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INFLUENCES ON SELF-CARE IN WOMEN WITH HEART FAILURE: A PILOT STUDY

Joy Corcione

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INFLUENCES ON SELF-CARE IN WOMEN WITH HEART FAILURE: A PILOT
STUDY

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING
THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON
SCHOOL OF NURSING

BY
JOY CORCIONE, PHD, MBA, RN

AUGUST, 2016

Approval Form D-3

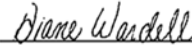
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Houston, Texas

June 29, 2016

Date

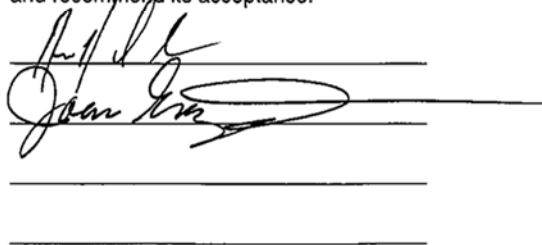
To the Dean for the School of Nursing:

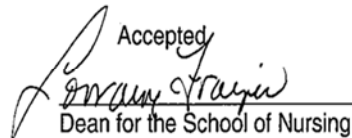
I am submitting a dissertation written by Joy Corcione and entitled "Influences on Self-Care in Women with Heart Failure: A Pilot Study." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.



Diane Wardell, Committee Chair

We have read this dissertation
and recommend its acceptance:



Accepted

Dean for the School of Nursing

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Joy Corcione, PhD, MBA, RN

Influences on Self-Care in Women With Heart Failure: A Pilot Study

August 2016

Abstract

Background: Heart Failure self-care becomes exceedingly difficult to perform as the disease progresses. Social support greatly facilitates self-care behavior, which is vital in managing heart failure. Women with heart failure represent a significant and growing vulnerable population because they experience more adverse psychosocial factors affecting self-care and greater psychosocial adversity than do men. **Objectives:** This pilot study sought to gain a deeper understanding about how sources of social support influence heart failure self-care behavior in women. **Methods:** A cross-sectional, concurrent, mixed method, embedded quantitative dominant design with a follow-up variant was used in this pilot study. A total of 16 female study participants were recruited from two different generational cohorts, those born from 1925 to 1942 and those born from 1943 to 1960. The Multidimensional Scale of Perceived Social Support (MSPSS), the European Heart Failure Self-Care Behavioral Scale – 9 (EHFScBS-9), the Duke Activity Status Index (DASI), the Standardized Mini Mental State Exam (SMMSE), the Geriatric Depression Scale - Short Form (GDS-SF), and the Self-Assessed New York Heart Association Functional Class Questionnaire (SA-NYHAFCQ) instruments were used along with a semi-structured interview which sought to elaborate instrument findings. **Findings:** Significant differences were found between cohorts for the MSPSS

(total, special person and friend) and significant correlations were found between the MSPSS (family, friend) and the GDS-SF and SMMSE. Social support mean average for both groups was high at 6.45; depressive symptoms low at 2.31 and heart failure self-care moderate to low at 2.74. Interview data indicated that: (1) “special person” were those that helped the most, (2) distance influenced support given, (3) religion/spirituality was used to cope and function as a source of support, (4) self-care was viewed as only performed by participants with no help from others, (5) participants felt they didn’t need self-care help but often did and (6) instrumental support mostly provided. **Conclusion:** This study uncovered differences between cohorts and their social support networks even with a small sample size. The raises the question of whether future research should further explore cohort group adaptation. Understanding cohort differences may lead to more targeted interventions in this vulnerable population.

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Summary

This pilot study provided insight into sources of social support and how those sources facilitated self-care in women with heart failure. Insightful information was gained through the use of reliable instruments (Appendices B - G) and brief, semi-structured interviews.

There were several minor changes that occurred from the time of the approved study proposal and the start of the pilot study. First, this study could not obtain permission to recruit at the Advanced Heart Failure Clinic at the Texas Medical Center. Secondly, only 16 participants were recruited as opposed to the minimum of 52 needed to provide adequate power to this study. However, additional cardiologists from the cardiology clinic did give permission to have their patients recruited for the study and this helped in gaining study participants. Thirdly, clinic receptionists were not used to screen patients. The primary investigator screened all patients and those eligible for the study were approached and the study explained, while the patients were in the clinic waiting room or the examination room. A study announcement was only placed in the clinical waiting room and kept there for the entire recruiting period. Lastly, Qualtrics software was not used to produce study analytics, instead all data, excluding interview data, was put into an SPSS formatted database and analyzed.

The results of this pilot study showed some significant differences between cohorts from the social support instrument and some correlations between social support, depression and cognition. Non-parametric statistical tests were used instead of the standard statistical tests mentioned in the study proposal due to a small sample size. Additionally, caution should be used in generalizing these findings due to small sample

size. Furthermore, the interview data revealed interesting themes in the area of spirituality/religion, distance and support, “special person”, the meaning of self-care, denial of help with self-care and receiving primarily instrumental support from others.

Women With Heart Failure and Their Perception of Social Support and its Affects on
Heart Failure Self-Care Behavior

A Dissertation Proposal

University of Texas Health Science Center, School of Nursing

Joy Corcione, PhD(c), MBA, RN

January 12, 2016

Specific Aims

Heart Failure (HF) is associated with a high burden of cost to the health care system and to the patient with its high morbidity and poor survival rate (Robinson et al., 2011). HF is characterized by numerous hospital readmissions and extensive use of health care resources (Desai & Stevenson, 2012). Today, approximately 5.7 million people in the United States (US) alone have HF (Mozaffarian et al., 2015; Roger, 2013) and the number is growing substantially due to the increase in the aging population and better management of HF.

Self-care is defined as a “naturalistic decision-making process that influences actions that maintain physiologic stability, facilitate the perception of symptoms, and direct the management of those symptoms.” (Riegel, Dickson & Faulkner, 2015, p. 1). Self-care is vitally important in managing HF (Riegel et al., 2009) and can improve heart performance, decrease demands on the body and enhance wellbeing (Thomas & Clark, 2011). Self-care can also improve mortality, morbidity and symptom burden through proper medications, behavioral and lifestyle changes, and the nurturing of positive social relationships (Riegel et al., 2009; Riegel, Dickson, Kuhn, Page & Worrell-Carter, 2010). HF self-care becomes exceedingly difficult to perform as the disease progresses; therefore social support becomes important in facilitating HF self-care. Social support is defined as “the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations” (Cobb, 1976, p.300).

Woman with HF represent a significant and growing vulnerable population (Thomas & Clark, 2011). Women tend to have lower self-confidence when it comes to self-care (Riegel et al., 2010), they experience greater negative emotions (Martensson,

Karlsson & Fridlund, 2002) decreased social support, particularly from family (Riegel et al., 2010), and experience more adverse psychosocial factors which affect self-care (Heo, Moser, Lennie, Riegel, & Chung, 2008; Thomas & Clark, 2011). They also develop more HF symptoms and experience greater psychosocial adversity than do men (Riegel et al., 2010).

Patient self-care is vital in managing HF and social support greatly facilitates self-care behaviors (Gallagher, Luttk, & Jaarsma, 2011; Graven & Grant, 2014). More studies are needed that include woman in order to understand how social support influences HF self-care. Additionally, socioeconomic influences upon generational groups suggest that there may be differences in social support among women from different generational cohorts (Strauss & Howe, 1992).

The purpose of this particular study is to gain a deeper understanding about the sources of perceived social support and how these sources influence HF self-care behavior in women. The proposed research study will use a mixed method exploratory concurrent design with an emphasis on the quantitative results that will be further explained by the qualitative approach (Creswell & Clark, 2011).

This study represents the beginning of a long-term research objective that will focus on understanding the various psychosocial factors that can influence the self-care behavior of female HF patients. Further research in this area will hopefully provide insight into the factors that facilitate positive HF self-care and interventions that promote these factors. Study aims and hypotheses are as follows:

Aim 1: To determine the magnitude of perceived social support from others in a group of women with HF.

Hypothesis 1.1: The perceived magnitude of social support from others, by women with HF, will vary. *Hypothesis 1.2:* Two different generational cohorts of women with HF may experience a difference in the magnitude of perceived social support from others.

Aim 2: To determine whether there is an association between perceived social support and self-care in women with HF.

Hypothesis 2.1: There is an association between perceived social support and self-care in women with HF.

Aim 3: To understand how women with HF describe different sources of perceived social support and how those sources influence HF self-care.

Research Strategy

Significance

In 2012, the overall prevalence of HF was between 2.2 to 2.4% of the US population (Mozaffarian et al., 2015; Heidenreich et al., 2013). That percentage is expected to increase by 25% in 2030 to 3% of the population (Heidenreich et al., 2013). In 2012, the prevalence rates for white, non-Hispanic women were 2.2%, 3.2% for non-Hispanic black women and 2.1% for Hispanic women (Mozaffarian et al., 2015). New annual cases of HF for women 55 and over were 455,000 and all age mortality for women due to HF was 57.8% (Mozaffarian et al., 2015). Also in 2010, a total of 522,000 women were discharged from the hospital for HF compared to 501,000 HF discharges for men (Mozaffarian et al., 2015). According to Sabbadini, Travan and Toigo (2012), women have a longer life expectancy than men and therefore represent the oldest age groups. Currently, worldwide, there are 60 million more women than men in the 60 or older age group. Furthermore, the fastest growing age group are those 75 and older and

within a few decades over half of the elderly population will be over 75 with women representing most of this group. These trends represent changes in the social and health care environments, which could challenge the ability of these elderly women to provide HF self-care.

Patient self-care is instrumental in managing HF (Riegel et al., 2009). Orem developed a grand theory of nursing self-care which provided an organized and structured approach to articulating the concept of patients engaging in their own care (Timmins & Horan, 2007; Riegel & Dickson, 2008). Furthermore, middle range theories, such as transition theory, were developed that further defined self-care. Transitions theory, conceptualized as “a passage from one life phase, condition, or status to another...” (Chick & Meleis, 1986, p. 239) led to situation-specific theory (Im, 2014). Situation-specific theories are used for specific conditions, populations and/or situations and are more concrete (Riegel & Dickson, 2008; Riegel, Dickson & Faulkner, 2015). HF self-care is an example of how situation-specific theory is applied to a specific disease and population. Self-care enables the engagement of healthy behaviors such as daily monitoring and adherence to the plan of care and adequate management of symptoms and evaluation of applied treatment actions (Riegel, Lee, Dickson, & Carlson, 2009). We know that self-care is critical to the management of HF because medication, diet, weight compliance, and the recognition of HF symptoms are all needed to insure proper HF management and the prevention of hospital admission and readmission. However, the concept of self-care is very complex and additional studies are needed to further investigate factors that encourage or discourage self-care behavior.

Few investigations have examined the mechanisms underlying the relationship between social support and health, although several possible mechanisms have been proposed over the years (Cohen, 1988b). Social support may influence health by directly or indirectly affecting health behaviors (Berkman, 1982; Cohen, 1988b) by information that is received when one is in a supportive relationship (Berkman, 1982; Cohen, 1988b), and by receiving tangible resources. Another proposed mechanism linking social support to health is that social support may be associated with more positive affective states such as increased feelings of belonging, intimacy, improved sense of self-worth (Berkman, 1982; Cohen, 1988b) and an increased sense of control (Cohen, 1988b). The positive psychological states derived from support systems may increase health-promoting behaviors, or they may dampen or prevent the pathogenic physiological reactions associated with negative mental states. Social support is a well-known psychosocial factor that influences physical health. House, Umberson and Landis (1981) described four main categories of social support, which included emotional, appraisal, informational and instrumental support. Emotional support is usually provided by family and close friends and provides empathy, concern, caring, love and trust. Appraisal support provides information that function as feedback, affirmation or social comparison, its function being evaluative in nature. Informational support can be given as advice, or suggestions that assist the person in responding to demands. Instrumental support can be in the form of money, time, goods and services (House et al., 1988). Although there are studies that show that social support can influence self-care behavior in HF patients, (Falk, Wahn & Lidell, 2007; Riegel & Carlson, 2002, Scotto, 2005; Riegel, et al., 2006; Schnell, Naimark & McClement, 2006; Ming et al., 2011; Dickson, Howe, Schipper &

Katz, 2013) more studies are needed to uncover which types of social support make the most difference in positive self-care behavior and whether the types of social support differ between genders (Riegel et al., 2010; Siabani, Leeder & Davidson, 2013).

Recent quantitative studies (Gallagher et al., 2011; Graven & Grant, 2014; B. Riegel, Dickson, Kuhn, Page, & Worrall-Carter, 2010; Riegel et al., 2009; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008) probed social support and self-care as they related to gender differences. There is some evidence that social support functions differently in women compared to men (Riegel et al., 2010). Riegel et al. (2010) revealed that higher emotional support to women translated to more self-care and lower emotional support translated into more social isolation. Women tend to be more socially isolated as they age and social isolation has a negative impact on self-care and HF prognosis (Stamp, 2014).

To uncover a better understanding of social support in women, exploring the types of relationships that provide social support would give us a better understanding as to whether these relationships have a positive or negative influence on self-care. More research is needed with female-only populations and studies need to uncover how social support relationships influence self-care behaviors of women with HF (Gallagher et al., 2011).

Furthermore, in an integrative review by Graven & Grant (2014), 13 studies were identified as examining the relationship between social support and HF self-care but only one study (Riegel & Carlson, 2004) had a majority of female study participants. Males were predominantly represented in these studies. Another review estimates that women comprise 50% of the HF population in the US, but only about 28% are involved in any HF studies (Hsich & Pina, 2009). Therefore, many new advances in HF treatment mostly

apply to men and not to women (Rhodes & Bowles, 2002; Hsich & Pina, 2009). A lack of research about women with HF represents a gap in research that must be filled so that better information can be gained as to how to effectively treat women with HF.

A generational cohort are a group of people born during a particular time period and share a unique character based on historical and social events that occur during their different life stages (Strauss & Howe, 1991; Rindfleisch, 1994). There is no exact time span in a generation, however, most generation theorists estimate a generation to be anywhere from 15 to 33 years in length (Strauss & Howe, 1991). The generational cohort concept emphasizes that the social, political and historical climate and events during a particular generation shape attitudes and values of that particular generation. This is in contrast to a more traditional belief that people are influenced more by their age than by their social, political or historical context in which they lived (Sessa, Kabacoff, Deal, & Brown, 2007).

One source, Patten & Fry (2015), defined the “silent” generation as those born from 1928 to 1945 and the “boomer” generation as those born from 1946 to 1964, and compared the two cohorts in terms of marital status, female education, and female labor force status. The “silent” generation, at the ages of 18 to 33, had 64% of their cohort married while the “boomer” generation, at the same age, had only 49% who were married. Additionally, 66% of the female “silent” generation cohort had at least a high school education while the “boomer” generation had 82% with at least a high school education. Finally, 60% of the female “boomer” generation was in the civilian labor force while only 38% of the female “silent” generation was in the labor force. These social

statistics could be factors that might influence perceived social support sources and HF self-care behaviors between these two cohorts (Patten & Fry, 2015).

Finally, this study will provide needed insight into who provides the perceived social support, the magnitude of that support and how the support affects HF self-care. A better understanding of perceived social support will enable clinicians to provide interventions that support and enhance the effectiveness of perceived social support in positively enhancing HF self-care behavior possibly limiting this population's vulnerability to decreased HF self-care and increased social isolation.

Conceptual Framework

The Moser and Watkins (2008) conceptual framework shows the factors affecting HF self-care. Within this model, current symptom status, aging and psychosocial factors all affect the decision-making mechanisms necessary to conduct HF self-care. This study looks at social support and how it influences HF self-care and factors such as socioeconomic status, educational level, cognitive status and comorbidities which could have some influence on HF self-care decision making.

Conceptual Framework of Factors Affecting Decision Making and HF Self-Care

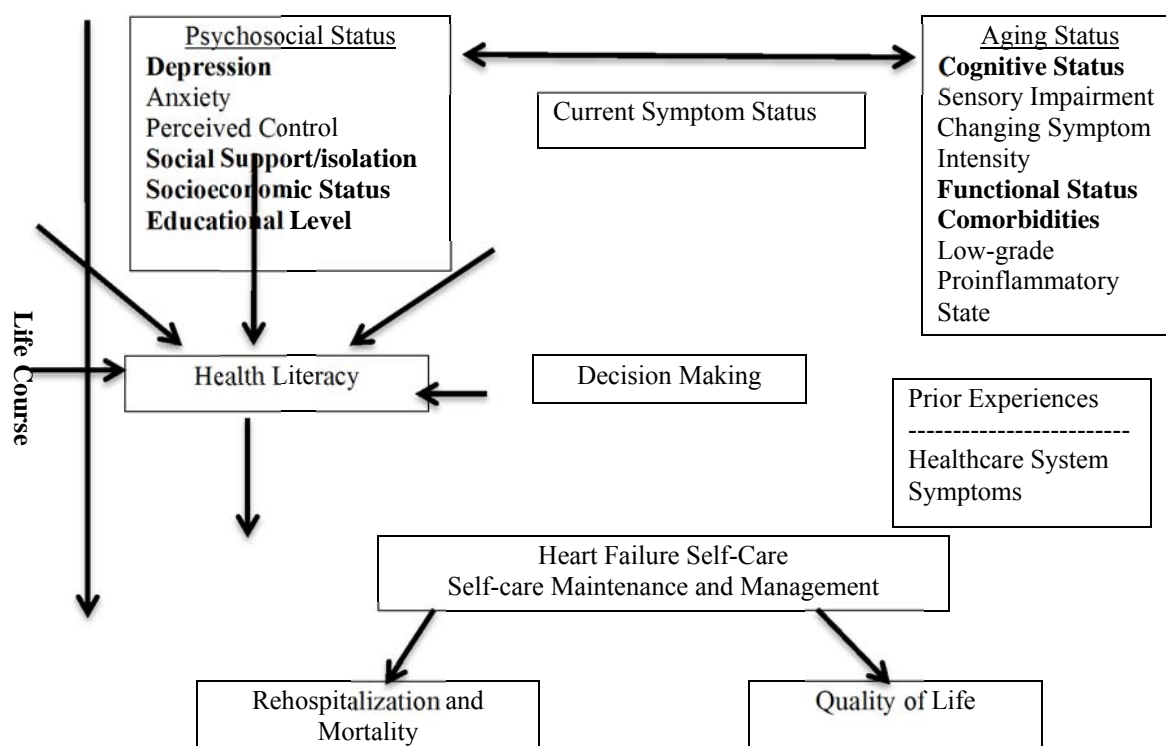


Figure 1. Bold items represent those factors, which will be addressed in this study. Adapted from “Conceptualizing self-care in heart failure: a life course model of patient characteristics,” by Moser, D.K., & Watkins, J. F., 2008, *Journal of Cardiovascular Nursing*, 23, p. 206.

Innovation

There were no studies in 2015 that contained all female study participants spanning more than one generational cohort nor were any comparisons made between generational cohorts that might provide insight into possible perceived social support differences between generational cohorts that could effect HF self-care. Considering that women represent half of the HF population (Hsich & Pina, 2009), future studies should recruit a female majority in order to escalate research findings specific to women with HF. Current HF protocols are based on research heavily dominated by male study participants and therefore are specific to men without regard to possible differences in HF treatment for women (Rhodes & Bowles, 2002; Hsich & Pina, 2009). Women are

becoming a vulnerable population because of their increased prevalence of HF and the lack of evidence that supports proper HF treatment specific to women. This study seeks to study only women but broadly expands the age group to include two generational cohorts in order to examine if there are any differences in how social support might influence their HF self-care.

Approach

Research Design and Methods

A cross-sectional, mixed method, exploratory concurrent design will be used with an emphasis on quantitative results to be further explained by a qualitative approach (Creswell & Clark, 2011). The quantitative phase will be performed using valid and reliable instruments that measure perceived social support and HF self-care. The qualitative phase will use a semi-structured interview with questions designed to help explain quantitative results (Creswell & Clark, 2011). A variant design, called the follow-up explanations variant, will be used. This variant design entails interviewing all participants of the quantitative phase as opposed to interviewing a purposeful sample based on criteria only known after the quantitative phase is completed. Inferences will be made based on a comparison, contrast or synthesis of the results of both strands and explained in the discussion (Creswell & Clark, 2011). After IRB approval, study subjects will be recruited from a HF and cardiology clinic within a large metropolitan area medical center located in the Gulf Coast region of the US.

Population, Sample and Sampling Procedures

Inclusion criteria for study participation are as follows: (a) New York Heart Association (NYHA) HF Functional class II, III or IV, (b) HF diagnosis for at least two

months which allows the patient to understand the self-care tasks required and areas of self-care that need improvement, (c) adult women with birth years from 1925 to 1960.

Exclusion criteria are as follows: (a) patients with diagnosed psychiatric or physical disorders which can cause the patient not to understand or comply with study instructions or not be able to perform self-care tasks, (b) non-English communicators who won't be able to follow written or verbal instructions, and (c) patients with ventricular assist devices (VAD) or heart transplants.

A letter of support was obtained from UT Physicians (See Appendix I) with two other cardiologists agreeing to allow their patients to be recruited for this study. Additionally, another letter of support is in progress from the UT Physician Heart Failure Clinic cardiologists. Once IRB approval and letters of support are obtained, patient recruiting will begin. To begin recruitment, the receptionist will screen the patients coming into the waiting room who meet the inclusion and exclusion criteria and will give them a brochure (See attachment) and direct them to the PI, who will also be in the waiting room to explain the study, answer any questions and confirm study eligibility.

In addition to proactively contacting patients, announcements (see attachments) will be placed in cardiologists' offices and waiting rooms explaining the study, eligibility criteria and the benefits of participation and whom to contact for additional information and study sign-up. A \$12 paid parking voucher will be offered to participants.

G*Power 3.1.9.2 for MAC was used to compute sample size using the t-test parameters of an alpha of 0.05 and a power of 0.80 with an effect size of 0.80, which is considered a large effect size (Cohen, 1988a). The t-test will be used to analyze hypothesis 1.2 (two cohort groups: women ages 55 – 73 and 74 - 91). A minimum sample

of 52 was calculated for two equally divided cohort groups (26 for each cohort group).

When using a sample size of 52 to determine the effect size and the F-test parameters for the other two hypotheses, 1.1 and 2.1, a calculated effect size of 0.18 was obtained for both hypotheses, which is considered to be a small effect size (Cohen, 1988a). A 10 to 15 % attrition rate is assumed due to possible participant fatigue, leaving the site before completing the study, or other unexpected conditions that emerge. To account for these factors, a reasonable sample size of 60 is anticipated.

Instruments

This study will use valid instruments to determine descriptive statistics of the study population and to analyze study data. Below is a table of instruments, which will be used in this study, and their perspective psychometric properties.

Table 1

Instrument Description and Psychometric Properties

Instrument / Description (Reference)	Reliability / Validity (Reference)
Standardized Mini Mental State Exam / SMMSE is widely used and includes tests of orientation, attention, memory, language and visual-spatial using 11 questions. The subject is given 10 seconds to answer each question. If answered correctly the question is given a score of one. Scores of 20 - 25 indicate, "may be normal", 24 - 21 "mild or early impairment", 21 - 10 "moderate impairment and 9 - 0" severe impairment". It takes five to ten minutes to complete. (Molloy, Alemayehu & Roberts, 1991).	Intra class correlation coefficient is 0.90 compared to 0.69 for the MMSE// When comparing the SMMSE to two other instrument results using two reference standards, consultant geriatricians and a competency clinic assessment, the SMMSE area under the "receiver operating characteristic" (ROC) curve was 0.94. (Vertesi, Lever, Molloy, Sanderson, Pokoradi & Principi, 2001).
Geriatric Depression Scale – Short Form/ GDS-SF is a 15-item screening tool used to identify depressive symptoms in older adults. It generally takes about 7 minutes to administer. Scores > than 5 suggests depression and should be followed-up,	Cronbach's alpha was 0.87. / Using depression as the criterion validity the sensitivity, for a score of 5 as a cut-off point, was 84.2% and the specificity was 68.8%. (Lach, Chang & Edwards, 2010).

<p>scores > than 10 usually indicate depression. (Sheikh & Yesavage, 1986).</p>	
<p>Duke Activity Status Index / DASI is a 12-item, self-administered questionnaire that asks questions about physical work capacity to measure a patient's functional status by estimating peak metabolic equivalents (METs). Each question is designated a weight and all weights are added for "yes" answers to get a score. A VO_2 and MET is then calculated. (Hlatky et al., 1989).</p>	<p>Using HF patients, Cronbach's alpha reliability was 0.86. / Criterion-related validity was tested and supported by comparing the DASI scores to each New York Heart Association classification. Construct validity was supported by a negative correlation between DASI score and health-related quality of life ($r = -0.64$, p-value < 0.001) and depression ($r = -0.44$, p-value < 0.001) scores indicating better functional status associated with better health-related quality of life and lower depressive symptoms. (Fan, Lee, Frazier, Lennie & Moser, 2015).</p>
<p>Self-Assessed New York Heart Association Functional Class questionnaire / SA-NYHAFCQ Classifies the severity of HF. Four questions are asked about the severity of HF symptoms and the one the patient checks corresponds to the functional class of the patient. (The Criteria Committee of the New York Heart Association. <i>Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels</i>. 9th ed. Boston, Mass: Little, Brown & Co).</p>	<p>Inter observer concordance for 50 patients and two independent cardiologists agreed on the NYHA class in 54% of cases. / Not Available. (Holland, Rechel, Stepien, Harvey & Brooksby, 2010).</p>
<p>Multidimensional Scale of Perceived Social Support / MSPSS measures the perceived social support from three sources of social support (significant other, family and friend). The instrument consists of a 7-point Likert scale with responses ranging from 1-Very Strongly Disagree to 7-Very Strongly Agree. Total score ranges from 12 to 84 and subscale scores range from 4 to 28. Lower scores indicate less perceived social support. (Dahlem 1991; Pedersen, 2009; Zimet, Dahlem, Zimet, & Farley, 1988; Zimet GD 1990)</p>	<p>Cronbach's alpha total score (0.93 – 0.98) subscales (0.91 – 0.81) / Validity checked with depression and anxiety scores. The MSPSS total score moderately diverged based on a significant negative correlation with depression ($r = -0.25$, $P < .01$). All three subscales significantly inversely correlated to the depression subscales (family: $r = -0.24$, $P < .01$; friend $r = -0.24$, $P, .01$) and significant other ($r = -0.13$, $P, .05$) and family was significantly inversely correlated with anxiety ($r = -0.18$, $P < .01$). (Hardan-Khalil, K. & Mayo, A.M., 2015).</p>

<p>European Heart Failure Self-Care Behavior Scale / The EHFSBS-9 is a 9-item questionnaire rated on a 5-point Likert scale, 1 = "I completely agree" to 5 = "I completely disagree", which measures the extent of HF self-care behavior. Low scores indicate better self-care behavior. The 9-item instrument has been used since 2009 with good reliability and validity. (Jaarsma, Arestedt, Martensson, Dracup, & Stromberg, 2009; Lee, 2013; Vellone et al., 2014).</p>	<p>Total item correlations ranged from 0.25 – 0.65. Coefficient alpha were 0.80 / Convergent validity with another HF instrument (SCHFI) had moderate to strong correlations with the SCHIFI. (Lee et al., 2014).</p>
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Data Collection

Subject recruitment will be completed when 30 participants are recruited for each of the two generational cohorts, which accounts for the additional 10 to 15% needed for attrition. After the consent is signed, the participants will be given a study packet that will contain the demographic form, the MSPSS, the EHFSBS-9, the SA-NYHAFQC, the DASI and the GDS-SF to fill out while they are waiting for their appointment. After their appointment, the PI will take them to a quiet and private room so that the interview and SMMSE can be conducted. The SMMSE, DASI and GDS-SF questionnaires were chosen because HF patients in elderly populations frequently experience cognition and functional status impairments (Leto & Feola, 2014). Furthermore, two-thirds to three-quarters of HF patients experience depressive symptoms (Dickson, McCarthy & Katz, 2013).

Semi-structured interviews will be conducted to understand how perceived social support influences HF self-care in the total sample of participants. Interviews will be recorded using the IPHONE 6, with an attached "Blue Mikey" digital recording microphone for Apple IPHONE and IPAD, and with the Audio Memo app, which enables longer recordings than does the voice memo from the IPHONE 6. The IPAD will be used as a backup for the recording using the same Audio Memo app. Transcription

will be done using a professional transcriptionist and be sent through UT's email system with no patient identifiers. The PI will check the recorded interview against the transcription to insure transcription accuracy.

A data linking log will be in the form of an Excel spread sheet that will have the patient's name (from the consent), year of birth (from the demographic form), cohort category "boomers" = 1, or "silent" = 2 (from the demographic form) and a unique study identification number, developed by PI which will be given to each participant starting with number 01. Both IPHONE6 and IPAD will have air watch installed as a mobile device management tool authorized by UT. All data will be secured at all times during the study and write up. An IT security advisor was consulted. The MacBook laptop, IPHONE6, and IPAD are all encrypted and the advisor suggested that a file be created and placed on the computer desktop and used exclusively for the study.

Data Analysis

All data, except data from the interview, will be put into UT's licensed Qualtrics software, which is survey software that produces analytics and can also be used in SPSS for statistical analysis. The SMMSE, SA-NYHAFQC, DASI, GDS-SF and demographic forms will be used to calculate sample descriptive statistics. The MSPSS and EHFScBS-9 will be used to calculate study results. Data from the interview will be grouped by sources of perceived social support and a comparison, contrast and synthesis of the responses will be made to gain response clarity and insight. Both quantitative and qualitative data analysis will be merged and possible inferences made that will enable a better understanding of the factors influencing perceived social support and HF self-care.

Aim 1: To determine the magnitude of perceived social support from others in a group of women with HF.

Hypothesis 1.1: The perceived magnitude of social support from others, by women with HF, will vary.

This hypothesis will be measured using the F-test, ANOVA, with repeated measures within factors using three measures (sub-scale sources of social support) and one group. The total scores of each MSPSS sub-scale will be measured to determine if there are significant differences among the three sub-scale scores.

Hypothesis 1.2: There may be a difference in the magnitude of perceived social support from others in women with HF, from two different generational cohorts.

This hypothesis will be measured using a two-tailed t-test to measure differences between two independent means (two Cohort groups). The total MSPSS scores for each cohort will be measured to determine whether there is a significant difference between the scores representing each cohort.

Aim 2: To determine the association between perceived social support and self-care in women with HF.

Hypothesis 2.1: There is a direct association between perceived social support and self-care in women with HF.

This hypothesis will be measured using the Pearson Rho correlation with Tukey's test to determine whether the two total scores differ significantly.

Aim 3: To understand how women with HF describe different sources of perceived social support and how those sources influence HF self-care.

Research Time Line

	12/2015	01/2016	02/2016	03/2016	04/2016	05/2016
IRB Approval						
Recruit Subjects						
Collect Data						
Analyze Data						
Write Report						

Limitations

Our sample represents those HF patients that are managed by their physician and have access to health care and therefore does not represent many HF patients who don't have access to healthcare to manage their HF. Also, our sample consists of those patients with transportation to the medical center. Many HF patients are from a lower socioeconomic status and lack adequate transportation or do not have access to transportation that can take them to the medical center to receive appropriate HF care. Lastly, our sample does not include those patients in remote areas who might rely more on self-care since they might not have access to their physician as often as those patients living closer to a large medical facility.

Human Subjects

To minimize logistical problems and attrition rates in this older population, all forms will be filled out at one time and the interview will be conducted at the same time for all participants. Participants will be audio taped during their interview. Minimal risks are anticipated, however negative emotions could emerge when the subject discusses inadequate or lack of support from others. Fatigue could develop due to disease symptoms and age so a comfortable chair and close availability to restrooms and access to water will be insured. There is always a risk of a breach of confidentiality. Interviews will be conducted in a private room at the cardiologist's office. The PI, who has taken all

the required research training, will conduct interviews. IRB approval will be obtained prior to any interaction with the participants. Informed consent will be obtained from all participants and all confidential information obtained during chart review and data collection will be secured in a safe area free from potential breach. The PI will have any equipment, personal or school owned, secured by the appropriate University of Texas Health Science Center School of Nursing department. Interview participation and elaborating on their sources of social support and their self-care routines can provide the participant with a better understanding of their social support relationships and be able to obtain comfort in openly talking about their experiences. Results of the study will be made available to participants. Participants will receive a parking voucher to compensate them for their parking fees. Only women are included in this study since this population is barely represented in studies of social support and self-care in heart failure patients. This study will provide much needed information about this underrepresented population. Furthermore, since women generally outlive their spouses, more women with heart failure constitute a vulnerable population at risk for social isolation.

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Appendix A

Demographic Information Form (Larger and bolder print for the elderly)

Please answer the following questions to the best of your ability.

1. When is your birthday? Please check

Month

- Jan Feb March April May June July
 August Sept. Oct. Nov. Dec.

Day (please circle)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
 21 22 23 24 25 26 27 28 29 30 31

Year (please circle)

1925 1926 1927 1928 1929 1930 1931 1932 1933 1934 1935
 1936 1937 1938 1939 1940 1941 1942 1943 1944 1945 1946
 1947 1948 1949 1950 1951 1952 1953 1954 1955 1956 1957
 1958 1959 1960

2. What race are you?

- White (non-Hispanic, includes original people from Europe, the Middle East or North Africa)**
 White (Hispanic, includes original people from Cuba, Mexico, Puerto Rico, South or Central American or other Spanish culture or origin regardless of race)
 Black/African-American (people having origins in any black racial groups of Africa)
 American Indian/Alaskan Native (people having origins in any of the original peoples of North and South America)
 Asian (people having origins in any of the peoples of the Far East, Southeast Asia or the Indian Islands, Thailand and Vietnam)

- Native Hawaiian/other Pacific Islander (people having origins in any of the original people of Hawaii, Guam, Samoa or other Pacific Islands)**
- Unknown (you do not know your race)**
- From multiple races (you identify with more than one race)**
- Some other race (please specify) _____**
- No answer**

3. What is the highest level of school you have completed?

- Less than high school degree**
- High school degree or equivalent (e.g., GED)**
- Some college but no degree**
- Associate degree**
- Bachelor degree**
- Graduate degree**

4. What comorbidities (other medical conditions or diseases) do you have other than Heart Failure?

- Diabetes (Type 2)**
- Cardiovascular disease**
- Cerebrovascular disease (Did you ever have a stroke?)**
- Heart Attack**
- Peripheral Vascular Disease**
- Chronic Kidney Disease**
- Depression**

- Other (please specify) _____
- Don't know

5. Fill out table

List three people that give you the most support	Who are they? (friend, type of relative, other person)	Do they live with you? (YES or NO. If NO where do they live?)	How often do you see them?
1.			
2.			
3.			

6. What is your marital status?

- Married
- Divorced
- Widowed/Widower
- Single (never married)

7. How many children do you have?

- 0
- 1
- 2
- 3 or more

8. Have you had heart failure for at least two months? Yes/No

Appendix B

Standardised Mini-Mental State Exam

Name of patient: DOB: / / Name of examiner: Date of test: / /

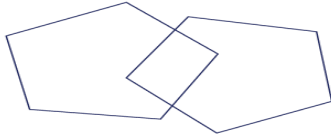
Standardised Mini-Mental State Examination (SMMSE)

Please see accompanying guide for directions for administration

Say: I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can.

1. (Allow 10 seconds for each reply). Say:
- a) What year is this? (Accept exact answer only) _____ / 1
- b) What season is this? (During the last week of the old season or first week of a new season, accept either) _____ / 1
- c) What month is this? (On the first day of a new month or the last day of the previous month, accept either) _____ / 1
- d) What is today's date? (Accept previous or next date) _____ / 1
- e) What day of the week is this? (Accept exact answer only) _____ / 1
2. (Allow 10 seconds for each reply). Say:
- a) What country are we in? (Accept exact answer only) _____ / 1
- b) What county are we in? (Accept exact answer only) _____ / 1
- c) What city/town are we in? (Accept exact answer only) _____ / 1
- d) (At home) What is the street address of this house? (Accept street name and house number or equivalent in rural areas)
(In facility) What is the name of this building? (Accept exact name of institution only) _____ / 1
- e) (At home) What room are we in? (Accept exact answer only)
(In facility) What floor of the building are we on? (Accept exact answer only) _____ / 1
3. Say: I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes (Say slowly at approximately one-second intervals).
- Ball Car Man**
- For repeated use: Bell, jar, fan; bill, tar, can; bull, bar, pan
- Say: Please repeat the three items for me. (Score one point for each correct reply on the first attempt) _____ / 3
- Allow 20 seconds for reply; if the person did not repeat all three, repeat until they are learned or up to a maximum of five times. (But only score first attempt).
4. Spell the word **WORLD**. (You may help the person to spell the word correctly) Say: Now spell it backwards please (Allow 30 seconds; if the subject cannot spell World even with assistance, score 0) Refer to accompanying guide for scoring instructions (Score on reverse of this sheet) _____ / 5
5. Say: Now what were the three objects I asked you to remember? _____ / 3
- (Score one point for each correct answer regardless of order; allow 10 seconds)
6. Show wristwatch. Ask: What is this called? _____ / 1
- (Score one point for correct response; accept "wristwatch" or "watch"; do not accept "clock" or "time", etc.; allow 10 seconds)
7. Show pencil. Ask: What is this called? _____ / 1
- (Score one point for correct response; accept "pencil" only; score 0 for pen; allow 10 seconds for reply)
8. Say: I would like you to repeat a phrase after me: *No ifs, ands, or buts*. _____ / 1
- (Allow 10 seconds for response. Score one point for a correct repetition. Must be exact, e.g. no ifs or buts, score 0)
9. Say: Read the words on this page and then do what it says. _____ / 1
- Then, hand the person the sheet with CLOSE YOUR EYES (score on reverse of this sheet) on it. If the subject just reads and does not close eyes, you may repeat: Read the words on this page and then do what it says, (a maximum of three times. See point No. 3 in Directions for Administration section of accompanying guide). Allow 10 seconds, score one point only if the subject closes eyes. The subject does not have to read aloud.
10. Hand the person a pencil and paper. Say: Write any complete sentence on that piece of paper. (Allow 30 seconds. Score one point. The sentence must make sense. Ignore spelling errors) _____ / 1
11. Place design (see reverse of this sheet), pencil, eraser and paper in front of the person. Say: Copy this design please. Allow multiple tries. Wait until the person is finished and hands it back. Score one point for a correctly copied diagram. The person must have drawn a four-sided figure between two five-sided figures. Maximum time: One minute. _____ / 1
12. Ask the person if he is right or left handed. Take a piece of paper, hold it up in front of the person and say the following:
Take this paper in your right/left hand (whichever is non-dominant), fold the paper in half once with both hands and put the paper down on the floor.
- Takes paper in correct hand. _____ / 1
- Folds it in half. _____ / 1
- Puts it on the floor. _____ / 1
- TOTAL TEST SCORE:** _____ / 30
- ADJUSTED SCORE : _____ /

Molloy DW, Alemayehu E, Roberts R. Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental state Examination. *American Journal of Psychiatry*, Vol. 14, 1991a, pp.102-105. The Standardised Mini-Mental State Examination (SMMSE) is the copyright of Dr D.W. Molloy and may not be reproduced without the written consent of the author.



Time:

D	L	R	O	W	=	<input type="text"/>

CLOSE YOUR EYES

Source: Adapted from “Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental state Examination”, Molloy, D.W., Alemayehu, E. & Roberts, R. (1991). *American Journal of Psychiatry*, 148,102-105.

Appendix C

Multidimensional Scale of Perceived Social Support (MSPSS)

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**

Circle the "2" if you **Strongly Disagree**

Circle the "3" if you **Mildly Disagree**

Circle the "4" if you are **Neutral**

Circle the "5" if you **Mildly Agree**

Circle the "6" if you **Strongly Agree**

Circle the "7" if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7

10. There is a special person in my
life who cares about my feelings. 1 2 3 4 5 6 7
11. My family is willing to help me
make decisions. 1 2 3 4 5 6 7
12. I can talk about my problems with
my friends. 1 2 3 4 5 6 7

Source: Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Percieved Social Support. *Journal of Personality Assessment*, 1988;52:30-41

Appendix D

European Heart Failure Self-Care Behavioral Scale - 9 (EHFScBS-9)

	I completely agree					I don't agree at all		
	1	2	3	4	5			
1.	I weigh myself every day			1	2	3	4	5
2.	If SOB increases I contact my doctor or nurse			1	2	3	4	5
3.	If legs/feet are more swollen, I contact my doctor or nurse			1	2	3	4	5
4.	If I gain weight more than 2kg in 7 days I contact my doctor or nurse			1	2	3	4	5
5.	I limit the amount of fluids			1	2	3	4	5
6.	If I experience fatigue I contact my doctor or nurse			1	2	3	4	5
7.	I eat a low-salt diet			1	2	3	4	5
8.	I take my medication as prescribed			1	2	3	4	5
9.	I exercise regularly			1	2	3	4	5

Source: European Heart Failure Self-Care Behavior Scale (EHFScBS-9). Adapted from "The European Heart Failure Self-Care Behaviour Scale: New insights into factorial structure, reliability, precision and scoring procedure" by Vellone, E., Jaarsma, T., Stromberg, A., Fida, R., Arestedt, K., Rocco, G., . . . Alvaro, R. (2014), *Patient Education and Counseling*, 94(1), 97-102. doi: 10.1016/j.pec.2013.09.014.

Appendix E

Self Assessed New York Heart Association Functional Class

Please tick one box containing the description which best summarizes your ability to do physical activity **before coming into hospital**:

- I can perform all physical activity without getting short of breath or tired, or having palpitations.
- I get short of breath or tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps.
- I get short of breath or tired, or have palpitations when performing day-to-day activities. For example, walking on the flat.
- I feel breathless at rest, and am mostly housebound. I am unable to carry out any physical activity without getting short of breath or tired, or having palpitations.

Source: Self-Assessed New York Heart Association Functional Class. Adapted from “Patients self-assessed functional status in heart failure by New York Heart Association Class: A prognostic predictor of hospitalizations, quality of life and death” by Holland, R., Rechel, B. Stepien, K., Harvey, I. & Brooksby, I. (2010). *Journal of Cardiac Failure*, 16, 150-156.

Appendix F

Duke Activity Status Index (DASI)

Instructions: Please answer 'yes' or 'no' to each question.

Can you:	Please Circle
1. Take care of yourself, that is, eat, dress, bathe or use the toilet?	Yes/No
2. Walk indoors, such as around your house?	Yes/No
3. Walk a block or two on level ground?	Yes/No
4. Climb a flight of stairs or walk up a hill?	Yes/No
5. Run a short distance?	Yes/No
6. Do light work around the house like dusting or washing dishes?	Yes/No
7. Do moderate work around the house like vacuuming, sweeping floors or carrying groceries?	Yes/No
8. Do heavy work around the house like scrubbing floors or lifting or moving heavy furniture?	Yes/No
9. Do yard work like raking leaves, weeding or pushing a power mower?	Yes/No
10. Have sexual relations?	Yes/No
11. Participate in moderate recreational activities like golf, bowling, dancing, doubles tennis or football?	Yes/No
12. Participate in strenuous sports like swimming, singles tennis, football, basketball or skiing?	Yes/No

Source: DASI. Adapted from “Clinical role of the Duke Activity Status Index in the selection of the optimal type of stress myocardial perfusion imaging study in patients with known or suspected ischemic heart disease” by Phillips, L, Wang, J.W., Pfeiffer, B., Gianos, E., Fisher, D., Shaw, L.J., & Mieres, J.H. (2011). *Journal of Nuclear Cardiology*, 18, 1015-1020 and “A brief self-administered questionnaire to determine functional capacity (The Duke Activity Status Index)” by Hlatky, M.A., Boineau, R.E., Higginbotham, M.B., Lee, K.L., Mark, D.B., Califf, R.M., Cobb, F.R. & Pryor, D.B. (1989). *American Journal of Cardiology*, 64, 561-564.

Appendix G

Geriatric Depression Scale – Short Form (GDS-SF)

Choose the best answer for how you have felt over the past week:	Please Circle
1. Are you basically satisfied with your life?	YES / NO
2. Have you dropped many of your activities and interests?	YES / NO
3. Do you feel that your life is empty?	YES / NO
4. Do you often get bored?	YES / NO
5. Are you in good spirits most of the time?	YES / NO
6. Are you afraid that something bad is going to happen to you?	YES / NO
7. Do you feel happy most of the time?	YES / NO
8. Do you often feel helpless?	YES / NO
9. Do you prefer to stay at home, rather than going out and doing new things?	YES / NO
10. Do you feel you have more problems with memory than most?	YES / NO
11. Do you think it is wonderful to be alive now?	YES / NO
12. Do you feel pretty worthless the way you are now?	YES / NO
13. Do you feel full of energy?	YES / NO
14. Do you feel that your situation is hopeless?	YES / NO
15. Do you think that most people are better off than you are?	YES / NO

Source: Retrieved on November 7, 2015, from
<http://web.stanford.edu/~yesavage/GDS.english.short.score.html>

Appendix H

Interview Guide

MSPSS

Questions about a special person in your life

If the answers are 1's and 2's ask the following: Tell me about why you feel that a special person isn't helpful or available to you if you need them?

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have a strong feeling either way about a special person in your life?

If the answers are 6's and 7's ask the following: Tell me about who that special person in your life is and how that person helps you?

Questions about a friend or friends in your life

If the answers are 1's and 2's ask the following: Tell me about why you feel you don't have friends in your life that can help or with whom you can share your problems.

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have strong feelings either way about your friends?

If the answers are 6's and 7's ask the following: Tell me about how your friends help you.

Questions about family

If the answers are 1's and 2's ask the following: Tell me about why you feel your family isn't helpful or available to you if you need them?

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have a strong feeling either way about your family helping or being there for you?

If the answers are 6's and 7's ask the following: Tell me about how your family helps you.

EHFScBS-9

Is there a family member, friend or special person that helps or hurts your ability to provide HF self-care and if so, how?

Do you feel you need help in providing yourself with HF care?

Appendix I

Letter of Support UT Physicians



Medical School
Department of Internal Medicine
Division of Cardiology

December 9, 2015

Joy Corcione, PhD(c), MBA, RN
SON Advisory Council Accelerated PhD Scholar
The University of Texas School of Nursing
6901 Bertner Avenue
Houston, TX 77030

Re: Women with Heart Failure and Their Perception of Social Support and its Effects on Heart Failure Self-Care Behavior

Dear Joy,

I have read and do support your dissertation proposal described above. I also agree to allow you to recruit potential participants from my clinic on the 6th floor of the University of Texas Professional Building (UTPB) at 6410 Fannin Street, usually held on Monday and Tuesday afternoons once you have secured the appropriate institutional approvals, including CPHS approval.

Sincerely,

Anne Hamilton Dougherty, M.D., F.A.C.C., F.H.R.S., F.A.H.A.
Professor of Medicine
Director, Cardiac Electrophysiology
Director, Cardiac Electrophysiology Fellowship
Co-Director, UT Cardiac Electrophysiology Institute
Vice President, Human Research Protection Programs

UTHealth | The University of Texas
Health Science Center at Houston
Division of Cardiology/Department of Internal Medicine
6431 Fannin | MSB 1.246 | Houston, Texas 77030
713-500-6590 tel | 713-500-6556 fax
Anne.H.Dougherty@uth.tmc.edu

cc:

Katherine Knight, Nurse Manager, UTP Administration - IM Clinic

713.500.6555 phone; 713.500.6556 fax
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Houston, TX 77030

Influences on Self-Care in Women With Heart Failure: A Pilot Study

Heart Failure (HF) is associated with a high burden of cost to the health care system and to the patient with its high morbidity and poor survival rate as it often involves numerous hospital admissions and extensive use of health care resources (Desai & Stevenson, 2012). Today, approximately 5.7 million people in the United States alone have HF (Mozaffarian et al., 2015) and the number is growing substantially due to the increase in the aging population and better management of HF (Heidenreich et al., 2013).

Self-care is defined as a “naturalistic decision-making process that influences actions that maintain physiologic stability, facilitate the perception of symptoms, and direct the management of those symptoms” (Riegel, Dickson & Faulkner, 2016 p. 226). Self-care is vitally important in managing HF (Riegel et al., 2009) and can improve heart performance, decrease demands on the body and enhance wellbeing (Thomas & Clark, 2011). Self-care can also improve mortality, morbidity and symptom burden through proper medications compliance, behavioral and lifestyle changes, and the nurturing of positive social relationships (Riegel et al., 2009; Graven & Grant, 2014). Self-care becomes exceedingly difficult to perform as HF progresses but continues to be vital in managing HF (Graven & Grant, 2014; Riegel & Carlson, 2002).

Social support, defined as “the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations” (Cobb, 1976, p. 300), becomes important because it greatly facilitates self-care behaviors (Gallagher, Luttk, & Jaarsma, 2011; Graven & Grant, 2014; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008). Few investigations have examined the mechanisms underlying the relationship between social support and health, although

several possible mechanisms have been proposed over the years (Cohen, 1988). Social support may influence health by directly or indirectly affecting health behaviors (Berkman, 1982; Cohen, 1988), by information that is received when one is in a supportive relationship (Berkman, 1982; Cohen, 1988), and by receiving tangible resources (Cohen, 1988). Another proposed mechanism linking social support to health is that social support may be associated with more positive affective states such as increased feelings of belonging, intimacy, improved sense of self-worth (Berkman, 1982; Cohen, 1988) and an increased sense of control (Cohen, 1988). The positive psychological states derived from support systems may increase health-promoting behaviors, or they may dampen or prevent the pathogenic physiological reactions associated with negative mental states. Therefore, more studies are needed to understand the important social support mechanisms that influence and facilitate HF self-care.

Woman with HF represent a significant and growing vulnerable population (Thomas & Clark, 2011). Women tend to have lower self-confidence when it comes to self-care (Riegel et al., 2010), they experience greater negative emotions (Martensson, Karlsson & Fridlund, 1998; Rhodes & Bowles, 2002), decreased social support, particularly from family (Riegel et al., 2010), and experience more adverse psychosocial factors which affect self-care (Heo, Moser, Lennie, Riegel, & Chung, 2008; Thomas & Clark, 2011). They also develop more HF symptoms and experience greater psychosocial adversity than do men (Riegel et al., 2010).

A generational cohort are a group of people born during a particular time period and share a unique character based on historical and social events that occur during their different life stages (Rindfleisch, 1994; Strauss & Howe, 1991). There is no exact agreed

upon time span in a generation with lengths ranging from 15 to 33 years (Rindfleisch, 1994). However, Strauss and Howe (1991) have defined a generation as a cohort-group whose length is approximately that of a “basic phase of life”, or about 22 years (Strauss & Howe, 1991, p. 34). The generational cohort concept emphasizes that the social, political and historical climate and events during a particular generation shape attitudes and values of that particular generation (Sessa, Kabacoff, Deal & Brown, 2007; Strauss & Howe, 1991). This is in contrast to a more traditional belief that people are influenced more by their age than by their social, political or historical context in which they lived (Sessa, et al., 2007).

This pilot study included age groups spanning two particular generational cohorts. According to Strauss and Howe (1991), the “silent” generation consisted of those born from 1925 to 1942 and the “boomer” generation consisted of those born from 1943 to 1960 (Strauss & Howe, 1991). Socioeconomic influences upon generational groups suggest that there may be differences in social support among women from different generational cohorts (Strauss & Howe, 1991). For example, the “silent” generation was the earliest to marry and have children. Men married, on average, at 23 years of age, women at 20 with 94% becoming mothers bearing an average of 3.3 children (Strauss & Howe, 1991). When in their 30’s, 38% of women in the “silent” generation were employed conversely 60% of the women in the “boomer” generation were employed (Patten & Fry, 2015). Additionally, within this cohort, those born in the 1930’s and early 1940’s experienced the highest increase in divorce rates (Strauss & Howe, 1991). Strauss and Howe (1991) noted that women that were considered to be the most nurturing of any other generation in the 20th century mothered the “boomer” generation. Even amongst

those mothers that worked, 80% of the “boomer” preschoolers were taken care of in their homes by relatives and only 2% were in institutional childcare. Furthermore, there was a strong bond between the mother and her “boomer” son with 32% of white “boomer” males and 44% of black “boomer” males indicating that their mothers were the one person that cares about them while only 8% of white males and 2% of black males stated the same for their fathers (Strauss & Howe, 1991).

The purpose of this pilot study was to gain a deeper understanding about the sources of perceived social support and how those sources influenced HF self-care behavior in women in two generational cohorts. Understanding sources of social support and how they influenced HF self-care is necessary in order to develop future interventions that might enhance social support and subsequently create more positive self-care behaviors in women with HF.

Conceptual Framework

Most studies in the area of HF self-care lack a viable model that illustrates the complexity involved in a patient’s decision to perform HF self-care (Hwang, Moser & Dracup, 2014). Moser and Watkins (2008) developed one of the most comprehensive conceptual framework models (See Figure 1) for HF self-care by reviewing the literature to find those factors and relationships that potentially influence the patient’s decision-making process (Moser & Watkins, 2008).

Within this model, five major factors potentially influence the patient’s decision to perform self-care (Moser & Watkins, 2008). These factors are psychosocial status, aging status, current symptom status, health literacy and prior experiences (Moser & Watkins, 2008). The Moser and Watkins (2008) model most closely illustrates the

potential relationships among the factors included in this pilot study which were: psychosocial status (depressive symptoms, social support and education level) and aging status (cognitive status, age, functional status and comorbidities) and provides a conceptual guide to understand the decision-making process used to determine HF self-care performance (Moser & Watkins, 2008).

Methods

Study Design

A cross-sectional, mixed method, concurrent, embedded quantitative dominant design with a follow-up variant approach was used in this pilot study (Creswell & Plano Clark, 2011). The pilot study's quantitative portion employed instruments that measured perceived social support and HF self-care. Additionally, questionnaires describing the population in terms of depressive symptoms, cognition and HF functional class levels, socioeconomic and demographic factors, and functional status were also used. The qualitative portion employed semi-structured interviews to further probe answers provided by the participants to the HF self-care and perceived social support instruments to obtain a richer understanding of who provided support, how they provided support and how that support influenced self-care. A mixed method follow-up variant design entailed interviewing all participants of the quantitative portion of the study, as opposed to only interviewing a purposeful sample based on criteria only known after the results of the quantitative portion are analyzed (Creswell & Plano Clark, 2011). The same participants concurrently engaged in both the quantitative and qualitative portions of the study. Inferences were made by comparing the quantitative and qualitative results noting whether patterns existed in the levels of social support given and how those patterns

affected HF self-care.

Sample and Setting

Approval was obtained from the Committee for the Protection of Human Subjects Institutional Review Board for the University of Texas Health Science Center Houston, located within a large metropolitan medical center in the Gulf Coast region of the United States. The pilot study was conducted in a cardiology clinic with over 17 cardiologists specializing in advanced diagnostic and imaging technologies.

Inclusion criteria for pilot study participation were as follows: (a) New York Heart Association (NYHA) HF Functional class II, III or IV, (b) HF diagnosis for at least two months, (c) adult women with birth years from 1925 to 1960. Exclusion criteria were: (a) patients with diagnosed psychiatric or physical disorders which could cause the patient not to understand or comply with study instructions or not be able to perform self-care tasks, (b) non-English communicators who could not follow written or verbal instructions, and (c) patients with ventricular assist devices (VAD) or heart transplants.

Sampling Procedures

The principle investigator (PI) prescreened patients with appointments at the clinic to determine eligibility. The patient was approached on their clinic day either in the waiting room or in the examination room. If the patient agreed to be in the pilot study, informed consent was obtained and the participant was given the following forms and instruments: Self-Assessed New York Heart Association Functional Class questionnaire (SA-NYHAFCQ), the demographic form, the Multidimensional Scale of Perceived Social Support (MSPSS), the European Heart Failure Self-Care Behavior Scale (EHFScBS-9), the Geriatric Depression Scale - Short Form (GDS-SF), and the Duke

Activity Status Index (DASI). After their physician appointment was finished, the PI and participant went to a private place within the clinic for the Standardized Mini Mental State Exam (SMMSE) and the interview. All data were collected in one session, which lasted no more than 50 minutes, and when completed, a \$12 gift card was given to participants.

Quantitative Data Collection and Analysis

Instruments. The following standardized instruments with acceptable psychometric properties were used: Multidimensional Scale of Perceived Social Support (MSPSS), European Heart Failure Self-Care Behavior Scale (EHFScBS-9), Self-Assessed New York Heart Association Functional Class questionnaire (SA-NYHAFCQ), Duke Activity Status Index (DASI-METS), Geriatric Depression Scale - Short Form (GDS-SF) and the Standardized Mini Mental State Exam (SMMSE). The MSPSS measures the perceived social support from three sources of social support (special person, family, friend). The instrument consists of a 7-point Likert scale with responses ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). Total score ranges from 12 to 84 and subscale scores range from 4 to 28. Lower scores indicate less perceived social support (Zimet, Dahlem, Zimet, & Farley, 1988). Cronbach alpha coefficient's total score range reported as 0.93 – 0.98 and subscales as 0.91 – 0.81 (Hardan-Khalil & Mayo, 2015). The EHFScBS-9 is a 9-item questionnaire rated on a 5-point Likert scale, 1 (*I completely agree*) to 5 (*I completely disagree*), which measures the extent of HF self-care behavior. Low scores indicate better self-care behavior. The 9-item instrument has been used since 2009 with good reliability and validity (Jaarsma, Arestedt, Martensson, Dracup, & Stromberg, 2009; Lee et al., 2013; Vellone et al., 2014).

Cronbach alpha coefficient is reported as 0.80 (Lee et al., 2014). SA-NYHAFQC is a self-administered questionnaire, which classifies HF severity with four questions about the severity of HF symptoms participant's experienced (The Criteria Committee of the New York Heart Association, 1994). Validity was established as higher HF functional class was associated with increased readmission rates (adjusted rate ratio 1.21; 95% CI 1.04–1.41; $P = .02$), worse quality of life, ($P = .002$ for MLHFQ; $P = .047$ for EQ-5D) and higher mortality rate, (hazard ratio 1.84; 95% CI 1.10–3.06; $P = .02$) (Holland, Stepien, Harvey, & Brooksby, 2010). The DASI is a self-administered questionnaire that measures a patient's functional status (Hlatky et al., 1989). This instrument had a Cronbach alpha coefficient reported as 0.86 in a HF patient pilot study by Fan, Lee, Frazier, Lennie and Moser (2015). The GDS - SF identifies depressive symptoms in older adults (Sheikh & Yesavage, 1986). This instrument has a reported Cronbach alpha coefficient of 0.87 (Lach, Chang & Edwards, 2010). The SMMSE is a screening test for cognitive impairment (Molloy, Alemayehu, & Roberts, 1991). Reliability and validity were both reported with an intra class correlation of 0.90 and area under the ROC curve as 0.94 when using two reference standards (Vertesi et al., 2001).

The participant also completed a demographic data form containing questions about birth date, comorbidities, race, education level, marital status, number of children and confirming a HF diagnosis for at least two months. Social support questions were also asked that included listing the type of people that provide support, where they live (location), and frequency of visits.

The SMMSE, DASI and GDS-SF questionnaires were used in this pilot study

because HF patients in elderly populations frequently experience cognition, and functional status impairments. (Leto & Feola, 2014). Additionally, two-thirds to three-quarters of HF patients experience some depressive symptoms (Dickson, McCarthy & Katz, 2013) while women with HF experience actual depression prevalence rates ranging from 11 to 67% (Rutledge, Reis, Linke, Greenberg, & Mills, 2006).

Data Analysis. For this study, descriptive statistics were calculated (minimum, maximum, mean, standard deviation) on the SMMSE, DASI (METS), EHFScBS-9, GDS-SF, MSPSS (total, special person, friend, family) and the demographic form (age). Frequencies (number and percent) were calculated on cohort and the demographic form (race, education level, comorbidities, support network – type of people that provide support, do they live with participant, location, and frequency of visits, marital status, and number of children). Additional calculations included correlations between instruments and differences between cohorts related to the MSPSS (total, special person, family, friend) and the EHFScBS-9. Statistical software for SPSS v. 24 (MAC) was used for all statistical output.

Qualitative Data Collection and Analysis

Most (15 out of 16) pilot study participants engaged in a brief, focused, semi-structured interview, ranging from 2 to 16 minutes. The purpose of the interview was to understand how perceived social support influences HF self-care. To decrease investigator bias, prior preconceived views held by the PI about HF in women and how they coped with their disease were examined. The preconceived views held were self-identified as being: (1) the spouse provides most of the support for self-care, (2) children are readily available to provide support to their mothers, (3) most elderly women with HF

have little or no support, and (4) that most elderly women are depressed and fail to provide adequate support for themselves. Bracketing these views was necessary in order to ask probing questions which clarified participant answers and to further gain deeper insight into the issues participants raised during their interviews.

An interview guide (See Figure 2) directed initial interview questions, however, additional probing questions were asked for clarification based on individual responses. As themes started to emerge, questions were added for subsequent participants to further develop the emerging theme. Prior to each interview, the PI reviewed the scores on the MSPSS. If the scores were high (6's and 7's), indicating high social support, low (1's and 2's) indicating low social support, neutral (3's, 4's or 5's) indicating neutral support or all high or low the participant would be asked specific questions about who gave support and how support was provided. Questions were asked in a conversational manner and unscripted. Richer data was obtained through probing questions such as: (1) "Do you need help with your self-care?" (2) "You indicated on the MSPSS that a "special person" provides you with support, who is that person?" (3) "What do you think self-care means?" (4) "What happens when the main person that provides social support isn't available?" (5) "What self-care areas are you concerned with the most?" and (6) "Do you do certain things to help you cope with your HF? If so, what?"

An audit trail was created by developing an excel file that listed all pre-screened participants, verified inclusion and exclusion criteria, assigned study numbers to all final participants, included reasons for non-participation, and added analytic and fields notes where applicable. Interviews were recorded and then later transcribed verbatim by a professional transcription service and checked by the PI for complete accuracy. Field and

analytical notes supplemented the qualitative analysis. All interview data was initially read and re-read by the PI to understand the overall participant feelings concerning social support and self-care. Then each interview was read and repeating themes and unique comments about social support and self-care were manually highlighted. Also, a consultation with a qualitative research expert was used throughout the collection and analysis of qualitative data.

Data Integration

The purpose of the study's qualitative portion was to understand the MSPSS participant answers related to who and how people in the participant's social network provide support for HF self-care. Major themes were compared to the MSPSS's total average scores as well as the average subscale scores (special person, friend, family) to provide a deeper understanding of the type of people that the participants felt provided support and how they provided support. Also scores from the EHFScBS-9 were compared with the MSPSS (total) in the quantitative analysis to determine whether higher social support scores translated into better or worse HF self-care. Scores from the MSPSS (total, special person, friend, family) and the EHFScBS-9 were compared to qualitative themes and further analyzed to provide a deeper understanding of the participant's meaning of social support. Inferences were made by analyzing the quantitative data and interview data to determine how the qualitative data helped to explain the quantitative results. Using both methods created a richer understanding of the responses to the instrument questions.

Findings

Sample

The initial sample size estimate for this study was 52. This number was computed using G*Power 3.1.9.2 for MAC with parameters of alpha equals 0.05, a power of 0.80 and an effect size of 0.80. However, an estimated 10 to 15% attrition rate due to possible participant fatigue, leaving the site before completing the study or other unexpected conditions, brought the final sample size to 60, equally distributed between cohorts. Prescreening and recruitment efforts lasted from February 19, 2016 to May 24, 2016. Patient's usually had appointments monthly, every two months or every three months so many of the patients initially screened were screened again if their appointments fell more than once during the recruitment time frame. This study's final recruitment sample size was 16 (See Figure 3 for enrollment characteristics) and is serving as a pilot study for a larger study to occur in the future. Pilot studies are conducted for many reasons to include assessing the feasibility of a full-scale study, assessing recruitment strategies, and identifying logistical problems that might surface in a larger study (Teddlie & Tashakkori, 2009). Furthermore, a pilot study's sample size is usually determined by pragmatic factors unknown prior to the study such as the number of patients who don't show up for their appointments, the number of patients diagnosed with HF or the number of physicians at a clinic that are willing to allow their patients to be recruited (Leon, Davis & Kraemer, 2011). This study uncovered factors related to recruitment, and instrument content that can be corrected and used to enhance the quality and power of a larger study.

Demographic and clinical characteristics

Table 1 lists age characteristics for this population, which were (min/max/mean [SD]), 57/88/75.38 [9.81] in years. The black race was the majority for the entire sample followed by white. Half of the study sample had up to a high school degree and a quarter had some college. Half were widowed and slightly over a third were married. Over half had three or more children with over three quarters with HF class 2 and 3. Major self-identified comorbidities were cardiovascular disease and depression.

Cohort differences for age, race, marital status, education level and number of children

Tables 2 - 6 show cohort 1 (birth years 1925 to 1942) represented 62.5% of the total sample and Cohort 2 (birth years 1943 to 1960) represented 37.5% of the total sample. In cohort 1, race consisted of roughly an equal split between white and black, but in cohort 2, there was more racial diversity. For marital status, the majority of cohort 1 was widowed and in cohort 2 most were married. In terms of education level, in cohort 1, half had a high school degree or less, and in cohort 2, half had less than a high school degree. Finally, for the number of children participants had, most of cohort 1 and 2 had three or more children in about equal proportions.

Population characteristics by instrument

Table 7 shows that the HF self-care score was low to moderate at a mean of 2.74. Cognition had a high mean score of 27.93 out of 30 indicating normal cognition for this population. The functional status DASI (METS) mean score was 4.69, which is considered in the low moderate range. The depressive symptoms mean score was 2.31

which is way below the above 5 score which is considered to be a possible indicator of depression. The MSPSS total (6.45), special person (6.59) and family (6.86) all had high mean scores indicating excellent social support. The MSPSS friends had a mean score of 5.89 indicating moderate support from friends.

Reliability Statistics

Table 8 lists the reliability statistics for the study instruments. The EHFSBS-9 and MSPSS (family) both had barely acceptable reliabilities but the MSPSS (total, friend, special person) all had good internal consistency. The DASI and GDS-SF had acceptable reliability values.

Social Support Network

See Tables 9, 10 and 11 for the percent and numbers for sources, location and frequency of contact of social support network. When the participants were asked to list three people that give them the most support (not ranked in order of helpfulness) three quarters responded, for Person 1, that their child gave them the most support followed by slightly more than half stating the same for Person 2 and finally, a quarter stating the same for Person 3. When asked who these supportive people were in terms of friend, relative or other person they responded that all the supportive people were relatives for Person 1, 15 out of 16 responded that they were relatives for Person 2 and half responded that they were relatives for Person 3. When asked if those supportive people lived with them they responded that over half of Person 1 lived with them, and a third lived with them for Persons 2 and 3. If the participant answered “no” that the supportive person did not live with them, then they were asked where the supportive person lived and 2 out of the 3 that responded stated that they lived in the same neighborhood, and 1 out of 3

responded that Person 1 lived in the same city. For Person 2, out of the two that responded, one lived in the same city and one lived in the same state. For Person 3, out of three that responded, one lived in the same neighborhood and two lived in the same city. Finally, when asked how often the participant sees the supportive people, 15 out of 16 responded daily for Person 1, eight responded "daily" for Person 2, and five responded "daily" for Person 3.

Correlations Between Scales and Cohorts

Table 12 shows the spearman rank order correlation, a non-parametric correlation more appropriate for small sample sizes, which was run to assess the relationship between the instrument averages and totals. The MSPSS (family) $r = .648$, $p < 0.009$ (2-tailed) at the 1% significance level was moderately and positively correlated with the SMMSE. The $r = -.544$, $p < .029$ at the 5% significance level was moderately and negatively correlated with the GDS-SF.

There were significant differences in the MSPSS between the cohorts using the non-parametric Student t-test equivalent, the Mann-Whitney U (See Table 13). The Mann-Whitney U test compares differences between independent groups for small sample sizes. Cohort 2 had larger significant average MSPSS (total) values than did cohort 1 (6.92 vs. 6.17, $p = .011$ (2-tailed)). Furthermore, differences were found in MSPSS (special person) where cohort 2 had larger values than did cohort 1 (7.00 vs. 6.35, $p = .056$ (2-tailed)). Finally, differences were detected for the MSPSS (friend) where cohort 2 had larger significant values than cohort 1 (6.88 vs. 5.30, $p = .009$ (2-tailed)). All

these differences indicated that cohort 2 had better support overall and among special persons and friends.

Qualitative Data

Interviews had varying time lengths with the shortest one lasting approximately two minutes whose participant expressed total satisfaction with the support she received and that the support was adequate in helping her with her self-care with no changes necessary. The longest interview lasting approximately 16 minutes whose participant was also pleased with her support but went into detail about each type of support and emphasized the support she received from church.

Themes that emerged from the interviews included: (1) “special persons” were friends, family or other person that helped the most, (2) distance to support network was a factor in receiving support, (3) religion/spirituality was used as a coping mechanism and source of support, (4) participants viewed self-care as those things that they can only do for themselves without the help from others, (5) participants felt that they didn’t need help with self-care even though they did and (6) participants received mostly instrumental support from support source.

Participants would often state that they had a “special person” assisting them. Family was mentioned as being the “special person” over half of the time with the participant’s children being mentioned the most. Others mentioned that all who helped were “special people” or that “special people” were others such as a nurse, colleague or neighbor. Therefore, sources of social support weren’t rigidly labeled and defined by the participants into the categories identified in the questionnaire.

Distance from the participant's support network was a factor in receiving support. Two thirds of the participants stated that support was given since the support person was in close proximity. Only one participant indicated that their support person, which was one of her children, was not near but approximately 240 miles away but was still readily accessible to her.

Spirituality/religion provided assistance in two distinct ways. One was as a mechanism to cope with the participants' HF and the other was a source of social support. Although spirituality and religion were not routinely nor initially asked, participants voluntarily spoke about how the church and their spiritual beliefs helped them cope with their HF and provided a source of support. About a quarter of the participants indicated church was family and they could count on church people when they needed them. Only one participant stated that they talked to people at church but didn't feel that the people at church could help them. Over half stated that church "uplifted" their spirits generally and also through "song", "prayer", "Bible reading", and "talking to Jesus", in addition to non-religious reasons such as "pretending that the disease didn't exist", "not thinking about their disease" and also "having a hobby".

Participants often viewed self-care as something they do only by themselves without the help from others. Over half of the participants used the word "self" when describing what self-care means to them but one participant indicated that they "took their meds" and "walked" for their self-care but didn't mention the word "self."

One fifth of the participants felt that they didn't need help with self-care. However, when asked if they get help with their HF self-care, these participants said yes and stated, for example, that they get help with "make[ing] sure that my medication is in

a pill box”, and “my daughter...she has done some meal preparation ...and then if I need to go someplace, she’s available for that.” There was an attitude of confidence and independence in this group and a positive attitude as indicated by one participant stating that she doesn’t feel sorry for herself.

Most participants received instrumental support through the support source. Participants indicated that the support source helped them with “anything and everything”, which included instrumental support like “run errands”, “do laundry”, and “cleaning.” Others stated that they felt that they received emotional support as indicated by responses such as: “always they talk with me to see how I feel,” and “they talk if I need to talk to them, I can talk to them.”

Some participants did not go through great effort to adhere to a special diet. For example, a few participants simply stated that they watched what they ate and a few others stated that they ate what they wanted.

Integrated Data. The MSPSS scores are interpreted as 1 to 2.9 being low support, 3 to 5 as moderate support and 5.1 to 7 as high support (Zimet et al., 1988). The MSPSS (family) subscale had the highest average score of 6.86 (See Table 7) indicating high social support from family. High levels of social support by family (relatives) were also indicated on the demographic form (See Table 9) and in the interviews. Additionally, the qualitative data indicated that family were also considered “special person” and in fact the “special person” was also family which would explain why both “special person” and “family” mean subscale scores were high (6.59 and 6.86) because participants were treating both support sources similarly and readily exchanging one for the other while answering the MSPSS instrument.

The scoring range for the EHFS_cBS-9 was 1 to 2 indicating good or satisfactory levels of HF self-care and 3 to 5 indicating low levels of HF self-care (Uchmanowicz, Lobo_z-Rudnicka, Jaarsma, & Lobo_z-Grudzien, 2014). The average score for the MSPSS (total) was 6.45, indicating high social support and 2.74 (See Table 7) for the EHFS_cBS-9, indicating moderate to low levels of HF self-care. A score of high social support and moderate to low self-care suggests that even with high social support some self-care might not be performed. The interview data suggested that participants did not go through great efforts to adhere to diet. Also many participants felt that they didn't need any help or support but did receive or in fact needed the support. These findings in the interview data might help explain why the support scores were high and the self-care scores lower than what could be expected from such high level of support. A HF diet seems to be one area of self-care that is difficult to maintain and those participants that felt that they didn't need help might be over confident in their ability to provide adequate self-care and therefore do not ask nor accept support when given.

The majority of participants had a heart failure class 2 indicating mild to moderate HF symptoms, which would explain the fact that the participants can still perform a lot of HF self-care themselves. Furthermore, the qualitative interview indicated that most participants used the word "self" when describing self-care which meant that they perform the care themselves without assistance.

The GDS-SF mean score was 2.31 which is considered low risk for depressive symptoms since a score greater than 5 is suggestive of depression and a score greater than 10 is almost always depression (Sheikh & Yesavage, 1986). In this study population, as indicated in the interview data, spirituality/religion was used as a coping mechanism for

the participant's HF and was also used as a source of support which may help to explain the low depressive symptom scores.

The DASI (METS) mean score was 4.69 METS (metabolic equivalent of task) which measures the magnitude of effort required to perform a specific activity (World Health Organization [WHO], 2016). A METS score from three to six indicates moderate activity (WHO, 2016) therefore the average participant in this study was able to perform moderate physical tasks. The qualitative interview revealed that some of the participants felt that they didn't need any help even though they often did or were given help. This attitude could be due to their ability to perform moderate physical activities and therefore they felt that they didn't need any help for those types of activities but might need help for more strenuous ones.

The EHFScBS-9, and MSPSS (family) all had barely acceptable reliabilities most likely due to the small size. Therefore inferences made when using these instruments or subscales should be used with caution.

Discussion

This study examined all female cohort groups with HF. Interestingly to note, some significant differences between cohort groups as pertaining to the MSPSS (total, special person, friend) were discovered even though the sample was very small. These differences might indicate that friends play more of a role in support for a younger cohort than for an older one maybe because more friends of the older cohort are deceased since they are most likely in the same age range as the older cohort. Also, the older cohort's friends most likely have their own ailments as one participant indicated when stating "I have three close friends, but two are older than I am ...but they have ailments too."

Therefore these friends might not have the ability to be of significant support to the older cohort. The MSPSS (family) subscale did not show significant differences between the cohorts in this study. Family was a strong source of support for both cohorts and most of the time the main source so this finding isn't surprising. Overall, the younger cohort had more social support than did the older cohort. This may also be due to the older cohort requiring more care and as more support is needed the less available support becomes due to a heavier burden.

The older cohort had more children than did the younger cohort and therefore had more family available to them as their condition worsened. This fact could facilitate social support and self-care because the support may be more reliable. It is possible that the cohorts might have had even more of a difference in terms of number of children if the demographic form had specifically asked about the number of children instead of asking if the participant had "three or more." In looking at one interview, the participant, who was in cohort 1, indicated that she had "seven kids of my own, see, and I think I have four living." The younger cohort had more support from a "special person" than did the older cohort, however, as indicated previously, "special person" and "friend" overlapped in the minds of some participants so that the friend could have been placed into the "special person" category. This is a potential confounding factor in using the "special person" terminology. "Special person" may not only overlap with "family" and "friend" subscale terminology but also with others that the participant deems helpful such as medical personnel or random persons who offer the participant help. Interestingly, there were no significant differences between the cohorts as related to the EHRScBS-9.

Although there are potentially many factors that can decrease cognitive decline and depressive symptoms, this study only focused on “special person”, “family” and “friend”, the three subscales from the MSPSS instrument. A positive correlation was found between the MSPSS (family) and the SMMSE. This result indicates that social support may have a positive correlation with cognition and as social support increased, cognitive decline decreased. This concept is not new (Holtzman et al., 2004; Seeman, Lusignolo, Albert, & Berkman, 2001) and serves to reinforce the importance of social support as one ages, specifically when having a chronic disease such as HF. Furthermore, the MSPSS (friend) and the GDS-SF were negatively correlated indicating that increased MSPSS (friend) support can decrease depressive symptoms in this population, another important reason to enhance social support opportunities. Finally, one must keep in mind that a negative mood, decreased cognition, and increased HF symptoms have the potential to negatively affect the type and amount of social support received by the participant.

In this study, the participants viewed self-care as care that is done by them without assistance. Riegel et al. (2016) indicated that self-care could involve others either directly or indirectly (Riegel et al., 2016). However, this study’s participants believed that self-care meant that only they are the ones performing self-care. This misconception may be important in terms of patient education between the provider and the patient. Self-care is important to manage HF and how it gets done isn’t as important as whether it gets done. Patients might not ask for help with self-care if they feel their independence is threatened and therefore self-care might not take place. It is these subtle nuances and disconnects between patient and provider that can cause a decrease in self-care

performance. Further research should be done that explores the socio demographic factors that differ among cohorts and how those factors affect social support and ultimately self-care.

Limitations

This study had several limitations. The main limitation was sample size, which resulted in limited statistical analysis. A larger sample size might have uncovered issues not seen in a small sample. Also, consent rate was low (24.61%) due to many factors, the primary of which were “no shows” and “no time”. Since our participants were recruited during their doctor appointments, many times they were pressed for time because those that took them to their appointments had other work or childcare responsibilities. Those responsibilities often required them to limit the time they could provide to the PI so it is possible that the participant was unable to devote more time to their questionnaire answers or interview. Additionally, it is possible there could have been a bias in those willing to participate because they wanted their excellent social support system to be known while others without good social support might have been reluctant to discuss their situation. Furthermore, this study sample represented those HF patients that were managed by a physician, had access to health care and transportation to their doctor appointments. Many HF patients, particularly those living in rural areas, may not have access to specialized doctors or clinics and therefore might not be able to receive this level of specialized care to manage their HF as needed. Moreover, there are potentially other factors responsible for decreased cognition and depressive symptoms, as well as, the decreased or increased levels of social support in this particular population. All these potential factors should be further explored.

This study's findings suggest that an increase in social support might have an effect in decreasing cognitive decline and depressive symptoms in female HF patients. Also, it might be insightful to add generational cohort data to HF self-care studies to explore possible differences between cohorts that could affect self-care behavior and the social support received.

It might be beneficial for future research to focus on women with HF in rural areas who have none or little access to specialized HF clinics. Also, researching a younger cohort and comparing them to an older cohort might be insightful in comparing social support sources and self-care behavior in two different generational cohorts other than the two researched for this study. Moreover, research which has a larger focus on the specific self-care needs expressed by participants and how social support can help participants better adhere to diet, specifically, and other self-care activities, generally, might uncover useful information that can be used in future interventions. Finally, recruitment at HF clinics, which only treat HF patients, and at low-income clinics, which usually have longer waiting times, needs to be explored to increase the number of potential study subjects and consent rates since patients might be more apt to consent if they have longer wait times.

Conclusions

Specific sources of social support were uncovered and their unique ways of providing social support to the female HF patient were discovered through focused interviews. Since some significant differences were seen in the two cohort groups, even with this very small sample size, raises the question of whether future research should include more cohort groups. Understanding cohort differences in terms of socio

demographic and other factors could uncover unique differences among cohorts which could lead to more targeted interventions for this vulnerable population.

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Table 1

Demographic and Clinical Characteristics of Population (n=16)

	Minimum	Maximum	Mean	SD
Age (years)	57	88	75.38	9.81

	Frequency	Percent (%)
Race		
White	5	31.3
Black	8	50.0
Hispanic	1	6.3
Asian	1	6.3
Multiracial	1	6.3
Education Level		
Less than high school	4	25.0
High school or equivalent	4	25.0
Some college	4	25.0
Bachelor degree	3	18.8
Graduate degree	1	6.3
Marital Status		

Married	6	37.5
Divorced	2	12.5
Widowed	8	50.0
Number of children		
Two	5	31.3
Three or more	11	68.8
SANYHAFC		
Class II	9	56.3
Class III	5	31.3
Class IV	2	12.5
Comorbidities		
Diabetes	1	6.3
Cardiovascular Disease	5	31.3
Stroke	2	12.5
Heart Attack	3	18.8
Peripheral Vascular Disease	1	6.3
Depression	3	18.8
Other	8	50.0

Table 2

Number of Participants in Each Cohort

	Frequency	Percent
Valid 1925-1942	10	62.5
1943-1960	6	37.5

Total	16	100.0
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Table 3

Cohort Differences for Race

			Cohort		Total
			1925-1942	1943-1960	
What race are you?	White	Count	4	1	5
		% within cohort	40.0%	16.7%	31.3%
	Hispanic	Count	0	1	1
		% within cohort	0.0%	16.7%	6.3%
	Black	Count	5	3	8
		% within cohort	50.0%	50.0%	50.0%
Asian	Count	0	1	1	
	% within cohort	0.0%	16.7%	6.3%	
multi racial	Count	1	0	1	
	% within cohort	10.0%	0.0%	6.3%	
Total	Count	10	6	16	
	% within cohort	100.0%	100.0%	100.0%	

Table 4

Cohort Differences for Marital Status

			Cohort		Total
			1925-1942	1943-1960	
What is your marital status?	Married	Count % within cohort	1 10.0%	5 83.3%	6 37.5%
	Divorced	Count % within cohort	2 20.0%	0 0.0%	2 12.5%
	Widowed	Count % within cohort	7 70.0%	1 16.7%	8 50.0%
Total		Count % within cohort	10 100.0%	6 100.0%	16 100.0%

Table 5

Cohort Differences for Education Level

			Cohort		Total
			1925-1942	1943-1960	
What is the highest level of school you have completed?	Less than high school	Count % within cohort	1 10.0%	3 50.0%	4 25.0%
	High school or equivalent	Count % within cohort	4 40.0%	0 0.0%	4 25.0%
	Some college	Count % within cohort	3 30.0%	1 16.7%	4 25.0%
	Bachelor degree	Count % within cohort	2 20.0%	1 16.7%	3 18.8%
	Graduate degree	Count % within cohort	0 0.0%	1 16.7%	1 6.3%
Total	Count % within cohort	10 100.0%	6 100.0%	16 100.0%	

Table 6

Cohort Differences for Number of Children

			Cohort		Total
			1925-1942	1943-1960	
How many children do you have?	2.00	Count	3	2	5
		% within cohort	30.0%	33.3%	31.3%
	3 or more	Count	7	4	11
		% within cohort	70.0%	66.7%	68.8%
Total		Count	10	6	16
		% within cohort	100.0%	100.0%	100.0%

Table 7

Population Characteristics by Instrument

	N	Minimum	Maximum	Mean	SD
EHFScBS-9	16	1.22	3.89	2.74	0.72
SMMSE	15	25.00	30.00	27.93	1.58
DASI (METS)	16	3.29	8.23	4.69	1.24
GDS-SF	16	00	8.00	2.31	2.06
MSPSS (total)	16	4.42	7.00	6.45	0.76
MSPSS (special person)	16	2.75	7.00	6.59	1.06
MSPSS (family)	16	6.00	7.00	6.86	0.30
MSPSS (friend)	16	3.25	7.00	5.89	1.43

Table 8

Study Reliability Statistics

	Cronbach Alpha value
EHFScBS-9	.615
MSPSS (total)	.827
MSPSS (family)	.699
MSPSS (friend)	.801
MSPSS (special person)	.860
DASI	.770
GDS-SF	.721

Table 9

Social Support Network –Three People Who Give the Participant the Most Support and Their Relationship to the Participant (n=16)

	Person 1		Person 2		Person 3	
	%	n	%	n	%	n
Child (son or daughter)	75.0	12	56.3	9	25.0	4
Spouse	12.5	2	6.3	1	12.5	2
Grandchild	6.3	1	12.5	2	12.5	2
Other relative – sister	6.3	1	18.8	3	-	
Other – caregiver			6.3	1	-	
Friend					18.8	3
Relationship						
Relative	100.0	16	93.7	15	50.0	8
Friend					18.8	3
Other Person			6.3	1		
No Response					31.5	5

Table 10

Social Support Network – Location Where the People Live That Support the Participant (n=16)

	Person 1		Person 2		Person 3	
	%	n	%	n	%	n
Lives with participant	62.5	10	31.3	5	31.3	5
Does not live with participant	31.3	5	68.8	11	37.5	6
Missing data	6.3	1			31.3	5
Lives in:						
Same neighborhood	12.5	2			6.3	1
Same city	6.3	1	6.3	1	12.5	2
Same state			6.3	1		
Missing data	81.3	13	87.5	14	81.3	13

Table 11

Social Support Network – Frequency of Contact With the Supportive Person (n=16)

	Person 1		Person 2		Person 3	
	%	n	%	n	%	n
Daily (every day, all the time)	93.8	15	50.0	8	31.3	5
Weekly			12.5	2	18.8	3
Monthly			12.5	2		
Every 6 months or holidays			6.3	1	6.3	1
Other (when needed)	6.3	1				
Other (often, when needed, not often)			18.8	3		
Other (as often as possible, sometimes)					12.5	2
Missing Data					31.3	5

Table 12

Spearman's rho Correlations (r) Between Instruments

	SMMSE n = 15	GDS-SF n = 16
MSPSS (family)	.684** p = .009	
MSPSS (friend)	.	-.544* p = .029

* p < .05. ** 0 < .01.

Table 13

Mann-Whitney U Statistics Comparing Differences in Cohorts

	MSPSS (total) p = .011	MSPSS (special person) p = .056	MSPSS (friend) p = .009
Cohort 1 (1925 - 1942) n = 10	6.17	6.35	5.30
Cohort 2 (1943 - 1960) n = 6	6.92	7.00	6.88

Study Adaptation of the Moser & Watkins' Model

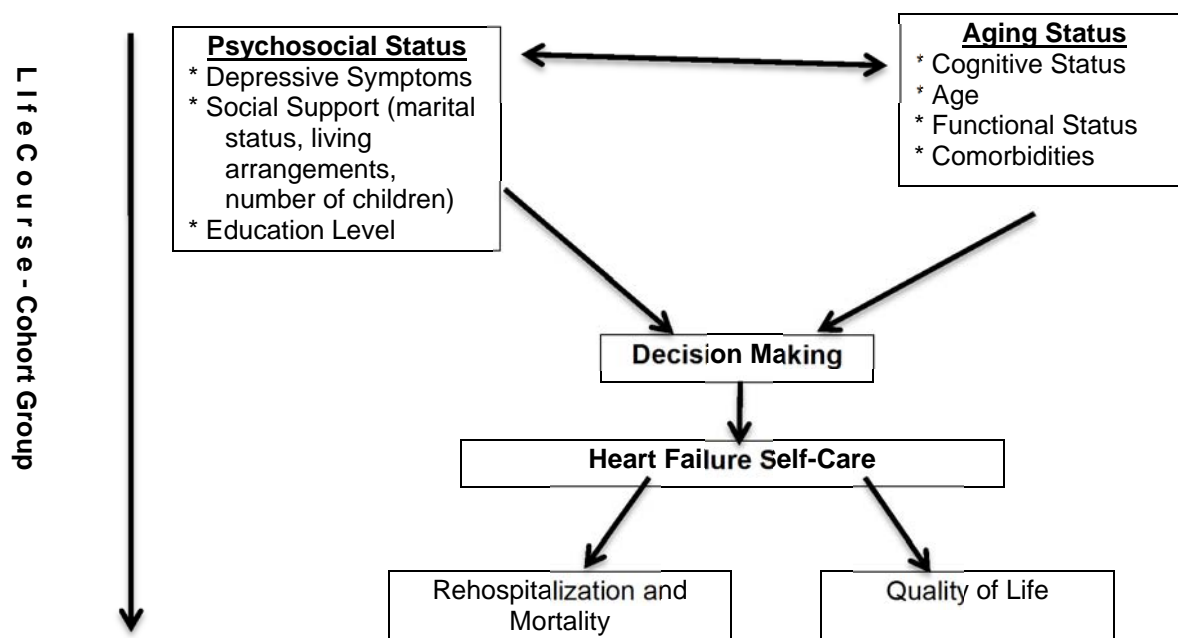


Figure 1. Adapted from "Conceptualizing self-care in heart failure: a life course model of patient characteristics," by D.K. Moser, & J.F. Watkins, 2008, *Journal of Cardiovascular Nursing*, 23, p. 206.

Interview Guide

MSPSS

Questions about a special person in your life

If the answers are 1's and 2's ask the following: Tell me about why you feel that a special person isn't helpful or available to you if you need them?

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have a strong feeling either way about a special person in your life?

If the answers are 6's and 7's ask the following: Tell me about who that special person in your life is and how that person helps you?

Questions about a friend or friends in your life

If the answers are 1's and 2's ask the following: Tell me about why you feel you don't have friends in your life that can help or with whom you can share your problems.

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have strong feelings either way about your friends?

If the answers are 6's and 7's ask the following: Tell me about how your friends help you.

Questions about family

If the answers are 1's and 2's ask the following: Tell me about why you feel your family isn't helpful or available to you if you need them?

If the answers are 3's, 4's and 5's ask the following: Tell me why you don't have a strong feeling either way about your family helping or being there for you?

If the answers are 6's and 7's ask the following: Tell me about how your family helps you.

EHFScBS-9

Is there a family member, friend or special person that helps or hurts your ability to provide HF self-care and if so, how?

Do you feel you need help in providing yourself with HF care?

Figure 2. Initial interview questions asked of all study participants.

Study Enrollment Characteristics

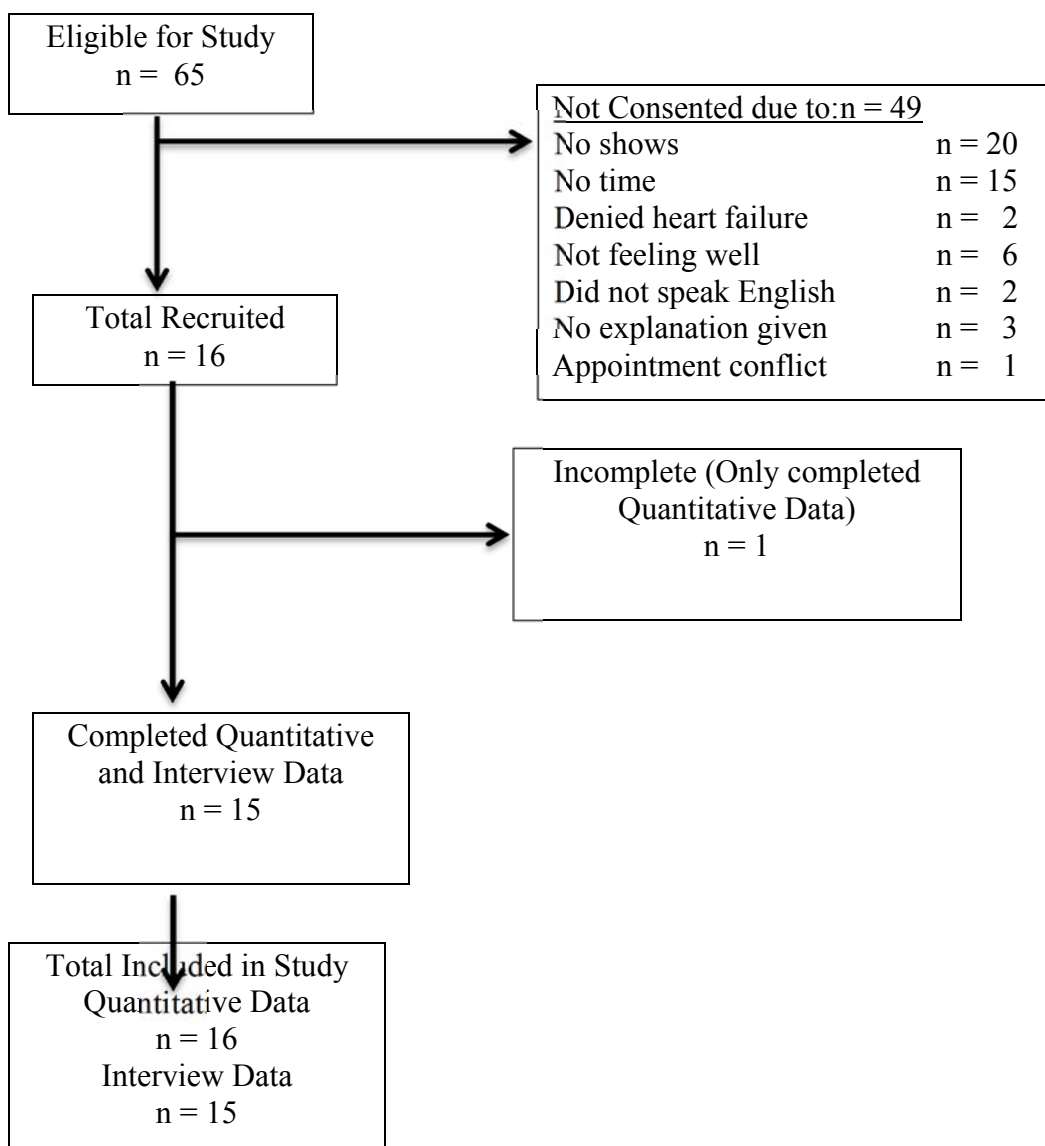


Figure 3. A flow chart depicting the number of study participants at each stage of recruitment.

Appendix A

Committee for the Protection of Human Subjects Study Approval



Committee for the Protection of Human Subjects

6410 Fannin Street, Suite 1100
Houston, Texas 77030

NOTICE OF APPROVAL TO IMPLEMENT REQUESTED CHANGES

February 05, 2016

HSC-SN-15-1040 - Women With Heart Failure and Their Perception of Social Support and its Affects on Heart Failure Self-Care Behavior □ PI: Dr. Joy Corcione

Reference Number: 133426

PROVISIONS; Unless otherwise noted, this approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered at this meeting, e.g. study documents, informed consent, etc.

APPROVED: By Expedited Review and Approval

CHANGE APPROVED: Revised Protocol Version 2.6 (dated 2/5/2016) Recruitment Material Version 1.3 (dated 2/5/2016)

REVIEW DATE: APPROVAL DATE: CHAIRPERSON:

Consent Document Version 0.4 (dated 2/5/2016) February 5, 2016 □ February 5, 2016 □ Rita Swinford, MD

Upon receipt of this letter, and subject to any provisions noted above, you may now implement the changes approved.

CHANGES: The principal investigator (PI) must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.

INFORMED CONSENT: Informed consent must be obtained by the PI or designee(s), using the format

and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that if revisions to the informed consent form were made and approved, then old blank copies of the ICF MUST be destroyed. Only copies of the appropriately dated, stamped approved informed consent form can be used when obtaining consent.

UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS: The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

RECORDS: The PI will maintain adequate records, including signed consent documents if required, in a manner that ensures subject confidentiality.

CURRICULUM VITAE
Joy Corcione, PhD, MBA, RN

EDUCATION:

University of Texas Health Science Center Houston, Texas	2016	PhD	Nursing
University of Texas Health Science Center Houston, Texas	2009	BSN	Nursing
Houston Community College Houston, Texas	2008	No degree	Pre-requisite Nursing Courses
University of Toledo Toledo, Ohio	1990	MBA	International Business
Bryant University Smithfield, RI	1982	BS	Business

PROFESSIONAL NURSING POSITIONS:

The Methodist Hospital DeBakey Heart & Vascular Center, Dunn 9 Intermediate Medical Unit Houston, Texas Staff Nurse	2010 - 2014
Triumph/Kindred Hospital Long-Term Care Unit Houston, Texas Staff Nurse PRN	2011 - 2012
Cy-Fair Medical Center Acute Care - Intermediate Medical Unit Houston, Texas Staff Nurse	2009 - 2010

PROFESSIONAL NON-NURSING POSITIONS

(1982 - 2007)

VTG, Inc.
Houston, Texas
Inside Sales Agent

Transcom International Inc.
Houston, Texas
Global Account Manager

NSA, Inc.
Houston, Texas
Regional International Sales Associate

Navcor International Inc.
Toledo, Ohio
Partner

Toledo Chamber of Commerce
Toledo, Ohio
Director, International Trade Assistance Center for NW Ohio

Adrian College
Adrian, Michigan
Instructor of Marketing and International Marketing

University of Toledo
Toledo, Ohio
Graduate Teaching and Research Assistant

US Army
Würzburg, Germany
Tactical Intelligence Officer (2nd Lt.)
Special Security Officer (1st Lt. to Captain)

PROFESSIONAL MEMBERSHIPS:

Sigma Theta Tau 2014 - present

POSTER SESSION:

Bryan, P. & Corcione, J. (2014, April). *Socioeconomic Risk Factors for Disease in an East Texas Hispanic Population*. Poster presented at the University of Texas Health Science Center Poster Day Event, Houston, Texas.

AWARDS AND RECOGNITION

2013 - 2016 Recipient of a fully funded fellowship from the University of Texas Health Science Center School of Nursing Advisory Council
2014 - 2016 Jonas Foundation for Nursing & Veterans Health Care Nurse Leadership Scholarship

- 1988 - 1990 Funded teaching and research assistantship awards from the University of
Toledo Graduate School of Business
- 1982 Who's Who Among Students in American Colleges and Universities
- 1982 Distinguished Military R.O.T.C. graduate
- 1982 Beta Gamma Sigma National Business Scholastic Honorary Society
- 1982 Alpha Mu Alpha National Marketing Honorary Society
- 1982 R.O.T.C. scholarship for outstanding leadership