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PERCEIVED SOCIAL SUPPORT AND SELF-CARE IN PATIENTS  
HOSPITALIZED WITH HEART FAILURE

by

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for the degree of Doctor of Philosophy  
in the College of Nursing  
at the University of Central Florida  
Orlando, Florida

Fall Term  
2015

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## ABSTRACT

Heart failure is a chronic, progressive syndrome that affects more than five million Americans. It is the most common hospital diagnosis for Medicare recipients, and the most frequent cause for readmissions, with an estimated annual cost of \$12 billion. In addition to the economic impact, heart failure exacerbations requiring hospitalizations result in worsening of the condition and quality of life for the patient, and is an independent risk factor for increased mortality. Self-care is a key component of managing this syndrome and approximately half of all readmissions are considered the result of inadequate self-care. Perceived social support has been associated with better self-care and reduced readmissions, but studies often used a proxy for social support. Heart failure self-care is included in guidelines from all major cardiology groups, yet only one study definitively showed evidence that better self-care is related to improved clinical outcomes. The purposes of this study were to determine if hospitalized heart failure patients had deficiencies in self-care and perceived social support when compared with a sample of community-dwelling heart failure patients, define the relationship of perceived social support to self-care, and establish the association of self-care confidence to self-care maintenance and self-care management.

Patients who met inclusion criteria and were hospitalized with an exacerbation of heart failure were approached after medical stabilization. Immediately following informed consent, patients were screened for ability to perform their own activities of daily living and given the Blessed Orientation-Memory-Concentration (BOMC) test to assure cognition sufficient for informed consent. Those that passed the BOMC then participated in the study. The Medical Outcomes Study – Social Support emotional/informational subscale (MOS-SS) and the three

Self-Care of Heart Failure Index (SCHFI) subscales were administered. Demographic and clinical data were collected from the electronic medical record and the participant. A weighted co-morbidity score was calculated from the Charlson Co-morbidity Index (CCI). Two-sample *t* tests with unequal variances and multiple regression were used to analyze the data. Control variables for the regression models included age, gender, CCI score, number of heart failure admissions in the past six months, whether or not living with another, and education level. Results were compared with a study of community-dwelling heart failure patients in North Carolina that was published by Cené et al. in 2013.

A convenience sample of 121 hospitalized heart failure patients at four Central Florida hospitals participated in the study; 25% of consented patients were not included because their BOMC cognition scores were outside of the parameter. The mean age of participants was 71.24 years. Gender and type of heart failure were evenly distributed. Over 30% of the sample was comprised of Black/African American patients and only 9% of the sample was Hispanic ethnicity, which was primarily due to the study's language criteria. The number of heart failure admissions in the prior six months ranged from one to 12, with a median of two; 47% of participants had only one admission. Cronbach's alpha was calculated for each subscale and determined to be within the range of other studies.

The MOS-SS score was significantly lower than in Cené's study. Self-care maintenance was also significantly lower than the community-dwelling study participants, while both self-care management and self-care confidence mean scores were essentially the same in both studies. However, when comparing the percentage of participants who scored at least a 70 on each scale, which is considered the minimum score for adequate self-care, participants in this study were

lower on self-care maintenance, similar on self-care management, and higher on self-care confidence when compared with Cené's community-dwelling patients. The only significant relationship with perceived social support in regression models was with self-care confidence. Other significant relationships in the regression models included: the number of heart failure hospitalizations in the previous six months and education with self-care maintenance, and education and age with self-care management. Self-care confidence was statistically significantly associated with both self-care maintenance and self-care management. Age, number of heart failure admissions in the past six months, and education were also related to self-care maintenance in the regression model.

In summary, perceived social support was only significantly related to self-care confidence, and self-care confidence was significantly associated with both self-care maintenance and self-care management in this sample of hospitalized heart failure patients. The percentage of patients with adequate self-care confidence scores was higher than scores reported for community-dwelling patients. In addition, 25% of consented patients demonstrated cognitive impairment.

This dissertation is dedicated to my mother, Dorothy E. Chamberlain, who instilled in me a love of reading and learning, and who encouraged me on many levels throughout this journey.

This dissertation is also dedicated to my husband, Roy W. Johnson, who made this endeavor possible. Roy handled the household chores and cooking, took care of our kitties, and went without vacations. He tolerated having minimal companionship and conversation. Roy celebrated with me and consoled me, and generally supported me through the entire process. I could not have completed this degree without his love and continuous encouragement.

## ACKNOWLEDGMENTS

I am grateful for the organizations that awarded grants to fund the research component of this dissertation. Theta Epsilon of Sigma Theta Tau, the Lupus Foundation of Florida, and the Metropolitan Orlando Chapter of the American Association of Critical-Care Nurses are much appreciated.

My dissertation committee chair, Dr. Mary Lou Sole, has been my mentor and teacher for many years. She suggested I go for a PhD years before I actually applied, and she never said “I told you so.” Mary Lou has offered constant encouragement and challenges. She ran the statistics on my first independent research study and she shared the podium with me for my first presentation at a national conference.

Thank you to my dissertation committee members, Drs. Donna Neff, Norma Conner, and Richard Hofler. Donna gave me an ear to discuss my theories and questions. Norma made sure the details were accurate and had great brainstorming ideas. Richard was patient as I struggled through statistics and taught him nursing terminology. Mary Lou kept it all together. This was a phenomenal dissertation committee and I greatly enjoyed the discussions.

Dr. Daleen Penoyer was another mentor who tried to get me to navigate the politics of a hospital system and helped me grow both personally and professionally. Her “Daleenisms” made me laugh and her honesty and time are tremendously appreciated.

Finally, I must thank the other two women in my cohort. Dr. Joy Parchment and Dr. Fanya Dejesus were instrumental in my survival during the past five years. “We are highly intelligent women!”

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## LIST OF ABBREVIATIONS

ACE	Angiotensin-converting enzyme inhibitor
ADL	Activities of daily living
BNP	B-type Natriuretic Peptide
BOMC	Blessed Orientation-Memory-Concentration test
CCI	Charlson Comorbidity Index
CMS	Center for Medicare and Medicaid
CNS	Clinical Nurse Specialist
DV	Dependent variable
HFpEF	Heart failure with preserved ejection fraction (Diastolic heart failure)
HFrEF	Heart failure with reduced ejection fraction (Systolic heart failure)
IRB	Institutional Review Board
IV	Independent variable
MOS-SS	Medical Outcome Study-Social Support
NYHA	New York Heart Association
PHI	Personal health information
PI	Primary investigator
RA	Research assistant
SCHF	Self-Care of Heart Failure Index

## CHAPTER 1 INTRODUCTION

### The Problem

Heart failure is a chronic progressive syndrome for more than 5 million Americans (Go et al., 2014) and the most common hospital diagnosis for individuals over 65 years of age (Krumholz, 2012). Readmission within 30 days of hospitalization occurs in 23% (*Hospital Compare*) of this population, resulting in an annual estimated cost of \$12 billion (Vest, Gamm, Oxford, Gonzalez, & Slawson, 2010). Heart failure is also the most common cause of readmissions for Medicare beneficiaries (Giamouzis et al., 2011), and up to 50% of readmissions are related to inadequate self-care (Dickson, Buck, & Riegel, 2011). The American Heart Association estimates that the number of Americans with heart failure will escalate to one in every 33 by the year 2030, and that the cost to treat this condition will exceed \$53 billion (Young et al., 2014). In addition to the economic impact of heart failure, exacerbation results in worsening of the condition, lower quality of life, and higher mortality for the patient (Riegel, Driscoll, et al., 2009). There is great interest in identifying effective interventions to improve self-care and reduce readmissions in heart failure patients.

Patient self-care of heart failure is considered a key component of the outpatient management of this syndrome. Perceived social support has been cited as a factor in promoting self-care and lowering readmissions in heart failure patients (Riegel, Moser, et al., 2009). Given the perceived importance of social support to improve self-care and reduce exacerbations and hospitalizations in heart failure patients, it is crucial to determine if hospitalized heart failure

patients are deficient in perceived social support and self-care. Table 1 displays the definitions of concepts utilized in this dissertation.

Table 1

*Definition of Terms*

Term	Definition
Emotional Support	Provision of a sense of caring, love, and/or trust (Graven & Grant, 2014).
Functional Support	Subjective and qualitative; perceived availability and/or adequacy of received social support (Cohen & Wills, 1985). More effective than structural support for buffering stress and positive health outcomes (Cene et al., 2013)
Heart failure	Chronic, progressive syndrome involving cardiac remodeling and ventricular inability to provide sufficient cardiac output and oxygenation of the organs (Go et al., 2014).
HFpEF	New acronym for diastolic heart failure in which stiffness impair ventricular filling leading to reduced cardiac output
HFrEF	New acronym for systolic heart failure in which ventricular contractions are weakened, leading to reduced cardiac output
Informational Support	Provision of information related to the stressor or to a solution (Graven & Grant, 2014).
Perceived Social Support	Belief that help is available from others (APA, 2014). More valuable for health outcomes than received support (Cene et al., 2013; Cohen, Sherrod, & Clark, 1986)
Readmission, all cause	A hospitalization for any reason following an index admission for a primary or secondary diagnosis of heart failure (Suter, 2013).
Self-care	A method to improve heart failure outcomes through a naturalistic decision-making process utilized by patients to select behaviors to maintain physiological stability and to respond to symptoms (Riegel, Moser, et al., 2009). Self-care encompasses self-care maintenance, self-care management, and self-care confidence (Riegel & Dickson, 2008).
Self-care confidence	Mediator/moderator of self-care management. Better self-care confidence associated with better self-care management (Riegel & Dickson, 2008).
Self-care maintenance	Monitoring for symptoms of heart failure and following the treatment plan; prerequisite for self-care management (Riegel & Dickson, 2008).
Self-care management	Ability to recognize and evaluate symptoms as relating to heart failure, recognizing a need for action, taking action to improve the symptom(s), and evaluating of the results of the action (Riegel & Dickson, 2008).

Term	Definition
Social Support	Positive relationships that mitigate stress and encourage health behaviors (Gallagher, Luttik, & Jaarsma, 2011); a resource provided by other persons that mitigates the potentially negative effects of high levels of stress (Cohen & Wills, 1985).
Structural Support	Objective and quantitative; involves frequency of contact with the social network and/or utilization of social support (Cohen & Wills, 1985)

### Background

Heart failure has the highest mortality rate of any disease with approximately 50% of patients dying within 5 years of diagnosis (Go et al., 2014). In addition, hospitalization in patients with chronic heart failure is an independent risk factor for shortened survival (Yancy et al., 2013). Much of the economic burden of caring for heart failure is related to hospitalization in the Medicare population and is considered preventable (*Pub.L. 111-148 Patient Protection and Affordable Care Act.*, 2010). The Center for Medicare and Medicaid (CMS) now includes all-cause readmission rates (readmission to the hospital for any diagnosis within 30 days following an admission for heart failure) as a quality measure, and penalizes hospitals that have readmission rates greater than the national mean by reducing total Medicare payments to the facility (Chmielewski, 2010). Consequently there are financial incentives for hospitals to find ways to reduce readmissions in heart failure patients.

The American College of Cardiology Foundation and the American Heart Association consider heart failure self-care a key component to reduce readmission rates and mortality (Yancy et al., 2013). Self-care in heart failure (Table 1) includes adhering to a treatment plan, monitoring and recognizing symptoms, taking appropriate actions to manage symptoms, and evaluating the effectiveness of their actions (Riegel, Moser, et al., 2009). Routine self-care components include taking multiple medications as prescribed, monitoring weight daily,

lowering sodium intake, eliminating or minimizing alcohol, eliminating tobacco, following up with healthcare providers, exercising, monitoring symptoms of worsening condition (e.g. increased edema, fatigue or dyspnea) and promptly notifying a healthcare provider of any deviations from the norm (Riegel, Moser, et al., 2009). Heart failure patients have a 40% greater risk of hospitalization or death if they do not adhere to at least some of the self-care behaviors, while those with expert self-care skills have almost a 56% risk reduction for hospital admissions, emergency department visits, or death (Riegel, Lee, & Dickson, 2011). Results from a meta-analysis indicate that the most challenging heart failure self-care issues are adherence to a low sodium diet, monitoring symptoms, and differentiating heart failure symptoms from other co-morbidities (V. V. Dickson, Deatrck, & Riegel, 2008). Two other challenges to adequate self-care are that a large percentage of heart failure patients have impaired cognition (Chapa et al., 2014; Riegel, Moser, et al., 2009), and up to 60% experience depression (Heo et al., 2014), both of which are known to negatively impact self-care in heart failure patients (Heo et al., 2014; Riegel, Moser, et al., 2009).

Perceived availability of social support for heart failure patients has been cited as a factor in enhancing adherence to the treatment plan, better self-care, and lowering readmissions (Riegel, Moser, et al., 2009). However, the cumulative knowledge from research on perceived availability of social support and self-care, and on perceived availability of social support and hospitalizations, remains limited because of the wide range of measures utilized and the frequent use of proxy measures such as marital status or loneliness. Often these studies did not delineate types of social support or failed to define and operationalize the concept. There are studies that reported proxy measures for social support, such as cohabitating, prolonged the time until heart

failure readmission when compared with those living alone (Amarasingham et al., 2010; Chin & Goldman, 1997; Chung, Moser, Lennie, & Frazier, 2013; Howie-Esquivel & Spicer, 2012; Wu et al., 2012), and that that living alone was associated with lower levels of social support (Arestedt, Saveman, Johansson, & Blomqvist, 2013).

There are several types of perceived social support (Table 1), but only the emotional and informational types of social support were reported as beneficial for self-care in a recent study of community-dwelling individuals with heart failure, and self-care confidence was determined to mediate the relationship between perceived availability of social support and self-care (Cene et al., 2013). Cené's finding that emotional and informational social support are the most beneficial types of perceived social support to improve illness-related outcomes is congruent with Cohen and Wills' (1985) Theory of Social Support in which social support has a buffering effect on stress and illness. Another study documented that involvement of family was associated with heart failure patient development of self-care expertise (Riegel, Lee, & Dickson, 2011) and other research showed higher levels of perceived social support were significantly related to participation in self-care by heart failure patients (Gallagher et al., 2011; Salyer, Schubert, & Chiaranai, 2012).

Self-care is the standard method for heart failure patients to manage this syndrome (Lindenfeld et al., 2010; McMurray et al., 2012; Riegel, Moser, et al., 2009; Yancy et al., 2013) but research has only recently demonstrated any relationship between better self-care and reduced hospitalizations (Lee, Moser, Lennie, & Riegel, 2011). Evidence shows that perceived social support can enhance self-care in heart failure patients and influence readmission rates. However, there is limited evidence for the effect of perceived availability of social support on

self-care in relation to hospitalizations. Given the perceived importance of perceived availability of social support to reduce exacerbations associated with hospital readmissions in heart failure patients, it is crucial to understand the relationship of perceived social support on heart failure patients' self-care, and if hospitalized patients perceive availability of emotional/informational social support and perform adequate self-care.

### Specific Aims and Research Questions

The purpose of this study is to evaluate the relationship of perceived emotional/informational social support to self-care maintenance, self-care management, and self-care confidence, and to test the relationship of self-care confidence to self-care maintenance and self-care management in patients 65 years of age or older hospitalized with a heart failure exacerbation. Based on the limited evidence that better perceived social support and self-care are related to lower hospitalization rates, this study examined if heart failure patients hospitalized with an exacerbation have deficiencies in perceived availability of social support and self-care.

#### Aim 1

Describe the level of emotional/informational perceived availability of social support, self-care maintenance, self-care management, and self-care confidence in patients 65 years of age or older hospitalized with a heart failure exacerbation.

### Research Question 1

What is the level of emotional/informational perceived availability of social support, as measured by the Medical Outcome Study-Social Support (MOS-SS) emotional/informational subscale, in patients 65 years of age or older hospitalized with a heart failure exacerbation, and how does this level compare with the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=83, sd 19.8)?

### Research Question 2

What is the level of self-care maintenance, as measured by the Self-Care of Heart Failure Index (SCHFI), in patients 65 years of age or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=70, sd 14)?

### Research Question 3

What is the level of self-care management, as measured by SCHFI, in patients 65 years of age or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=57, sd 24)?

#### Research Question 4

What is the level of self-care confidence, as measured by SCHFI, in patients 65 years of age or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009) and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=65, sd 17)?

#### Aim 2

Describe the relationship of perceived availability of emotional/informational social support to self-care maintenance, self-care management, and self-care confidence, and the relationship of self-care confidence to self-care maintenance and self-care management, in patients 65 years of age or older hospitalized with a heart failure exacerbation.

#### Research Question 5

What is the relationship of perceived availability of emotional/informational social support, as measured by the MOS-SS emotional/ informational subscale, to self-care maintenance, self-care management, and self-care confidence, as measured by SCHFI subscales, in patients 65 years of age or older hospitalized with a heart failure exacerbation.

#### Research Question 6

What is the relationship of self-care confidence, as measured by the SCHFI subscale, to self-care maintenance and self-care management, as measured by SCHFI subscales, in patients 65 years of age or older hospitalized with a heart failure exacerbation.

## Conceptual Framework

The study will be based on an integration of two conceptual frameworks: the Self-Care of Heart Failure Theory and the Stress Buffering Model of the Social Support Theory. The Self-Care of Heart Failure Theory is a nursing middle range theory that has a foundation in Orem's Self-Care Model and Bandura's Theory of Self-Efficacy (Buck et al., 2012). The Social Support Theory originated in the psychology discipline.

### Self-Care of Heart Failure Theory

Self-care is a component of all published major heart failure guidelines (Lindenfeld et al., 2010; McMurray et al., 2012; Riegel, Moser, et al., 2009; Yancy et al., 2013). Re-hospitalization of heart failure patients is often attributed to patient non-adherence with the treatment plan, which is failed self-care (Salyer et al., 2012). Riegel and Dickson (2008) propose five stages within three components of the self-care process in the Theory of Self-Care in Heart Failure. (See Figure 1.) Self-care maintenance, which is the first component, involves monitoring for symptoms of heart failure and following the designated treatment plan (Riegel & Dickson, 2008). Self-care maintenance is a crucial prerequisite to successful progression through the remaining stages. The next four stages fall within the concept of self-care management: an ability to recognize and evaluate symptoms as relating to heart failure, recognizing a need for action, implementing an action to improve the symptom(s), and evaluation of the results of the action (Riegel & Dickson, 2008). Self-care confidence influences self-care management, with patients having a high degree of self-care confidence being more successful with self-care management (Riegel & Dickson, 2008). Numerous studies have documented that higher levels

of self-care confidence improve self-care maintenance and also self-care management (Buck et al., 2012; Cene et al., 2013; V. V. Dickson et al., 2008; Riegel, Lee, Albert, et al., 2011; Riegel, Lee, & Dickson, 2011; Salyer et al., 2012).



*Figure 1. Self-Care of Heart Failure Model.*  
[http://www.self-careofheartfailureindex.com/?page\\_id=6](http://www.self-careofheartfailureindex.com/?page_id=6)

The Theory of Self-Care of Heart Failure is based on several premises. The first is that patients make decisions via naturalistic decision-making. Naturalistic decision-making is focused on the process rather than the expected result and uses situation-specific, contextual and prior experience (Riegel, Lee, & Dickson, 2011). In this type of decision-making, individuals attend to cues that are deemed relevant to them. They then assess the situation and seek feedback on their interpretation of the situation rather than considering multiple options (Riegel, Carlson, & Glaser, 2000). An individual's assessment of the situation and resulting behaviors are influenced by beliefs and values, knowledge, goals, and situation-specific factors (Riegel et al., 2000).

According to Riegel et al. (2000), the stages of the Self-Care of Heart Failure Theory rely on four key beliefs. First, the severity of symptoms is less important than the perceived importance of the symptom. Second, patients will respond to periodic changes in their condition, or to an inability to participate in normal activities, rather than defining signs and symptoms. Third, patients do not have the capacity to assess their own ability of symptom recognition. Fourth, patients must have intact cognition and a willingness to participate in their treatment for successful self-care management. There are also three theoretical propositions that were added to the theory as it was evaluated in research and practice: patients must be able to recognize their heart failure symptoms in order to successfully perform self-care; patients with higher levels of knowledge, experience, skill and compatible values will be better able to perform self-care, and the patient's degree of confidence in his/her ability for self-care management influences self-care outcomes (Riegel & Dickson, 2008).

#### Stress-Buffering Model of the Social Support Theory

The Social Support Theory was originally proposed by Cohen and Wills in the early 1980's. Social support, as used in this theory, is a resource provided by other persons that mitigates the potentially negative effects of high levels of stress (Cohen & Wills, 1985) and that individuals perceive as available (or actually provided) by nonprofessionals (Gottlieb & Bergen, 2010). The Social Support Theory includes two models. The Main-Effect Model suggests that social support is of consistent benefit, regardless of stressful conditions, and is generally found when social integration is measured rather than stress-coping mechanisms (Cohen, 1988). The Stress-Buffering Model (see Figure 2), which will be part of the framework for this study to

explain the relationship between perceived availability of social support and heart failure self-care, suggests that social support diminishes potentially harmful effects of stress and is effective primarily for persons in stressful situations (Cohen, 1988). However, buffering of stress can only occur when there is congruence between the needs of the individual and the type of available social support, thus emotional and informational types of social support are most beneficial for a wide-range of stressful situations such as illness (Cohen & Wills, 1985). Both models assume that stress is associated with illness through biological or neurohormonal processes and/or behavioral responses (Cohen, 1988).

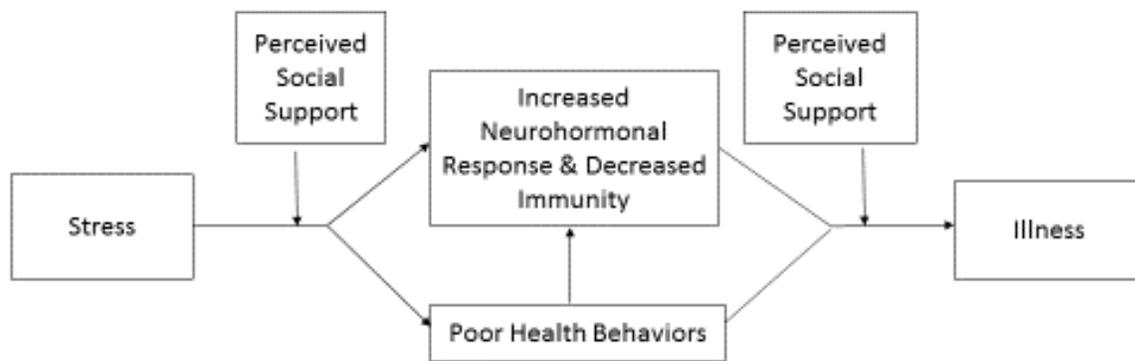


Figure 2. Stress-Buffering Model. Adapted from: Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychol*, 7(3), p. 278.

Social support is a complex and multifaceted construct that is actually comprised of several dynamic concepts (Hupcey, 1998). “Support networks, supportive behaviors, and a subjective appraisal of support” were suggested as the three components of social support by one researcher (Vaux, 1988, p. 28) and Cohen later agreed with the need for separate constructs that he delineated as social networks, supportive behaviors and perceived support (Cohen, 1992).

The belief that social support is available if needed, or perceived social support, is the paradigm that will be utilized in this study. An antecedent of the concept of perceived social support is close personal relationships (Gottlieb & Bergen, 2010), which display mutuality and affection and tend to make available a broader range of social support than casual relationships. In addition, close relationships that are “more strictly defined by normative role definitions”, such as a spouse, sibling, or parent, offer more focused support than more casual associations (Gottlieb & Bergen, 2010,p. 512). There is a similar alternative theory that isolation is a causative factor in illness as opposed to social integration and close personal relationships enhancing health, although Cohen (1988) indicates that isolation can be defined as a stressor and fit into the Stress-Buffering Model.

There has been interest in the relationship between social support and improved health outcomes for years (Cohen & McKay, 1984; Gore, 1978; Gottlieb, 1987; Langer & Rodin, 1976; Langlie, 1977; Minkler, 1981; Uchino, 2006). Several theories link perceived social support to health. First, persons within a social support network may encourage an individual to seek medical care or take actions to maintain and promote health. The second proposition proposes that over time perceived availability of social support provides an individual with more confidence and a sense of control (Minkler, 1981). The third proposition is that social support buffers stress and thus enhances coping with stressful situations (Minkler, 1981). All three propositions complement the writer’s experiences in working with heart failure patients to adopt and improve self-care practices and the premises of this proposed study. The first two of Minkler’s hypotheses are aligned with the informational type of social support, and the second and third are associated with the emotional type of social support.

According to Cohen and Wills, perceived social support reduces the effect of stress by several possible mechanisms which can then impact health: reducing the stress reaction, influencing physiologic reactions, impacting the perceived threat of the stressor, or providing a solution to the obstacle (Cohen & Wills, 1985). Social support may change an individual's perception of threat from a potentially stressful situation, or block some of the biologic or behavioral responses to stress. In addition, or alternatively, social support may assist with solutions to the event (Cohen et al., 1986). Informational support is the provision of information related to the stressor or a solution, and emotional support provides a sense of caring, love, and/or trust (Graven & Grant, 2014). Emotional and informational social support have repeatedly been shown to reduce the effects of stress (Cohen & Wills, 1985; Graven & Grant, 2014; Langford, Bowsher, Maloney, & Lillis, 1997). Social support may predict adjustment to physical and emotional stress, and the perception of social support is more important than received support (Lakey, Orehek, Hain, & Van Vleet, 2010; Nurullah, 2012). The Stress-Buffering Model's basic premise is that perceived social support provides a barrier for the effects of negative stressors (Cohen, 1988; Cohen et al., 1986; Cohen & Wills, 1985) such as illness.

#### Heart Failure Perceived Social Support Self-Care Model

A merger of the Social Support Theory and the Self-Care of Heart Failure Theory (Figure 3) is used as a framework for this study. Perceived availability of social support will facilitate self-care maintenance responsibilities, and self-care management through monitoring and assisting with determining appropriate solutions to identified symptoms indicating worsening heart failure, and/or evaluating the effectiveness of actions in response to the selected solution,

and self-care confidence through the perception of potential shared problem-solving. Although the model in Figure 3 depicts a relationship between self-care maintenance and self-care management, this will not be tested in the present study. As incorporated into the Self-Care of Heart Failure Theory, higher levels of self-care confidence will be associated with better self-care. The assumptions that are included with this approach include:

- The perceived social support must match the perceived needs of the individual (Cohen, 1988).
- Motivation and intact cognition are required for self-care (Riegel, Lee, Dickson, & Carlson, 2009).
- Patients will use naturalistic decision-making in self-care (Riegel & Dickson, 2008).
- Self-care maintenance is a prerequisite for successful self-care management (Riegel & Dickson, 2008).
- Having at least one close personal relationship is a prerequisite for perceived social support (Gottlieb & Bergen, 2010).

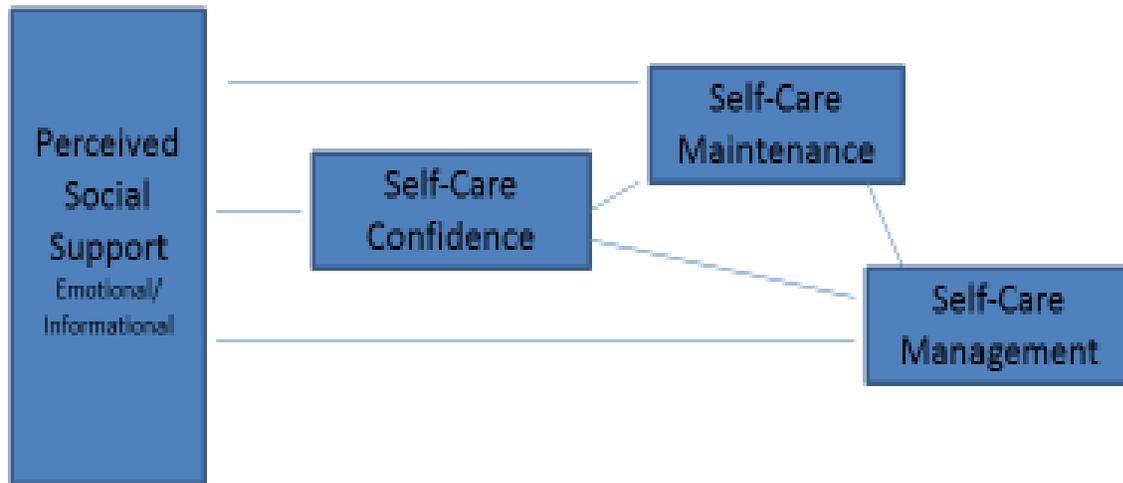


Figure 3. Heart Failure Perceived Social Support Self-Care Model.

Conversely, lower levels of perceived availability of social support will be associated with inadequate levels of self-care (self-care maintenance and self-care management) in heart failure patients. Since higher levels of perceived availability of social support and better self-care are associated with lower readmission rates in heart failure patients, it is expected that poorer levels of perceived availability of social support will be associated with inadequate self-care and more exacerbations/readmissions. Therefore patients hospitalized with heart failure exacerbations are expected to have low scores on measures of both perceived availability of social support and self-care.

#### Implications for Nursing

It is critical to reduce repeated exacerbations for patients with heart failure in order to slow the progression of the condition and reduce potentially preventable costs. Heart failure is a progressive chronic condition characterized by periodic exacerbations and a worsening quality of

life for those afflicted with the illness. Self-care is a key component of managing the syndrome on an outpatient basis and avoiding exacerbations, yet patients have difficulties with successfully recognizing symptoms and taking appropriate actions that would avoid hospitalizations (Riegel, Moser, et al., 2009). Research has shown that perceived social support for patients with heart failure can be associated with reduced hospital admissions (Löfvenmark, Mattiasson, Billing, & Edner, 2009; Rodriguez-Artalejo et al., 2006; Volz et al., 2011; Wu et al., 2012).

Perceived availability of social support has been cited as a factor in better self-care and lowering readmissions (Riegel, Moser, et al., 2009). Given the importance of social support to reduce exacerbations leading to readmissions in heart failure patients, it is crucial to understand the influence of perceived availability of social support on heart failure patients' self-care and thus the relationship to lowering readmission rates. The purpose of this study was to evaluate the relationship of perceived availability of social support to self-care maintenance, self-care management, and self-care confidence, and to test the relationship of self-care confidence to self-care maintenance and self-care management in patients hospitalized with a heart failure exacerbation. Based on the limited evidence that better perceived availability of social support and self-care are related to lower hospitalization rates, this study examined if heart failure patients hospitalized with an exacerbation have deficiencies in perceived availability of social support and self-care.

### Summary

The progressive condition of heart failure has a significant impact on quality of life and mortality for the greater than 5 million Americans with the syndrome, and on the United States'

healthcare expenditures. Heart failure is the most common hospital discharge diagnosis for CMS, with a projected annual cost of greater than \$53 billion by 2030 (Young et al., 2014). With a readmission rate of greater than 20%, and evidence that many readmissions are preventable, it is imperative that effective strategies are identified to alleviate these problems. Heart failure self-care and perceived availability of social support for heart failure patients have shown some positive associations with better patient outcomes including reduced hospitalizations. This study furthers the existing research through exploring the relationship of perceived availability of social support on heart failure patients' self-care and if hospitalized patients with a heart failure exacerbation perceive availability of emotional/informational social support and perform adequate self-care.

## CHAPTER 2 LITERATURE REVIEW

### Introduction

Heart failure is a progressive and chronic syndrome of cardiac dysfunction that effects about two percent of the American population, and is the most common reason for hospitalization in the 13% of Americans age 65 years or older (Go et al., 2014). Heart failure is predominantly a disease of aging; the median age for patients with heart failure is 75 (Januzzi, 2014). It is estimated by the American Heart Association that as of 2030, with the aging of the American population, one of every 33 citizens will have a diagnosis of heart failure and the treatment cost will be greater than \$53 billion (Young et al., 2014). Exacerbations of heart failure negatively impact individuals with the condition as the heart and quality of life worsens and the risk of mortality increases (Riegel, Driscoll, et al., 2009). Currently the 30-day readmission rate following an index hospitalization is 23% (*Hospital Compare*).

Management of heart failure is reliant on self-care (Lindenfeld et al., 2010; McMurray et al., 2012; Riegel, Moser, et al., 2009; Yancy et al., 2013), which is actually a partnership between the patient and family and professionals such as physicians, pharmacists, and nurses. Heart failure self-care (Figure 1) includes self-care maintenance, self-care management, and self-care confidence. Self-care maintenance is comprised of following the treatment plan and monitoring for symptoms of worsening heart failure and self-care management involves making a decision and taking appropriate actions to alleviate heart failure symptoms, and evaluating the effectiveness of the actions. Self-care maintenance is a necessary prerequisite for self-care management. Self-care confidence both mediates and moderates self-care maintenance and self-

care management such that higher levels of self-care confidence is associated with better self-care maintenance and self-care management (Riegel, Lee, Albert, et al., 2011; Riegel, Lee, & Dickson, 2011).

Studies have demonstrated that self-care may be enhanced when heart failure patients perceive higher levels of social support (Cene et al., 2013; Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Gallagher et al., 2011; Krumholz et al., 1998; Riegel & Dickson, 2008; Riegel, Lee, Albert, et al., 2011; Riegel, Lee, & Dickson, 2011; Tsuchihashi-Makaya, Kato, Chishaki, Takeshita, & Tsutsui, 2009). To date, only one study has definitively validated reduced hospitalizations with above average self-care (Lee et al., 2011). This chapter discusses self-care for heart failure patients and reviews the limited literature (Appendix A) on how perceived social support is related to self-care and readmission.

### Self-Care

Heart failure self-care components, shown in Table 2, require patients to manage multiple aspects of their condition. Every day patients are expected to take medications as prescribed, eat a low sodium diet, and exercise. They need to monitor daily weight and symptoms such as edema, fatigue, and dyspnea as measures of fluid status and possible worsening of the condition. Prompt reporting of any changes to a healthcare provider is necessary to potentially alter treatment and prevent hospitalization. Patients also have a number of scheduled provider appointments to titrate medications, monitor the patient for treatment effectiveness, and for preventive care (Riegel, Moser, et al., 2009). Typically patients have the most challenges with adhering to a low sodium diet, monitoring for heart failure symptoms and

differentiating between heart failure symptoms and those of co-morbidities (Dickson et al., 2008).

Table 2

*Self-Care Components*

Components
Adhering to medication regimen
Monitoring daily weight
Monitoring for edema and other symptoms
Promptly reporting deviations from the norm
Eating a low sodium diet
Exercising daily
Keeping medical appointments
Eliminating tobacco
Minimizing or eliminating alcohol
Preventive care (vaccines, dental health, etc.)
Stress management
Manage co-morbidities

### Self-Care and Readmission

The first empirical evidence that self-care is associated with better heart failure patient outcomes was published in 2011, even though self-care has been included as a recommendation in all the major heart failure guidelines (Lindenfeld et al., 2010; McMurray et al., 2012; Riegel, Moser, et al., 2009; Yancy et al., 2013). Lee, et al. (2011) conducted a secondary analysis in which he compared heart failure patients who were symptom free, those with below average self-care management, and those with above average self-care management. Results demonstrated that patients who practiced above average self-care management had about the same risk of an all-cause event (hospitalization, emergency department visit, or death) as patients who were

symptom free, and a 56% lower risk of an event than patients with below average self-care management (Lee et al., 2011). While results were not reported separately for hospitalizations or readmissions, this study was the first published that empirically demonstrated that above average self-care management has an important impact on outcomes for heart failure patients. Two systematic reviews published prior to the Lee article gave introductory evidence that self-care may improve heart failure patient outcomes, although the articles do not provide a clear association between health outcomes and self-care (Jovicic, Holroyd-Leduc, & Straus, 2006; McAlister, Stewart, Ferrua, & McMurray, 2004).

McAlister et al. (2004) in a systematic review reported that heart failure patient risk for all-cause hospitalization was reduced by 27% when the patient participated in a multi-disciplinary team intervention to promote self-care. The Jovicic et al. (2006) review included 5 studies, each with a 1 year follow up period, and described a 41% reduction in the odds of all-cause hospital readmissions as the result of self-care management. The studies included in the Jovicic review (2006) all tested educational interventions aimed at improving self-care management, while the McAllister review stated that only 3 of the 23 studies included showed a significant reduction in all-cause hospitalizations (Jovicic et al., 2006; McAlister et al., 2004). Both of these systematic reviews proposed reduced hospital readmissions for heart failure patients but did not directly demonstrate the association between self-care and hospitalizations.

## Challenges to Self-Care

### Co-Morbidities

The majority of heart failure patients are elderly (Go et al., 2014), and therefore would be expected to have co-morbidities. Higher mortality is associated with excessive co-morbidities (Ekundayo et al., 2009), defined as a raw score of at least five on the Charlson Comorbidity Index (Oudejans, Mosterd, Zuithoff, & Hoes, 2012). Heart failure patients often have difficulty differentiating symptoms of various conditions and tend to identify the condition with which they have the most experience or that they deem to have the direst consequences (V. V. Dickson, Buck, & Riegel, 2011). The most common co-morbidities for heart failure patients are displayed in Table 3. In addition, co-morbidities moderate the relationship between self-care maintenance and self-care confidence, resulting in inadequate self-care (V. V. Dickson, Buck, H., Riegel, B., 2013). Depression is particularly prevalent in patients with heart failure, and this may be due to living with a chronic illness (Corotto, McCarey, Adams, Khazanie, & Whellan, 2013) or to neurohormonal activation in response to a reduced cardiac output (Riegel, Lee, & Dickson, 2011). Depression is associated with less adherence to self-care activities, waiting a longer time to report symptoms of exacerbation, and a higher hospitalization rate in heart failure patients (Riegel, Lee, & Dickson, 2011; Riegel, Moser, et al., 2009).

Table 3

*Common Heart Failure Co-Morbidities*

Condition	Condition
Anemia <sup>5</sup>	Anxiety <sup>3</sup>
Arthritis <sup>1</sup>	Chronic Obstructive Pulmonary Disease <sup>5</sup>
Coronary Artery Disease <sup>1</sup>	Depression <sup>6</sup>
Diabetes Mellitus <sup>1</sup>	Hypertension <sup>1</sup>
Hyperlipidemia <sup>4</sup>	Renal Dysfunction <sup>1</sup>
Sleep Disordered Breathing <sup>2</sup>	

<sup>1</sup>Riegel, Moser, et al., 2009; <sup>2</sup>Trupp, 2013; <sup>3</sup>Riegel, Lee, & Dickson, 2011; <sup>4</sup>Corotto et al., 2013; <sup>5</sup>Dickson, Buck, et al., 2013; <sup>6</sup>Chapa et al., 2014; Meada, Shen, Schwarz, Farrell, & Mallon, 2013

Cognitive Impairment

Up to 50% of heart failure patients have some degree of cognitive impairment (Riegel, Moser, et al., 2009). Patients with heart failure tend to be elderly, have less perfusion to the brain (Riegel, Lee, Dickson, & Medscape, 2011; Riegel, Moser, et al., 2009) and those with heart failure with reduced ejection fraction (HFrEF) are at risk for cardiothrombotic events as a result of stasis (Corotto et al., 2013). A number of studies have demonstrated that cognitive impairment is associated with less adherence to self-care practices in heart failure patients (Corotto et al., 2013; Dickson et al., 2008; Riegel, Lee, Albert, et al., 2011; Riegel, Lee, & Dickson, 2011). Consequently, the author of the Theory of Heart Failure Self-Care modified the theory to require a prerequisite of intact cognition for successful self-care (Riegel et al., 2002; Riegel & Carlson, 2002; Riegel & Dickson, 2008).

## Interventions to Improve Self-Care

According to the American Heart Association's State of the Science on Promoting Self-Care in Persons with Heart Failure (2009), there is a need for knowledge, and both situational skills and tactical skills in order to successfully manage self-care. There is limited evidence but several interventions have shown effectiveness in improving self-care:

- Patient and family teaching
- Motivational interviewing
- Disease management or care coordination programs
- Telemonitoring
- Social support (Riegel, Moser, et al., 2009)

Heart failure self-care is complex and patients generally need assistance to develop mastery. A number of studies focused on various aspects of the above listed strategies and demonstrated improvement in self-care (Dunlay, Eveleth, Shah, McNallan, & Roger, 2011; Harrison et al., 2002; Jaarsma, Abu-Saad, Dracup, & Halfens, 2000; Riegel & Carlson, 2002, 2004; Wright, 2003) but did not result in improved clinical outcomes such as better quality of life or reduced mortality. Only the WHARF trial (Goldberg et al., 2003) showed that strict adherence to one component of self-care maintenance, weight monitoring, along with education, telemonitoring, and daily nurse contact, significantly reduced mortality in the intervention group.

## Social Support and Self-Care

Cené et al. (2013) determined that emotional and informational social support are the only categories of social support significantly related to heart failure self-care. Self-care

maintenance was both positively associated with, and mediated by, perceived social support in this study, but self-care management was not statistically significant (Cene et al., 2013). Cene's study reinforced Riegel's earlier research with confirmation that self-care confidence mediates the association between self-care maintenance and perceived availability of social support (Riegel & Dickson, 2008).

Riegel, Lee, and Dickson (2011) did not specifically measure types of social support, but reported that family involvement and assistance with self-care was the primary difference in whether or not heart failure patients developed expertise in heart failure self-care skills. This study had a very small sample size but did confirm earlier findings that of all sources of social support, family has the strongest influence in helping heart failure patients to develop self-care skills (Dunbar et al., 2008). Other studies also provided evidence that heart failure patients with higher levels of emotional social support were significantly more likely to participate in self-care activities (Gallagher et al., 2011; Salyer et al., 2012), including consulting a healthcare provider for weight gain, limiting fluid intake, adhering to the medication regime, exercising regularly, and getting an annual influenza vaccine. The participants with better self-care rated perceived emotional support high even though they ranked the quality of the relationships as moderate (Gallagher et al., 2011) which is substantiation of Cohen's theory that perceived social support is more important than received social support for healthcare outcomes (Cohen, 1988, 1992; Cohen et al., 1986).

Only when social support was rated at a high level in the Gallagher study (2011) was there a positive association between social support and heart failure self-care. Matching perceived need and perception of social support is a key component of the Theory of Social

Support (Cohen & Wills, 1985) and may explain why only high levels of support were related to better self-care. No relationship between marital status and self-care (Salyer et al., 2012) was found in one secondary study in which marital status was used as a proxy for social support and the authors attribute this to a limited measure of marital status in the original research.

There is a great deal of information about social support and self-care in heart failure. However, very little directly measures the type of social support related to self-care, and many of the studies utilized structural measures such as marital status or cohabitation as a proxy for social support.

### Social Support and Readmission

The research literature on social support's relationship with heart failure patients' readmissions was primarily related to functional or received social support such as living alone and/or loneliness, and five studies reported gender-specific results. Overall, there was a paucity of research related to perceived social support and readmission.

Wu, et al. (2012) found that the self-care maintenance component of medication adherence, which is a known risk factor for readmission (Wu et al., 2009), mediates the association between cardiovascular hospitalizations and perceived social support, and that better social support leads to improved medication adherence and lower rates of readmission. Both medication adherence and perceived social support were independent predictors of lower hospital readmission rates (Wu et al., 2012). In particular, emotional support reduced the risk of readmissions (Krumholz et al., 1998), and another study documented that both high levels of

social interaction and emotional support were independent predictors of lower readmission rates in heart failure patients (Tsuchihashi-Makaya et al., 2009).

### Effect of Living Alone or Loneliness

Married heart failure patients, and those living with another person, had a longer time until readmission than those living alone (Amarasingham et al., 2010; Chin & Goldman, 1997; Chung et al., 2013; Howie-Esquivel & Spicer, 2012; Wu et al., 2012), and Arestedt et al. (2013) reported that living alone was associated with lower levels of social support. Although severity of illness was most predictive of post discharge resource utilization, being unmarried and lower income levels were most predictive of readmission (Roe-Prior, 2007). Heart failure patients living with another person reported larger social network size and less loneliness (Löfvenmark et al., 2009). Alternatively, social isolation and loneliness in heart failure patients was associated with higher readmission rates (Löfvenmark et al., 2009; Rodriguez-Artalejo et al., 2006), and loneliness tended to correlate with low numbers of social contacts and dissatisfaction with the quality of social contacts (Löfvenmark et al., 2009). In addition to living alone, spending at least 2 hours a day at home alone, or having almost no daily contact with family living apart from the heart failure patient, was related to more readmissions (Rodriguez-Artalejo et al., 2006).

Although another study did not consider cohabitation, caregiver support was found to reduce readmissions (Schwarz & Elman, 2003). In contrast, three studies did not show a relationship between marital status and readmission (Heo, Moser, Chung, & Lennie, 2012; Luttik, Jaarsma, Veeger, & van Veldhuisen, 2006; Watkins, Mansi, Thompson, Mansi, & Parish, 2013), although study participants who were married in Luttik et al. (2006) had a statistically non-significant 12% fewer admissions than those who lived alone. The other two studies had atypical samples.

The Watkins (2013) study population characteristics were predominantly African American with poor health literacy, a lack of commercial insurance, and drug abuse as a comorbidity. In Heo et al. (2012), the mean age of subjects was only 61 years which is young for a chronic condition that has increasing prevalence in the Medicare population (Yancy et al., 2013).

Marital status, or living with another, without assessing the quality of the relationship may seem a weak proxy for social support. However, the majority of these studies found statistically significant positive associations between lower heart failure readmissions and cohabitation.

### Gender Specific

Three of five studies reported higher readmission rates for women than men, and linked the differences to social support (Chin & Goldman, 1997; Krumholz et al., 1998; Löfvenmark et al., 2009). Women are often more socially isolated and widowed, and less apt to have anyone to assist with symptom identification and appropriate interventions; this is probably related to the fact that they tend to live longer than men and be diagnosed with heart failure at a later age (Stamp, 2014). Both Chin, et al. (1997) and Löfvenmark et al. (2009) reported heart failure patients' perception of aloneness was related to higher rates of readmission for women than men. The women who were readmitted in these studies were more likely to be unmarried (Chin & Goldman, 1997) or to report loneliness (Löfvenmark et al., 2009). Women were also more likely to request post-discharge assistance that was not available from friends or family (Chin & Goldman, 1997). A small Australian mixed methods study on heart failure supported these findings although readmissions were not measured: this study reported that women in this study had significantly less social support than men and were less likely to be married (Riegel,

Dickson, Kuhn, Page, & Worrall-Carter, 2010). On the other hand, emotional support may have a protective effect for women as stronger levels of perceived social support was linked to fewer readmissions for women but not for men (Krumholz et al., 1998).

Conversely, male gender was an independent predictor of readmissions in a study where the population included a large proportion of indigent men with histories of substance abuse (Amarasingham et al., 2010), and men in a Swedish study were more likely to have lower levels of social support (Arestedt et al., 2013). However, participants were significantly younger than potential participants who declined to consent and different imputation methods were used for missing data in the various study instruments (Arestedt et al., 2013), which may have affected results.

### Summary

The syndrome of heart failure is a concern for patients and families, healthcare providers and institutions, and the economy. Self-care is a key component of management of the condition, but the complexities of self-care and other factors make this a challenge for most patients. Co-morbidities including depression, cognitive impairment, age, gender, and social factors are known to impact the ability of patients to successfully master self-care. Only two studies of interventions to improve components of heart failure self-care demonstrated an improvement in clinical outcomes (Goldberg et al., 2003; Wu et al., 2009).

Many of the frequent heart failure hospital readmissions are considered preventable, and are considered “failed” self-care (Salyer et al., 2012), yet no studies have been conducted with hospitalized patients to confirm that these patients’ self-care skills are inadequate. Only one

study has offered empirical evidence that above average self-care improves clinical outcomes such as readmissions and mortality (Lee et al., 2011).

Perceived social support is more important than actual received support for healthcare outcomes (Cohen, 1988, 1992). Most of the heart failure-social support research utilized structural measures such as marital status or cohabitation rather than emotional/ informational functional support instruments known to influence healthcare outcomes. There is very little research related to perceived emotional/information social support and reducing heart failure readmissions.

It is interesting to note that very few studies considered the type of support. In addition, none of the studies tested self-care or perceived social support in heart failure patients who had been readmitted to the hospital. To date there are no published studies to confirm the premises that early readmissions are associated with “failed” self-care and/or low levels of perceived social support.

## CHAPTER 3 METHODOLOGY

### Introduction

This was a multi-site descriptive study of perceived availability of social support and self-care in hospitalized 50 years of age or older patients with heart failure. The sites were the two large hospital systems located in Central Florida, which treat a large number of patients with heart.

### Sample and Setting

The study population was comprised of a convenience sample of individuals admitted to heart failure units in four Central Florida hospitals. The two largest hospital systems in Central Florida treated 1940 patients with heart failure (DRG 291-293) during the latest Medicare reporting period, which is approximately 162 unique admissions per month. This volume was sufficient to recruit 120 individuals who completed the survey instrument within the proposed four to five month data collection period. Sample size was planned for a minimum of 120 participants based on an excess of fifteen participants for the predictor and six co-variants for linear regression.

### Inclusion Criteria

Patients were eligible to participate in the study if they were aged 50 or older and New York Heart Association (NYHA) functional Class II-IV at the time of the hospitalization, had a hospital diagnosis of heart failure and a history of heart failure (not newly diagnosed), and were competent to consent. Participants had to be able to understand and read English.

### Exclusion Criteria

Exclusion criteria included significant cognitive impairment; residence in an assisted living or skilled nursing facility; end-stage heart failure as indicated by referral for a ventricular assist device, cardiac transplant, or hospice services, or if milrinone was a planned discharge medication, or there existed written documentation of poor prognosis. Patients with a psychiatric or medical condition that would prevent participation, as determined by the initial Clinical Nurse Specialist (CNS) and/or charge nurse screening, were also excluded. Those unable to perform their own activities of daily living (ADL), per self-report, were also ineligible.

### Ethical Considerations

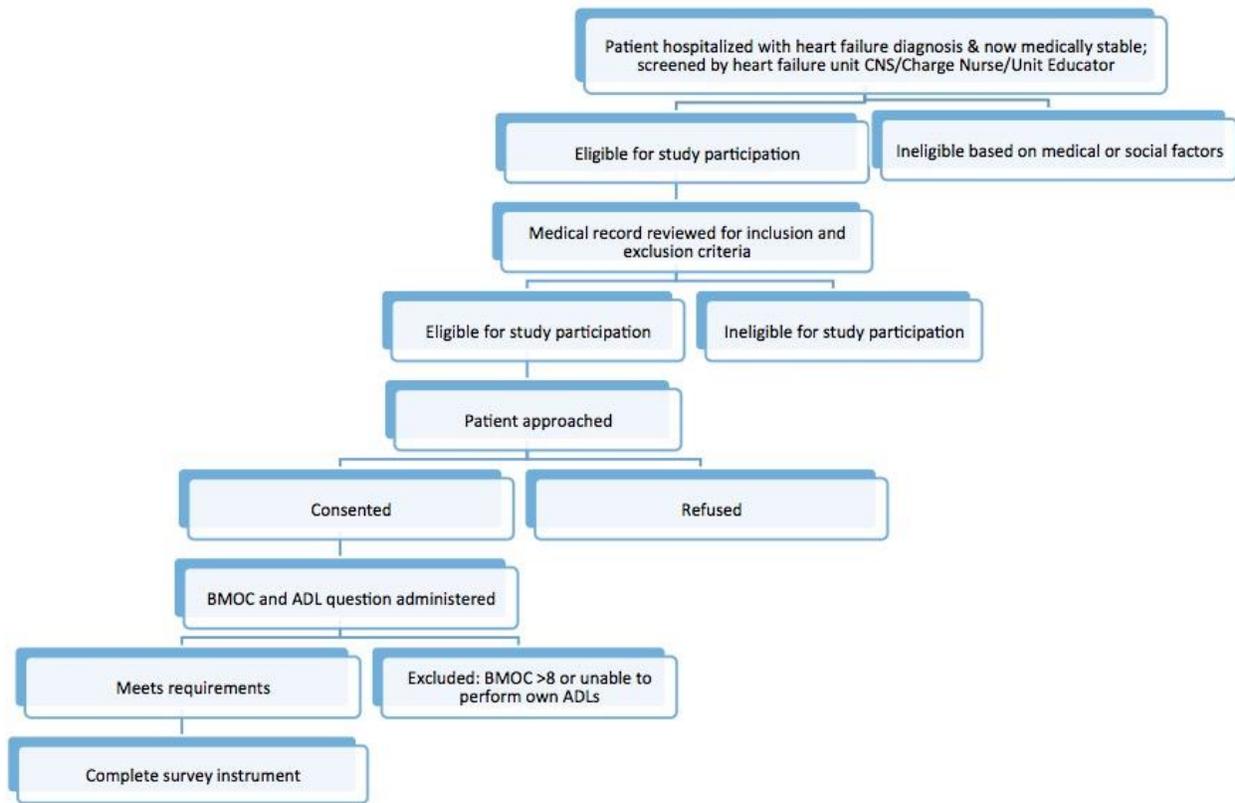
Institutional Review Board (IRB) approval was obtained from Florida Hospital and Orlando Health. The University of Central Florida IRB had agreements with both agencies to allow approval from the clinical site. Participant informed consent (Appendix B) was obtained by the primary investigator (PI) or research assistant (RA). Once consent was obtained, the PI or RA administered the Blessed Orientation-Memory-Concentration (BOMC) survey to assure cognitive ability to give informed consent. Recruited patients with a BOMC score of more than eight were not allowed to continue in the study. (These individuals were thanked and given the incentive.) The medical record was reviewed for screening purposes and to collect demographic and clinical data but no identifiable patient health information (PHI) was collected, and individual participant results were identified only by a code. Consents were stored in a locked section of the PI's office, and this was a separate location from the collected data. Data was

stored on a password protected computer database and stored in a locked filing cabinet in the PI's home office.

### Procedures

#### Recruitment

The recruitment process is depicted in Figure 4. Patients with heart failure were challenging to identify as this was often not the admitting diagnosis and chart review is a lengthy process. Therefore patients were identified through admittance to a heart failure unit and assistance of the associated CNS and/or a unit charge nurse or educator. Potential participants were further screened for study inclusion and exclusion criteria through the medical record by the PI or RA. The PI or RA approached eligible patients for consent prior to discharge and when medically stable, which was anticipated to be at least day three following admission. The consented patient was then screened with the BOMC to determine cognitive competency for informed consent, and asked “Are you able to bathe and prepare meals by yourself?” to assure the patient was able to provide self-care. A score of eight or less on the BOMC and ability to provide self-care were required for continued participation (Cené et al., 2013). Participants were offered an incentive for participation, which was a \$5 gift card to a Publix grocery store. The gift card was given to all individuals who consent and complete the survey tool, or who were not allowed to continue due to initial screening criteria. Sample size was based on participants who completed the survey tool.



*Figure 4.* Recruitment flow diagram.

ADL=Activities of Daily Living; BOMC= Blessed Orientation-Memory-Concentration Test; CNS=Clinical Nurse Specialist

### Data Collection

At least one RA, a registered nurse with heart failure experience, was recruited as a research assistant (RA) and trained by the PI. The PI and RA pilot tested study procedures to determine administration times and flow. The first two surveys collected were administered jointly to assure inter-rater reliability. In addition, all surveys collected by the RA were reviewed by the PI to assure adherence to the data collection procedures.

Data collection was conducted only by the PI or RA. Following consent and acceptable BOMC and ADL screening, participants were verbally administered study instruments in paper/pencil

format (Appendix C). Visitors were asked to leave the room while the patient completed the survey to avoid bias. The investigator checked each completed survey to assure no unintentional missing data. The entire recruitment/consent/data collection process was expected to take a maximum of 45 minutes, with approximately 30 minutes for the patient. Table 3 shows the number of items and estimated participant completion time for each component of the survey instrument.

Table 4

*Study Instruments and Estimated Participant Completion Times*

Instrument	Items	Completion
BOMC & ADL question	7	≤5 minutes <sup>1</sup>
SCHFI (3 subscales)	22	5-8 minutes <sup>2</sup>
MOS-SS (1 subscale)	8	2 minutes <sup>3</sup>
Totals	37	2-15 minutes

<sup>1</sup>Katzman Brown, Fuld, Peek, Schechter, & Schimmel, 1983; <sup>2</sup>Yu, Lee, Thompson, Woo, & Leung, 2010;

<sup>3</sup>Sherbourne & Stewart, 1991.

Measures

The BOMC and ADL question (Appendix C) was completed following consent in order to assure that the participant met criteria for the study. The data collection instrument (Appendix C) included demographic and clinical data, the SCHFI, and the MOS-SS emotional/informational subscale. Demographic and clinical data on the survey instrument included living with another, number of close relationships, highest education level, if receiving Medicaid as an estimate of economic status, number of hospitalizations in the past six months, race and ethnicity (American Indian/Alaska native, Asian, Black/African American, Native Hawaiian/Other Pacific Islander or White/Caucasians, and Hispanic/ Latino or Not

Hispanic/Latino) (US Office of Management and Budget, 1997), if received formal support services such as home health or Meals on Wheels. Demographic and clinical characteristics that were collected from the electronic medical record included: age, gender, ejection fraction, type of heart failure: heart failure with reduced ejection fraction (HFrEF) or heart failure with preserved ejection fraction (HFpEF), B-type Natriuretic Peptide (BNP) level, co-morbidity risk factors calculated with the Charleston Comorbidity Index (CCI), and evidence based medications (e.g., beta blocker, angiotensin converting enzyme (ACE) inhibitor, aldosterone antagonist for HFrEF or antihypertensives for those with HFpEF) (Matchem, 2014; Yancy et al., 2013).

#### Blessed Orientation- Memory-Concentration Test (BOMC)

The BOMC (Appendix D) six-item instrument for evaluating mild, moderate, or severe cognitive impairment in the elderly was shortened from the original 1968 survey, and validated with the Mini-Mental State Examination measure and the original Blessed test (Katzman et al., 1983). Scores are based on incorrectly answering the questions and range from zero to 28, with higher scores indicative of worse cognitive impairment (Baum et al., 2008). A score of zero to eight is considered normal or minimal cognitive impairment ("Short Orientation-Memory Concentration test of cognitive impairment," 2012), and eight was the cut-off point for participant eligibility in this study.

### Self-Care of Heart Failure Index (SCHFI)

The SCHFI version 6.2 (Appendix E) has three subscales. Self-care maintenance has 10 items on a 4 point Likert scale (1 is “never or rarely” and 4 is “always or daily”). The self-care management section is answered only if the respondent has had symptoms in the past month (Riegel, Lee, et al., 2009) so in this study all patients responded as they were hospitalized for acute heart failure. The self-care management subscale has two 5 point questions to evaluate recognition of symptoms related to heart failure and the effectiveness of the patient’s response to the symptom recognition. This section also has four items on a 4 point Likert scale (1 is “not likely” and 4 is “very likely”). The final subscale has six 4 point-items related to self-care confidence and 4 is “extremely confident”). Each subscale is evaluated independently and has a scoring range from zero to 100. With the SCHFI, higher scores reflect better self-care and a score of at least 70 is indicative of adequate self-care for each of the subscales (Riegel, Lee, et al., 2009). The Cené et al. (2013) study had a mean of 70 (14) for self-care maintenance, a mean of 57 (24) for self-care management, and a mean of 65 (17) for self-care confidence.

Cronbach’s alpha for self-care confidence was .83, while self-care maintenance was .55 and management was .60 (Table 4) when the latest version of the SCHFI was tested (Riegel, Lee, et al., 2009). The author explained the low alpha for self-care maintenance being related to this subscale measuring a variety of constructs linked to heart failure self-care, and Cronbach’s alpha is a measure of internal reliability based on the same concepts (Riegel, Lee, et al., 2009). Vellone’s (2013) psychometric testing of the SCHFI version 6.2 determined that factor score determinacy coefficients were a better measure of reliability than Cronbach’s alpha. Factor

determinacy for self-care maintenance was .78-.83, for self-care management was .74-.90, and for self-care confidence .85-.87 (Vellone et al., 2013).

#### Medical Outcomes Study of Social Support (MOS-SS)

The 19-item MOS-SS (Appendix F) was developed with simple, easily understood items for patients with chronic illnesses (Sherbourne & Stewart, 1991). Each of the 5 point Likert scale (1 is none of the time and 5 is all of the time) subscales in the MOS-SS may be utilized independently and each is scored separately on a transformed scale of zero to 100, with higher scores related to higher availability of perceived availability of social support (Sherbourne & Stewart, 1991). Only the eight-item emotional/informational subscale was utilized in this study. The emotional/ informational subscale in the original validation study had a mean of 69.6 with a standard deviation of 25.5 and Cronbach's alpha for this subscale was .96 (Table 4) when tested with almost 3000 individuals with chronic illnesses participating in a two-year multi-site longitudinal study (Sherbourne & Stewart, 1991). Cronbach's alpha was .94 in a recent perceived availability of social support and self-care study of community-dwelling patients with heart failure and the mean was 83 with a standard deviation of 19.8 (Cene et al., 2013). Several published studies have utilized the MOS-SS with heart failure patients (Bennett et al., 2001; Cene et al., 2013; Kao, Tseng, Lin, & Cheng, 2013; Salyer et al., 2012).

#### Charlson Co-Morbidity Index (CCI)

The CCI was originally developed as a predictor of mortality for use in longitudinal studies, and was validated with the Kaplan and Feinstein system and a sample of almost 700

breast cancer patients (Charlson, Pompei, Ales, & MacKenzie, 1987). (See Appendix G.) The CCI utilizes a weighted index of co-morbidities (AIDS is scored a six while heart failure and myocardial infarction are both counted as one) and ages (each decade over 40 years of age adds one point) to create a risk score (Peterson, Paget, Lachs, Reid, & Charlson, 2012). The number of comorbidity points and age points are summed for a risk score (Charlson et al., 1987), and this score can be then stratified into low, medium, or high risk ranges (Peterson et al., 2012) as shown in Table 4. In later studies, the CCI also demonstrated ability to predict risk for healthcare resource use, complications, hospitalization, and length of hospital stay (Dickson, Buck, et al., 2013) and has been utilized extensively in research (Charlson et al., 1987; Dickson Buck et al., 2013; Frenkel, Jongerius, Mandjes-van Uiter, van Munster, & de Rooij, 2014; Peterson et al., 2012)

Table 5

*Charlson Co-Morbidity Index*

Score	Risk Range
0-1	Low risk
2-3	Moderate risk
≥4	High risk

Peterson et al., 2012

All of these instruments were validated, translated into multiple languages, and utilized in a number of published heart failure studies. In addition, the four instruments were within the public domain.

### Data Analysis

An investigator administered each survey and assured it was completed. If a participant was unable to complete the entire survey, the data was still to be included in the study provided that at least one subscale was completed. Attrition was not an issue as all data collection was completed at the time of recruitment. Dummy variables were created for categorical independent variables with more than two choices (i.e. educational level). Frequencies were examined for outliers and for missing data. Imputation was planned to be utilized if there were greater than 10% missing data.

Prior to beginning analysis, data were examined for assumptions. The dependent variable data were checked for normal distribution by frequency skew and histogram. The P-P plot and histogram were evaluated for linearity and normal distribution of the residuals. Multicollinearity was measured and tolerance levels above .60 were considered absence of multicollinearity. Multicollinearity was expected between some items, with a plan for one or more variables to be omitted if this was the case.

Means and frequencies were presented on demographic and clinical characteristics. Cronbach's alpha for internal consistency reliability was calculated for the SCHFI and MOS-SS subscales. Table 5 displays the Cronbach's alpha results from the literature.

Table 6

*Variable Type, Subscales, Scales, and Alphas*

Type of Variable	Measure	Items	Cronbach's Alpha
DV	Self-care maintenance	10	.55 <sup>1</sup>
DV	Self-care management	6	.60 <sup>1</sup>
DV	Self-care confidence	6	.83 <sup>1</sup>
IV	Emotional/Informational Support	8	.96 <sup>2</sup>

<sup>1</sup>Riegel, Lee, et al., 2009; <sup>2</sup>Sherbourne & Stewart, 1991; DV=dependent variable; IV=independent variable

Multiple linear regression was used to calculate relationships between each of the heart failure self-care components (dependent variables) and the emotional/ informational perceived availability of social support (predictor), and the relationship between self-care confidence and self-care maintenance, and self-care confidence and self-care management, while controlling for possible confounders. Planned statistics were based on a presumption that assumptions would be met for these analyses. If assumptions were not met, the plan was for alternative tests to be utilized.

#### Research Question 1

What is the level of emotional/informational perceived availability of social support, as measured by the MOS-SS emotional/informational subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=83, sd 19.8)?

### Hypothesis 1

Patients with chronic heart failure 50 years or older hospitalized with an exacerbation will have lower perceived availability of emotional/informational social support as compared with the reported mean in the community-dwelling Cené et al. (2013) study.

### Analysis 1

Two sample t-test with unequal variances.

## Research Questions 2 – 4

### Research Question 2

What is the level of self-care maintenance, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=70, sd 14)?

### Research Question 3

What is the level of self-care management, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=57, sd 24)?

### Research Question 4

What is the level of self-care confidence, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare

with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009) and the reported mean in the community-dwelling Cené et al. (2013) study (n=149, mean=65, sd 17)?

*Hypothesis 1 for Research Questions 2 – 4.* Patients with heart failure 50 years or older hospitalized with an exacerbation will have a mean SCHFI score of less than 70 on each of the subscales for self-care maintenance, self-care management, and self-care confidence, which are considered the cut-points for self-care adequacy (Riegel, Lee, Dickson, & Carlson, 2009).

*Hypothesis 2 for Research Questions 2 – 4.* Patients with heart failure 50 years or older hospitalized with an exacerbation will have a mean SCHFI score of on each of the subscales for self-care maintenance, self-care management, and self-care confidence, and less than the reported means in the community-dwelling Cené et al. (2013) study.

*Analysis for Research Questions 2 – 4.* Frequency of means less than 70 for each of the subscales. Two-sample *t*-test with unequal variances for each of the subscales comparing study means with Cené et al. reported means and with the standardized cut point of 70 for each of the subscales.

#### Research Question 5

What is the relationship of perceived emotional/informational social support, as measured by the MOS-SS emotional/informational subscale, to self-care maintenance, self-care management, and self-care confidence, as measured by SCHFI subscales, in patients 50 years or older hospitalized with a heart failure exacerbation?

### Hypothesis 5

Perceived availability of emotional/informational support, as measured by the MOS-SS subscale will predict self-care maintenance, self-care management, and self-care confidence, as measured by SCHFI subscales.

### Analysis 5

Linear regression was utilized with the perceived emotional/ informational social support score as the independent variable (predictor) with each of the three self-care dependent variables. Control variables included: age, gender, living with another or not, co-morbidities as measured with the Charlson Comorbidity Index (CCI) (Appendix F), educational level, and the number of heart failure hospitalizations in the past six months.

### Research Question 6

What is the relationship of self-care confidence, as measured by the SCHFI subscale, to self-care maintenance and self-care management, as measured by SCHFI subscales, in patients 50 years of age or older hospitalized with a heart failure exacerbation.

### Hypothesis 6

Self-care confidence SCHFI subscale scores will predict self-care maintenance and self-care management, as measured by SCHFI subscales.

### Analysis 6

Linear regression was utilized with the perceived emotional/ informational social support score as the independent variable (predictor) with each of the three self-care dependent variables.

Control variables included: age, gender, living with another or not, co-morbidities as measured with the CCI, educational level, and number of heart failure hospitalizations in the past six months.

### Summary

This descriptive study recruited a sample of patients with heart failure 50 years or older hospitalized with an exacerbation to determine the level and association of perceived emotional/informational social support and self-care maintenance, self-care management, and self-care confidence. After consent, participants were screened for ability to perform their own activities of daily living and intact cognition prior to additional data collection. Clinical and demographic information were collected, and two additional instruments were administered: MOS-SS emotional/informational subscale, and SCHFI. Descriptive statistics, independent sample *t* test, and multiple regression were the data analysis tools. Results were compared with Cené et al. (2013) outcomes for perceived availability of social support and with standardized cut points for self-care scores (Riegel, Lee, et al., 2009).

## CHAPTER 4 RESULTS

### Introduction

The purpose of this study was to evaluate perceived social support and self-care characteristics of patients hospitalized with an exacerbation of heart failure, and to compare these characteristics with a study of ambulatory patients with heart failure (Cene et al., 2013).

Hospitalization of patients with heart failure is often considered “failed self-care” (Cene et al., 2013; V. V. Dickson et al., 2011), and both social support and self-care are considered means to reduce hospitalizations (Cene et al., 2013; Dunbar et al., 2008; Riegel & Dickson, 2008; Wu et al., 2012), yet the literature does not include any studies that evaluate hospitalized patients with heart failure for deficiencies in these areas. This study helps fill that gap.

Data were collected from a convenience sample of patients at four Central Florida hospitals who met criteria between April 2 and August 22, 2015. The PI monitored and/or visited each site at least twice a week to identify eligible subjects. One hundred eighty-three individuals were identified as meeting criteria for the study. Of these, 22 (12.02%) declined to participate. Forty of the 161 patients who consented scored greater than an eight on the Blessed Orientation-Memory-Concentration Test, which is indicative of more than nominally impaired cognition. These 40 did not complete the survey instrument and were not included in the study. A total of 121 hospitalized patients with heart failure completed the survey tool. Distribution of the sample was 14% from the northern community hospital, 21% from the southern community hospital, 22% from one medical center, and 43% from the other medical center. Figure 5 displays the recruitment process.

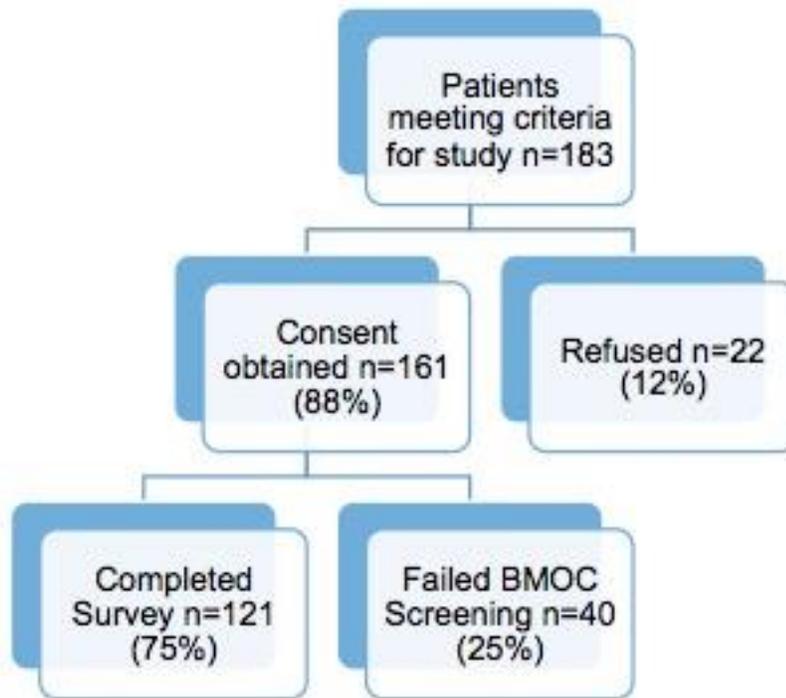


Figure 5. Recruitment flow.

Prior to data analysis, missing data, outliers, and assumptions were assessed. Missing data was not an issue and potential outliers were within 3.3 standard deviations (Tabachnick, 2013), which is acceptable. The three dependent variables of self-care maintenance, self-care management, and self-care confidence were all normally distributed. Independent variables were within acceptable normal distributions except for the variable measuring the number of close relationships which had a skew of 3.71. A statistician was consulted and recommended no transformation as the sample size was sufficiently large to approximate normal distribution (Hofler, 2015a). Statistical analysis was completed with SPSS version 23 for windows. Table 7 presents the statistics of the dependent and independent variables. This study is comparing

results of hospitalized patients with heart failure with Cené's (2013) results of community-dwelling patients with heart failure, so results from that study are included in appropriate tables.

Table 7

*Statistics of Dependent and Independent Variables*

	SCMain	SCMan	SCConf	MOS	Age	CCI	Rel	Hosp
n	121	121	121	121	121	121	121	121
Mean	63.22	57.18	66.02	70.99	71.24	7.43	10.62	2.31
Median	78.13	63.33	62.50	66.67	71.00	7.00	6.00	2.00
SD	27.69	18.37	25.05	22.48	9.80	2.11	14.95	1.85
Skewness	-.873	-.367	-.264	-.291	-.047	.69	3.71	2.19
Kurtosis	-.207	-.161	-.771	-.773	-.58	.68	16.29	6.52
Minimum	0	16.67	0	16.67	52	3	0	1
Maximum	100	100	100	100	92	15	100	12

SCMain=self-care maintenance; SCMan=self-care management; SCConf=self-care confidence; MOS=emotional/informational subscale; CCI=Charlson Comorbidity Index; Rel=number of close relationships; Hosp=number of hospitalizations for heart failure in past six months

Description of the Sample

This study was approved by the institutional review boards (IRB) of the two hospital systems for the inclusion of participants aged 65 years and older. Due to the number of individuals who failed the cognitive screening the inclusion criteria were modified to include those 50 years and older. The change was approved by the dissertation committee and IRBs at the clinical sites. Twenty-seven patients less than 65 years were included in the total sample.

Table 8 shows the characteristics of the study participants who completed the survey instrument. The age range was 52 to 92 years of age with a mean of 71.24. Participants were 49.60% male. Racially, 30.60% (37) were Black/African American and 66.90% (81) were

White/Caucasians. Eleven (9.10%) participants self-identified Hispanic ethnicity. Only 31 (25.61%) lived alone. The majority of participants had at least a high school education (75.20%) while 30 (24.80%) participants had less than 12 years of education. The number of close relationships varied widely, ranging from zero to 100. The mean for close relationships was 10.62 (14.95) and the median was 6.00. The majority of participants (n=103, 85.10%) had some form of Medicare healthcare coverage and 28 (23.10%) had Medicaid.

Sixty (49.60%) participants had heart failure with reduced ejection fraction (HFrEF) and the mean EF for these patients was 27.73% (10.94); the remaining individuals had heart failure with preserved ejection fraction (HFpEF) and a normal EF. Of the participants diagnosed with HFrEF, 90% were prescribed a beta blocker, 65% were prescribed an angiotensin-converting enzyme inhibitor or angiotensin II receptor blocker, and 36% were prescribed an aldosterone antagonist. All of the participants with HFpEF had hypertensive medications prescribed. The mean Charlson Comorbidity Index (CCI) score was 7.43 (2.11). Only 24 (19.80%) of the participants were receiving social services at the time of their admission to the hospital. The number of heart failure hospitalizations in the past six months varied from one to 12 with a mean of 2.31 (1.85) and a median of two; ten percent of participants had more than five admissions during the six-month period and 47% had only one admission.

Table 8

*Demographics*

Variable	n	Frequency	Mean (SD)	Cené	Range
Age	121		71.24 (9.8)	61 (12)	52-92
<65 years of age	27	77.68%			
≥65 years of age	94	22.32%			
Gender:					
Male	60	49.60%		49%	
Female	61	50.40%		51%	
Race					
Black (African American)	37	30.60%		44%	
White (Caucasian)	81	69.40%			
Ethnicity					
Hispanic	11	9.10%			
Non-Hispanic	110	90.90%			
Living arrangement					
With Spouse	48	39.67%		39%	
With non-spouse	42	34.71%			
Living alone	31	25.61%			
Primary Health Insurance					
Medicare	103	85.10%			
Medicaid	28	23.10%			
Educational level:					
<12 years	30	24.80%			
High School graduate	39	32.20%			
> High School	52	43.00%			
Co-morbidities*			7.43 (2.11)		3-15
Receiving social services***	24	19.80%	1.80 (.40)		
Number of hospitalizations**			2.31 (1.85)		1-12
Number of close relationships			10.62 (14.95)		0-100
Type of HF:					
HFrEF	60	49.60%			
HFpEF	61	50.40%			
Medications Prescribed					
Beta blocker	54	90%			
ACE or ARB	39	65%			
Aldosterone Antagonist	22	36%			
Antihypertensive	61	100%			
Ejection Fraction			41.90% (16.63)		
HFrEF			27.73 (10.94)		10-55
HFpEF			56.07 (5.47)		45-70

\*Co-morbidities from the Charlson Co-morbidity Index (CCI)

\*\*Number of HF hospitalizations in past 6 mos.

\*\*\*Receiving social services at time of hospital admission.

ACE or ARB= angiotensin converting enzyme inhibitor or angiotensin II receptor blocker; HF= heart failure; HFrEF= heart failure with reduced ejection fraction; HFpEF= heart failure with preserved ejection fraction

### Description of the Survey Scales

The variables for each scale were summed and converted to a 0-100 scale to standardize results and facilitate comparisons. Higher scores indicate stronger support or self-care abilities. Cronbach's alpha, as a test for internal consistency reliability, was calculated for each scale, assessed and compared with other studies. Values of .70-.75 are considered adequate although alpha coefficients of at least .80 are preferred (Polit, 2010). Table 9 displays Cronbach's alpha for each of the subscales. Table 10 shows the means for each of the subscales.

Table 9

#### *Cronbach's Alpha and Comparisons with Cené and Riegel*

Scale	$\alpha$	Cené	Riegel
MOS-SS Emotional/Informational	.93	.94	NA
Self-care Maintenance	.69	.46	.55
Self-care Management	.56	.65	.60
Self-care Confidence	.81	.78	.83

Cené et al., 2013, p. 204; Riegel, Lee, Dickson, & Carlson, 2009, p. 487; MOS-SS=Medical Outcomes Study

Table 10

#### *Means, Standard Deviations, and Comparisons with Cené*

Scale	mean	sd	Cené mean	Cené sd
MOS-SS Emotional/Informational	70.99	27.69	83.00	19.80
Self-care Maintenance	63.22	18.37	70.00	14.00
Self-care Management	57.18	25.05	57.00	24.00
Self-care Confidence	66.02	22.40	65.00	17.00

Cené et al., 2013, p. 205.

### Medical Outcomes Study-Social Support: Emotional/Informational Subscale (MOS-SS)

Cronbach's alpha for the eight-item MOS-SS demonstrated strong internal consistency of .93 for this study. Cené reported a Cronbach's alpha of .94 (Cene et al., 2013). The mean for this study was 70.99 (27.69) and a median of 78.13; possible scores were 0-100 with higher scores indicating higher levels of perceived social support.

### Self-Care of Heart Failure Index (SCHFI)

The SCHFI is comprised of three subscales, each of which is scored independently with possible results of 0-100. Barbara Riegel, author of the SCHFI, defines adequate heart failure self-care as a score of at least 70 for each of the subscales (Riegel, Lee, et al., 2009). The SCHFI has been utilized extensively in American nursing research even though the Cronbach's alpha for the self-care maintenance and the self-care management subscales are generally lower than the acceptable internal consistency limit of .70 (Polit, 2010). Dr. Riegel justifies the low alpha results on the subscales as measuring a variety of constructs while Cronbach's alpha is designed for similar concepts (Riegel, 2009). Factor analysis documented better reliability than Cronbach's alpha (Vellone et al., 2014). The self-care maintenance subscale has one negative item and it was recoded prior to totaling the score for this subscale.

#### Self-Care Maintenance

The mean for the ten-item self-care maintenance subscale was 63.22 (18.37). In the Cené study (2013), self-care maintenance was higher with a mean of 70.00 (14.00) (Cene et al., 2013). Forty-one percent of the study participants scored at least 70%, indicating self-care adequacy. In the Cené study (2013), 52% of the participants scored at least 70% on the self-care maintenance

subscale (Cene et al., 2013). Cené's reported Cronbach's alpha was .46 (Cene et al., 2013) and this study's alpha was higher at .69.

### Self-Care Management

On the self-care management subscale, Cronbach's alpha was .56, which was lower than Cené's calculated alpha of .65. The results were very similar on the five-item self-care management subscale as both studies reported a mean of 57.00. In this study, 33% of the sample had adequate self-care management as demonstrated by a score of 70 or higher. Cené reported 32% adequate self-care management (Cene et al., 2013).

### Self-Care Confidence

The means for the six-item self-care confidence subscale were also homogeneous (mean=66.02, sd=22.40) versus the Cené study with a mean of 65.00 (17.00) (Cene et al., 2013). Cené research found that 33% of the self-care confidence scores were at least 70% while this study was higher with 46% of the participants achieving adequate self-care confidence. Cronbach's alpha was .81 for this study, compared with Cené's .78 (Cene et al., 2013).

The community-dwelling participants in Cené's research had a mean in the adequate range for self-care maintenance but not self-care management or self-care confidence. None of the means in this study achieved the minimum of 70, indicating poor self-care for all subscales.

## Research Questions

The purpose of this study was accomplished through testing of six hypotheses. Prior to analysis, dummy variables were created for the three-choice categorical variable for education. Multicollinearity was not an issue as tolerance scores were greater than .72 for all independent variables. The P-P plots of regression standardized residual demonstrated essentially normal distributions.

### Research Question 1

What is the level of emotional/informational perceived availability of social support, as measured by the MOS-SS emotional/informational subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the reported mean in the community-dwelling Cené et al. (2013) study?

This question was addressed with a two-sample *t* test with unequal variances to compare the means of the MOS-SS score in this study and the Cené study. Results are shown in Table 11. A statistically significant difference was found ( $t=-4.007$ ,  $df=211$ ,  $p<.001$ ) between Cené's findings (mean=83.00, sd=19.80, n=148) and MOS-SS scores in this study (mean=70.99 sd=27.69, n=121).

Table 11

#### *T-Test Comparison of MOS-SS with Cené study*

Scale	n	Mean (SD)	<i>t</i>	<i>df</i>	<i>p</i>
This Study	121	70.99 (27.69)	-4.007	211	<.001
Cené	148	83.00 (19.80)			

Cené et al., 2013, p. 205. MOS-SS=Medical Outcomes Study

## Research Question 2

What is the level of self-care maintenance, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the Cené et al. (2013) study?

The means of the SCHFI subscale scores in this study and the Cené scores were compared with a two-sample *t* test with unequal variances. Results for all SCHFI subscales are shown in Tables 12 and 13. There was a statistically significant difference found ( $t=-3.343$ ,  $df=220$ ,  $p<.002$ ) between this study (mean=63.22, sd=18.37, n=121) and Cené's results (mean=70.00, sd=19.80, n=148) for self-care maintenance (Cene et al., 2013). Fifty-two percent of the community-dwelling patients in Cené's study achieved the standard of 70 for adequate self-care while only 41% were at or above 70 on self-care maintenance in the current study. Per  $X^2$  analysis, this was not a significant difference.

Table 12

*T Test Comparisons of SCHFI with Cené Study*

Scale	<i>n</i>	Mean (SD)	<i>n</i>	Cené Mean (SD)	<i>t</i>	<i>df</i>	<i>p</i>
Self-care Maintenance	121	63.22 (18.37)	148	70.00 (14.00)	-3.343	220	<.002
Self-care Management	121	57.18 (25.05)	112	57.00 (24.00)	.056	231	.955
Self-care Confidence	121	66.02 (22.48)	148	65.00 (17.00)	.412	219	.681

Cené et al., 2013, p. 205.

Table 13

*SCHFI Self-Care Adequacy Comparisons with Cené Study*

Scale		Cené	Standard	X <sup>2</sup>	<i>p</i>
Self-Care Maintenance	41%	52%	70%	3.06	.08
Self-Care Management	33%	32%	70%	0.02	.88
Self-Care Confidence	46%	33%	70%	4.85	≤0.28

Cené et al., 2013, p. 205; Riegel, Lee, et al., 2009, p. 492.

Research Question 3

What is the level of self-care management, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009), and the reported mean in the community-dwelling Cené et al. (2013) study?

Using a two-sample *t* test with unequal variances, an insignificant difference was found between the self-management score in this study (mean=57.18, sd=25.05, n=121 *t*=.056, *df*=23, *p*=.955) and the Cené study (mean=57.00, sd=24.00, n=112) (Cene et al., 2013). The self-care

management subscale is answered only if the individual experienced heart failure symptoms in the past month (Riegel, 2009). The percent of participants who achieved at least a 70 on this subscale was essentially the same (33% vs. 32%) in the two studies.

#### Research Question 4

What is the level of self-care confidence, as measured by the SCHFI subscale, in patients 50 years or older hospitalized with a heart failure exacerbation, and how does this level compare with the standardized cut point of 70 for adequacy of self-care (Riegel, 2009) and the reported mean in the community-dwelling Cené et al. (2013) study?

This question was also answered with a two-sample *t* test with unequal variances. Insignificant results were found between the means of the self-care confidence subscale scores in this study (mean=66.02, sd=22.48, n=121, *t*=.412, *df*=219, *p*=.681) and the Cené study (mean=65.00, sd=17.00, n=148). Even though the means were similar, in this study 46% of the participants scored at least a 70 on the subscale, indicative of adequate self-care confidence, which was quite a bit higher than the 33% in the Cené study (Cene et al., 2013). This was a statistically significant difference in adequacy scores based on the  $X^2$  test.

#### Research Question 5

What is the relationship of perceived emotional/informational social support, as measured by the MOS-SS emotional/informational subscale, to self-care maintenance, self-care management, and self-care confidence, as measured by SCHFI subscales, in patients 50 years or older hospitalized with a heart failure exacerbation?

Linear regression was utilized with the perceived emotional/ informational social support score (MOS-SS) as the independent variable (predictor) with each of the three self-care subscales as dependent variables. Control variables included: age, gender, living with another or not, co-morbidities as measured with the Charlson Comorbidity Index (CCI), educational level, and number of heart failure hospitalizations in the past six months.

*Self-care maintenance.* The model was statistically significant ( $F=2.486$ ,  $df=8$ ,  $p<.017$ ) at  $\alpha=.05$ . Nine percent of the variance in self-care maintenance was explained by the model. Linear regression standard coefficients were analyzed. The number of hospitalizations in the past six months is statistically significant ( $\beta=.245$ ,  $t=2.656$ ,  $p<.010$ ) as was having no education above a high school education ( $\beta=-.210$ ,  $t=-2.118$ ,  $p<.037$ ). No other independent variables in the model are significantly related with self-care maintenance. Table 14 displays the coefficients table.

*Self-care management and confidence.* Both self-care management and self-care confidence regression models failed the F test for significance but had significant  $t$  tests for variables, and a significant  $t$  test dominates a weak F test (Hofler, 2015b). Having less than a high school education ( $\beta=.212$ ,  $t=2.072$ ,  $p<.041$ ) was positively associated with self-care management as compared to having more than a high school education. In addition, age was negatively related to self-care management ( $\beta=-.210$ ,  $t=-1.965$ ) and was significant at the .052 level. For self-care confidence, both co-morbidities ( $\beta=.235$ ,  $t=2.279$ ,  $p<.025$ ) and perceived social support ( $\beta=.210$ ,  $t=-2.210$ ,  $p<.029$ ) were positively and significantly related. Tables 15 and 16 show the coefficient tables.

## Research Question 6

What is the relationship of self-care confidence, as measured by the SCHFI subscale, to self-care maintenance and self-care management, as measured by SCHFI subscales, in patients 50 years of age or older hospitalized with a heart failure exacerbation. Multiple regression was also utilized for research question six, but the predictor was the self-care confidence subscale and the dependent variables were the other two SCHFI subscales. Control variables included age, gender, living alone or with another, co-morbidities measured by the Charlson Comorbidity Index (CCI), educational level, and number of heart failure hospitalizations in the past six months.

*Self-care maintenance.* This model predicts 22% of the variance in self-care maintenance and this is statistically significant ( $F=5.236$ ,  $df=8$ ,  $p<.001$ ). Self-care confidence ( $\beta=.388$ ,  $t=4.676$ ,  $p<.001$ ) is positively associated with self-care maintenance. The number of heart failure admissions in the past six months ( $\beta=.265$ ,  $t=3.101$ ,  $p<.003$ ), and having less than a high school education ( $\beta=.265$ ,  $t=3.101$ ,  $p<.011$ ), or no more than a high school education ( $\beta=-.237$ ,  $t=-2.613$ ,  $p<.011$ ), when compared with having more than a high school education, were also statistically related to self-care maintenance. Age showed a positive relationship that was significant at the .60 level ( $\beta=.184$ ,  $t=1.903$ ). Table 17 shows the coefficient table.

*Self-care management.* The model estimates 15.8% of the variance in self-care management and this is also statistically significant ( $F=3.815$ ,  $df=8$ ,  $p<.002$ ). Self-care confidence ( $\beta=.327$ ,  $t=3.793$ ,  $p<.001$ ) is the only variable significantly related to self-care management. Table 18 displays the coefficient table.

Table 14

*Coefficients: Self-Care Maintenance (Predictor=MOS-SS)*

Model	Coefficients		Beta	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity	
	B	Std. Error				Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
	(Constant)	36.622				13.769		2.660	.009	9.341	63.904	
MOS-SS	.101	.061	.152	1.652	.101	-.020	.221	.212	.154	.144	.899	1.113
Gender	2.030	3.577	.055	.568	.571	-5.056	9.117	.096	.054	.049	.793	1.260
Age	.188	.197	.100	.952	.343	-.203	.578	.169	.090	.083	.684	1.461
Livingw/	-4.110	3.768	-.097	-1.091	.278	-11.576	3.356	-.091	-.103	-.095	.958	1.044
NoHS	-5.211	4.255	-.123	-1.225	.223	-13.643	3.220	-.017	-.115	-.107	.751	1.331
HS	-8.206	3.875	-.210	-2.118	.036	-15.884	-.529	-.154	-.196	-.184	.774	1.293
No. HF admits	2.431	.915	.245	2.656	.009	.617	4.244	.145	.243	.231	.889	1.125
CCI Score	.870	.869	.100	1.002	.319	-.851	2.592	.174	.094	.087	.759	1.317

$F=2.486$ ,  $df=8$ ,  $p<.017$ ; MOS-SS-Medical Outcomes Study – Social Support, Emotional/Informational Subscale; Living w/=living with someone; NoHS=dummy variable for education; HS=dummy variable for education; No HF admits=number of HF hospitalizations in past 6 months; CCI=Charlson Comorbidity Index

Table 15

*Coefficients: Self-Care Management (Predictor=MOS-SS)*

Model	Coefficients		Beta	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity	
	B	Std.				Lower	Upper	Zero-order	Partial	Part	Tolerance	VIF
		Error				Bound	Bound					
(Constant)	76.453	19.108		4.001	<.001	38.593	114.313					
MOSSS	.081	.085	.090	.964	.337	-.086	.249	.059	.091	.085	.899	1.113
Gender	5.586	4.964	.112	1.125	.263	-4.249	15.420	.136	.106	.100	.793	1.260
Age	-.538	.274	-.210	-1.965	.052	-1.080	.005	-.106	-.183	-.174	.684	1.461
Living w/	-2.975	5.229	-.052	-.569	.571	-13.336	7.386	-.050	-.054	-.050	.958	1.044
NoHS	12.237	5.905	.212	2.072	.041	.536	23.938	.271	.192	.184	.751	1.331
HS	-4.177	5.377	-.078	-.777	.439	-14.832	6.477	-.172	-.073	-.069	.774	1.293
No. HF admits	-.148	1.270	-.011	-.117	.907	-2.665	2.369	.006	-.011	-.010	.889	1.125
CCI Score	.971	1.206	.082	.805	.423	-1.418	3.360	.050	.076	.071	.759	1.317

$F=1.918$ ,  $df=8$ ,  $p<.065$ ; MOS-SS=Medical Outcomes Study – Social Support, Emotional/Informational Subscale; Living w/=living with someone; NoHS=dummy variable for education; HS=dummy variable for education; No HF admits=number of HF hospitalizations in past 6 months; CCI=Charlson Comorbidity Index

Table 16

*Coefficients: Self-Care Confidence (Predictor=MOS-SS)*

Model	Coefficients		Beta	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity	
	B	Std.				Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
		Error										
(Constant)	62.915	17.396		3.617	<.001	28.447	97.382					
MOS-SS	.170	.077	.210	2.210	.029	.018	.323	.171	.204	.199	.899	1.113
Gender	-1.555	4.519	-.035	-.344	.731	-10.509	7.398	.029	-.033	-.031	.793	1.260
Age	-.408	.249	-.178	-1.638	.104	-.902	.086	-.028	-.153	-.147	.684	1.461
Living w/	2.413	4.761	.047	.507	.613	-7.020	11.846	.007	.048	.046	.958	1.044
NoHS	6.942	5.376	.134	1.291	.199	-3.711	17.594	.111	.121	.116	.751	1.331
HS	1.870	4.896	.039	.382	.703	-7.830	11.570	-.042	.036	.034	.774	1.293
No. HF admits	-.642	1.156	-.053	-.555	.580	-2.933	1.650	-.018	-.052	-.050	.889	1.125
CCI Score	2.502	1.098	.235	2.279	.025	.327	4.677	.172	.211	.205	.759	1.317

$F=1.466$ ,  $df=8$ ,  $p<.18$ ; MOS-SS=Medical Outcomes Study – Social Support, Emotional/Informational Subscale; Living w/=living with someone; NoHS=dummy variable for education; HS=dummy variable for education; No HF admits=number of HF hospitalizations in past 6 months; CCI=Charlson Comorbidity Index

Table 17

*Coefficients: Self-Care Maintenance (Predictor=Self-Care Confidence)*

Model	Coefficients		Beta	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity	
	B	Std.				Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
		Error										
(Constant)	18.797	13.375		1.405	.163	-7.703	45.297					
Gender	2.608	3.311	.071	.788	.432	-3.952	9.168	.096	.074	.064	.794	1.260
Age	.344	.181	.184	1.903	.060	-.014	.702	.169	.177	.153	.698	1.433
Living w/	-5.298	3.451	-.125	-1.535	.128	-12.136	1.541	-.091	-.144	-.124	.979	1.021
NoHS	-7.848	3.921	-.185	-2.002	.048	-15.617	-.079	-.017	-.186	-.161	.759	1.318
HS	-9.260	3.544	-.237	-2.613	.010	-16.282	-2.239	-.154	-.240	-.211	.793	1.262
No. HF admits	2.632	.849	.265	3.101	.002	.950	4.313	.145	.281	.250	.887	1.128
CCI Score	.069	.822	.008	.084	.933	-1.559	1.697	.174	.008	.007	.728	1.374
SCConf	.317	.068	.388	4.676	<.001	.183	.451	.369	.404	.377	.945	1.059

$F=5.236$ ,  $df=8$ ,  $p<.001$ ; Living w/=living with someone; NoHS=dummy variable for education; HS=dummy variable for education; No HF admits=number of HF hospitalizations in past 6 months; CCI=Charlson Comorbidity Index; SCConf=self-care confidence

Table 18

*Coefficients: Self-Care Management (Predictor=Self-Care Confidence)*

Model	Coefficients				95.0% Confidence		Correlations		Collinearity			
	B	Std. Error			Lower Bound	Upper Bound	Zero-order	Partial	Tolerance	VIF		
	Beta	t	Sig.			Part						
(Constant)	12.706	3.032		4.191	<.001	6.699	18.714					
Gender	.990	.751	.124	1.319	.190	-.497	2.477	.136	.124	.110	.794	1.260
Age	-.060	.041	-.148	-1.474	.143	-.142	.021	-.106	-.138	-.123	.698	1.433
Living w/ NoHS	-.645	.782	-.070	-.824	.412	-2.195	.905	-.050	-.078	-.069	.979	1.021
HS	1.524	.889	.165	1.715	.089	-.237	3.285	.271	.160	.144	.759	1.318
No. HF admits	-.808	.803	-.095	-1.006	.317	-2.400	.784	-.172	-.095	-.084	.793	1.262
CCI Score	.014	.192	.006	.070	.944	-.368	.395	.006	.007	.006	.887	1.128
SCConf	.009	.186	.005	.048	.962	-.360	.378	.050	.005	.004	.728	1.374
	.058	.015	.327	3.793	<.001	.028	.089	.357	.337	.318	.945	1.059

$F=3.815$ ,  $df=8$ ,  $p<.002$ ; Living w/=living with someone; NoHS=dummy variable for education; HS=dummy variable for education; No HF admits=number of HF hospitalizations in past 6 months; CCI=Charlson Comorbidity Index; SCConf=self-care confidence

### Summary

The convenience sample included 121 hospitalized patients with heart failure in Central Florida hospitals. The mean age was over 71 years and both gender and type of heart failure were evenly distributed. The median number of hospital admissions in the prior six months was two, but 47% of the participants had only the one admission. Calculated Cronbach's alphas for the study instruments were comparable to those in other studies. Linear regression and two-sample *t*-tests with unequal variances were utilized to evaluate the data. The Chi-square test was used to determine differences in adequacy scores between the two studies.

Data analysis demonstrated statistically significant differences between the means of the MOS-SS and Self-Care Maintenance subscales when comparing this study with results from the Cené (2013) findings. Self-care management and self-care confidence were not significantly different.

Regression statistics to determine the relationship of MOS-SS to each of the self-care subscales, controlling for age, gender, number of close relationships, number of hospitalizations in the past six months, and education, indicated that perceived social support was statistically significant only for self-care confidence, along with the number of co-morbidities. MOS-SS was not a significant contributor for the variance in either self-care maintenance or self-care management. In self-care maintenance, only the number of hospitalizations in the past six months and having no more than a high school education were significant. Age and having less than a high school education were statistically significant for self-care management.

The associations of self-care confidence to both self-care maintenance and self-care management were statistically significant. For self-care maintenance, having no more than a high school education, the number of heart failure hospitalizations in the past six months, age, and self-care confidence were significant contributors to the model. The model explained 22% of the variance in self-care maintenance. Almost 16% of the variance was explained by the self-care management model, and self-care confidence was the only variable that contributed significantly to the model.

## CHAPTER 5 DISCUSSION

### Introduction

Hospitalizations for heart failure exacerbation are often considered “failed self-care (Cene et al. 2013; Dickson et al., 2011). Enhancing social support and self-care are both considered strategies to reduce hospital admissions in patients with heart failure (Cene et al., 2013; Dunbar et al., 2008; Riegel & Dickson, 2008; Wu et al., 2012). The purpose of this study was to evaluate the relationship of perceived emotional and informational social support to self-care maintenance, self-care management, and self-care confidence, and to test the relationship of self-care confidence to self-care maintenance and self-care management in patients at least 50 years of age hospitalized with a heart failure exacerbation. This study was based on a model which the principal investigator blended from the Self-Care of Heart Failure Theory and the Stress Buffering Model of the Social Support Theory. Based on limited evidence that better perceived social support and self-care are related to lower heart failure hospitalization rates, this study examined if hospitalized patients with heart failure with an exacerbation have deficiencies in perceived availability of social support and in self-care. To date, this is the first study to evaluate hospitalized patients with heart for deficiencies in perceived social support and self-care. This chapter compares and contrasts findings from this research with studies in the literature. Recommendations for future research and practice implications are examined.

### Sample

The sample in this study was similar to national statistics for patients with heart failure and Central Florida demographics (Table 19). The convenience sample of hospitalized patients with heart failure in this study had a mean age of 71.24 years and both gender and heart failure type were equally distributed. County statistics of residents living below the poverty level ranged from 11.30 – 17.9% (*Florida charts*, 2015). In this study Medicaid was used as a proxy for low income level and a greater percentage of participants received Medicaid than was listed in county statistics. The Hispanic population was underrepresented in this study, due to language exclusion criteria. Blacks/African Americans were overrepresented but this was expected as Blacks/African Americans are more likely to develop heart failure and to have poorer outcomes (Go et al., 2014), as well as a higher risk for hospitalization (ARR=3.4,  $p<.001$ ) when compared to Whites/Caucasians (Albert, 2009). The educational level in the primary metropolitan county was somewhat higher than the research participants, which was probably related to older age.

Table 19

*Comparison of Sample with National and Local Demographics*

	This study	National HF	Central FL
Males	49.60%	50.00%	
Age	71.2 yrs.	75 yrs <sup>1</sup>	
Type of HF <sup>2</sup>			
HF <sub>r</sub> EF	49.60%	50.00%	
HF <sub>p</sub> EF	50.40%	50.00%	
Race/Ethnicity <sup>3</sup>			
White	69.40%		71.10%
Black	30.60%		15.80%
Hispanic	9.10%		27.00%
<Poverty level <sup>3</sup>	23.10%		11.3-17.9%
≥HS graduate <sup>3</sup>	75.20%		86.90%

<sup>1</sup>Florida healthcare landscape, 2015; <sup>2</sup>Get with the guidelines: heart failure, 2014; <sup>3</sup>Data Center, 2013. HF=heart failure; HF<sub>r</sub>EF=heart failure with reduced ejection fraction; HF<sub>p</sub>EF=heart failure with preserved ejection fraction; HS=high school.

Perceived Social Support

It was hypothesized that hospitalized patients with heart failure would have lower levels of perceived emotional and informational social support, as measured with the MOS-SS, when compared to the Cené study and this was the finding. This study's mean was significantly lower in comparison with Cené, and is the expected result if higher levels of perceived social support are related to lower rates of hospitalizations as indicated in a Scientific Statement on Heart Failure Self-Care from the American Heart Association (Riegel, Moser, et al., 2009). However, perceived social support was statistically significant only for self-care confidence when using multiple regression with MOS-SS as the predictor and control variables for age, gender, living with another or not, co-morbidities measured with the CCI, educational level, and number of

heart failure readmissions in the past six months. These results supported findings from some studies while contrasting with others.

Only two studies of hospitalized patients with heart failure were identified and neither found a significant relationship between social support and self-care (Cameron Worrall-Carter, Riegel, Lo, & Stewart, 2009; Rockwell & Riegel, 2001). Rockwell (2001) analyzed predictors of self-care in hospitalized patients with heart failure at multiple sites in southern California, and Cameron et al. (2009) used living with another or not as a proxy for social support with an Australian sample. Although findings were similar, both studies used different instruments than this study.

Alternatively, three studies evaluating perceived social support and self-care reported significant associations between perceived social support and self-care maintenance, but not self-care management, in samples of community-dwelling patients with heart failure (Cene et al., 2013; Salyer et al., 2012). The Salyer (2012) research of all HF/rEF patients found that perceived social support had a positive indirect effect on self-care management through self-care confidence, and Cené et al. (2013) reported that self-care confidence was a mediator of the association between self-care maintenance and perceived social support. One other study tested heart failure patients who had a partner to assist with self-care, with statistically significant relationships found between the partner-provided social support and both self-care maintenance and self-care management (Sebern & Riegel, 2009).

The hypothesized positive relationship between perceived social support and self-care maintenance and self-care management was not supported in this study. However, the difference may be that perceived social support is more important for patients with heart failure who are not

hospitalized. Variations in settings and measurement tools may explain the mixed results on social support in other studies. Also, perceived social support is not the same as actual social support.

### Self-Care

As with perceived social support, it was hypothesized that each of the self-care subscale scores would be lower for hospitalized individuals than for the community-dwelling patients with heart failure. There was a statistically significant difference found on self-care maintenance. As expected, hospitalized patients with heart failure scored lower than those in the community. In addition, just 41% of the participants in this study had adequate self-care maintenance, as indicated by a score of 70 or greater, which was not significantly lower than the 52% in the Cené study (Cene et al., 2013). Self-care in patients with heart failure is considered an important piece of disease management guidelines, both to reduce readmission rates and mortality (Yancy et al., 2013), and research has shown an increase in mortality and hospitalizations if patients do not comply with at least some of the recommended self-care behaviors (Riegel, Lee, & Dickson, 2011). Self-care maintenance involves following a treatment plan and is a prerequisite for self-care management that involves taking an appropriate action when a symptom is identified and evaluating its effectiveness. Table 20 displays a sampling of SCHFI scores and participant characteristics from several studies, showing that poor or barely adequate scores are often the norm.

In contrast, neither self-care management, which requires the patient to take an action to alleviate symptoms and evaluate the effect, nor self-care confidence were statistically different

between this study and that of Cené, with almost identical means in both studies. Adequate self-care management percentages were essentially the same as in the Cené study. However, for self-care confidence there was a statistically significant larger percentage of self-care confidence scores within the adequate range for hospitalized patients than for community dwelling patients. Perhaps patients in this study gained confidence that they can adhere to self-care recommendations, or enhanced their knowledge of heart failure self-care, from the hospitalization experience. Another explanation may be that patients were over-confident and had a difference in their perceived and actual self-care skills. It may also be that a large percentage of this study's participants felt confident in their self-care abilities as 47% had only been hospitalized once in the past six months. Heart failure is a syndrome with expected exacerbations and the average six month re-hospitalization rate in Medicare patients has been estimated at 45% (Krumholz, Parent, Tu, Vccarino, Want, Radford, & Hennen, 1997).

Table 20

*Self-Care Scores and Adequacy Percentages*

	n	Age	Black	Males	SCMain	≥70	SCMan	≥70	SCConf	≥70
Harkness <sup>1</sup>	100	72	27%	68%	67 (16)	NR	51 (24)	NR	55 (20)	NR
Dickson <sup>2</sup>	112	59	25%	62%	73 (14)	64%	70 (19)	60%	71 (15)	50%
Salyer <sup>3</sup>	97	57	46%	57%	70 (16)	NR	62 (20)	NR	66 (17)	NR
Dickson <sup>4</sup>	30	60	100%	60%	60 (18)	<25	51 (19)	<25%	62 (18)	<25%
Dickson <sup>5</sup>	41	49	27%	63%	72 (14)	61%	71 (19)	44%	NR	NR
Cené <sup>6</sup>	150	61	43%	49%	70 (14)	52%	57 (24)	32%	65 (17)	33%
Cameron <sup>7</sup>	52	73	NR	76%	68 (17)	52%	50 (17)	12%	62 (20)	36%
This study	121	71	31%	50%	63 (18)	41%	57 (25)	33%	66 (22)	46%

SCMain=self-care maintenance; SCMan=self-care management; SCConf=self-care confidence; NR=not reported. Values rounded to nearest whole number.

<sup>1</sup>Harkness, Heckman, Akhtar-Danesh, Demers, Quinn, & McKelvie, 2014; <sup>2</sup>Dickson, Buck, et al., 2013; <sup>3</sup>Salyer et al., 2012; <sup>4</sup>Dickson, McCarthy, Howe, Schipper, & Katz, 2013; <sup>5</sup>Dickson et al., 2008; <sup>6</sup>Cené et al., 2013; <sup>7</sup>Cameron et al., 2009.

There were other differences between this study and that of Cené that may explain the lack of variation in self-care management and self-care confidence scores. Participants in this study were older, had a higher income, and a lower ratio of Black/African Americans than Whites/Caucasians (Cene et al., 2013). Low income has been shown to influence heart failure with more frequent hospitalizations (Amarasingham et al., 2010; Lindenauer et al., 2013), but not specifically self-care. A recent longitudinal randomized control trial tested home visits as an intervention to improve self-care in heart failure patients and did not find either income or age to be associated with self-care in either the control or intervention group (Trojhan, 2013). Another study to assess variables that influence poor outcomes after hospital discharge in elderly patients with heart failure also did not show significance for age and income (Roe-Prior, 2007). The

racial variation (44% of participants were Black/African American in the Cené study compared to 31% in this study) may be a reason for a difference in self-care confidence adequacy scores between this study and Cené's. In addition, demographics of Chapel Hill show a smaller urban area that is approximately one-fourth the size of Central Florida, with an average age of 25.1 years and only an 8.8% Black/African American population ("Chapel Hill, NC,"). This indicates that the large percentage of Black/African Americans in the sample may have comprised individuals from surrounding rural areas.

A mixed methods analysis of both ambulatory and hospitalized Black/African American patients with heart failure indicated that heart failure self-care is strongly influenced by cultural beliefs and social standards (Dickson et al., 2013). Less than 25% of the patients in that study had adequate self-care scores (Dickson et al., 2013), although the means were comparable to Cené and this study (see Table 20). Qualitative findings included having a strong spirituality in which a higher power is in control, and a perception among participants that heart failure is inevitable or due to stress, which limited motivation for self-care activities (Dickson et al., 2013). Davis, Hummelfarb, Szanton, Hayat, & Allen (2015) assessed SCHFI subscales and cognition in patients with heart failure; results of this study showed inadequate self-care scores on all the self-care scales, but Black/African American patients had scores more than 7% lower on self-care maintenance.

The regression model in this study explained 9% of the variance in self-care maintenance. A greater number of heart failure admissions in the past six months was associated with better self-care maintenance, and less than a high school education was related to lower self-care maintenance. It may be that patients with more heart failure hospitalizations were sicker than the

rest of the sample, although there was no correlation between the number of hospitalizations in the past six months and the CCI score. Patients with more advanced heart failure are expected to have more frequent exacerbations leading to hospitalizations. One study found that more years of schooling predicted better self-care behaviors although almost half of the elderly sample had completed only grade school, and that self-care behaviors can be taught regardless of the education level (Rockwell & Riegel, 2001). Further, a study of more than 600 patients with heart failure who completed six months of a disease management program showed no education-associated differences for hospitalizations or mortality, and also that the least well-educated had the greatest reduction sodium intake (Smith, Forkner, Krasuki, Galbreath, & Freeman, 2006). Both the Rockwell and Smith studies demonstrated that people with lower levels of education can develop effective self-care skills (Rockwell & Riegel, 2001; Smith et al., 2006).

Having less than a high school education was positively related and age was negatively associated, with self-care management in this study, while only age was a significant contributor to Cené's model for self-care management. It may be that these individuals are more likely to strictly adhere to provider instructions or to request assistance, and the Rockwell et al. (2001) and Smith et al. (2006) research demonstrated the ability for individuals with lower levels of education to develop effective self-care behaviors. In two different studies, age was a factor in less effective self-care: in one, patients with heart failure greater than 73 years of age had more difficulty than younger patients in recognizing symptoms of the syndrome (Riegel, Lee, & Dickson, 2011) and in the other study, age was associated with more cognitive decline and severity of heart failure (Riegel, Dickson, Cameron, et al., 2010). Self-care confidence was positively associated with the number of comorbidities and with perceived social support.

A predictor of self-care confidence in regression models was positively and significantly associated with both self-care maintenance and self-care management when controlling for age, gender, living with another or not, co-morbidities as measured with the CCI, educational level, and number of heart failure hospitalizations in the past six months. The number of heart failure admissions in the past six months and age also positively contributed to the model that explained 22% of self-care maintenance. Having less than a high school education, or no more than a high school education, were both negatively related to self-care maintenance. Only self-care confidence was statistically significant in contributing to a model that explains 15.8% of the variance for self-care management.

These findings support those of other studies (Cene et al., 2013; Heo, Moser, Lennie, Riegel, & Chung, 2008; Lee et al., 2011; Riegel, Lee, Albert et al., 2011). Self-care confidence was reported as a mediator of both self-care maintenance and self-care management in the Cené study (Cene et al., 2013), and is considered a moderator in the theory of heart failure self-care (Riegel, Lee, & Dickson, 2011). In two other studies, self-care confidence was determined to be the key factor in individuals developing into “experts” in self-care (Lee et al., 2011; Riegel, Lee, Albert, et al., 2011). Although mediation and moderation were not tested in this study, self-care confidence was significantly and positively associated with self-care maintenance and self-care management.

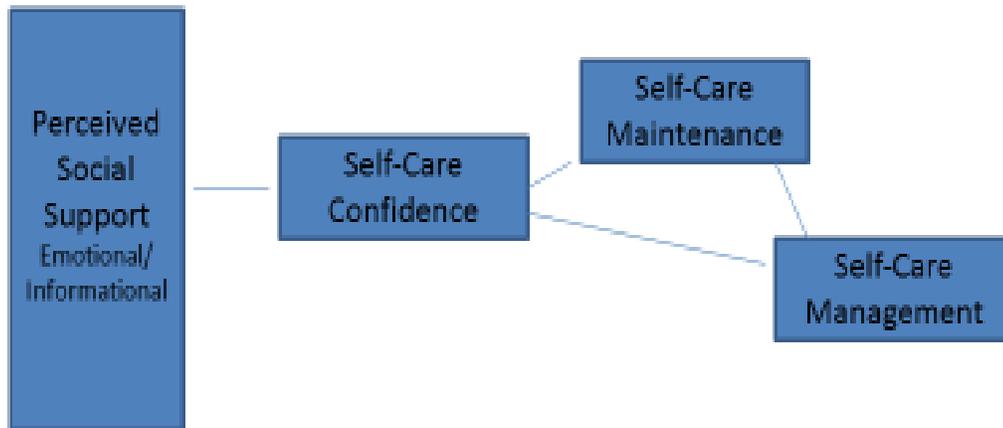


Figure 6. Modified Heart Failure Perceived Social Support Self-Care Model.

Based on the findings in this study, the theoretical model was revised to remove the connection between perceived social support and self-care maintenance and self-care management.

### Cognition

Potential cognitive deficits was not part of this study, although Cené et al. (2013) included the Blessed Orientation-Memory-Concentration score (mean=3.30; sd=2.70) as a variable. The BOMC was used as a post consent screening tool to assure adequate cognition for informed consent. A large percentage (25%) of consented individuals were not included in this study because cognitive deficits were identified by having a BOMC score of greater than eight, even though the Principal Investigator had already excluded potential participants that nursing staff or medical record documentation indicated had memory issues. It is estimated that 25-50% of patients with heart failure have some degree of cognitive impairment (Hjelm, Brostrom,

Riegel, Arestedt, & Stromberg, 2015; Pressler et al., 2010), with the causes likely to be multifactorial (Ampadu & Morley, 2015). A study of veterans with heart failure found that 58% had cognitive impairment when tested with the Mini Mental Status Examination, and the deficits were most often with immediate and delayed memory as well as verbal learning; the veterans with cognitive deficiencies were significantly less likely to comply with their medication regimen (Hawkins et al., 2012). Intact cognitive abilities are necessary for successful self-care (Riegel & Dickson, 2008), and even mild cognitive impairment may negatively influence learning abilities and self-care compliance even though the individual may perform general activities of daily living (Davis et al., 2015). Current heart failure guidelines do not recommend routine testing of cognition so impairments may be unrecognized.

### Implications for Practice

The results of this study contribute to the body of knowledge on heart failure self-care through focusing on hospitalized patients. Study findings have implications for nursing practice related to patient cognition and to self-care, especially patient self-care confidence.

This study supported the findings of other studies that many patients with heart failure have not achieved adequate self-care skills. Good self-care maintenance is the qualification for self-care management, and hospitalized patients had significantly lower self-care maintenance scores than a sample of community-dwelling patients with heart failure. Self-care behaviors require knowledge and skill as a prerequisite, so it is crucial that patients are given in-depth education when they are diagnosed with heart failure, and that this education is assessed and reinforced at every healthcare encounter. Patient education is a fundamental responsibility of

nursing (*Cardiovascular nursing: Scope and standards of practice*, 2015) and it is important that nurses use techniques such as teach back to assure comprehension of education. The large percentage of consented patients who were found to have cognitive deficits may indicate that patient education may not be fully understood or retained if given during hospitalization. A mixed methods study of post-discharge orthopedic patients found that almost half of the patients perceived poor reception and retention of discharge instructions, and that 41% of the patients did not recall getting information on medication side effects (Tocco, 2012). These findings reinforce the need for friends or family to be included in patient education sessions.

Self-care confidence was strongly related to better self-care maintenance and self-care management in this study. Nursing assessment of self-care confidence in patients with heart failure may provide an indicator of whether an individual needs additional resources to facilitate self-care behaviors. Promoting patient knowledge and skills may bolster self-care confidence, which may improve self-care maintenance and self-care management, and thus leading to better outcomes for these patients.

One fourth of consented patients in this study showed evidence of cognitive impairment, even after initial screening of the patients' records. While it is known that up to half of all patients with heart failure have some degree of cognitive impairment, it is unknown whether cognitive issues are greater in patients hospitalized with heart failure, and if the BOMC scores would improve if screening was conducted at admission and again at discharge. It is possible that exacerbations, through decreased perfusion and oxygenation, create a temporary worsening in cognition. It is also possible that the patients' cognitive impairments hindered self-care and led to hospitalization. In addition, we do not know if community-dwelling patients with heart

failure also have more cognitive issues than identified. Utilizing a short, validated tool to assess cognition on a regular basis is encouraged in order to identify a baseline and assure patients are able to understand patient education of their treatment plans as even mild cognitive impairments are associated with the ability to learn.

### Limitations and Strengths

This research was a descriptive comparative study of a convenience sample of hospitalized patients in four Central Florida hospitals and results were compared to a study of community dwelling patients with heart failure in North Carolina. The Hispanic population in this study was underrepresented as a result of language barriers and exclusion criteria. More than half of study participants had no more than two admissions in the prior six months; heart failure is a syndrome characterized by periodic exacerbations and prolonged periods between hospitalizations may not be indicative of “failed self-care.” Therefore results may not be generalizable to the national or international heart failure population. Due to the cross sectional design, causality cannot be inferred and there is no assessment of later outcomes. Despite limitations, there were strengths in this study.

The research questions were based on a theoretical framework and prior studies of the relationships of perceived social support and self-care to hospitalizations. The mean age was higher, and closer to the national mean, than most published nursing heart failure studies. This study also had a strong percentage of Black patients, as well as women, which is often not the case. Finally, the evaluation of self-care in hospitalized patients fills a gap in the literature.

### Recommendations for Future Research

More information is needed about mild cognitive issues, the best means to identify it, and the effect it has on self-care for patients with heart failure. It is also crucial to determine if hospitalized patients have higher levels of cognitive impairment and whether or not it is temporary. Based on findings of cognition in inpatient versus ambulatory settings, the most effective time for patient education may need to be assessed along with determination of patients' retention of information. Currently the American Heart Association's heart failure monitoring and quality improvement program advocates for 60 minutes of heart failure patient education prior to hospital discharge ("Get with the guidelines: heart failure," 2014), and this is supported in the American Association of Heart Failure Nurses' position paper on patient education (Rasmussen, 2015). If patients do have temporary cognitive impairments and/if they do not retain the information, during hospitalization may not be the most effective time to teach self-care.

Additional evidence is needed to confirm or refute the premise that up to half of heart failure readmissions are related to failed self-care (Dickson et al., 2011; Salyer et al., 2012) and if so, in what time frame? This study demonstrated lower self-care maintenance for hospitalized patients as compared to a sample of community dwelling patients with heart failure but a large percent of participants had only one hospitalization in the prior six months, and a strong percentage of participants had adequate self-care confidence scores. Additional studies are also needed to determine a consensus on the role of perceived and/or actual support on heart failure self-care; validated tools that measure emotional and informational types of social support need

to be tested rather than proxy measures. It is also important to determine treatment strategies and patient education that are congruent with patients' belief systems.

Most nursing research related to heart failure self-care has utilized education or support strategies with an expectation that these interventions will result in better self-care. Self-care confidence has been repeatedly shown to be strongly related to self-care maintenance and self-care management, and interventions to improve self-care confidence need to be identified and tested. Further, results of the interventions need to be assessed as to clinical outcomes over a period of time.

### Summary

Self-care for patients with heart failure is a key to management of the syndrome when patients are not in the hospital, and failed self-care is thought to be the cause of up to 50% of readmissions. This study did find a lower mean on self-care maintenance in hospitalized patients with heart failure but no difference on self-care management or self-care confidence when compared to community dwelling patients. In addition, participants in this study had a significantly higher percentage of adequate self-care confidence scores than the community dwelling patients. Cognitive deficiencies were identified in 25% of potential pre-screened participants for this study and this requires additional research to determine if unidentified mild cognitive impairments are more prevalent in the heart failure population as a whole, or if exacerbations cause a temporary worsening of cognition. Both situations have implications for most effectively assisting patients with heart failure to achieve knowledge and skills for successful self-care.

APPENDIX A  
LITERATURE SUMMARY TABLE

Author/Year/ Country; Study Design & Sample	Instruments & Outcome variables	Results	Limitations & Comments
Amarasingham et al. 2010; United States  Descriptive; n=1372	<u>Outcomes:</u> non-elective all cause readmission within 30 days of discharge and mortality for patients < or ≥ 45 years of age	24.1% readmitted within 30 days. Single, male, number of home address changes and residence in a census tract of the lowest socioeconomic quintile were significant ( $p \leq .05$ ) components of the model. Higher risk patients were readmitted earlier within the 30 day post discharge period ( $p < .001$ ).	<u>Limitations:</u> Tested in one urban health system with atypical population
Arestedt et al. 2013; Sweden; Cross-sectional; N=349	<u>Instruments:</u> MLHFQ, SF-12, ISSI ( $\alpha$ not reported for subscales); <u>Outcomes:</u> age, financial status, gender, and cohabitation relationships with social support in HF patients	Male gender, perceived financial challenges, living alone, and higher NYHA classes were associated with lower levels of social support. Higher levels of social support was associated with higher HRQOL.	<u>Limitations:</u> Non-participants were significantly older than participants; different imputation methods were used for missing data on instruments. No alpha was reported for instruments.
Cené et al. 2013; United States; Cross-sectional; N=150	<u>Instruments:</u> BOMC, CESD, SCHFI, MOS-SS; <u>Outcomes:</u> association between perceived social support and self-care in community-dwelling HF patients, and mediation of the relationship	Higher levels of perceived emotional/informational social support associated with better self-care maintenance ( $\beta = .13, p < .05$ ) and with unadjusted self-care management ( $\beta = .23, p < .05$ ) but not adjusted. Self-care confidence mediates the relationship between perceived social support and self-care (32% $\beta$ change for self-care maintenance and 20% for self-care management).	<u>Limitations:</u> Gender differences were not assessed; participants were from one site in NC

Author/Year/ Country; Study Design & Sample	Instruments & Outcome variables	Results	Limitations & Comments
Chin & Goldman 1997; United States; Prospective descriptive; N=257	<u>Instruments</u> : Researcher developed 7 item compliance scale with a question on needing additional help after discharge not available from family/friends; <u>Outcomes</u> : death and hospital readmission within 60 days	31% were readmitted w/in 60 days and 5% died. Independent correlates included single marital status (HR 2.1, 95% CI 1.3-3.3. Non-married patients were more likely to be female (69%, $p \leq .01$ ) and express a need for more assistance (that couldn't be provided by family/friends) after DC (62% vs 35%).	<u>Limitations</u> : Data collected at 1 urban hospital; Used marital status as proxy for SS. <u>Comments</u> : Unable to identify a low risk group
Chung et al 2009; United States; Prospective, longitudinal (Part of RICH study); N=166	<u>Outcomes</u> : Event-free survival (mortality and cardiac readmission)	56% of participants were married; Longer time to readmission in non-depressed patients ( $p = .05$ ) and in married patients ( $p = .009$ ). Marital status independent predictor of event-free survival (OR 2.48, 95% CI 1.38-4.43) even when other factors were controlled.	<u>Limitations</u> : Only 32.3% of qualified candidates participated in RICH study; used marital status as measure of an aspect of SS; quality of marital relationship was not assessed
Gallagher et al. (2011); Australia & The Netherlands; 2ndary cross-sectional analysis prior to randomization; N=333	<u>Instruments</u> : EHFScBS ( $\alpha = .71$ ), SS questions were pulled from the original COACH study but instrument was not identified ( $\alpha = .96$ ); <u>Outcomes</u> : Types of SS & impact on HF self-care	High SS levels related to better self-care ( $p < .003$ ), including consulting a healthcare provider for weight gain ( $p < .03$ ), limiting fluid intake ( $p < .03$ ), adhering to the medication regime ( $p < .05$ ), exercising regularly ( $p < .001$ ), and getting an annual influenza vaccine ( $p < .02$ ). SS must match patient's perceived need to influence self-care.	<u>Limitations</u> : Only cohabitating intimate relationships; original study was not designed to measure social support; SS instruments were not identified <u>Comments</u> : SS=relationships with a partner that promote health or buffer stress
Happ et al. 1997; United States; Qualitative 2ndary analysis; N=16	<u>Outcomes</u> : Social and behavioral factors influencing cardiac-related readmission	Supportive relationships and individual motivation were preventive factors for readmission.	<u>Limitations</u> : Only used available documentation. <u>Comments</u> : Sample was 8 readmitted and 8 not readmitted patients.

Author/Year/ Country; Study Design & Sample	Instruments & Outcome variables	Results	Limitations & Comments
Rodriguez-Artalejo et al. 2006; Spain; Prospective descriptive; N=371	<u>Instruments:</u> 4-item questionnaire: marital status, living with another person, saw or had telephone contact with family members living apart daily or almost daily, and were at home alone for less than 2 hrs/day. Is there anybody with whom you can share secrets and feelings, someone that you feel you can trust? Is there anybody who looks after you due to your disease? <u>Outcomes:</u> Time to 1 <sup>st</sup> readmission	6.4 mos follow up after index admission. 36.4% readmitted & 18.3% died. Living alone statistically significantly associated with readmission. Readmission more frequent among patients with moderate (HR 1.87, 95% CI 1.06-3.29; p<.05) or low (HR 1.98, 95% CI 1.07-3.68; p<.05) social networks. Inverse relationship between social isolation and readmission rate (p<.04).	<u>Limitations:</u> Questions to evaluate social, functional, and emotional support were not validated and demonstrated redundancy.
Roe-Prior 2007; United States; 2ndary analysis descriptive; N=103	<u>Outcomes:</u> All-cause rehospitalizations, ED use, & unscheduled physician office or clinic visits	43 patients had 57 readmissions during a 90 day period. Being unmarried ( $\beta=.25$ , $p=.02$ ) and having low income ( $\beta=.17$ , $p=.06$ ) were most predictive of readmission but illness severity was more important than sociodemographic factors in predicting service use post discharge.	<u>Limitations:</u> Excluded participants had worse functional status and more co-morbidities than completers. <u>Comments:</u> Study was done prior to Medicare drug benefit
Salyer et al. 2012; United States; 2ndary analysis, pilot; N=97	<u>Instruments:</u> MOS-SS, SCHFI; <u>Outcomes:</u> relationship of social support and self-care in HF patients, and if self-care confidence mediates the relationship	The best predictor of self-care management was self-care confidence. Self-care confidence mediated the effects of large social network size, and the relationship between social support and self-care. No relationship between marital status and self-care.	<u>Limitations:</u> Difference in characteristics in participants and nonparticipants. Marital status was dichotomous measure.
Schwarz & Elman 2003; United States; Prospective longitudinal study; N=128 dyads	<u>Instruments:</u> MISSB ( $\alpha=.92$ ). <u>Outcomes:</u> 90 day HF readmissions, changes in functional status and caregiver stress	44% of patients were readmitted within 90 days ( $35.57 \pm 26.7$ days, range 1 – 90 days). Caregiver support reduced the risk for readmission (p<.05) although higher rates of caregiver depression and stress raised the risk for readmission (p<.05).	<u>Limitations:</u> Convenience sample

Author/Year/ Country; Study Design & Sample	Instruments & Outcome variables	Results	Limitations & Comments
Tsuchihashi-Makaya et al. 2009; Japan; Prospective descriptive; N=136	<u>Instruments</u> : PSSS; <u>Outcomes</u> : HF readmission or cardiac death	Mean PSSS=71.4 and positive social interaction score was lower than other subscales. 25.2% were readmitted and 1 died. Readmitted patients had lower PSSS total, affectionate, and positive social interactions scores. Low SS was an independent predictor of HF readmissions.	
Volz et al. 2011; Switzerland; Cohort; N=111	<u>Instruments</u> : DS 14 ( $\alpha=.86-.87$ ); ESSI-G ( $\alpha=.88$ ); <u>Outcomes</u> : Death, cardiac-related readmission, HRQOL	Mean follow up period was $2.80 \pm 1.10$ years (range 1 – 5 years). 11 died & 24 had readmissions. SS did not show an association with readmission or Type D personality. Severe anxiety was associated with cardiac-related readmission (HR=3.21, 95% CI 1.04-9.93, p.04).	<u>Limitations</u> : 10% of patients with lower SS were lost to follow up;95% of sample had high level of social support
Watkins et al. 2013; United States; Cohort; N=357	<u>Outcomes</u> : time to readmission, HF readmission rate, and in-hospital survival	Marital status was not significant for HF readmissions (HR=1.16, 95% CI .86-1.56; p>.05)	<u>Limitations</u> : Chart review at one hospital; <u>Comments</u> : Sample had large percentage of drug abuse, 73% African Americans, poor health literacy, and only 5.6% had commercial insurance.
Wu et al. 2010; United States; Prospective longitudinal; N=135	<u>Outcomes</u> : cardiac-related readmission or all-cause mortality <u>Instruments</u> : Medication Adherence Scale, Medication Event Monitoring System	African Americans were admitted at a higher rate than Caucasians (47% vs 19%, $p<.005$ ) and were 3.19% more likely to have an event ( $p<.023$ ) but no differences in mortality. Medication adherence mediates ethnicity as to readmissions	
Wu et al. 2012; United States; 2ndary analysis; N=218	<u>Instruments</u> : (MPSS) ( $\alpha=.85$ ); <u>Outcomes</u> : Event-free survival (CV hospitalization and death)	Lower SS was related to living alone ( $p=.001$ ). Low SS (25% vs 17%, $p=.03$ ) was linked to hospitalizations. Medication adherence mediates the association between HF outcomes and SS - better SS leads to improved medication adherence and outcomes.	

Abbreviations used in the table.

<b>DC</b>	Discharge	<b>AVAT</b>	Availability of Attachment	<b>EHFScBS</b>	European Heart Failure Self-Care Behavior Scale	<b>MPSS/MS-PSS</b>	Multidimensional Scale of Perceived Social Support
<b>HF</b>	Heart Failure	<b>AVSI</b>	Availability of Social Integration	<b>ESSI</b>	Enriched Social Support Instrument	<b>PSSS</b>	Perceived Social Support Survey of Medical Outcome Study
<b>SS</b>	Social Support	<b>BOMC</b>	Blessed orientation-memory-concentration	<b>ISSI</b>	Interview Schedule for Social Interaction	<b>SCHFI</b>	Self-Care of Heart Failure Index
<b>ADAT</b>	Adequacy of Attachment	<b>BSI</b>	Brief Symptom Inventory	<b>MISSB</b>	Modified Inventory of Socially Supportive Behaviors Scale	<b>UCLA-SSI</b>	UCLA Social Support Inventory
<b>ADSI</b>	Adequacy of Social Integration	<b>CESD</b>	Center for Epidemiological Study-Depression	<b>MOS-SS</b>	Medical Outcomes Study Social Support		
				<b>HRQOL</b>	Health-related quality of life		

APPENDIX B  
INFORMED CONSENT FORMS

## PERCEIVED SOCIAL SUPPORT AND SELF-CARE IN PATIENTS HOSPITALIZED WITH HEART FAILURE

### ORLANDO HEALTH INFORMED CONSENT FORM

Good medical care includes obtaining informed consent before beginning any experimental procedure or research. "Informed consent" is a process. We will tell you about the nature, purpose, alternatives and possible side effects of the research, and then you decide whether or not you want to take part. This research study is being conducted by:

Principal Investigator(s): Lyne Chamberlain, MSN, CNS

Co-Investigator(s): Mary Lou Sole, PhD, RN

Sub-Investigator(s): Christine Townsend, MSN, CNS

Sponsor: N/A

Investigational Site(s): Orlando Regional Medical Center.  
South Seminole Hospital  
Dr. P. Phillips Hospital

We are asking you to take part in a research study. This consent form gives detailed information about the research study. The researcher will discuss this information with you. Please ask any questions you may have. If you agree to take part in the research study, we will ask you to sign this form. You can change your mind and withdraw your consent at any time. There is no penalty to you if you do this.

**1. PURPOSE OF RESEARCH STUDY:**

The purpose of this study is to find out how much family and social support patients have that are in the hospital with heart failure, and how they take care of themselves at home. Results are expected to be published in professional nursing journals.

**2. EXPECTED DURATION:**

You can expect to be part of this research study for about 15 minutes - until the survey questionnaire is finished.

**3. PROCEDURES TO BE FOLLOWED:**

- This will take place at your bedside in your hospital room.
- You will be asked a few questions to test your short-term memory.
- After that screening, you will complete a 2 page survey that asks about how you care for yourself related to your heart failure.
- The screening and survey is expected to take about 15 minutes.
- You will be given a gift card for participating.

**4. IDENTIFICATION OF EXPERIMENTAL PROCEDURES/TREATMENTS: N/A**

**5. POTENTIAL RISKS AND DISCOMFORTS:**

There are no risks involved beyond what you would expect in everyday life. It is possible some of the survey questions may make you feel tired or uncomfortable. If you have these feelings, please let the study staff know. You can stop the study at any time, which will in no way affect the care you receive.

**6. POTENTIAL BENEFIT TO YOU OR OTHERS:**

There is no direct expected benefit to you for taking part in this study. However, taking part in this study may help us to understand needs of patients in the hospital with heart failure so that we can better treat other heart failure

patients in the hospital.

**7. ALTERNATIVE PROCEDURES OR TREATMENTS:**

Since this study does not offer treatment, your alternative is to not take part

**8. CONFIDENTIALITY OF RECORDS:**

The confidentiality of your record is carefully guarded. Your consent will be kept in a locked area of the researcher's office. This will be in a different area than the survey results. Survey results will not have any information that can identify you personally. Your survey results will be stored on a password-protected computer and in a locked areas of the researcher's office that is separate from where consents are stored.

Publications from this study will not contain any information that can identify you, No information that can identify you will be released to any third party except as provided herein or as required by law.

**9. COMPENSATION:**

A Publix gift card will be given to each participant to compensate for the time to complete the survey.

**10. RESEARCH RELATED INJURY: N/A**

**11. QUESTIONS**

For more information about your rights as a research participant, you may call the Institutional Review Board Office, at (321) 841-5895. You are free to call *Lyne Chamberlain* at (407) 823-2744 with any questions concerning this research study that you have now or in the future.

**12. VOLUNTARY PARTICIPATION:**

You are free to refuse or stop participation in this research study at any time without penalty or loss of benefits to which you are otherwise entitled. You are free to seek care from a physician of your choice at any time. If you do not take part in or withdraw from the study, you may continue to receive care for which you will be financially responsible.

**13. ADDITIONAL RISKS: N/A**

**14. INVOLUNTARY TERMINATION: N/A**

**15. PROCEDURES FOR WITHDRAWAL: N/A**

**16. NEW FINDINGS: N/A**

**17. NUMBER OF PARTICIPANTS:**

The total number enrolled at all sites will be *150* participants.

**18. ADDITIONAL COST:**

There will be no cost to you if you decide to be part of this study.

**19. FINANCIAL DISCLOSURE: N/A**

**PERCEIVED SOCIAL SUPPORT AND SELF-CARE IN PATIENTS  
HOSPITALIZED WITH HEART FAILURE**

20. **SIGNATURES:** My signature indicates that I consent and authorize **Lyne Chamberlain** and whomever she may designate as her assistant(s) including Orlando Health, Inc., its employees and its agents to perform the research described above.

**I AM MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS STUDY. I HAVE READ, OR HAD READ TO ME IN A LANGUAGE THAT I UNDERSTAND, ALL OF THE ABOVE, ASKED QUESTIONS, RECEIVED ANSWERS CONCERNING AREAS I DID NOT UNDERSTAND, AND WILLINGLY GIVE MY CONSENT TO PARTICIPATE IN THIS STUDY. UPON SIGNING THIS CONSENT FORM, I WILL BE GIVEN A SIGNED AND DATED COPY.**

---

PRINTED NAME OF RESEARCH PARTICIPANT

---

Signature of Participant

---

Date

**I have explained and defined in detail the research procedure(s) in which the research participant has consented to participate.**

---

Signature of Investigator/Designee Obtaining Consent

---

Date

## FLORIDA HOSPITAL CONSENT

**TITLE** – Perceived Social Support and Self-Care in Patients Hospitalized with Heart Failure

**IRBNet #: 661180-1**

**Sponsor's Name and Protocol #: University of Central Florida**

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**Principal Investigator:** Mary Lou Sole, PhD, RN, FAAN  
**Address:** College of Nursing, University of Central Florida  
12201 Research Parkway, Orlando, FL 32826  
**Phone Number:** (407) 823-2744  
**Sub-investigator:** Lyne Chamberlain, MSN, CNS, PhD Candidate  
**Address:** College of Nursing, University of Central Florida  
12201 Research Parkway, Orlando, FL 32826  
**Phone Number:** (407) 823-2744

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### **INTRODUCTION**

You are being invited to participate in a research study because you are in the hospital with heart failure. A member of the research team will discuss the study with you. Please ask the study staff to explain words or information you do not understand. Understanding this study's risks and benefits will allow you to make an informed choice about whether to be part of this research study. This process is called informed consent.

This study is part of a larger study that is being conducted at several sites in the Central Florida. Up to 150 participants will be enrolled at Florida Hospital and the other area hospitals.

At this time, it is expected that you will be in the study for 15-30 minutes until you complete the survey.

### **PURPOSE**

The purpose of this study is to find out how much family and social support patients have that are in the hospital with heart failure, and how they take care of themselves at home. Results are expected to be published in professional nursing journals.

## **PROCEDURES AND SUBJECT RESPONSIBILITIES**

- You will be asked a few questions to test your short-term memory.
- You may be asked to complete a 2 page survey that asks about how you care for yourself related to your heart failure.
- The screening and survey is expected to take about 15 minutes.
- Information from your medical record will be collected including other medical conditions you have (diabetes, etc.), test results for BNP (a laboratory test) and ejection fraction (echocardiogram), the type of heart failure you have, whether you are on certain types of medications, and your age.
- You will be given a \$5 gift card for participating.

## **RISKS**

This section will cover the potential risks of which we are currently aware.

### ***General / Unforeseeable***

There are no risks involved beyond what would reasonably be encountered in everyday life. It is possible the survey questions could cause you to feel tired or uncomfortable. If you have these feelings, please let the study staff know. You can stop the study at any time, which will in no way affect the care you receive.

## **POTENTIAL BENEFITS**

There is no direct expected benefit to you for taking part in this study. However, taking part in this study may help us to understand needs of patients in the hospital with heart failure so that we can better treat other heart failure patients in the hospital.

## **COSTS/PAYMENTS FOR PARTICIPATION IN THE RESEARCH**

You will receive a \$5 Publix gift card for your participation.

## **STUDY RELATED QUESTIONS**

If you have any questions concerning your participation in this study or if at any time you feel you have experienced a research-related injury, contact:

Mary Lou Sole, PhD, RN  
Address: 12201 Research Parkway, Orlando, FL 32826  
Phone: (407) 823-2744

Or

Lyne Chamberlain, MSN, CNS  
Address: 12201 Research Parkway, Orlando, FL 32826  
Phone: (407) 758-9054

## **QUESTIONS ABOUT YOUR RIGHTS**

If you would like to talk to someone regarding your rights as a research participant, you may contact the Florida Hospital Institutional Review Board at (407) 303-5581 or at [FH.IRB.General@flhosp.org](mailto:FH.IRB.General@flhosp.org). The Florida Hospital Institutional Review Board is the ethical review board that reviewed the study and gave permission for this study to be conducted at Florida Hospital.

## **VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THE RESEARCH**

Participation in this study is voluntary. You may decide not to participate in this study or you may withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled.

If you are an employee of Florida Hospital, you should know that your participation or lack of participation in this study will not affect your employment or relationship with Florida Hospital.

You may withdraw from the study by telling the principal investigator or her study team.

Your participation in this study may be stopped at any time by the study staff without your consent because:

- the study researcher thinks it necessary for your health or safety;
- Florida Hospital IRB or other administrative area of Florida Hospital have decided to stop the study; or
- administrative reasons require your withdrawal.

## **CONFIDENTIALITY**

Your identity and your personal records will be kept confidential to the extent permitted by the applicable laws and/or regulations and will not be made publicly available. If results of this study are published or presented at a conference, your identity will not be revealed. Confidentiality will be maintained during and after your participation in this study.

## **HIPAA AUTHORIZATION TO RELEASE INFORMATION FOR RESEARCH**

If you have not received a copy of the Florida Hospital Privacy Notice, please request one. If you have questions about your privacy rights, you may contact Florida Hospital's Privacy Officer at PH: (407) 303-9659.

Privacy laws, including the Health Insurance Portability & Accountability Act (HIPAA) and other federal and state laws, rules, and regulations, protect your individually identifiable health information (also called Protected Health Information or PHI). If you agree to be in this study, privacy laws require you to sign this Authorization that describes your rights and explains how your Protected Health Information (PHI) will be used and disclosed for this research study.

By signing this informed consent/HIPAA Authorization, you will be authorizing the principal investigator and her research staff to use (which includes reviewing your medical records as necessary to conduct the study) your PHI for the purposes described below. By signing this form, you will also be authorizing your doctors, Florida Hospital personnel, and individuals who provide health care services at Florida Hospital to disclose your PHI for the purposes described below. This includes information from your past and present medical records.

This Authorization does not have an expiration date. This means the researchers and others associated with this study may use and disclose your protected health information for as long as necessary to complete the study.

If you volunteer to take part in this research study, it is very unlikely anyone can identify you because your name will not be included with the research data. Your name will appear only on this consent, and the consent will be kept in a different location than the research data. Study information may identify you in the following ways:

- Other medical conditions you have
- Medications you take
- Type of heart failure you have
- Test results for BNP (a laboratory test) and Ejection Fraction (echocardiogram)
- Age
- Gender
- Race/ethnicity
- If you have Medicare and/or Medicaid

This study includes a research team at the University of Central Florida's College of Nursing. They may use your health information and share it with others. We want you to know who may use this information and how they may use it.

**1. Who may use and give out information about you?**

The Investigator and research staff will have information about your health but not your name or identifying information. They may give this information to others during and after the study.

**2. Who may see this information?**

The following people, agencies and businesses may get information from us that does not include your name:

- Healthcare professionals taking part in the study;
- Florida Hospital Institutional Review Board (IRB)
- Accreditation organizations
- University of Central Florida College of Nursing faculty and one student involved in this study
- U.S. Department of Health and Human Services (DHHS), which includes:

- U.S. Food and Drug Administration (FDA)
- U.S. Office of Human Research Protections (OHRP)

**3. What information may be used and shared?**

If you decide to be in this study, medical information that relates to your participation will be created, used, and/or shared. This may include the following types of medical information:

- Information from your medical chart related to this study. This may include physical examinations, blood tests, echocardiogram results and any other information that you may release to us, including information about your health history.

**4. Why will this information be used and/or shared?**

Information about you and your health may be given to others to carry out the research study. The investigators will analyze and evaluate the results of the study.

**5. What if I decide not to give permission to use and give out my health information?**

If you sign this consent form, you will be giving permission to use and give out the health information listed above (#3) for the purposes described above (#4). If you decide not to give permission, you will not be able to be in this research. However, this will not change your relationship with your doctor or with Florida Hospital and you will still be able to receive all benefits to which you are entitled.

**6. May I review or copy the information obtained from me or created about me?**

You have the right to review and copy your health information.

**7. May I withdraw or revoke (cancel) my permission?**

Yes, but this authorization (permission) will never expire (end) unless you revoke (cancel) it in writing.

You may withdraw or take away your permission to use and disclose your health information at any time. When you withdraw your permission, information that has already been gathered may still be used and given to others.

**8. Is my health information protected after it has been given to others?**

No identifiable health information will be shared with anyone except the research team and Institutional Review Board.

**9. How long is my information kept?**

Research with private health information must be maintained for seven years after the research study has been closed at the Florida Hospital site.

**Do not sign this form unless a member of the research team has reviewed the study and this informed consent/authorization with you and you have had a chance to ask questions and receive satisfactory answers.**

**If you agree to participate in this study, you will receive a signed and dated copy of this consent form/authorization for your records.**

**CONSENT**

I have been informed about this study's purpose, procedures, possible benefits and risks, and the use and disclosure of my health care information from this research. My questions have been answered. I freely consent to participate in this research study. I authorize the use and disclosure of my health information to the parties listed in the authorization section of this consent for the purposes described above. By signing this consent form I have not waived any of the legal rights to which I am otherwise entitled.

CONSENT SIGNATURE *(must be signed by the subject and the person explaining the study to the subject on the same date and at the same time)*

**DO NOT SIGN THIS CONSENT AFTER 05/12/2016**

---

Subject Signature Printed Name Date

---

Person Obtaining Consent - Signature Printed Name Date

APPENDIX C  
PARTICIPANT SURVEY INSTRUMENT

## PARTICIPANT SURVEY INSTRUMENT

Code: \_\_\_\_\_ Gender: M F Age: \_\_\_\_\_

“Are you able to bathe yourself and prepare your own meals?” **Yes No**  
(either independently or with only minimal assistance)

**Ability for self-care is necessary to continue.**

“Now I would like to give you a short memory test that will take about 5 minutes. Some questions will be easy; some may be more difficult. Are you ready?”

			Maximum Errors	Score		Weighted Score
1	What year is it now?	1			x 4 =	
2	What month is it now?	1			x 3 =	
	<i>Repeat this memory phrase after me: "John Brown, 42 Market Street, Chicago"</i>					
3	About what time is it (within 1 hour)?	2			x 4 =	
4	Count backwards 20 to 1	2			x 2 =	
5	Say the months in reverse order (start with December)	2			x 2 =	
6	Repeat the memory phase: John (1) Brown (1) 42 (1) Market (1) Chicago (1)	5			x 2 =	

**A total score of ≤8 is necessary to continue.**

**TOTAL**

### Medical Record Clinical Data:

1	BNP		
2	Type of HF	HFpEF	HFrEF
3	Ejection Fraction		
4	Beta-blocker	NA	
5	ACE I or ARB	NA	
6	Aldosterone Antagonist	NA	
7	Antihypertensive(s)		NA

8 \_\_\_\_\_ Weighted co-morbidities (from CCI)

*“People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?”*

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
9					
10					
11					
12					
13					
14					
15					
16					

*“Think about how you have been feeling in the couple of weeks before coming to the hospital. Listed below are common instructions given to persons with heart failure. How routinely do you do the following?”*

	Never or rarely	Sometimes	Frequently	Always or daily
17				
18				
19				
20				
21				
22				
23				
24				
25				
26				

*“Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?”*

	Not likely	Somewhat likely	Likely	Very likely
27 Reduce the salt in your diet?				
28 Reduce your fluid intake?				
29 Take an extra water pill?				
30 Call your doctor or nurse for guidance?				

*“Think of a remedy you tried the last time you had trouble breathing or ankle swelling.”*

	I did not try anything	Not sure	Somewhat sure	Sure	Very sure
31 How <u>sure</u> were you that the remedy helped or did not help?					

*“In general, how confident are you that you can:”*

	Not confident	Somewhat confident	Confident	Very confident
32 Keep yourself <u>free of heart failure symptoms</u> ?				
33 <u>Follow the treatment advice</u> you have been given?				
34 Evaluate the importance of your symptoms?				
35 <u>Recognize the changes</u> in your health if they occur?				
36 <u>Do something</u> that will relieve your symptoms?				
37 <u>Evaluate</u> how well a remedy works?				

38 How many close relationships (friends or family) do you have? \_\_\_\_\_

39 Are you married and live with a spouse? Yes No

40 **OR** Do you live with someone you are not married to? Yes No

41 Do you have Medicare? Yes No

42 Do you have Medicaid? Yes No

43 Highest educational level <12 years High school graduate Some college or graduate Post college graduate

44 How many times have you been in the hospital for heart failure in the past 6 months? \_\_\_\_\_

45 Do you receive any services such as home health care or Meals on Wheels? Yes No

46 Race: American Indian/Alaska native Asian Black/African American  
Native Hawaiian/Other Pacific Islander White

47 Ethnicity: Hispanic/Latino Not Hispanic/Latino

APPENDIX D  
BLESSED ORIENTATION-MEMORY-CONCENTRATION TEST (BOMC)

## BLESSED ORIENTATION-MEMORY-CONCENTRATION TEST (BOMC)

"Now I'd like to give you a short memory test that will take about 5 minutes. Some questions will be easy; some may be more difficult. Are you ready?"

Items	Maximum Error	Score	Weighted Score
1 What year is it now?	1	X4=	
2 What month is it now?	1	X3=	
<i>Repeat this memory phase after me: "John Brown, 42 Market Street, Chicago"</i>			
3 About what time is it (within 1 hour)?	1	X4=	
4 Count backwards 20 to 1.	2	X2=	
5 Say the months in reverse order (start with December).	2	X2=	
6 Repeat the memory phrase.	5	X2=	
<i>John (1)</i>			
<i>Brown (1)</i>			
<i>42 (1)</i>			
<i>Market (1)</i>			
<i>Chicago (1)</i>			

### TOTAL

The scores from each of the six items are multiplied to yield a weighted score. Score 1 for each incorrect response. Weighted error scores greater than 10 are consistent with dementia.

Scoring items 4 and 5: For uncorrected errors, score "2"; for self-corrected errors, score "1". For no errors, score "0"

Scoring the memory phrase: If no cue is necessary and the patient recalls both name and address, score "0". If patient cannot spontaneously recall the name and address, cue with "John Brown" one time only. If this cue is necessary, the patient automatically has 2 errors.

Score 1 point for each subsequent "unit" the participant cannot recall.

Source: Katzman R., et al. Validation of a short orientation-memory-concentration test of cognitive impairment. *Am T Psychiatry* 1983; 140:734-9.

APPENDIX E  
SELF-CARE OF HEART FAILURE INDEX

## SELF-CARE OF HEART FAILURE INDEX

*All answers are confidential.*

“Think about how you have been feeling in the last month as you complete these items.”

**SECTION A:** Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

	Never or rarely	Sometimes	Frequently	Always or daily
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

**SECTION B:** Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure. Circle one number.

	Have not had these	I did not recognize it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
11. How quickly did you recognize these as a symptom of heart failure?	N/A	0	1	2	3	4

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies? Circle one number for each remedy.

	Not Likely	Somewhat Likely	Likely	Very Likely
12. Reduce the salt in your diet	1	2	3	4
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

Think of a remedy you tried the last time you had trouble breathing or ankle swelling, Circle one number.

	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
16. How <u>sure</u> were you that the remedy helped or did not help?	0	1	2	3	4

**SECTION C:** In general, how confident are you that you can:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself <u>free of heart failure symptoms</u> ?	1	2	3	4
18. <u>Follow the treatment advice</u> you have been given?	1	2	3	4
19. <u>Evaluate the importance</u> of your symptoms?	1	2	3	4
20. <u>Recognize changes</u> in your health if they occur?	1	2	3	4
21. <u>Do something</u> that will relieve your symptoms?	1	2	3	4
22. <u>Evaluate</u> how well a remedy works?	1	2	3	4

## SCHFII DIRECTIONS AND SCORING

Directions for Use: The time interval used in the directions can be adjusted to reflect your study design. For example, if your follow-up is 3 months, ask patients to “think about how you have been feeling in the last 3 months”. We recommend that no longer than 3 months be used, though, because of issues with recall.

Scoring: Previously we advocated use of a total score but we now strongly recommend that the 3 scales (self-care maintenance, management, and confidence) be used separately. Self-care is best represented by maintenance and management. Confidence is an important process that probably moderates the relationship between self-care and outcomes. This change benefits users because now even asymptomatic patients will have self-care maintenance and confidence scores. Self-care management scores remain appropriate only in persons who have been symptomatic. Specific formulas for calculating scale scores are available in the 2009 article.

*Maintenance.* To calculate the Maintenance scale scores, each scale score is standardized to a 0 to 100 range. There is one negatively worded item in the maintenance scale (# 8). After reverse-coding that item, standardize the raw score to a 0-100 scale. Note that more than half of the items in this section A should be answered for the scale to be an adequate measure of self-care maintenance.

*Management.* Score the management scale only if the patient reported having trouble breathing or ankle swelling in the past interval. Otherwise, ignore responses, even if the patient answers the items. Note that the first item (In the past month, have you had trouble breathing or ankle swelling?) is used only for this purpose and not in the scale score. Note that at least 2 of the 4 possible remedies must be answered for the scale to be an adequate measure of self-care management.

*Confidence.* Self-care confidence scores (Section C) should be standardized as described above. Note that more than half of the items in this section should be answered for the scale to be an adequate measure of self-care confidence.

(Riegel, 2009)

APPENDIX F  
MEDICAL OUTCOMES STUDY: SOCIAL SUPPORT SURVEY  
EMOTIONAL/INFORMATION SUBSCALE

**MEDICAL OUTCOMES STUDY: SOCIAL SUPPORT SURVEY  
EMOTIONAL/INFORMATIONAL SUBSCALE**

**People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.**

**Emotional/informational Support**

	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5

**SCORING INSTRUCTIONS**

A higher score for the individual scale indicates more support.

- To obtain a score, calculate the average of the scores for each item in the subscale.
- To compare to published means in the article referenced below, scale scores can be transformed to a 0 - 100 scale using the following formula:

$$100 \times \frac{(\text{observed score} - \text{minimum possible score})}{(\text{maximum possible score} - \text{minimum possible score})}$$

[http://www.rand.org/health/surveys\\_tools/mos/mos\\_socialsupport\\_survey.html](http://www.rand.org/health/surveys_tools/mos/mos_socialsupport_survey.html)

APPENDIX G  
CHARLSON CO-MORBIDITY INDEX

## Charlson Co-Morbidity Index

1. Scoring: Comorbidity Component (Apply 1 point to each unless otherwise noted)
  1. Myocardial Infarction
  2. Congestive Heart Failure
  3. Peripheral Vascular Disease
  4. Cerebrovascular Disease
  5. Dementia
  6. COPD
  7. Connective Tissue Disease
  8. Peptic Ulcer Disease
  9. Diabetes Mellitus (1 point uncomplicated, 2 points if end-organ damage)
  10. Moderate to Severe Chronic Kidney Disease (2 points)
  11. Hemiplegia (2 points)
  12. Leukemia (2 points)
  13. Malignant Lymphoma (2 points)
  14. Solid Tumor (2 points, 6 points if metastatic)
  15. Liver Disease (1 point mild, 3 points if moderate to severe)
  16. AIDS (6 points)
2. Scoring: Age
  1. Age <40 years: 0 points
  2. Age 41- 50 years: 1 points
  3. Age 51- 60 years: 2 points
  4. Age 61- 70 years: 3 points
  5. Age 71- 80 years: 4 points
3. Interpretation
  1. Calculate Charlson Score or Index (i)
    1. Add Comorbidity score to age score
    2. Total denoted as 'i' below
  2. Calculate Charlson Probability (10 year mortality)
    1. Calculate  $Y = e^{(i * 0.9)}$
    2. Calculate  $Z = 0.983^Y$
    3. where Z is the 10 year survival (Moses, 2014)

APPENDIX H  
IRB AUTHORIZATIONS

Office  
12201



University of Central Florida Institutional Review Board  
of Research & Commercialization  
Research Parkway, Suite 501

Orlando, Telephone: 407Florida -82332826-2901-3246, 407  
-882-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

[Notice that UCF will Rely Upon Other IRB for Review and Approval](#)

From : **UCF Institutional Review Board**  
**FWA00000351, IRB00001138**

To : **Lyne Chamberlain**

Date : **May 15, 2015**

IRB Number: **SBE-15-11211**

Study Title: **Perceived social support and self-care in patients hospitalized with heart failure**

Dear Researcher:

The research protocol noted above was reviewed by the University of Central Florida IRB Designated Reviewer on May 15, 2015. The UCF IRB accepts the Orlando Health and Florida Hospital's Institutional Review Board review and approval of this study for the protection of human subjects in research. **The expiration date will be the date assigned by the Orlando Health and Florida Hospital's Institutional Review Board and the consent process will be the process approved by that IRB.**

This project may move forward as described in the protocol. It is understood that the Orlando Health and Florida Hospital's IRB is the IRB of Record for this study, but local issues involving the UCF population should be brought to the attention of the UCF IRB as well for local oversight, if needed.

All data, including signed consent forms if applicable, must be retained and secured per protocol for a minimum of five years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained and secured per protocol. Additional requirements may be imposed by your funding agency, your

department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

**Failure to provide a continuing review report for renewal of the study to the Orlando Health and Florida Hospital**

**IRB could lead to study suspension, a loss of funding and/or publication possibilities, or a report of noncompliance to sponsors or funding agencies. If this study is funded by any branch of the Department of Health and Human Services (DHHS), an Office for Human Research Protections (OHRP) IRB Authorization form must be signed by the signatory officials of both institutions and a copy of the form must be kept on file at the IRB office of both institutions.**

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:



Signature applied by Patria Davis on 05/15/2015 09:12:05 AM EDT

IRB Coordinator

ORLANDO HEALTH AUTHORIZATION



*When it matters most.*

orlandohealth.com

1414 Kuhl Ave.  
Orlando, FL 32806  
321.843.7000

DATE: March 11, 2015

TO: Lyne Chamberlain, MSN  
FROM: Orlando Regional Medical Center (ORMC) IRB

PROJECT TITLE: [724336-1] Perceived social support and self-care in patients hospitalized with heart failure

REFERENCE #: 15.020.02

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: March 11, 2015

REVIEW CATEGORY: Exemption category # 2 and 4

Thank you for your submission of New Project materials for this project. The Orlando Regional Medical Center (ORMC) IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at (321) 841-5895. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Orlando Regional Medical Center (ORMC) IRB's records.

*Orlando Health Facilities:* • ARNOLD PALMER HOSPITAL FOR CHILDREN •  
SOUTH SEMINOLE HOSPITAL

• UF HEALTH CENTER AT ORLANDO HEALTH • WINNIE PALMER HOSPITAL  
FOR WOMEN & BABIES

• SOUTH LAKE HOSPITAL • DR. P. PHILLIPS HOSPITAL • ORLANDO  
REGIONAL MEDICAL CENTER  
• HEALTH CENTRAL HOSPITAL

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ORLANDO HEALTH MODIFICATION  
ACKNOWLEDGEMENT

1414 Kuhl Ave.

DATE: July 2, 2015  
TO: Lyne Chamberlain, MSN  
FROM: Orlando Regional Medical Center (ORMC) IRB  
PROJECT TITLE: [724336-3] Perceived social support and self-care in patients hospitalized with heart failure  
REFERENCE #: 15.020.02  
SUBMISSION TYPE: Amendment/Modification  
ACTION: ACKNOWLEDGED  
EFFECTIVE DATE: July 2, 2015

orlandohealth.com  
STUDY EXPIRATION DATE:

Thank you for submitting the Amendment/Modification materials for this project. The Orlando Regional Medical Center (ORMC) IRB has ACKNOWLEDGED your submission. No further action on submission 724336-3 is required at this time. The change in age range does not affect the exempt status of this project.

The following items are acknowledged in this submission:

- Amendment/Modification - Change age range (UPLOADED: 07/1/2015)
- Protocol - Revised Protocol (UPLOADED: 07/1/2015)

If you have any questions, please contact the IRB Office at (321) 841-5895. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Orlando Regional Medical Center (ORMC) IRB's records.

*Orlando Health Facilities:* • ARNOLD PALMER HOSPITAL FOR CHILDREN • SOUTH SEMINOLE HOSPITAL

- UF HEALTH CENTER AT ORLANDO HEALTH • WINNIE PALMER HOSPITAL FOR WOMEN & BABIES
- SOUTH LAKE HOSPITAL • DR. P. PHILLIPS HOSPITAL • ORLANDO REGIONAL MEDICAL CENTER
- HEALTH CENTRAL HOSPITAL

FLORIDA HOSPITAL IRB APPROVAL

Florida Hospital  
Institutional Review Board  
901 N. Lake Destiny Drive, 4th Floor  
Maitland, FL 32751



FWA: 00002060

DATE: May 13, 2015  
TO: Mary Lou Sole, PhD  
FROM: Florida Hospital Institutional Review Board (IRB)  
PROJECT TITLE: [661180-1] Perceived social support and self-care in patients hospitalized with heart failure  
SPONSOR: University of Central Florida  
REFERENCE #:  
SUBMISSION TYPE: New Project  
ACTION: APPROVED  
APPROVAL DATE: May 13, 2015  
EXPIRATION DATE: May 12, 2016  
REVIEW TYPE: Expedited Review  
REVIEW CATEGORY: Expedited review category # 5 & 7

Telephone: (407) 303-5581

Fax: (407) 303-3638

Note: If this is an expedited or exempt action, the IRB members will be made aware via published meeting minutes.

**NOTE: BEFORE BEGINNING THIS PROJECT AT FLORIDA HOSPITAL, YOU MUST OBTAIN THE APPROVAL OF BOTH THE IRB AND THE OFFICE OF RESEARCH ADMINISTRATION.**

Thank you for your submission of New Project materials for this project. The Florida Hospital IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulations. Material reviewed for this submission includes:

Application Form - Chamberlain Application Sole 04-22-2015.pdf (UPDATED: 04/22/2015)

Consent Form - Revised consent w/ IRB recommended changes (UPDATED: 05/6/2015)  
Data Collection - eligibility screening form (UPDATED: 05/8/2015)  
Letter - Nursing Scientific Review Board Approval (UPDATED: 03/19/2015)  
Letter - FHO permission (UPDATED: 02/23/2015)  
Other - Review prep to research (UPDATED: 05/8/2015)  
Other - Delegation Log (UPDATED: 04/20/2015)  
Protocol - Revised Protocol (UPDATED: 05/8/2015)  
Protocol - VOID Protocol (UPDATED: 03/19/2015)

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Please remember that informed consent is a process beginning with a description of the study and assurance of participant understanding followed by a FHIRB approved signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by the FHIRB prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED (WHICH INCLUDES SERIOUS AND UNEXPECTED) PROBLEMS involving risks to subjects or others must be reported promptly to this office. Please use the appropriate reporting forms for that submission. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee at a time period as noted above. Please use the appropriate forms for this procedure. The FHIRB reviews renewal submissions one month prior to the study expiration noted above, as well. Your documentation for continuing review should be received with sufficient time for review and continued approval before one month prior to the expiration date of May 12, 2016.

Please note that all research records must be retained according to ORA's Research Records Retention and Storage SOP.

If you have any questions, please contact the Florida Hospital IRB at 407 303 5581 or [FH.IRB.general@flhosp.org](mailto:FH.IRB.general@flhosp.org). Please include your project title and IRBNet ID number in all correspondence with this office.

**NOTE: Investigators must obtain approval from the IRB before pursuing marketing tactics, i.e. articles, interviews, related to procedures/drugs/medical devices considered "new", "innovative", or part of a clinical trial. For IRB approval or to verify if the IRB must review/approve, please contact the IRB at 407-303-5581.**

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within the Florida Hospital IRB records.



Office of Research Administration  
901 N Lake Destiny Rd  
Suite 400  
Maitland, FL 32751  
407.303.7756

## OFFICE OF RESEARCH ADMINISTRATION CERTIFICATE OF INSTITUTIONAL CLEARANCE

Sponsor Protocol # 661180  
PI: Mary Lou Sole, PhD  
Project Title: [661180-2] Perceived social support and self-care in patients hospitalized with heart failure  
APPROVED as of: May 13, 2015

Congratulations! Florida Hospital's Office of Research Administration has given Institutional Approval to the research study identified above. Please refer to the IRBNet ID# in all communications and documents related to this project.

It is the responsibility of the Principal Investigator to notify the ORA of any amendments to the Protocol, amendments to the research contract, and any publications arising from the study.

In addition, it is the responsibility of the PI to notify the ORA of any Federal Sanction(s), including Debarment and/or Suspension(s).

If you have any questions about research policy and procedures, research budgets, or if we may assist you in any way, please feel free to contact the ORA.

Sincerely,

Michelle C. Dolske, PhD  
Administrative Director

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*The ORA's mission is to provide support and safeguards for Florida Hospital, investigators, research team members, research subjects, and data to ensure integrity of research at Florida Hospital.*

FLORIDA HOSPITAL MODIFICATION APPROVAL

Florida



Hospital

Institutional Review Board  
901 N. Lake Destiny Drive, 4th Floor  
Maitland, FL 32751

DATE: July 6, 2015  
TO: Mary Lou Sole, PhD  
FROM: Florida Hospital Institutional Review Board (IRB)

PROJECT TITLE: [661180-3] Perceived social support and self-care in patients hospitalized with heart failure

SPONSOR: University of Central Florida

REFERENCE #:

SUBMISSION TYPE: Amendment/Modification

TYPE:

ACTION: APPROVED

APPROVAL DATE: July 6, 2015

EXPIRATION DATE: May 12, 2016

DATE:

REVIEW TYPE: Expedited Review

Note: If this is an expedited or exempt action, the IRB members will be made aware via published meeting minutes.

Thank you for your submission of Amendment/Modification materials for this project. The Florida Hospital IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission. This submission has received Expedited Review based on the applicable federal regulations. Material reviewed for this submission includes:

- Amendment/Modification - Change Request Form 7215mls.docx (UPDATED: 07/2/2015)
- Other - Eligibility screening (UPDATED: 07/2/2015)
- Protocol - Revised Protocol (UPDATED: 07/2/2015)

Please remember that informed consent is a process beginning with a description of the study and assurance of participant understanding followed by a FHIRB approved signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by the FHIRB prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED (WHICH INCLUDES SERIOUS AND UNEXPECTED) PROBLEMS involving risks to subjects or others must be reported promptly to this office. Please use the appropriate reporting forms for that submission. All FDA and sponsor reporting requirements should also be followed.

- 1 -

Generated on IRBNet

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office. This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee at a time period as noted above. Please use the appropriate forms for this procedure.

The FHIRB reviews renewal submissions one month prior to the study expiration noted above, as well. Your documentation for continuing review should be received with sufficient time for review and continued approval before one month prior to the expiration date of May 12, 2016. Please note that all research records must be retained according to ORA's Research Records Retention and Storage SOP.

If you have any questions, please contact the Florida Hospital IRB at 407 303 5581 or [FH.IRB.general@flhosp.org](mailto:FH.IRB.general@flhosp.org). Please include your project title and IRBNet ID number in all correspondence with this office.

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This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within the Florida Hospital IRB records.

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