FACTORS ASSOCIATED WITH SELF-CARE OF HEART FAILURE PATIENTS 4-6 WEEKS POST DISCHARGE

By

TERESA K. LAGERLOF, BSN, MSN

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Frances Payne Bolton School of Nursing

CASE WESTERN RESERVE UNIVERSITY

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CASE WESTERN RESERVE UNIVERSITY

FRANCES PAYNE BOLTON SCHOOL OF NURSING

We hereby approve the scholarly written project of

Teresa K. Lagerlof, BSN, MSN

Committee Chair

Patricia W. Underwood, PhD, RN, FAAN

Committee Member

Marilyn Lotas, PhD, RN, FAAN

Committee Member

Deborah Lindell, DNP, RN, CNE, ANEF

June 11, 2014
Abstract

Heart Failure is the most frequent discharge diagnosis, with research indicating that due to poor self-care post-discharge, the rates of readmission within the first month are continuing to escalate. Heart failure is one of the most important public health concerns today. This study had two purposes: to evaluate factors associated with self-care among a convenience sample (N=30) of heart failure patients 4-6 weeks following hospital discharge and to describe perceptions of help needed from providers and others. A descriptive, correlational design was combined with a qualitative assessment of help needed. The relationship of age, gender, level of education, living alone or with someone, with or without help, and perceived availability of social support (measured by ESSI) to self care (measured by SCHFI) was evaluated descriptively due to small sample size. The three self-scales of the SCHFI (self-care maintenance, self-care management & confidence) were analyzed separately according to Riegel et al., (2009) Instrument validity was previously established and reliability met or exceeded prior studies.

Following IRB approval, a sample of predominantly female (57%), HF patients aged 35-87 (mean = 65), with high school or less education (53%), were interviewed in their homes. Half the participants lived alone. None of the mean SCHFI subscale scores achieved the desired level of 70/100. There was a trend for patients >65, living alone, with no help, to score higher on SCHFI subscales. The participants with less than high school education scored higher on self-care management. This may be due to seeing less leeway in adhering to their treatment advice from their healthcare provider. This warrants future study. Social support was moderately correlated with self-care confidence. Constant comparative analysis and thematic extraction revealed that people could be more helpful to these HF patients by providing social services,
education/coaching, and help with activities of daily living. Participants also wanted more information from providers and commented on preferred styles of interacting such as listening and not appearing rushed. Naturalistic decision-making theory (Lipshitz, et al, 2000) as well as Orem’s (2000) self-care theory aligned well with understanding heart failure patients’ management of daily choices examined in this pilot study.
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Factors Associated with Self-Care of Heart Failure Patients 4-6 Weeks Post Discharge

Chapter 1 – Introduction and Problem Statement

Problem Statement

The problem of increased prevalence of heart failure in the United States coincides with increased cost burden. The projected prevalence of heart failure will be approximately 8 million patients by the year 2030. Taking into account the growing population, this burden will increase especially among those aged 80 and over (Fang, Mensah, Croft & Keenan, 2008). Eighty percent of the cost of caring for heart failure patients at the present cost of $20.9 billion (direct and indirect total cost), is expected to rise to $53.1 billion by 2030. Heart failure is the most frequent discharge diagnosis for older Americans, and as a result of poor self-management of their heart failure, these persons have the highest rehospitalization rates ranging from 29 to 47% of all cause total hospitalizations (Konstam, Dracup, Baker et al., 1994; Prospective Payment Commission, 1992). The big issue here is the increased incidence of re-hospitalization of these patients within 30-90 days of their discharge from the hospital, thus raising the cost burden to over $30 billion dollars annually (Institute for Healthcare Improvement, 2009). Currently, there is a 21% rehospitalization rate after 30 days post discharge (Hernandez, Reiner, Fonarow, Hammill, Heidenreich & Yancy, 2010). Thus, if we are going to be effective in stopping this revolving door, we need to understand what is happening in the early post-discharge period, and understand, despite difficulties measuring self-care, what is lacking in self-care, self-management in order to help our heart failure patients deal with their challenges.

This pilot study has probed the causes of heart failure patients’ lacking self-care of their heart failure and what complications occurred in the early post-discharge period.
Background and Significance

Data available at this time indicate that between 33% and 50% of heart failure readmissions occur within the first 4-6 weeks of discharge, and are preventable (Rich, Vinson, Shah, & McNamara, 1990). The centers for Medicare and Medicaid (CMS) is rating readmissions as a publicly reported metric, hence lowering reimbursement to hospitals with disproportionate risk-standardized readmission rates (Quality Net, 2011). It is important for nurses and all interdisciplinary healthcare professionals to have an understanding of this as it has become a ‘team effort’ to support heart failure patients’ ability to ‘self-manage’ their syndrome of heart failure and design interventions appropriately. In the hospital setting, this system of support needs to be initiated before discharge and maintained on a continuum throughout the first months of the patient’s returning to the community (Philibin & DiSalvo, 2013; Andrulis, Acuff, Weiss & Anderson, 1996; Baucus, 2009; Fang, Mensah, Croft, & Keenan, 2008). Self-care maintenance of heart failure patients once discharged, affects outcomes; and additionally, the growing understanding of the type of social support needed by this aggregate to achieve success, by means of the development of data collection tools to measure self-care and social support, healthcare providers can better help their patients (Vaglio, Conrad, Poston, O’Keefe, Haddock, House & Spertus, 2004).

Joynt and Jha (2010) found that among 905,764 patients discharged from the hospital in their sample, patients discharged from public hospitals (27.9%) had higher readmission rates than non-profit hospitals (25.7%, p<0.001). Some answers to the questions surrounding what is happening were presented at the American Heart Associations’ Quality of Care and Outcomes Research Scientific Sessions (2013). Patients hospitalized for acute heart failure survive longer, but overall, long-term survival statistics continue to be low. According to Dr. Samuel W. Joffe,
MD, “heart failure is a lethal disease with a worse life expectancy than many forms of cancer” (2013).

Most cardiovascular disease has been managed over the past two decades with new techniques, better pacemakers, defibrillators and invasive mechanical ventricular assist devices (VAD). We have added exhaustive pharmacologic agents (Packer, 1987) to treatment plans for heart failure, yet it is one of the most important public health concerns today (Schwartz & Piano, 1990; Packer, 1987; Eriksson, 1995). Heart failure is not a specific disease, but rather the inability of the heart to pump blood to manage the body’s metabolic demand. Heart failure is sometimes precipitated by unrelated stress or comorbidity. Both the organ system and the psychosocial health of persons with heart failure are affected. Therefore, the problem extends beyond myocardium malfunctioning (Quaal, 1992). Self-care management of heart failure patients may reduce rehospitalization and effect positive outcomes (Hibbard, Mahoney, Stock & Tussler, 2006). Continued study is necessary to advance clinical practice and help our patients.

Theory

Self-care management is defined by Naylor (1990) as the behavior necessary to maintain physiologic symptom stability, follow an individual treatment plan and remain as healthy as personally possible. Event-free survival was observed to be possible in heart failure patients who practiced above-average self-care management (Lee, Tkacs, & Riegel, 2009). According to Carlson, Riegel, and Moser (2001), self-care is managed when heart failure patients learned the links between the prescribed treatment regimen for their heart failure and their own physiology and acted on that information. However, despite understanding their diagnosis, many persons with heart failure have had difficulty differentiating symptoms. For this reason, the clinical
teaching during their hospitalization may not have been enough to uphold a healthy outcome for them once in the community and living at home. Although certain approaches have been used in the clinical environment to teach heart failure self-management, there are yet an outlier group of patients in which the intervention strategies could not be sustained. One of the more successful strategies to promote self-care management has been through the use of motivational counseling with heart failure patients (Riegel et al., 2006). Social living situations and the amount of help heart failure patients perceived they were getting, has been seen to influence interventions (Vaglio, Conrad, Poston, O’Keefe, Haddock, House & Spertus, 2004) therefore correlating positively for a wider proportion of this aggregate.

Orem (2001) developed a self-care theory that conceptualized self-care agency as “a human power constituted of a complex set of capabilities, including knowledge and skills” (Orem, 2001). Orem’s Theory can be summarized by the following points:

- Self-care is necessary for health maintenance and well-being
- Culture and education influence individuals.
- Persons perform purposeful actions to meet self-care needs.
- Each person possesses interests, talents, values, capabilities and personal disposition.
- Each individual is self-reliant and responsible for his/her own care.
- Individuals are separate from their environment.

Self-care abilities are influenced by sociocultural background and developmental state.

- Self-care capabilities are recalled or learned as needed.
- Self-care demands and abilities offset a person’s self-care deficits.
- An individual’s health, life-experience, sociocultural orientation, resources, and age mediate self-care.
Another related theory arguing that self-care in heart failure was a naturalistic decision-making process, (Lipshitz et al., 2001) based on real-world specific situations, and the patient acted to prevent worsening of heart failure symptoms. In naturalistic decision-making, patients made decisions that were meaningful and familiar based on the interaction between the person, the problem and the environment. In naturalistic decision-making, decision rules were used contextually to achieve an external or internal end. Therapeutic self-care demand has been known as a combination of regulatory care measures needed at a point in time, by a person to meet a functional demand. Self-care agency has been known as a type of human agency acquired to meet the elements of a stable or changing therapeutic self-care demand. Patient variables were involved which changed over time and included socioeconomic conditions, age and developmental stage, health condition and culture (Lipshitz, et al., 2001; Orem, et al., 2001).

Decision-making has been an ongoing component of heart failure patients’ ability to live with the heart failure condition, and manage lifestyle choices to maintain optimum health in the context of individual symptoms. The daily choices which must have been made to control symptoms of heart failure, and prevent worsening, were called the interventions and in this study, naturalistic decision-making aligned seamlessly with Orem’s self-care theory. Naturalistic decision-making has been demonstrated by a step-by-step process whereby decision rules were meaningful in a real-world setting, and were based on the interaction between what problem the person was having, and his environment. Naturalistic decision-making has been applicable for firefighters, intensive care nursing environments, where peoples’ experience motivated their approach to the contextual problem at hand (Lipshitz, Klein, Orasanu, & Salas, 2001).
Purpose and Research Questions

The purpose of this pilot study was to identify factors associated with self-care in community-dwelling heart failure patients 4-6 weeks post discharge from the hospital. Research testing the effectiveness of self-care has been impeded by problems measuring self-care in heart failure patients (Riegel, et al., 2004). Heart failure continues to be the most prevalent cause of hospitalization in older adults (Heart Failure Society of America, 2009). Recent research indicates that half of all of the heart failure admissions could have been avoided (Hibbard, Mahoney, Stock & Tussler, 2007) and that patient self-management was important to positive health outcomes. The goal of this study was to assess where in the self-care process was the patient having a problem during the early post-discharge period. So many problems in early post-discharge may have been the result of the individual performing actions directed toward themselves and their new health problems. Orem’s health self-care requisites were the basis for using the theory that the health deviation state of having new requisites challenged the patient to interpret symptoms for maintaining health (Orem, 2001). Orem’s theory of self-care agency has been understood as the complex acquired ability to know and meet components of stable, or changing self care demands which, in either case were called patient variables. These variables were values of which, in time and over time were affected by a range of factors (Orem, 2001).

Although it is known that the self-care behavior has been seen to reduce readmission to the hospital, it is not clear what influences self-care. Therefore, the purpose of this study has been to examine self-management decision-making and personal and environmental factors, e.g.: patient demographics (age, gender, social living situation, social situation, level of education and social support) and examine their potential to impede or enhance self-care in the heart failure patient. In this pilot study, self-care behaviors, as well as age, gender, social living situation,
social situation, level of education and social support have been seen to be key predictors in reducing rehospitalization in the early post discharge period. Both quantitative and qualitative elements have been explored:

Research Question 1: What is the relationship among heart failure patients’ age, gender, social living situation, social situation, level of education, social support, and self-care behavior between 4-6 weeks post-discharge?

Research Question 2: What do patients perceive would help them better manage their care at home?

Research Question 3: In what ways do patients perceive health care providers could better help them?

In particular, this pilot study has attempted to probe the causes of early re-hospitalization in heart failure patients, and how they related to self-care (Appendix D) under the domains of self-care-maintenance, self-care management, self-care confidence, as well as the amount of positive social support during that crucial time period. This insight helps health care providers to get a better understanding on how to help heart failure patients to deal with health care challenges and complications which confront them after discharge.
Chapter 2 – Literature Review

The search strategy used to find studies related to self-care, self-maintenance, self-management and social support of heart failure patients, as well as research describing problems that heart failure patients encountered early in the post discharge period has been detailed in this chapter. The following databases were searched: Medline (using PubMed), Embase (using Embase.com) Cinhal (using EBSCO host) and BioMed Central, and Science Direct. The searches were conducted from February, 2013 until present. Significant studies were found from 1987 through February of 2014. A total of 38,800 research articles were found. The researcher narrowed the search to articles using valid instruments which have been used in the clinical arena, and excluded articles covering psychiatric and nursing home case studies.

Studies explicating the importance of self-care abilities in heart failure patients

Carlson, Riegel and Moser (2001) assessed for demographic and clinical factors which evaluated abilities of HF patients who had experience performing self care, with those HF patients who did not have experience. They examined clinical factors which may have interfered with self-care. The descriptive, cross-sectional comparative study design discussed lifestyle changes which were made by HF patients to accommodate their symptoms.

Riegel and Dickson, (2008) described a situation-specific theory of heart failure, and used an integrative approach which links nursing perspective research and clinical practice with a conceptual scheme based on abstract thinking, memos and dialogue between colleagues, students and research participants.

Riegel, Lee, Dickson, and Carlson (2009) summarized the recent changes and what was learned from the updated psychometric profile of the Riegel, et al. (2009) SCHFI tool which
scored the self-care behaviors in heart failure patients. The article emphasized that this data collection tool has been placed in the public domain.

Jaarsma, Stromberg, Martensson, and Dracup (2003) have developed the European Heart Failure Self-care Behavior scale (EHFScBS) which has a survey-format, test and retest self-administered survey. The design and development took place in three phases:

1) analysis of concept,
2) levels and selection of specific self-care behavior items
3) scales were tested and completed during the patient’s hospitalization, measuring the level of self-care in heart failure patients.

The mean scores and standard deviation reflected validity and reliability mechanisms used by individual patients to perform self-care.

Gallagher, Luttik, and Jaarsma (2011) studied social support in heart failure patients as a variable which contributed significantly to the heart failure patient’s ability to perform self-care. Their study was a cross-sectional descriptive design. It categorized the heart failure patient into low, moderate and high functioning in regard to self-care, social strength and support based upon the patient’s perception of how much support they want and are getting from a partner. The presence of a partner should be one of the variables which is questioned, and assessed for during the process of discovering what is necessary for the heart failure patient to achieve success (and reduce re-hospitalization).

Vaglio, Conrad, Poston, O’Keefe, Haddock, House and Spertus (2004) studied the quality of post-discharge social support outcomes of 271 cardiac patients participating in an observational research study from February to April of 1999. The Social Support Instrument (ESSI) used a survey-formatted self-report, and was conducted at discharge and monthly, for 6
months, recorded their recovery and support process. ENRICHD Social Support Instrument is a self-report measured where individual items were summed for a total score, with higher scores indicating greater social support (Vaglio et al., 2004). Concurrent and predictive validity were overviewed by calculating the correlation coefficient between the ESSI total score and the SF-36, a 36-item short-form health survey (McHorney, Ware, & Raczek, 1993).

Artinian, Magnan, Sloan and Lang (2002) discussed the heart failure patient’s environment and how to affect positive outcomes by examining the frequency of performing self-care and empowering their knowledge-base by teaching self-care while preparing patients for discharge from the hospital. Artinian et al. (2002) studied 110 participants as they were being readied for home-going post-hospitalization.

Various strategies have been explored to enhance self-care in heart failure patients. Shared appointments in an office setting was studied by Yehle, Sands, Rhynders and Newton (2009) where an advanced-practice nurse led team held teaching sessions with heart failure patients, and their pilot study tested repeated measures analysis of variance at baseline and 8 weeks. The patients were divided into a control group and an intervention group and change in self-care knowledge over time was compared. The Self-Care of Heart Failure Index was completed by both groups revealing no difference in rates of self-care change in total scores. However, results of the study showed that shared medical appointments (intervention group) improved knowledge of heart failure increased in patients and their families in a supportive environment visit with an advanced practice nurse.

An education strategy was trialed by Caldwell, Peters and Dracup (2005) where simplified teaching of symptoms caused by fluid-overload was taught using a step-by-step format in a rural heart failure clinic. Self-care by heart failure patients included knowledge of
recognizing signs of fluid overload. Fluid overload is one of the key symptoms of worsening heart failure and is exhibited by increased leg and ankle edema, increased weight greater than 3 lb in 3 days, abdominal girth expansion- abdominal bloating and nausea, lack of appetite and problems sleeping at night due to increased pressure/ breathlessness. Simple symptom recognition which focused upon one problem (fluid overload) sought to determine if teaching self-care of patient symptoms could improve behavioral management. Measuring from baseline of the sample of N=36 white males with mean age of 71 yr, ejection fraction of 47% and BNP at baseline and 3 months could be correlated with increased self-care in the intervention group.

**Review of tools used to measure self-care in heart failure management**

Riegel and Dickson (2008) defined self-care as a naturalistic process whereby decision-making results in choosing behavior that will maintain physiologic constancy (maintenance) and symptom response when problems occur (management). Heart failure confidence is the mediating effect on the various outcomes. Riegel et al. (2008) discussed related terms (self-monitoring and treatment adherence) in the self care of heart failure conceptual model from which the SCHFI (self-care of heart failure index) tool was based. Four propositions were tested:

1) symptom recognition being the most crucial for self-care management;

2) self-care was stronger in patients with past experience with their heart failure, having more knowledge, skill and congruent values (knowledge of their condition was built-in to this model by the survey style and psychometric analysis);

3) confidence of self-care moderated the relationship between self-care and outcomes;
4) confidence mediated the relationship between outcome and level of self-care ability. Therefore, these propositions were verification, early on, in the theory of situation-specific self-care of heart failure.

**Studies that have described problems encountered by HF patients in the early discharge period**

The literature was inadequate regarding published causes for post-discharge heart failure patient challenges causing rehospitalization between 4-6 weeks. This pilot study compiled evaluative research outlining self-care behavior in a community dwelling population of heart failure patients. The purpose was to find out what was happening in the early post-discharge period complicating outcomes/correlated with rehospitalization. The survey of heart failure patients 4-6 weeks post discharge, has built on current research helping clinicians learn what could help this population, what correlated with successful outcome.

Teijlingen and Hundley, (2001) argued that researchers have an ethical obligation to make the best use of research experience by reporting pilot study results. That pilot-testing a survey questionnaire yielded results, it was better to deal with the actual survey- the successes the failures, before embarking upon the great time, effort, financial investment of a full study (Mason & Zuercher, 1998).

There were relatively few studies that addressed personal heart failure early post-hospitalization experience. But there existed studies involving frequent telephone follow-up with recently discharged heart failure patients (Grady, Dracup, Kennedy, Moser, Piano, Warner-Stevenson & Young, 2000). Grady et al. (2000) explored the use of an integrated approach implementing hospital discharge. They identified that hypoperfusion was a symptom complex
which was difficult to identify over the phone or when a visiting nurse charted a lowered blood pressure, or patients complained of increased fatigue. The decreased renal function, decreased serum sodium, cool extremities have been difficult to assess by telephone contact.

Use of home technologies has emerged to aid in communication between the early post-discharged patient and the hospital/clinic healthcare team. The technologies studied have used a question and answer process written to address heart failure symptoms and recommend home guidelines to help patients. Future studies need to be well-grounded to ensure home technologies were useful by detailing the practice-based interventions, outcomes (Clark, McAlister, Cleland, Stewart, 2007) There had been a gap in the literature regarding early post-discharge heart failure experience and relatively few studies that measured self-care of heart failure patients in early post discharge experience.
Chapter 3 Methodology

Study Design

The study used a descriptive, correlational design to examine factors that were associated with self-care of heart failure patients 4-6 weeks post discharge from the hospital. The phenomenon of self-care was viewed within the context of Orem’s Theory of Self-Care (Orem, 2001) and Naturalistic Decision-Making, a model developed by Lipshitz et al., (2001). Patients were surveyed in their homes to determine self-care abilities using the Self-Care of Heart Failure Index (SCHFI) created by Riegel et al. (2001). The SCHFI measures self-care maintenance, self-care management of symptoms, and self-care confidence. Critical variables (age, gender, social living situation, social situation, level of education, and social support) that have been suggested by the theoretical frameworks and the literature for their potential to influence self-care were examined. The ENRICHD Social Support Index (ESSI) was used to measure social support. While it was recognized that a descriptive correlational design could not determine causality, it could help to paint a picture of what has happened at a given point in time and suggest factors that may be associated with positive or negative outcomes. If factors were subject to manipulation, such as social support, it helped the clinician to determine possible avenues for intervention. For the purpose of scholarly study, the survey-design methodology has enabled researchers to identify patients who had difficulty adhering to recommended therapy for their heart failure and/or who were deficient in self-care confidence.

A correlational design cannot determine causality. Outcomes in self-care might be due to factors other than those measured. Variability in cardiac status was limited by including only those patients who had an ejection fraction of 40% or less. Since differences among healthcare providers may influence self-care, only patients of one physician were included, to allow the
pilot study to focus more on within patient variables. This did not rule out, however, the possibility of within provider variations as they related to specific patients.

In addition to the quantitative focus of the study, patients were asked two open-ended questions designed to assess their perceptions about other potential factors which could influence management of their heart failure following discharge. Analysis of the qualitative data has provided guidance for future clinical interventions and suggested hypotheses to be tested in future research. Thus, this pilot study that has combined correlational and qualitative descriptive methods, was developed to answer the following questions:

“What is the relationship between age, gender, social living situation, social situation, level of education, and social support and self-care in heart failure patients 4-6 weeks post discharge?”

“What do patients perceive would help them better manage their care at home?”

“In what ways do patients perceive health care providers could better help them?”

Sample

A convenience sample of patients who were part of a local community-dwelling clinical practice was selected. Participants were part of a physician practice with community patients. They were invited to participate in the study using the following inclusion criteria:

- primary or secondary diagnosis of heart failure confirmed by an ejection fraction of 40% (or less). Heart failure patients from the physician group-practice met this criteria. Because oxygen-rich blood must be pumped out of LV (left ventricle) at a little more than half (the amount of blood) with each heartbeat, the EF (ejection fraction),
particularly the LVEF, (left ventricular ejection fraction) must pump out at least 55-70% with each heartbeat. An EF of 40% or less will confirm a diagnosis of heart failure.

- Cognitively intact (physician practice assessment)

Participants with documented cognitive impairment, and/or major psychiatric diagnosis (as determined by physician assessment and history) were excluded.

The sample size needed for this pilot study was greater than or equal to 30 \( (N \geq 30) \).

According to Hertzog (2008), the literature is sparse in the area of published guidelines for exact pilot study sample size. According to Stallard (2012), when applying for pilot study funding, a planned sample size should be about 0.03 times that of the size of the future definitive study. Julious (2005) emphasized a sample size of at least 12 \( (N=12) \) for a pilot study. An audit of medical research methodology for pilot sample sizes by Billingham, Whitehead and Julious (2013), reported that the range of sample sizes in 79 trials (both pilot and feasibility studies), were from 10 to 300 participants.

**Instruments**

**SCHFI.** The SCHFI (Appendix D), Self-Care of Heart Failure Index is a data collection instrument developed by Riegel et al. (2007 & 2009) which measures the patients’ ability to manage personal self-care of heart failure in self-report survey methodology. This instrument had undergone significant testing and revision. The current study used the most recent version (version 6) that had been recommended for research on the self-care of community dwelling heart failure patients. The SCHFI includes three subscales: self-care maintenance, self-care management, and self-care confidence. The self-care maintenance subscale measures how well patients adhere to their treatment plans from never (0) to always (4) in relation to 10 behaviors...
dealing with daily weights, medication compliance, use of a low salt diet etc. The self-care management scale measures how quickly patients recognize and take appropriate actions to respond to problems associated with water retention and breathing difficulties. Six appropriate responses are rated from never (0) to quickly (4). The self-care confidence subscale asks patients to rate their confidence from not confident (0), to extremely confident (4) in performing any of the 6 behaviors related to treatment plans, recognizing symptoms, interventions for managing symptoms and evaluating results of the intervention.

The validity and reliability of the SCHFI have been examined extensively (Riegel et al., 2009). Construct validity of the SCHFI with its three subscales was confirmed by factor analysis (Riegel et al., 2009). In addition, concurrent validity of these scales was determined by comparing scores on the SCHFI to scores on the European Heart Failure Self-care Behavior scale (Jaarsma, et al., 2003). Whereas the SCHFI was coded so as to indicate that the higher the score, the better self-care being practiced; by contrast, 12-item European Heart Failure Self-care Behavior scale (EHFScBS) used 5 points in the responses 1 equaling “agree completely” and 5 equaling “I don’t agree at all”. EHFScBS Lower scores indicated best self-care. Self-care maintenance was hypothesized to be negatively related to HFScBS and this hypothesis was supported (r=-0.65, p<.001). Qualitative assessment of validity for the SCHFI used data from three mixed method studies (Riegel et al., 2006; Riegel, Dickson, Goldberg, Deatrick, 2007; Dickson, Deatrick & Riegel, 2008) and supported the convergent validity of SCHFI. Convergence of both quantitative and qualitative results fortified the validity appraisal (Greene, Caracelli, & Graham, 1989).

Internal consistency of SCHFI subscales was determined by using the coefficient alpha in a study of 154 community dwelling heart failure patients. The coefficient alphas were as follows:
self-care maintenance (10 items, alpha=.55), self-care management (6 items alpha=.60), self-care confidence (6 items, alpha=.83). Although two of the subscales had somewhat lower levels of internal consistency, the authors suggested that their repeated testing of the instrument “provided evidence that the structure of the instrument is more powerful than the individual items” (Riegel et al., 2009, p. 494). They concluded that the internal consistency was acceptable.

As researchers are aware, the Cronbach’s alpha is used as an index of reliability—hence connected to the inter-relatedness of the items. By squaring this correlation, and subtracting it from 1.0, we get for example, if a survey has a reliability of 0.80, there is also a random error (error variance) of 0.36 in the score (0.80x0.80=0.64; 1.0-0.64= 0.36). Alpha is important in the evaluation of questionnaires as were used in this authors’ pilot study.

Reigel and colleagues were also concerned about the possibility that patients would provide responses that they determined the interviewer wanted to hear, so social desirability of the responses was examined. “Social desirability was assessed by correlating individual SCHFI scale scores with the social desirability scale score. None of the scale scores were significantly correlated with social desirability” (Riegel et al., 2009, p. 490). Thus, appropriate methods testing validity and reliability have been verified.

**ESSI.** The ESSI was selected to measure social support because it had been used previously in a study of cardiac patients (Vaglio et al., 2004). This social support instrument (see Appendix D), assesses the perceived availability of several forms of social support including listening, advice, affect, aid, and help with decision-making. It also assesses the availability of a confidant. All items are rated on a five-point ordinal scale from “none of the time” to “all of the time.” A seventh item (the patient’s marital status) was omitted because the response option differed and it was redundant with a demographic question that asked about the participant’s
social living situation. Moreover, Vaglio et al., (2004) found that this question had the lowest
correlation with the total ESSI score. For this latter reason, it was omitted in many studies.
Vaglio et al. (2004) evaluated the “test-retest” reliability of the ESSI and found no significant
differences in mean scores. Therefore, a single test could be carried out. The Cronbach’s alpha (a
= 0.88) showed good internal consistency (Vaglio et al., 2004).

Construct validity was evaluated by comparing social support differences between two
groups that were assumed to be different in social resources – depressed and non-depressed
individuals. An independent t-test confirmed the ability of the ESSI to discriminate between the
two groups. Non-depressed persons had significantly higher ESSI scores (p < 0.001). Vaglio et
al. (2004) also tested the concurrent and predictive validity by comparing the ESSI with the SF-
36 Social Functioning subscale. There was a weak but significant correlation between ESSI and
SF-36 Social Functioning scores at baseline and 6 months. Thus the reliability and validity of the
ESSI have been supported. The ESSI instrument is in the public domain.

Rationale for Demographic variables chosen for Pilot Study

The demographic variables which were chosen to measure included age, gender, social
living situation, social situation, level of education and perceived amount of social support in
relation to the patient’s heart failure self-care level. The rationale for choosing these particular
variables without including the race, and economic status, etc, were based on the real-world
settings, and challenges faced by individual heart failure patients in researchers’ clinical practice.
A one-time interview (which did not ask for name or date of birth, race or income, only gender,
age, social living situation, social situation, education and perceived level of social support) with
questioning to focus on the individual, created a culturally safe environment. The researcher did
not require a signature from the participant, but only a consent (agree to participate/ not agree to participate) wherein participants could feel less pressure, but also feel that the researcher cared about what were the problems, what were the challenges for participants as individuals with heart failure 4-6 weeks post-discharge. There could be a heightened awareness of which patients may be at greater risk for problems and re-admission considering these factors.

Table 1

<table>
<thead>
<tr>
<th>Concept</th>
<th>Theoretical Definition</th>
<th>Operational Definition</th>
<th>Empirical Referent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social living situation</td>
<td>Living arrangement which entails sharing private living space with another person in heterosexual or same sex relationship</td>
<td>1) Cohabitation with a significant other, not married but in monogamous relationship 2) Living with daughter, son or grandchild, family member 3) Roommates or friends sharing apartment 4) Frequent intimate partners</td>
<td>Marital status – legally married</td>
</tr>
<tr>
<td>Social Situation</td>
<td>Participant living alone either with support of another person or without support</td>
<td>Single participant dwelling alone his/her needs met through neighbors, church affiliations, etc.</td>
<td>Loner able to navigate: personal needs met through local agencies in community</td>
</tr>
<tr>
<td>Heart Failure (HF)</td>
<td>Theoretically not a specific disease, but rather the inability of the heart to pump blood to meet the needs of body</td>
<td>Ejection fraction of 40% or less confirms diagnosis of HF. Used as inclusion criteria for physician practice &amp; this pilot study.</td>
<td>Based upon experience, there is decreased cardiac output related to mechanical factors preload, afterload, inotropic state</td>
</tr>
<tr>
<td>Ejection Fraction (EF)</td>
<td>Defined as ratio of the volume of blood pumped out of the left ventricle over the end-filling volume with each heartbeat. Normal EF is</td>
<td>Severity of cardiac disease is best determined by the left ventricular ejection fraction; results of echocardiogram</td>
<td>Decreased ejection fraction is caused by heart failure, cardiomyopathy, hypoperfusion to vital organs (kidney,</td>
</tr>
</tbody>
</table>
between 55-70% with each heartbeat. An EF of <40% will confirm HF diagnosis.

brain) and differential diagnosis list which is beyond the scope of this pilot study.

Demographics included: dichotomous continuous variable of participant age being either ≥65, or <65; gender- male or female, social living situation- living alone or living with someone, social situation- alone/no support or alone /with support, educational level- education up to high school/ did not graduate/less than high school or, high school graduate and additional education/ trade school/ advanced degree, and perceived level of social support.

Procedure
The study obtained participants from a local independent practice. The physician indicated willingness to allow access to his patients by signing the “Permission to Approach Your Patient” form (Appendix A). The physician provided a list of participants who met the inclusion criteria. The physician contacted the identified potential participants, e.g., through an initial phone contact, using the scripts shown in Appendix B1 to inquire if the investigator could call them in the early post-hospitalization period to set up a time to participate in the survey. As part of the procedure, after the participants consented to participate in the study, they were interviewed at a time of their convenience in their homes. The researcher read the questions that made up the SCHFI and ESSI instruments, recorded their responses to the demographic questions, and asked the two open-ended questions. The answers were written down verbatim by the researcher, and prompts were used when there was confusion with the research question two or research question three. For research question two “What would help you at home to take care of yourself” the prompt: “What do you need at home to help you take care of yourself?” For
research question three, “What do you think your health care provider could do more to help you” the prompt was, “Name some things they could do to help.”

The script identified the investigator as a Nurse Practitioner and DNP student at the Frances Payne Bolton School of Nursing working with heart failure patients. It was important to note that in the script patients were assured that whatever they decided, neither he/she, nor the physician would know about their participation, and it would not influence the care they received from the physician practice.

The investigator followed up interested potential participants via phone to explain additional details of the study and set up a time for a meeting. If individuals were interested in participating in the study, appointments were made so that the investigator could meet with them in their homes. The final decision regarding their participation was made at that time. At the meeting the survey was explained, each participant would understand that they were invited to speak about what has happened since they were in the hospital, and what might help them. The participant would indicate the consent to participate in the study and be assigned a “Survey Participant Number” (Appendix B2). Individuals could withdraw at any time if they decided not to participate, without repercussion. If they decided to proceed, they understood that their participation was voluntary, that their answers were anonymous and their survey number were not linked to a name list, i.e., their anonymity would be protected.

The investigator was CREC certified through human subject’s research ethics in accordance with NIH research requirements. All participants were provided with a full explanation of the study, talking with them about what has happened since they were in the hospital. The investigator conducted the survey in the participant’s home. The check-off format
of the participation consent form (Appendix B) satisfied the informed consent for each patient’s participation in the study. All personal information was de-identified to ensure strict anonymity.

After a participant had given the consent to participate in the study, the demographic and survey questions were asked, and the participant’s answers were documented on patients’ survey response form. The completed hard copies of the surveys were kept by the investigator in a secure file cabinet in the investigator’s office, locked for a period of three years. The electronic data will be saved in the researcher’s private computer which has a detailed code and is password-protected. The Case Western Reserve University Institutional Review Board (IRB) had deemed the study exempt under code 45(CFR Code of Federal Regulations, part 46.101(b) (2).

Data Management

Quantitative data were recorded by the investigator on the questionnaire at the time of the interview and subsequently entered into an Excel spreadsheet, which in turn was used to generate the input file for statistical analysis using SPSS 21. Qualitative data were collected as verbatim responses to the two open-ended questions listed above and written on each participant questionnaire sheet. Themes were categorized using constant comparative analysis (Dye, et al., 2000), and categories were collapsed and described.

Instrument Scoring for Research Question One

SCHFI. The Self-Care of Heart Failure Index (SCHFI) was the primary instrument used to measure the heart failure patient’s ability to manage their care following hospital discharge. It includes three subscales: SCHFI A: Self-care Maintenance, SCHFI B: Self-care Management, and SCHFI C: Self-care Confidence. The scoring for each of the 10 items on the SCHFI A: Self-
care Maintenance sub-scale (Section A in Appendix D) was 1 (Never/Rarely) to 4 (Frequently/Always). Thus, the possible total sub-scale scores ranged from 10-40. A score for SCHFI A: Self-Care Maintenance having a range between 10-100, was determined from the raw sum-score of the ten questions minus 10 multiplied by 3.333 (or 100/30). A score of 3 for each of the ten questions would give a value of 67 using this scoring procedure. Riegel et al., (2009, page 492) state that:

“Scores on the SCHFI rose in a linear fashion as expertise increased (self-care maintenance: 70.0 (SD, 16.9), 80.0 (SD, 12.2), 85.0 (SD, 5.0); self-care management: 62.0 (SD, 12.9), 73.2 (SD, 11.6), 87.6 (SD, 5.9), for poor, good, and expert, respectively), except for confidence, which was highest in patients judged to be good but not expert in self-care (62.1 [SD, 10.3], 77.7 [SD, 12.9], 72.3 [SD, 12.0]).”

In addition they state (Riegel et al., 2009, page 492):

“We have consistently used a cut-point of 70 or greater on each SCHFI scale to judge self-care adequacy”

Hence, values near 70 are considered to be adequate in this study.

The scoring for SCHFI B: Self-care Management (Section B in Appendix D) uses a scale with a 1 to 4 point range, except for questions 11 and 16 that use a scale with a 0 to 4 point range. The first response (question 11a) is an acknowledgement of the patient having trouble with breathing or ankle swelling since arrival home from hospital has an additional score of “0” for “I Did Not Recognize It”. If “yes” question 11b asks “How quickly did you recognize it as a symptom of heart failure?” and uses a 0 to 4 point range; 0=“I Did Not Recognize It”; 1=“Not Quickly”, 2=“Somewhat Quickly”, 3=“Quickly”, and 4=“Very Quickly”. The next four questions (12-15) in uses a scale with a 1 to 4 point range; 1=“Not Likely”, 2=“Somewhat
Likely”, 3=“Likely”, and 4=“Very Likely”. The final question (question 16) that asks about a remedy that was tried has a similar 1 to 4 scale with an additional value of “0” for “I Did Not Try Anything”. Thus, the 6 items lowest raw sum-score is 4, whereas the highest raw sum-score is 24. A score for SCHFI sub-scale “B: Self-Care Management” having a range 0-100 is determined from the raw sum-score of the six items minus 4 multiplied by 5 (or 100/20). For this definition of the SCHFI B: Self-Care Management sub-scale, a score of 3 for each of the six questions gives a value of 70, and “A score of 70 or greater can be used as the cut-point to judge self-care adequacy in research” (Riegel et. al, 2009, page 494).

The scoring for SCHFI C: Self-care Confidence (Section C in Appendix D) uses a similar 1 to 4 point range scale; 1=“Not Confident”, 2=“Somewhat Confident”, 3=“Very Confident”, and 4=“Extremely Confident” for all six questions (questions 17 through 22). The raw sum-score for the six question range between 6 and 24. A score for the SCHFI C: Self-Care Confidence sub-scale having a range 0-100 is determined from the raw sum-score of the six items minus 6 multiplied by 5.56 (100/18). A participant answering 3 (very confident) for each of the six questions yields a score of 67, and, again, values above 70 are considered to be adequate.

Riegel and associates (2009) suggest that average scores for the three sub-scales should meet or be just slightly lower than the cut point of 70. For the purpose of this study, participants will be classified as poor (0 to < 70), good (70 to <80), or expert (80 to 100). Heart failure patients who were scored as expert described how they were able to keep themselves symptom-free (Riegel et al., 2009).

**ESSI.** Each of the items on the ESSI (Enriched Social Support Instrument) social support (section D in Appendix D) instrument were scored in the 0 to 4 point range; 0=“None of the
time”, 1=“Rarely”, 2=“Some of the time”, 3=“Most of the time”, and 4=“All of the time” for all six questions. The raw sum-score for the six questions had a potential range between 0 and 24. A score for Social Support, having a range 0-100 was determined from the total raw score of the six questions by multiplying it by 4.17 (100/24). According to this, a score of 50 and below would indicate an inadequate level of perceived availability of social support (No authors listed: The ENRICHD Investigators, 2000).

Reliability Analysis

The Cronbach’s alpha on the 10-item Self-Care Maintenance scale was 0.55 in the 2009 update study by Riegel et al. In making a comment about the Cronbach’s alpha for the Riegel, et al. (2009) study, SCHFI Self-care Maintenance of the sample (n=154), the 0.55 was not statistically different from the original SCHFI v4. According to Riegel (2009), “because the addition of items to the maintenance scale did not significantly change the coefficient alpha, the structure of the instrument is more powerful than the individual items.”

The internal consistency of the instrument ESSI will be carried out in a similar fashion by determining the Cronbach’s alpha of the 6 measures that are used to obtain the total score.
Analysis of Qualitative data: “The two open-ended questions were evaluated using the constant comparison method of qualitative analysis. Constant comparative analysis of qualitative data (Dye, et al., 2000), where an analytic process of data analysis is begun simultaneously with data collection. Analysis occurs at the conclusion of the interview. Responses to each of the open-ended questions were analyzed separately. The written patient transcripts in the study at hand, documented with respect to what would better manage their care and ways healthcare providers could be more helpful, in separate analysis; responses to each question established the data units of interest.
Within participants, within question data units, were identified and categorized by comparing each data unit with the previous one to determine whether it was similar or different. If the latter, it was placed in a new category. When data units were categorized, the categories were compared and collapsed. Memos were written to note the basis for re-grouping the categories. These memos established an audit trail that was important to the confirmability of the analysis. Data analysis concluded with the identification of distinct themes that reflected what was helpful in a general sense and particularly from health professionals as heart failure patients attempted to manage their care post discharge.

**Trustworthiness of Data.**

Several steps were taken to support the trustworthiness of the data analysis. Initially, the researcher listened intently and engaged in “bracketing” a process of attempting to screen out any preconceptions the researcher may have about what categories could be identified. Researcher had worked with a heart-failure population since 1997, being aware of how deliberate identification of all ideas personally held regarding the phenomena being studied must be ignored. Participant answers which were unclear, were sought out, and repeated using planned prompts by the researcher. This occurred within the context of the interview because there were no plans to re-contact the participants following the data analysis. These steps contributed to the credibility of the data.

A review of the private physician’s practice criteria was included earlier in this chapter; the participants were part of a community-dwelling cardiology practice, where patients were invited to participate in the study if they were assessed to have a diagnosis of heart failure (ejection fracture of 40% or less), and were cognitively intact per physician assessment.
Chapter 4 – Analysis of Data and Themes

The purpose of this pilot study was to identify factors associated with self-care in heart failure patients 4–6 weeks post discharge from the hospital. Prior research relating to the effectiveness of self-care in HF had been hampered by lack of effective means to measure self-care in this population, lack of evaluation of the multiplicity of social support available (or absent), and integrated contextual considerations. The relationships between the heart failure patient’s age, gender, social living situation, social situation, level of education, social support and self-care have been identified by the pilot study sample (N=30) as key. By examining HF patients’ self-care behavior in terms of measuring self-care maintenance, self-care management, and self-care confidence, with a larger sample, a stepwise regression might have best explained the influence of the Independent Variables; however, in this pilot study, our sample included only 30 participants (N=30). Therefore, data were examined more descriptively. And, in addition, both quantitative and qualitative elements were explored (by means of study participants’ data collection results) and study participants responded to the two open-ended questions, “What do patients perceive would help them better manage their care at home” and “In what ways do patients perceive health care providers could better help them.”

Sample

A total of 33 subjects were identified and approached following the process described in Appendix B1 and B2. Three of the subjects were subsequently eliminated; one prospective participant was discharged to a women’s shelter following hospitalization, and lost to follow up. Two subjects were discharged to nursing homes out of the community. The remaining 30 subjects were interviewed and the results from their interviews were the basis for the analysis.
and discussion below. The sample contained a diverse population, although the ethnic backgrounds of the subjects were not recorded or used in any of the analysis. The ages of the sample ranged from 35 to 87 with an average age of 65; there were 13 male subjects and 17 females. Sixteen participants had an education of high school or less, whereas fourteen participants had an education beyond high school. Fifteen subjects were living alone and fifteen were living with someone. Twenty subjects had some form of social support (a spouse or other person that could help them), and ten had no social support they could reliably depend upon.

The results and analysis of the data collected during interviews between April 15 and May 10, 2014, are shown below, and the discussion of the data is carried out in Chapter 5. The calculated scores for the three sub-scales investigated (the SCHFI subscales A: Self-care Maintenance, B: Self-care Management, and C: Self-care Confidence, and the ESSI: Social Support) together with the demographic information obtained during the interviews (age, gender, level of education, social living situation and social situation) are summarized in Appendix .

**Instrument Scoring for Research Question One**

The Self-Care of Heart Failure Index (SCHFI) was the primary instrument used to measure the heart failure patient’s ability to manage their care following hospital discharge. As mentioned in Chapter 3, the items in the three scales SCHFI A: Self-care Maintenance, SCHFI B: Self-care Management, and SCHFI C: Self-care Confidence were used to form scales with values between 0 and 100. Riegel and associates (2009) suggest that average scores for the three sub-scales should meet or be just slightly lower than the cut point of 70. The items in the Enriched Social Support Instrument (ESSI) (section D in Appendix D) were used in a similar fashion obtain values between 0 and 100. Although ESSI is an independent variable, the scale is
derived from a subject's perceived level of social support, and can thus be used as a tool to understand the social support in conjunction with the SCHFI subscales.

Research Question One: “What is the relationship between age, gender, social living situation, social situation, level of education, and social support and self-care in heart failure patients 4-6 weeks post discharge?” This question was first examined using the dependent variables being part of SCHFI followed by an analysis of the independent variables. Regression and correlational analysis, including statistical comparisons, were carried out but are omitted due to the small sample size. Therefore, only a descriptive review of the independent variables in relation to the dependent variable is included.

**SCHFI:** The number of subjects (and the percentage) at the different levels of self-care based for the SCHFI sub-scales are shown in Tables 2 through 4; Table 2 for the ten items making up SCHFI A: Self-care Management, Table 3 for the six items making up SCHFI B: Self-care Maintenance, and Table 4 for the six item making up SCHFI C: Self-care Confidence.

### Table 2

**SCHFI A: Self-Care Management - Comparative Frequency of Health Behaviors (N = 30)**

<table>
<thead>
<tr>
<th>Health Behavior</th>
<th>Standard Mean*</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your doctor or nurse appointments</td>
<td>3.77</td>
<td>0.430</td>
</tr>
<tr>
<td>Use a system (pillbox, reminders) to help you remember your medicines</td>
<td>3.67</td>
<td>0.884</td>
</tr>
<tr>
<td>Remember to take one of your medicines</td>
<td>3.30</td>
<td>1.149</td>
</tr>
<tr>
<td>Eat a low-salt diet</td>
<td>3.07</td>
<td>0.828</td>
</tr>
<tr>
<td>Weigh yourself</td>
<td>2.97</td>
<td>1.098</td>
</tr>
<tr>
<td>Try to avoid getting sick (e.g., flu shot, avoid ill people)</td>
<td>2.87</td>
<td>1.074</td>
</tr>
<tr>
<td>Do some physical activity</td>
<td>2.77</td>
<td>0.774</td>
</tr>
<tr>
<td>Check your ankles for swelling</td>
<td>2.50</td>
<td>1.075</td>
</tr>
<tr>
<td>Ask for low-salt items when eating out or visiting others</td>
<td>2.40</td>
<td>1.163</td>
</tr>
<tr>
<td>Exercise for 30 min</td>
<td>2.23</td>
<td>0.935</td>
</tr>
</tbody>
</table>

* (Scale: 1 = Never or Rarely – 4 = Always or Daily)
Table 3

**SCHFI B: Self-Care Maintenance - Comparative Frequency of Health Behaviors (N = 30)**

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Standard Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Call your doctor or nurse for guidance**</td>
<td>2.90</td>
<td>0.960</td>
</tr>
<tr>
<td>Reduce the salt in your diet**</td>
<td>2.70</td>
<td>1.119</td>
</tr>
<tr>
<td>Reduce your fluid intake**</td>
<td>2.20</td>
<td>1.215</td>
</tr>
<tr>
<td>Think of a remedy you tried the last time you had trouble breathing or ankle swelling, How sure were you that the remedy helped or did not help?***</td>
<td>2.13</td>
<td>1.137</td>
</tr>
<tr>
<td>How quickly did you recognize it as a symptom of heart failure? *</td>
<td>2.07</td>
<td>1.337</td>
</tr>
<tr>
<td>Take an extra water pill**</td>
<td>2.03</td>
<td>1.245</td>
</tr>
</tbody>
</table>

* (Scale: 0 = I Did Not Recognize It, 1 = Not Quickly – 4 = Very Quickly)
** (Scale: 1 = Not Likely – 4 = Very Likely)
*** (Scale: 0 = I Did Not Try Anything, 1 = Not Sure – 4 = Very Sure)

Table 4

**SCHFI C: Self-Care Confidence - Comparative Frequency of Health Behaviors (N = 30)**

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Standard Mean* (SD)</th>
<th>Not (%)</th>
<th>Somewhat (%)</th>
<th>Very / Extremely (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>follow the treatment advice you have been given</td>
<td>3.23 (0.858)</td>
<td>2 (6.7%)</td>
<td>2 (6.7%)</td>
<td>26 (86.6%)</td>
</tr>
<tr>
<td>In recognize changes in your health if they occur</td>
<td>3.17 (0.791)</td>
<td>1 (3.3%)</td>
<td>4 (13.3%)</td>
<td>25 (83.4%)</td>
</tr>
<tr>
<td>do something that will relieve your symptoms</td>
<td>3.13 (0.819)</td>
<td>1 (3.3%)</td>
<td>5 (16.7%)</td>
<td>24 (80.0%)</td>
</tr>
<tr>
<td>evaluate the importance of your symptoms</td>
<td>3.07 (0.691)</td>
<td>1 (3.3%)</td>
<td>3 (10.0%)</td>
<td>26 (86.6%)</td>
</tr>
<tr>
<td>keep yourself free of heart failure symptoms</td>
<td>2.97 (0.809)</td>
<td>1 (3.3%)</td>
<td>7 (23.3%)</td>
<td>22 (73.4%)</td>
</tr>
<tr>
<td>evaluate how well a remedy works</td>
<td>2.83 (0.874)</td>
<td>2 (6.7%)</td>
<td>8 (26.7%)</td>
<td>20 (66.6%)</td>
</tr>
</tbody>
</table>

* (Scale: 1 = Not Confident – 4 = Extremely Confident)
As can be seen from Table 2, the participants’ least frequent health behaviors include exercise, restricting salt, and checking for ankle swelling; while the patients’ most frequent health behaviors involve keeping medical appointments and taking their heart failure medications.

The confidence levels, clearly indicate that at least 80% of the participants were very to extremely confident in carrying out most of the desired health behaviors. Although less confident, majority were still very to extremely confident that they could keep themselves free of symptoms (73%) and evaluate the effectiveness of a remedy (67%). Although self-care confidence is not exactly part of self-care, it can affect patient outcomes, as indicated by the correlations between the confidence sub-scale and the maintenance and management behavior sub-scales (see Table 6). Self-care confidence is an important factor which probably moderates the relationship between level of self-care and success in assessing a patient’s ability to maintain HF health stability.

Table 5

Comparison of SCHFI Sub-Scale Standardized Means (N=30)

<table>
<thead>
<tr>
<th></th>
<th>Standardized Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care Maintenance</td>
<td>65.1</td>
<td>19.4</td>
</tr>
<tr>
<td>Self-Care Management</td>
<td>50.5</td>
<td>23.8</td>
</tr>
<tr>
<td>Self-Care Confidence</td>
<td>67.3</td>
<td>25.2</td>
</tr>
</tbody>
</table>

Although Riegel et al. (2009) have posited that a standardized mean of 70 or above is desired, none of the means for the sub-scales for this study have achieved that level. Self-Care
Confidence and Self-Care Maintenance have come close, however, to that value, at 67 and 65, respectively.

Table 6

*SCHIFI Sub-scale Pearson Correlations (N=30)*

<table>
<thead>
<tr>
<th>SCHFI Cronbach’s Alpha</th>
<th>Self Care Maintenance</th>
<th>Self Care Management</th>
<th>Self-Care Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Care Maintenance</td>
<td>0.81</td>
<td>-</td>
<td>0.579**</td>
</tr>
<tr>
<td>Self Care Management</td>
<td>0.76</td>
<td>0.579**</td>
<td>-</td>
</tr>
<tr>
<td>Self-Care Confidence</td>
<td>0.92</td>
<td>0.476**</td>
<td>0.524**</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).**

**ESSI - Social Support**

The number of participants (and the percentage) having different levels of social support as measured by the ESSI are shown in Table 7. The mean scores are all reasonably high which means that most subjects had a reasonable level of perceived available social support. Although the response levels for the items making up ESSI are in the range 0 (None of the time) to 4 (Most of the time) the columns in Table 6 are arranged in such a way that response levels 0 and 1 have been combined (None of the time/Rarely, and response levels 3 and 4 have been combined (Most/All of the time). More than 70% of the participants perceived that support in the forms of good advice, emotional support, listening, and a trust worthy confidant, were available most of the time.
Table 7

Comparative Availability of Forms of Support (ESSI) (N = 30)

<table>
<thead>
<tr>
<th>Form of Support: Someone to:</th>
<th>Standard Mean* (SD)</th>
<th>Availability of Support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>None of the time / Rarely</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some of the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Most / All of the time</td>
</tr>
<tr>
<td>give you good advice about a problem?</td>
<td>3.10 (0.85)</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 (20.0%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23 (76.7%)</td>
</tr>
<tr>
<td>feel close to, someone in whom you can trust and confide in?</td>
<td>3.07 (0.91)</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 (26.7%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21 (70.0%)</td>
</tr>
<tr>
<td>provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td>3.07 (1.11)</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5 (16.7%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23 (76.7%)</td>
</tr>
<tr>
<td>listen to you when you need to talk?</td>
<td>3.00 (0.91)</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 (20.0%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>22 (73.3%)</td>
</tr>
<tr>
<td>show you love and affection?</td>
<td>2.83 (1.15)</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19 (63.4%)</td>
</tr>
<tr>
<td>help with daily chores?</td>
<td>2.60 (1.38)</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 (20.0%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17 (56.7%)</td>
</tr>
<tr>
<td>* (Scale: 0= None of the time – 4 = All of the time)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Correlation between Self-Care (SCHFI) and Social Support (ESSI)

The relationship of between the levels of social support as measured by the ESSI to each of the self-care SCHFI sub-scales was also examined, and are shown in Table 8. As can be seen in Table 8, the social support (ESSI) was not significantly correlated with either self-care maintenance or self-care management. However, there was a significant moderate and positive relationship between social support and self-care confidence ($r = 0.49$, $p = 0.001$).

Table 8

Relationship of ESSI to SCHIFI Sub-scale (N=30)

<table>
<thead>
<tr>
<th>ESSI (Social Support)</th>
<th>Self-care Maintenance</th>
<th>Self-care Management</th>
<th>Self-care Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.21</td>
<td>0.19</td>
<td><strong>0.49</strong></td>
<td></td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).**
The three subscales making up SCHFI with respect to the minimum level of adequate self-care ($\geq 70$) are shown in Table 9. The levels above 70 are subdivided into two groups; “Good” in the range 70-80 and “Expert” for score higher than 80.

Table 9

<table>
<thead>
<tr>
<th></th>
<th>Standard Mean (SD)</th>
<th>Poor (&lt;70)</th>
<th>Good (70-80)</th>
<th>Expert (&gt;80)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A: Self-Care Maintenance</td>
<td>65.1 (19.4)</td>
<td>15 (50.0%)</td>
<td>12 (40.0%)</td>
<td>3 (10.0%)</td>
</tr>
<tr>
<td>B: Self-Care Management</td>
<td>50.5 (23.8)</td>
<td>22 (73.3%)</td>
<td>4 (13.3%)</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>C: Self-Care Confidence</td>
<td>67.3 (25.2)</td>
<td>15 (50.0%)</td>
<td>4 (13.3%)</td>
<td>11 (36.7%)</td>
</tr>
</tbody>
</table>

Self-care (SCHFI) and Social Support (ESSI) for the different Demographic Groups

A series of histograms were generated to examine the difference in mean standard scores on the SCHFI subscales for dichotomized independent variables; Gender (male/female), Education (high school or less/beyond high school), Social Living Situation (alone/with someone), Social Situation (without/with help), and Age ($<65 / \geq 65$) (Figures 2 - 6).

The value used to judge self-care adequacy ($\geq 70$) is indicated with a horizontal line in these figures. It can be seen that only females, subjects with an education beyond high school, subjects living with someone or have access to help, have an average score above 70 for Social Support. The only other score that obtains values above 70 is C: Self-Care Confidence, which occurs for participants that have an education beyond high school and for participants that live without help.
Figure 2 suggests that the self-care management and confidence is greater in females than males. However, in the case of certain males, perhaps those interviewed who have had to take care of themselves and their HF, perhaps alone although asking for help, are better able to complete their HF self-care maintenance. This is an interesting finding, which requires future study.
The subjects older than or equal to 65 had a higher score for the self-care sub-scales compared to the subjects being younger than 65. This older group is also the group with the best social support. Surprisingly, the subjects below 65 have a very low score for self-care management.
Interestingly, those respondents who had a high school education or less, were better able to manage their HF self-care than the participants with greater than high school education. Is it possible that those with less education, have greater trust in their healthcare providers, thus faithfully following their treatment plan as advised by their healthcare providers? Certainly, this is a factor which requires future investigation.
Figure 5. The average values of the SCHFI sub-scales and ESSI for different social living situations.

Again, it appears from Figure 5, that those who are living alone are maintaining their HF self-care slightly better than those respondents who have had someone who was cohabitating. The study participants who are able to manage their HF and, in addition, do so with the confidence that they are responding correctly and in a timely fashion to symptoms. This finding will require future investigation.
It can be seen in Figure 6 that the group or respondents that do not have anyone to help is also the group that has the highest level of self-care confidence.

Research question one can be said to have brought out specific patterns in the relationships between participants’ age, gender, social living situation, social situation, level of education and perceived social support and level of self-care in this pilot sample of HF participants. The self-care of participants aged 65 and over ≥ 65 is consistently higher than those younger in age (below 65), with self-care maintenance, management and confidence correlation at .63, .80, and .65 respectively at the 0.01 (99%) level, 2-tailed. The participants aged below 65
were consistently lower with regard to their subscale correlation with self-care maintenance, management, and confidence, scoring respectively .50, .34 and .48 none of which were significant. Another pattern emerged among participants who were in a SS Social Situation living alone, without support, where 10 participants out of 30 (N=30) were significantly correlated at .92 (99%) level, 2-tailed. Interesting point to note that individuals without support in their social situation scored above the standardized mean of over 70 in self-care confidence.

Open ended questions

The responses of each study participant were written verbatim on each patient’s data collection sheet. Responses were then categorized using constant comparative analysis (Dye et al., 2000), categories were collapsed, and the resulting themes were described. Details were added in a memo format as needed, statement responses that were not clear, were clarified within the context of the interview, as each participant was not contacted more than one time. By means of bracketing direct quotes made by participants, and repeating the quote to ensure that it be correctly documented, trustworthiness of data was ensured. Of note: this mixed culture of heart failure patients was warmly accepting of the researcher and did not hesitate to share their post-discharge experiences. Participants were reminded again by the researcher that their privacy and entrusted confidentiality would be maintained, none of the survey participant numbers would be in any way connected to a name list, and all addresses and contact information was shredded and disposed.
Research Question Two: “What do patients perceive would help them better manage their care at home?”

Seven participants indicated satisfaction with their own care management once they were discharged to home. The seven participants who indicated satisfaction with their own care management at home could not name anything else they would have needed during this time period of 4-6 weeks post-discharge. Participants’ comments seemed to cluster into three themes: 1) Social Services (for help with financial, medical insurance, general public aid obtaining food stamps, transportation), 2) Activities of Daily Living Assistance at home, Nursing Aid), and 3) Individualized Counseling and Specific Education geared to the problem at hand (smoking cessation, weight loss, dietary and cooking advice).

Some of the comments reflecting a need for Social Services at home:

- ‘Had to quit my roofing job, got no medical insurance now’
- “I need a ride to my hospital appointments, I don’t drive”
- “Stairs are a problem for me”
- “I ran out of my medication, and I can’t afford refills on these heart pills”
- “Need some help cleaning, doing laundry” (requesting funding for housekeeper service)
- Need a lift to my AA [alcoholics anonymous] meetings’

Some themes reflecting a need for Activities of Daily Living, Home Help:

- “It is difficult to get to the bathroom, I’m too exhausted to walk very far with this heart”
- “Need some help with my bath”

Some themes reflecting a need for Individualized Counseling and Specific Education:
• “Don’t understand about my not eating salty foods now I can get my own food at home”
• “I need to lose weight, cook healthy meals now I’m home”
• “Don’t understand why I get tired so easy at home”
• “Don’t know which of these [pills, medications] are affecting my manhood, home with girlfriend”

Research Question Three: “In what ways do patients perceive healthcare providers could better help them?”

The participants (N=30) responded to this question with short, positive statements which indicated that they were satisfied with their healthcare providers, the help given them by their healthcare providers. Themes reflected both formal and informal support which was needed by this post-discharge HF aggregate. Many respondents expressed wanting a more personalized approach upon being discharged from hospital to home. Nineteen respondents communicated needing more education and information from their healthcare providers both in and outside of the hospital.

Themes reflecting the need for additional education from their Healthcare Providers:
• “My doc told me I need to quit smoking, it is too hard to stop, I been [smoking] for so long”
• “I need them [healthcare providers] teaching me why I go to deallaysis [dialysis] now”
• “They [providers] tell me, you’re not doing this, you’re not doing that”
• “They [Healthcare Providers] could get me a lift chair [for elevating legs and feet] My feet are tight, my leg skin’s tight.” (requesting a written prescription-durable medical equipment)

Themes perhaps requiring informal support (attention) from healthcare provider:
• “They [healthcare provider] could of looked at me straight, asking, not rushing me, on the way out [of the hospital]”
• “He [grandson] tell the doctor, nurses, they doing good for me.” Expression on participant’s face seemed to be reaching out for something, asking with her eyes for Provider support similar to what she was receiving from her grandson.

It must be noted, that family, close friends, good neighbors, church affiliations factored into certain patients’ social situation in spite of some participants living alone. Although few study participants mentioned it (n=4), the second open-ended question involving healthcare providers was answered slightly more positively when the respondent had a loved one/ close neighbor with whom they shared a special bond.

As this study explicates, the first 4-6 weeks post discharge brings with it many changes both in functional capacity and needing new strategies for coping with being home, having heart failure and the necessity for confidence in ones’ self-care behavior. The literature supports the fact that strong self-care behavior precludes re-hospitalization early on (Clark, et al., 2007). Social support factors strongly into study participant’s level of confidence in performing self-care of their heart failure. The two open ended questions brought out some important detail in what types of social support, Activity of daily living assistance and individualized attention could be
necessary to keep the HF population, recently discharged from hospital, performing self-care more diligently. There seems to be a need for more individualized ‘counseling’ or education about topics which are peripheral to the participant’s heart failure. Levels of fatigue at home (research question one) are a concern, and at this point an advanced practice nurse would need to assess the type of fatigue- is it generalized muscle fatigue, weakness due to increasing girth, increased venous pressure (right ventricular involvement increased), or diminished bowel sounds and constipation-(causing lethargy) due to gastrointestinal stasis secondary to their heart failure.
Chapter 5 – Discussion of Findings

Heart Failure patients are particularly vulnerable to various challenges during the first 4-6 weeks after discharge, leading to possible re-hospitalization. There is a 21% re-hospitalization rate after 30 days post discharge, most readmissions occur within the first 4-6 weeks of discharge, and are preventable (Rich, et al., 1990).

The researcher had experience with heart failure patients with a primarily indigent background, and the point of this study was to find out what challenges are especially surfacing during this window of between 4-6 weeks post discharge. This study population could be interviewed, whereas the population typically seen by the author, were lost to follow-up. It was the purpose of this pilot study to outline and methodically attempt to discover reasons why a particular population (of HF patients) at a particular time period was experiencing challenges.

As shown in chapter 4, the self-care of the heart failure population in this study had the following standardized mean scores: Self-care Maintenance 65, Self-care Management 50, Self-care Confidence 67, whereas a score of 70 represents the minimum level for an assessment of adequate self-care. Since the purpose of this pilot study was to identify factors associated with self-care in heart failure patients 4-6 weeks post discharge from the hospital, it is important to understand why some of these self-care measures are below the level needed for successful self-care post discharge. Prior research relating to the effectiveness of heart failure patients’ self-care post-discharge, has been hampered by the lack of valid means of self-care measurement.

The relationships between heart failure patients’ age, gender, social living situation, social situation (help/no help), level of education, and perceived availability of social support and self care have been identified by the pilot study sample (N=30). In addition, qualitative elements were elicited through participants’ answers to the two open-ended research questions:
“What do patients perceive would help them better manage their care at home” and “In what ways do patients perceive health care providers could better help them” combined to contribute to the richness of the data.

**Research Question One: Quantitative factors influencing self-care**

The literature review (Chapter two) in this pilot study reiterates various studies which have been completed within the past decade, assessing clinical factors which influence HF patients’ performance of self-care. Carlson, et al. (2001) used a descriptive, comparative cross-sectional design to discuss the lifestyle changes which were made by patients to help alleviate symptoms. Other studies used cross-sectional descriptive designs which assess for partner-support in order to help with HF self-care. Riegel and colleagues (2007, 2009) developed the SCHFI (self-care of heart failure index) which is one of the instruments used, and previously described, to measure self-care in this pilot study. The ESSI instrument (ENRICHD social support instrument) described by Vaglio et al. (2004), was used to measure patients’ perceptions of available forms of social support. By means of data collection tools, an assessment can, therefore, be made alerting Healthcare Providers to those patients who may require additional help. Factors which comprised having skills in HF self-care, included a combination of behavioral and process-oriented decisions which were made in response to symptom-recognition, and confidence to act to relieve symptoms, maintain health and communicate with healthcare providers in an ongoing manner. Demographic and social variables were examined for their potential to influence self-care. The sample size (N = 30) limited the power to explore these relationships using statistics. Therefore, the relationships were viewed descriptively for trends/patterns which might be tested in a larger study. Figures 1-6 (Chapter 4) presented a visual
description of the potential relationships between the predictor variables and the three components of self-care. There was a trend for patients over the age of 65, living alone, and who had no help, to score higher on self-care maintenance, self-care management, and confidence. Of the participants who reported having symptoms due to their heart failure such as trouble breathing or ankle swelling (n=25 or 83%), the results in Table 2 suggests a low likelihood that these patients responded to their symptoms and used self-care maintenance to remedy their situation. However, the respondents who did take an extra water pill (diuretic, with health-care provider recommendation), felt that the remedy worked.

**Self-Care Maintenance.** Self-care maintenance behaviors that were most frequently performed included keeping follow-up medical appointments, using a pillbox/reminder system, remembering to take their medications (mean = 3.30) and eating a low-salt diet. Standard mean of less than 3 on a 4 point scale were noted for the other six maintenance behaviors including daily weights, avoiding getting sick (getting a flu shot, avoiding ill people), being physically active, exercising for 30 min, checking for the presence of edema, and asking for low-salt items. What is the reason for not getting a flu shot or for not trying to avoid ill people? Of concern, is why these behaviors are not practiced; what about the exercise presents a problem for the patient? Has the patient had an increase in shortness of breath when attempting exercise? What reasons the patient has for not exercising is important for healthcare providers to understand. There is strong rationale for being continually alert to behaviors which are poorly performed or ignored in the HF patient.
There is a pattern to the types of behaviors which were performed less frequently. Physical activity and weighing oneself, eating a low-salt diet and checking ankles for swelling were not practiced as often. What is the reason for this low response? The provider would need to look into reasons why. On the other hand, the behaviors practiced more frequently were keeping health care provider appointments and using a pillbox system to remember medications. It is good that 26 out of 30 from our sample (N=30) were diligent about these last two items.

Of the participants who reported having symptoms due to their heart failure such as trouble breathing or ankle swelling (n=25 or 83%), the results in Table 2 suggest a low likelihood that these patients responded to their symptoms and used self-care maintenance to remedy their situation. What is particularly distressing, is that the symptom of having trouble breathing is such an alarming symptom and indicative of worsening fluid build-up as deep respirations with adventitious lung sounds-crackling sounds in the lung as air is attempting to move through narrowed air passages. However, the respondents who did take an extra water pill (diuretic, with health-care provider recommendation), felt that the remedy worked. Symptoms must be acted upon immediately with this aggregate of patients. The SCHFI tool is one solution for the healthcare provider to be alerted to possible problems as this in the patient being cared for.

Participants ≥65 years of age had high scores in self-care maintenance (Fig.3), which may indicate that they were serious about following their treatment. Study subjects 65 and younger scored poorly on the SCHFI (Fig. 3), while scoring lower than older patients in all subscales, and the reasons behind their lower scores could be attributed to having to work to earn a living, and perhaps are too busy, too exhausted to maintain health activities. This is a topic for future research.
**Self-Care Management.** Management of symptoms included behaviors which were performed to remedy a HF symptom; seeking guidance by calling the healthcare provider was a frequently followed behavior in the study group, (mean=2.90) or, reducing salt in the diet (standard mean=2.70). The item asks if the participant takes a water pill, which would be skipped if the person is not taking a diuretic. According to the instrument author, Riegel et al., (2009), “if the patient is not taking a diuretic, this item can be skipped and scoring adjusted using the same general formula ….. raw score sum minus lowest possible raw score multiplied by 5.’’ [Lowest raw score is 4, highest is 24 -4=20, multiplied by 5]. It must be noted that the SCHFI scale B, self-care management, is somewhat complex; however, it was the SCHFI author’s instrument, and the study scoring effectively measured self-care management in this population.

It must be added that out of the sample (N=30), eight participants scored good-expert (27%) and twenty-two participants scored poorly (73%). The question must be asked about the reason some participants (n=22) did not recognize their symptoms as secondary to their HF. This is important information. The healthcare provider must be aware of patients who are not sure about certain symptoms being serious and further education for the patient, educational support ongoing.

The management of symptoms requires critical thinking and adherence to treatment guidelines. Study participants performed the behaviors in SCHFI sub-scale B less often, the scoring reflects this, but, surprisingly, the group of participants who had less formal education, did better in the area of managing their HF symptoms, than the group with greater than a high school education. It could be that less educated patients may have a greater trust in their healthcare provider, faithfully following treatment plan.
It is not clear if the subjects who have a high degree of self-care confidence choose not to seek help, or if the fact that the subjects that do not have any help have to develop their own self-care skill, and their own network, and hence get more confident. However, in responding to the data collection instruments and open-ended questions, those respondents who had unusual social situations wherein they had to navigate needs without the help of a spouse or significant other, but were able to take care of their maintenance and management of HF self-care with greater self-care confidence, warrants further investigation.

**Self-Care Confidence.** The sub-scale self-care confidence standardized mean= 67; again, none of the subscale means in this study achieved the standardized mean of 70 or above that Riegel desired (2009). Riegel states that, “we strongly discourage users from calculating a total, combined SCHFI score. Instead, the data will be far more useful if the scales (Maintenance, Management, Confidence) are used individually” (Reigel, 2009, p. 493). “A score of 70 or greater can be used as the cut-point to judge self-care adequacy in research” Reigel, 2009, p 493). However, she concludes in her use of SCHFI to measure self-care behavior, that there is evidence that self-care behavior practiced and scored at levels lower than 70 can be beneficial. One result from this pilot is that 87% of the subjects felt very confident in following treatment advise given (mean=3.23), which is the most frequent behavior practiced in this subset of confidence item (Table 4). The subjects appear to be able to recognize changes in their health (mean=3.17), address such changes if they occurred (standardized mean=3.13), and do something that will remedy their situation (mean=3.07). These are interesting results, in that the within total sample, 15 participants scored at the good/expert level, as shown in Table 9. An important finding from this is that these patients are able to act on symptoms they are observing
and have the self-care skill to remedy the symptoms. In relation to the confidence sub-scale, it is the more educated study participants (education beyond high school) who had a standardized mean score above 70. This is in contrast to our finding that those individuals with high school or less education scored much higher in self-care management. This would need to be studied in future research.

**Social Support (ESSI).** The average score on most of the Social Support (ESSI) items are 3 and above. The participants feel that they have someone from whom to get advice. They have someone they can trust and feel close to (mean=3.07) as well as providing emotional support (mean=3.07) and that listens to them when they need to talk (mean=3.00). However, the scores were slightly lower for the items related to someone that shows love and affection (standardized mean=2.83) and able to help with chores (mean=2.83). The participants older than or equal to 65 scored the highest in ESSI social support items; this is something worth noting- not as a behavior, per se, but that this perception of social support in the older group is strong. Perhaps they have a more supportive environment, have nurturing grown children, or are themselves not working and able to spend more time in a socially enriched environment. The older participants may have perceived that their social support received from spouse, significant other, or family member/neighbor was strong enough to motivate better care of themselves – demonstrate good self-care in their HF. Younger participants have perhaps less time to pursue supportive relationships if they are working to support a family, are fatigued due to HF, or have small children to attend to. This may lead to hypotheses for later studies to help inform practice involving this age group of HF patients.
Descriptive analysis of the SCHFI and ESSI

Further analysis of the information shown in Appendix E can be used to qualitatively assess different behavior of the groups making up the dichotomous demographic variables of the subjects. Although the average score was below the level of adequate behavior, the number of subjects who demonstrated an adequate self-care behavior with respect self-care maintenance and self-care confidence was half of the subject population. As shown in Table 8, half the subjects scored above the level of adequate self-care behavior (≥ 70) for SCHFI sub-scale A: Self-care Maintenance and C: Self-care Confidence.

In addition, the data were quantitatively analyzed for correlation between the three sub-scales (A, B, C) for the different dichotomous demographic variables of the subjects. Because of the overall small population in this pilot study, and even smaller populations of the sub-groups, this analysis was at best descriptive. Although the quantitative analysis suggests a strong correlation between self-care maintenance and self-care management for the entire sample (r=0.58, p=0.01), the descriptive examination suggests that this correlation may be stronger for females, subjects without support and high school or below education. This means that if the subjects in these demographic groups maintain themselves, they will also manage their self-care; the reverse is also true. Again, although the quantitative analysis suggests a moderate, positive correlation between self-care maintenance and self-care confidence for the entire population (r=0.48, p=0.01), the analysis also suggests that this correlation is even stronger for subjects who are ≥65, females and subjects living with someone. The qualitative analyses imply that there is a strong correlation between SCHFI self-care scales C: Self-care Confidence and the two sub-scales for virtually all demographic subsets. This means that if patients feel confident about their self-care, they will manage and maintain their self-care better. One surprise is that the analysis
suggests that subjects with an education level of high school or less show good correlation for self-care confidence. The participants with less than high school education require the educational and treatment advice that healthcare providers can give. This study may point to the fact that this group is following the HC Provider advice, as opposed to those with over high school education, who may be disregarding treatment advice.

**Research Questions Two and Three**

First, it is clear that the older participants answered the open-ended questions somewhat differently than the younger participants. The older folks were proud, satisfied with being able to be at home; an 80 yr old gentleman participant responded to the research question 2, about perceptions of what would help at home, to take care of yourself. The gentleman answered, “doin alright at home. I got good neighbors.” An older woman participant answered that she was living alone in her apartment, but that she, “got her grandson lookin’ in on me. We got each other.” Of interest is also to note that these two individuals scored well over Riegel’s 70 level; 73 and 77, respectively, on the SCHFI self-care maintenance subscale.

When asking the open-ended research question 3, about what way do you think your healthcare provider could have helped you better deal with challenges after your hospitalization, a married mother of 3 in her 30’s answered emotionally,“ They [healthcare providers] tell me, you’re not doing this, you’re not doing that!” in terms of her, “taking care of myself [herself]”. This individual scored 83 on SCHFI, self-care confidence items. In addition to those comments, this individual requested that her [provider] could, “help me to lose weight.”

Interestingly, a single divorcee in his 50’s answered, to the research question 3 regarding healthcare providers:”My two best mates take me to the doc now. They like ‘em [healthcare
provider], so do I. My doc told me I need to quit smoking, it is too hard to stop. I been [smoking] for so long.” This individual scored 100 on the SCHFI self-care confidence scale, but lower on the maintenance, management (47, 45 respectively). Perhaps the self-care confidence reflected other areas of his life, besides self-care of heart failure. Healthcare providers can start the conversation, read between what some patients are saying, and listen.

The individual who answered that a ‘lift chair’ was needed, would have been appealing to the health care provider for a prescription so that the chair could be considered a DME. The participant who was having increased fatigue at home now,(research question one) which is a concern, and at this point an advanced practice nurse would need to assess the type of fatigue- is it generalized muscle fatigue, weakness due to increasing girth, increased venous pressure (right ventricular involvement increased), or diminished bowel sounds and constipation-(causing lethargy) due to gastrointestinal stasis secondary to their heart failure.

There are many areas for teaching, many programs in the community which could help, exercise rehabilitation, community-health center classes on cooking for heart failure, weight loss. Finding funding sources for these issues and many more is needed now.

Theoretical considerations: Orem’s self-care theory; Naturalistic decision-making

Both theories, Orem’s (2000) self-care theory, and Lipshitz, et al.,(2000) Naturalistic decision-making theory, assisted the researcher in this study. The patients had to make decisions, which included everyday lifestyle choices, self-care demands on patients’ socioeconomic situations, for their health (heart failure) condition and had to be balanced to meet the individual’s needs. Orem’s self-care theory aligned with Naturalistic Decision-Making theory (Lipshitz et al., 2001) to provide the basis for understanding and examining self-care behavior in
this pilot study. Orem’s self-care theory (Orem, 2001) was helpful to the researcher in conceptualizing the complexity of self-care agency, and necessity in a disease state. The Naturalistic theory decision-rules (Lipshitz et al., 2001) based upon real life situation, related well with understanding HF patients’ management of daily choices examined in this pilot study.

Recommendations for practice and policy

Healthcare providers can use this study to learn about how to help heart failure patients who are or will be at risk in the future. The scoring explanations and use of SCHFI and ESSI to measure the factors associated with problems in self-care could help healthcare providers be aware of challenges faced by HF patients in the window of 4-6 weeks post discharge. In addition, it is important for the entire healthcare team to be aware that readmission of HF patients post-discharge, is one of the most costly readmissions. The data generated by HF readmissions is being used by Medicare to base cuts in reimbursement to the hospital by 2% in the 2014 costs and by 3% in 2015. The issue of reducing reimbursement to hospitals will ultimately cause cuts or affect care for all inpatient medical services (Kocher & Adashi, 2011). It will behoove healthcare provider teams to carefully plan the in-hospital and discharge-care to include ongoing education at regular intervals, keeping the age, gender, social living situation, social situation, and social support factored in to achieve the best outcomes for the factors associated with self-care of heart failure patients 4-6 weeks post discharge.

Recommendations for Future Research

Heart failure self-care needs to be seen in real world situations, and continued study is necessary to understand why, for example, the younger population (less than or equal to 65) of
this pilot study scored consistently lower than the older group (greater than 65). The subjects in
the younger group may have contextual factors such as working hard to earn a living and having
no time to take care of themselves, not managing their HF. Certainly, future research
interventions will need to find positive approaches, while recognizing the availability of
measurement resources discussed in this study.

Limitations

As reported earlier in the study, one limitation to the use of the SCHFI data collection
instrument, was the fact that only two of the classic heart failure symptoms (of their multitude of
symptoms) were actually assessed to determine level of self-care management. According to
Riegel et al (2009),”The decision was made to assess only two symptoms because the self-care
treatments differ for most symptoms. That is, the appropriate response to fatigue differs from that
of shortness of breath. Furthermore, in our original Self-management of Heart Failure tool…..we
evaluated the response to 6 separate symptoms, and the tool was ungainly.”

Another limitation to the pilot study was that our sample (N=30) was small, and involved
a convenience sample of local community dwelling heart failure patients from a single site.

In keeping with the recommendations of Riegel, et al., (2009), the scores between scales
(maintenance, management, confidence) will better serve our patients if clinicians score them
individually. Data described in the bivariate correlation of subsets of self care maintenance with
self-care management yielded a weak Pearson correlation, but the bivariate correlation between
self-care maintenance with self-care confidence was strong (r=0.80, p =0.01) in elders over 65.
Summary

While it has been known that effective self-care behavior can reduce readmission to the hospital, it has not been clear what challenges and complications confronted heart failure patients during this crucial window between 4-6 weeks post-hospitalization. The correlations which are summarized in Tables 5 and 7 indicate that the sub-scales (A: Self-care Maintenance, B: Self-care Management, C: Self-care Confidence, and Social Support), show strong correlation between scales A, B, and C (SCHFI, Table 5); the results from this study indicated internal consistency with similar values as compared to the Reigel et al (2009, p.494) study of 154 community-dwelling heart failure patients. The correlation between the three SCHIFI scales and ESSI (Table 7) show strong correlation between SCHFI C: Self-care Confidence and ESSI: Social Support. This may be due to the fact that subjects who have good social support feel more confident in a self-care situation.

This pilot study attempted to explore what was happening, what factors were associated with self-care of heart failure patients, during this window of 4-6 weeks following post discharge and used a descriptive, correlational design. The Figure 3 histogram showed the average values of the SCHFI and ESSI sub-scales dichotomized values of age; below or equal to the age of 65. The ages of respondents were critical. The subjects older than 65 had higher scores on the SCHFI and ESSI due to the fact that this group had the highest level of social support. The level of education showed a strong reflection as to whether or not individuals would follow medical advice: surprisingly, those with high school or less, had the highest scores for self-care management in performing self-care to keep from re-hospitalization. Perhaps this is due, in part to enormous faith in their healthcare professionals, in listening to treatment plan of care for their own individual management of heart failure, following their health professionals’ advice.
By using the SCHFI, healthcare providers will be better able to compare the scores of the patients who practice above average self-care and those who do not (therefore being alert to providing more guidance/encouragement to the patient who is at risk). Lee (2009) was able to track those HF patients who were able to be symptom-free by practicing expert-level self-care, and lower their risk of having an event requiring re-hospitalization (p<0.05).

The relationship of social support as measured by the ESSI, to each of the SCHFI sub-scales was examined. There was a significant and positive relationship between social support and confidence (r=0.49, p<0.001). Surprisingly, self-care confidence was an important factor which moderated the relationship between self-care and outcome. The ESSI and SCHFI worked to adequately describe the pilot population of HF patients for the researcher, and possibly improve healthcare provider perspective in caring for our patients.
Appendix A

Teresa K. Lagerlof RN
FPB School of Nursing
Case Western Reserve University

Dear Dr. Michael Koch,

I am requesting permission to approach your patient about completing a survey for a pilot nursing study, “What factors are associated with self-management in heart failure patients 4-6 weeks post discharge?” This will involve completing a survey of 27 questions about self-management decision-making in heart failure patients.

The goal of this study is to assess where in the self-care process patients are having a problem. I am currently working in an indigent out-patient clinic where my patients are often lost to follow-up. I am from Case Western Reserve University and I decided that I wanted to find out what recently discharged patients are experiencing. Hopefully, providers can learn what this population needs help with, and in which specific areas. Barriers such as lack of transportation, lack of social support, etc. may be some of the factors.

The survey will take approximately 15 minutes to complete, and confidentiality will be maintained throughout the process. No names will be attached to the survey and data will be deidentified.

Thank you; I will share my general study results with you (only) while maintaining patient privacy in accordance to HIPPA guidelines. I am CREC certified in conducting human research, and will be happy to share my research questions with you.

Please check:

☑ Yes, my patients may be approached to make his/her own decisions about taking part of this study.

☐ No, my patients may not be approached about this study

[Signature of Dr. Michael Koch] 1/31/2014

Questions about this study may be directed to Teresa Lagerlof, RN, MSN at 440-391-4485 or email: teresa.lagerlof@case.edu

Thank you
Appendix B1

**Interview Recruitment Script**

Script used by the physician and co-investigator for initial solicitation for interest in hearing more about the study:

- **Script used for initial phone recruitment by the physician:**

  Hello, this is Dr. [name of the physician]. A Nurse Practitioner and a DNP (Doctor of Nursing Practice) student at the Frances Payne Bolton School of Nursing, Case Western Reserve University, Teresa Lagerlof, who works with heart failure patients, is conducting a study about how people with heart failure are able to manage their disease after hospital discharge. We know that the 1st month after discharge is an important and sometimes difficult time and want to learn more about how to support patients during this time. She’d like to tell you more about the study and answer any questions you might have so you can decide if you want to be part of it or not. As you know, whether you participate in the study or not will have no effect on your care by your doctor and his staff. If you agree to be part of the study Teresa Lagerlof will meet with you one time. If you’d like to know more about the study, she can meet with you on whatever day is good for you. At that meeting, she’ll go over the study in detail and you can make your final decision about whether to be part of the study. If you agree to be part of the study, she’ll ask you to complete a short interview and you’ll talk about your experiences since you left the hospital. So, do you have any questions at this time? Would you like for Teresa Lagerlof to call you and let you know more about the study, and perhaps arrange a time for a meeting? This interview will be carried out outside your regular treatment. If you agree to be contacted by Teresa Lagerlof for more information may decline to participate at that point in time. Thus, I will not know if you are participating or not.

- **Script used for initial phone recruitment by co-investigator:**

  Hello, my name is Teresa Lagerlof. I’m a Nurse Practitioner and doctoral student at the Frances Payne Bolton School of Nursing, Case Western Reserve University, and I work with heart failure patients. I’m doing a study about how people with heart failure are able to manage their disease after hospital discharge. We know that the 1st month after discharge is an important and sometimes difficult time and want to learn more about how to support patients during this time. I’d like to tell you more about the study and answer any questions you might have so you can decide if you want to be part of it or not. As you know, whether you participate in the study or not will have no effect on your care by your doctor and his staff. If you agree to be part of the study we will meet one time. If you’d like to know more about the study, we can meet on whatever day is good for you. When we meet, I’ll go over the study in detail and you can make your final decision about whether to be part of the study. If you agree to be part of the study, I’ll ask you to complete a short interview and we’ll talk about your experiences since you left the hospital. So, do you have any questions at this time? Would you like to arrange a time for us to talk more about the study? This interview will be carried out outside your regular treatment, and [identification of the Doctor] and the staff at [identification of Doctor’s Office] will not know that you are participating.
Appendix B2

**Interview Participation Consent Form**

*Script used by Investigator at Meeting:*

- **BACKGROUND AND BASIC INFORMATION**
  - Hello, my name is Teresa Lagerlof, and I am a Nurse Practitioner and a DNP (Doctor of Nursing Practice) student at the Frances Payne Bolton School of Nursing, Case Western Reserve University, and I work with heart failure patients.
  - I'm involved with a study about how people with heart failure are able to manage their disease after hospital discharge.
  - We know that the 1st month after discharge is an important and sometimes difficult time and want to learn more about how to support patients during this time.
  - If it is okay with you, we can talk about what has happened since you were in the hospital.
  - We will talk about the experience of being a heart failure patient, talk about difficulties, after coming home from the hospital.
  - The questions we will talk about will be about how you felt when you returned home, and what extra help you would like.
  - The total amount of time it will take is about 15 minutes.

- **CONFIDENTIALITY**
  - This is completely voluntary and your name will not go on the questionnaire or any notes I make of our conversation (your identity is protected).
  - You may withdraw at any time and stop with the interview if you do not want to participate.
  - You may refuse to answer a specific question while taking the interview.

- **PURPOSE OF THE INTERVIEW**
  - The interview may result in a better understanding of potential problems heart failure patients' experiences, in particular, some of the difficulties once discharged from a hospital.
  - While this study may not benefit you directly, a better understanding may in turn help the healthcare providers to have a better understanding of how to help their patients when they return home.

*Participant Indicates Consent to Participate in the Interview and is Assigned an Interview Participant Number:*

- **PLEASE CHECK YOUR CHOICE – Interview Participant #:__________________________**
  - I agree to talk with Teresa Lagerlof, C-NP
  - I do not agree to talk with Teresa Lagerlof, C-NP
### Appendix C

<table>
<thead>
<tr>
<th>Demographic Information:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Age (to the nearest year):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Gender:</td>
<td>Male</td>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Social Living Situation</td>
<td>Living Alone</td>
<td></td>
<td>Living with someone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Social Situation:</td>
<td>Alone</td>
<td></td>
<td>with Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Education - highest level:</td>
<td>Education up to high school; did not graduate</td>
<td></td>
<td>Education including high school graduation &amp; over</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments: _______________________________________________________________

____________________________________________________________
## Appendix D

### Survey Participant #: __________

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

<table>
<thead>
<tr>
<th>Section A:</th>
<th>Never or Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always or Daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Weigh yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2 Check your ankles for swelling</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3 Try to avoid getting sick (e.g., flu shot, avoid ill people)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4 Do some physical activity</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5 Keep your doctor or nurse appointments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6 Eat a low-salt diet</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7 Exercise for 30 min</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8 Remember to take one of your medicines</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9 Ask for low-salt items when eating out or visiting others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10 Use a system (pillbox, reminders) to help you remember your medicines</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Section B: Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

11a. In the past month, have you had trouble breathing or ankle swelling?  Circle one.  (0) No  (1) Yes

11b. If “yes” on 11a … (Circle one number)

### Section B:

<table>
<thead>
<tr>
<th>How quickly did you recognize it as a symptom of heart failure?</th>
<th>I Did Not Recognize It</th>
<th>Not Quickly</th>
<th>Somewhat Quickly</th>
<th>Quickly</th>
<th>Very Quickly</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

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)

### Section B:

<table>
<thead>
<tr>
<th>Section B:</th>
<th>I Did Not Try Anything</th>
<th>Not Sure</th>
<th>Somewhat Sure</th>
<th>Sure</th>
<th>Very Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 Reduce the salt in your diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Reduce your fluid intake</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Take an extra water pill</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 Call your doctor or nurse for guidance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

### Section B:

How sure were you that the remedy helped or did not help?

<table>
<thead>
<tr>
<th>Section B:</th>
<th>I Did Not Try Anything</th>
<th>Not Confident</th>
<th>Somewhat Confident</th>
<th>Very Confident</th>
<th>Extremely Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>17 … keep yourself free of heart failure symptoms?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18 … follow the treatment advice you have given?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19 … evaluate the importance of your symptoms?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20 … recognize changes in your health if they occur?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21 … do something that will relieve your symptoms?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22 … evaluate how well a remedy works?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Section C: In general, how confident are you that you can ……

### Section C:

<table>
<thead>
<tr>
<th>Section C:</th>
<th>Not Confident</th>
<th>Somewhat Confident</th>
<th>Very Confident</th>
<th>Extremely Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>23 Is there someone available to whom you can count on to listen to you when you need to talk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24 Is there someone available to you to give you good advice about a problem?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25 Is there someone available to you who show you love and affection?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26 Is there someone available to help with daily chores?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27 Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28 Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### Section D: ESSI

<table>
<thead>
<tr>
<th>Section D:</th>
<th>None of the time</th>
<th>Rarely</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>23 Is there someone available to whom you can count on to listen to you when you need to talk?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
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<td>4</td>
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<tr>
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<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Study Questions

29. What would help you at home to take care of yourself?

30. What do you think your healthcare provider could do more to help you?
Appendix E

IRB Notice of Exemption

CASE WESTERN RESERVE UNIVERSITY

NOTICE OF EXEMPTION #2

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior.

CWRU IRB Protocol Number: IRB-2014-749

Protocol Title: Factors Associated with Self-Care of Heart Failure 4-6 Weeks Post Discharge

Responsible Investigator (RI): Patricia Underwood

Co-Investigator (CI): Teresa Lagerlof

RI Department: Nursing

Exemption Date: 04/15/2014

The CWRU Institutional Review Board (IRB) has deemed the above protocol EXEMPT under 45 Code of Federal Regulations (CFR) part 46.101(b)(2). The IRB will not conduct subsequent reviews of this protocol.

IF YOU WISH TO CHANGE THIS EXEMPTED PROTOCOL IN ANY WAY, YOU MUST SUBMIT AN ADDENDUM REQUEST AND WAIT FOR IRB APPROVAL PRIOR TO IMPLEMENTING ANY PROTOCOL CHANGE.

Any changes to the protocol that put it under the purview of the IRB would require a formal application to, and approval of, the IRB prior to implementation of the change.
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