breathe during activity.</p>
Lifestyle changes		<p>Wearing the external defibrillator is embarrassing and makes me feel so self-conscious. I hate wearing it and the monitoring of sodium intake is annoying.            Finding food that fits the low sodium allowances.</p> <p>Having to take medication.</p> <p>Diet and exercise.</p> <p>I can't do the things I used to and I can't eat the food I used to.</p> <p>Remembering to take meds.</p> <p>Watching my salt intake.</p> <p>Recognizing I need to contact nurse or doctor when even slight problems occur.</p>

*Question 3: How does your spouse or close caregiver help you manage your heart failure?*

Theme	Subtheme	Selected Responses
Informal support	Communication	<p>We talk a lot.</p> <p>Talking about it.</p> <p>She calls me every week to see what's going on and how I feel.</p> <p>She asks me if there is anything she can do to help me.</p> <p>Mostly, by giving me advice.</p>
	Decision making	<p>By showing interest and concern. It makes me think about my condition and helps me do what's right for me.</p>
	Reciprocity	<p>My caregiver helps by making sure I take my meds, keeps track of salt intake, and fluids.</p> <p>We talk a lot. He helps with my food and helps me walk.</p> <p>She keeps me moving. We have fun together doing things and asks daily about my health. She reads about my condition and is acutely aware when I feel a little fatigued. She never hesitates to take control if I'm feeling bad! She is a gift.</p> <p>She takes me to appointments, sets up my medications, and cooks low salt meals.</p>