SOMATIC AWARENESS AND SELF-SYMPHOM RECOGNITION IN ADVANCED HEART FAILURE PATIENTS

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Nursing

by

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ABSTRACT

Purpose: This study examined somatic awareness and self-symptom recognition in Stage D heart failure (HF) patients, comparing those patients who were newly diagnosed with HF to those patients with chronic HF.

Background: Heart failure is a chronic, debilitating disease that affects almost six million Americans. However, there is little known about how patients recognize and interpret symptoms of the disease. Two such phenomena lacking adequate attention are somatic awareness and self-symptom recognition. In addition, these concepts have not been studied in relation to the duration of time a patient has been diagnosed with HF.

Methods: The mixed methods design that guided this study was the concurrent triangulation design. Using this design, a prospective cross-sectional survey design was conducted to understand if a difference exists in somatic awareness between newly-diagnosed and chronic stage D HF patients. The newly-diagnosed group included patients with Stage D HF who had been diagnosed with HF for two years or less. The chronic HF group included patients diagnosed with HF for longer than two years. Somatic awareness was measured using the HF Somatic Perception Scale, v. 3, an 18-item Likert scale. In addition, explorative qualitative descriptive interviews were conducted to better understand self-symptom recognition in this sample. All qualitative data were coded using the items from the HF Somatic Perception Scale. Each “yes” answer to the items on the HF Somatic Perception Scale was analyzed to determine whether the participant perceived the symptom to be related to HF.
**Results:** The sample included newly-diagnosed Stage D HF patients (n=9) and chronic HF patients (n=11). Analysis indicated a difference between the newly-diagnosed and chronic groups, \( t(18) = -2.45, p = 0.03 \). The chronic group had a higher mean somatic awareness score, 28.82, compared to the newly-diagnosed group, 12.33. In addition, length of time from diagnosis was significantly correlated with the HF Somatic Perception total score \( (r_s = 0.53, p = 0.02) \). Qualitative analysis found that none of the participants recognized their HF symptoms as being a result of HF.

**Conclusions:** While results showed higher somatic awareness scores for the chronic group than for the newly-diagnosed group, it is unclear whether the difference is related to length-of-time of living with HF or to other variables, including co-morbidities with symptoms similar to HF. However, while participants did not attribute their symptoms to HF, it is not possible to conclude that they had poor self-symptom recognition; instead, they may have been accurate in relating their symptoms to another co-morbid condition. Implications from this research nevertheless include that Stage D HF patients may not recognize symptoms of HF, which is a concern because of the potential resulting delay in appropriate treatment. It follows that more effective education for advanced HF patients is needed to help them understand HF symptoms and so to participate more effectively in their treatment, thus potentially improving patient outcomes and decreasing the economic burden of HF overall. Future longitudinal research needs to be conducted on a larger sample to examine somatic awareness and self-symptom recognition before definitive conclusions can be reached.
## TABLE OF CONTENTS

LIST OF FIGURES .................................................................................................................. viii
LIST OF TABLES .................................................................................................................... ix
ACKNOWLEDGMENTS .......................................................................................................... x
DEDICATION .......................................................................................................................... xii

Chapter 1: Introduction to the Study ...................................................................................... 1
  Statement of the Problem ................................................................................................ 1
  Purpose of the Study ........................................................................................................ 3
  Research Questions ......................................................................................................... 4
  Conceptual Framework .................................................................................................... 4
  Definition of Key Terms ................................................................................................ 6
  Assumptions .................................................................................................................... 7
  Limitations ....................................................................................................................... 7
  Significance of the Study ............................................................................................... 8
  Chapter Summary .......................................................................................................... 8

Chapter 2: Review of Literature ............................................................................................ 10
  Introduction ..................................................................................................................... 10
  Search Strategies ........................................................................................................... 11
  Heart Failure Symptoms ............................................................................................... 14
  Healthcare Utilization ................................................................................................... 15
  Newly-Diagnosed versus Chronic ................................................................................ 16
  Somatic Awareness and Symptom Recognition ............................................................ 18
    Mediating factors for somatic awareness and symptom recognition. ......................... 25
    Outcomes. .................................................................................................................... 27
  Measurement of somatic awareness and symptom recognition. .................................. 29
    The HF somatic awareness/perception scale. ............................................................. 30
    The body awareness questionnaire. ............................................................................. 31
    The revised HF Self-Care Behavior Scale. ................................................................. 31
    The self-care HF index ............................................................................................... 31
    The 10-item HF data collection tool. .......................................................................... 32
    The self-management of HF instrument. ................................................................. 32
  Conceptual Framework .................................................................................................. 33
  Theoretical Foundations ................................................................................................. 33
  Conceptual Model ......................................................................................................... 33
    Concepts of the theory. ............................................................................................... 34
    Symptom experience. ................................................................................................. 35
    Symptom management strategies. ............................................................................... 35
  Outcomes. ....................................................................................................................... 36
  Adherence. ..................................................................................................................... 36
Assumptions. .................................................................................................................. 36
Research on The Symptom Management Theory. .......................................................... 37
  Research on the symptom experience concept. ......................................................... 38
  Research on symptom experience and management strategies. ............................... 39
Research on all three major concepts. ........................................................................ 39
Conclusion about Symptom Management Theory. ...................................................... 40
Other considered theories ........................................................................................... 41
  The middle-range Theory of Self-Care of Chronic Illness. ....................................... 41
  The situation-specific Theory of Heart Failure Self-Care. ....................................... 44
Chapter Summary ...................................................................................................... 46

Chapter 3: Research Design and Methods ................................................................. 48
Introduction ............................................................................................................... 48
  Design of the Study .................................................................................................. 48
    Quantitative Methodology ..................................................................................... 49
    Qualitative Methodology ....................................................................................... 50
Sample and Setting ..................................................................................................... 51
  Participants .............................................................................................................. 52
Study Measures .......................................................................................................... 52
  Somatic Awareness ................................................................................................. 54
  Self-Symptom Recognition ...................................................................................... 55
Data Collection ........................................................................................................... 54
Data Analysis ............................................................................................................. 57
  Descriptive Analysis ............................................................................................... 57
Analysis of Research Questions ................................................................................ 57
  Research question #1. ............................................................................................ 57
  Research question #2. ............................................................................................ 58
  Research question #3. ............................................................................................ 58
Reliability and Validity ............................................................................................... 59
  Quantitative ............................................................................................................ 59
  Qualitative .............................................................................................................. 60
Chapter Summary ...................................................................................................... 62

Chapter 4: Results .................................................................................................... 63
Sample ....................................................................................................................... 63
Statistics on the HF Somatic Perception Scale, v. 3 ................................................... 67
Research Question 1 Results .................................................................................... 67
Research Question 2 Results .................................................................................... 70
Research Question 3 Results .................................................................................... 71
Chapter Summary ...................................................................................................... 77
Chapter 5: Discussion .......................................................................................................................... 79
Overview of Significant Findings ....................................................................................................... 79
  Research question 1. .................................................................................................................. 79
  Research question 2. .................................................................................................................. 80
  Research question 3. .................................................................................................................. 80
  Correlations of items in the tool ................................................................................................ 84
The Symptom Management Theory and Advanced Heart Failure ............................................. 86
Study Limitations and Strengths ..................................................................................................... 86
Clinical Implications ...................................................................................................................... 88
Recommendations for Future Research ....................................................................................... 89
Chapter Summary ......................................................................................................................... 91

References ........................................................................................................................................ 93

Appendix A-Copyright Permission Theory of Symptom Management ........................................ 105
Appendix B-Copyright Permission Middle-Range Theory of Self Care of Chronic Illness ...... 111
Appendix C-Copyright Permission Self-Care of Heart Failure Model ....................................... 116
Appendix D-IRB Approval ............................................................................................................... 121
Appendix E-Consent for Research ................................................................................................. 123
Appendix F-HF Somatic Perception Scale, v. 3 .......................................................................... 131
Appendix G-Sample Coding ........................................................................................................... 132
LIST OF FIGURES

Figure 1. A Depiction of The Theory of Symptom Management ................................................. 6
Figure 2. Flowchart of Search Strategy .......................................................................................... 13
Figure 3. A Depiction of the Middle-Range Theory of Self Care of Chronic Illness ............... 43
Figure 4. A Depiction of the Self-Care of Heart Failure Model .................................................. 45
LIST OF TABLES

Table 1 - COMPARISON OF SIMILAR CONCEPTS .......................................................... 19
Table 2 - TOTAL SAMPLE DEMOGRAPHICS .................................................................. 63
Table 3 - INCLUDED PARTICIPANT DATA ..................................................................... 64
Table 4 - DEMOGRAPHIC DATA OF NEWLY-DIAGNOSED AND CHRONIC GROUPS .. 65
Table 5 - HF SOMATIC PERCEPTION SCALE FREQUENCIES ..................................... 66
Table 6 - GROUP STATISTICS HEART FAILURE SOMATIC AWARENESS SCORES ..... 67
Table 7 - HFSPS CORRELATIONS .................................................................................. 69
Table 8 - MANOVA TEST TO DETERMINE SIGNIFICANCE OF DIAGNOSIS

    TIME TO HF SOMATIC AWARENESS SCALE ............................................................. 70
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DEDICATION

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Somatic Awareness and Self-Symptom Recognition in Advanced Heart Failure Patients

Chapter 1: Introduction to the Study

Heart failure (HF) is a chronic, debilitating disease that affects almost six million Americans (American Heart Association [AHA], 2015a), a number expected to increase to eight million by the year 2030 (Go et al., 2015). Approximately 10% of those six million individuals are living with advanced heart failure—that is, with debilitating symptoms accompanying any physical exertion, and at times even occurring at rest (AHA, 2015b). Moreover, HF is listed as a contributing cause of death in one in nine deaths in the United States (U.S.) and half of all individuals with HF die within five years of diagnosis (Centers for Disease Control & Prevention [CDC], 2013). HF is also the most common primary medical diagnosis for hospitalized adults over the age of 65 (Longjian, 2011), with an estimated cost to the U.S. of $32 billion annually. This includes the cost of healthcare services, medications, and missed days of work (CDC, 2013). HF costs are expected to increase to 70 billion by the year 2030 (Heidenreich, 2013).

HF is clearly a debilitating disease that has a great impact on patients, healthcare providers, and our nation as a whole. However, little is known about how patients recognize and interpret symptoms of the disease, including the relevant phenomena of somatic awareness and self-symptom recognition. In addition, these concepts have not been studied in relation to the duration of time with the diagnosis of HF.

Statement of the Problem

Stage D HF patients are very ill individuals who struggle with such everyday tasks as walking from the bedroom to the bathroom, dressing, bathing, eating, washing clothes, cleaning, and more. According to the AHA (2015c), Stage D HF is refractory and requires specialized treatments. These patients easily decompensate which leads to poor health outcomes (e.g.,
hospitalization or death). Being able to recognize and address early signs of decompensation may help patients improve outcomes.

Somatic awareness (knowing something is physiologically wrong but not knowing what to attribute it to) and symptom recognition (someone—a healthcare provider, family member, or the individual experiencing the symptoms—knowing something is physiologically wrong and linking the changes to a specific disease entity) are concepts often found in the self-care literature, which focuses on activities individuals initiate to maintain their health. However, the concept of self-symptom recognition (the individual experiencing the symptoms knowing something is physiologically wrong and linking the changes to a specific disease entity) needs to be teased out and differentiated from symptom recognition, e.g. a healthcare provider recognizing the symptom is related to a particular disease.

Because the lack of somatic awareness and/or self-symptom recognition can lead to decreased self-care management, coping skills, self-regulation and quality of life, patients who lack those characteristics commonly experience poorer outcomes (Jaarsma, Nikolova-Simons, & Van der Wal, 2012; Jurgens, Lee, Reitana, & Riegel, 2013; Richard & Shea, 2012; Riegel & Dickson, 2008; White, Howie-Esquivel, & Caldwell, 2010). More specifically, a patient’s inability to identify and act appropriately in response to HF symptoms often include such undesirable results as treatment delays, uncertainty, obsession, increased hospital admissions, increased healthcare costs, and mortality (Artinian, Magnan, Sloan, & Lange, 2002; Bass, Beery, Gordon, Wizer, & Wagoner, 2004; Jaarsma et al., 2012; Jurgens, 2006; Lam & Smeltzer, 2013; Riegel & Carlson, 2002; Sethares, Sosa, Fisher, & Riegel, 2014; White et al., 2010). Despite these poor outcomes, researchers have not adequately defined somatic awareness and self-
symptom recognition, producing gaps in our understanding; moreover, fluid definitions of these concepts from study to study make comparing findings difficult.

An additional concern is that there are few studies in existing literature that included length-of-time from HF diagnosis as a variable, although there is evidence that it influences how patients perceive and act upon general symptoms and exacerbations (Friedman & Quinn, 2008). Greater length-of-time from initial HF diagnosis has been found to negatively impact mood, outlook on life, activity levels, knowledge of HF, quality of life, self-treatment, and rates of depression (Decker et al., 2009; Evans, Hupcey, Kitko, & Alonso, under review; Zambroski, 2003). Therefore, a closer look at whether and how length-of-time from diagnosis might affect somatic awareness and self-symptom recognition might prove useful in deepening understanding of patient perceptions and behavior and allowing for the design of more effective interventions.

**Purpose of the Study**

The purpose of this study was to examine somatic awareness and self-symptom recognition in advanced HF patients and to explore what effect length-of-time from initial diagnosis might have upon those characteristics. Newly-diagnosed Stage D HF patients were defined as those who had been diagnosed with HF for less than two years and were found to have Stage D HF at initial diagnosis; chronic patients were defined as those patients diagnosed with HF for two years or longer who had progressed to Stage D. This sample of patients is unique in that patients in both groups have end-stage HF. Two years was set as the time-limit demarcation because earlier research by this author and colleagues showed that patients with end-stage HF move through a continuum ranging from naïve expectations to resignation, with those living with HF greater than two years being resigned to the permanency and limitations of the disease.
(Evans et al., under review). This timing of this cognitive shift appears a logical point of demarcation for investigating other possible time-related changes.

**Research Questions**

The research questions that guided this study were:

1. Does somatic awareness differ in newly-diagnosed versus chronic Stage D HF patients?
2. Is there a difference in self-symptom recognition between newly-diagnosed and chronic Stage D HF patients?
3. To what disease(s) do Stage D HF patients with high somatic perception scores attribute their symptoms?

**Conceptual Framework**

The conceptual framework that guided this study is the middle-range Theory of Symptom Management, developed and subsequently tested by researchers at The University of California, San Francisco (The University of California, San Francisco [UCSF] School of Nursing, 2014). The theory has been used to investigate symptoms experienced by various populations (e.g., trauma, hospice, HIV, and asthma) in a variety of inpatient and outpatient settings (Bay & Bergman 2006; Humphreys, Lee, Neylan, & Marmar, 1999; Kayser-Jones et al., 2005; Nokes & Kendrew, 2001; Newcomb, 2010; Voss, 2005, & Voss et al., 2006). Although no research was found that focused on HF patients, the use of the theory with other chronic illnesses, such as asthma and HIV, demonstrated its applicability across diverse disease processes (Brant, Beck, & Miaskowski, 2010).

The Theory of Symptom Management showcases three distinct dimensions: symptom experience, components of symptom management strategies, and outcomes. All dimensions are
inter-related with outside forces of person, environment, and health and illness (Dodd et al. 2001).

Central to this study was the dimension of symptom experience, which points to the importance of three inter-related concepts: perception of symptoms, evaluation of symptoms, and response to symptoms. More specifically, this study examined advanced heart failure patients with a particular focus on perception of symptoms (somatic awareness) and evaluation of symptoms (self-symptom recognition).

According to Larson et al., (1994), “Perception of symptoms refers to whether an individual notices a change from the way he or she usually feels or behaves. Evaluation of symptoms refer to the judgments people make about their symptoms such as symptom severity, cause, treatability, and the effects of symptoms” (p. 273). As shown in Figure 1, The Theory of Symptom Management uses the word evaluation rather than recognition and bi-directional arrows are used under the dimension “Symptom Experience” (Dodd et al., 2001) to signify an iterative process. This will be discussed further in Chapter 2.
Definition of Key Terms

This study involves several key terms defined below:

**Advanced HF patients**: Patients diagnosed with Stage D HF (refractory or advanced HF requiring specialized treatments) as defined by the American Heart Association (2015b). The terms advanced HF, Stage D HF, and end-stage HF will all be used synonymously in this study.

**Chronic advanced HF patients**: Those patients living with HF for two or more years who have progressed to Stage D.

**Newly-diagnosed advanced HF patients**: Those patients living with HF for less than two years who have Stage D HF.

**Symptom**: “… Subjective experiences reflecting changes in a person’s biopsychosocial function, sensation, or cognition” (Larson et al., 1994, p. 273).
**Somatic awareness:** “Sensitivity to physical sensations and bodily activity secondary to physiological change” (Jurgens, 2006, p. 75).

**Self-Symptom Recognition:** A patient’s noting bodily changes and linking these changes with a particular disease rather than other potential causes (e.g., attributing ankle swelling to HF rather than standing on one’s feet all day).

**Assumptions**

Assumptions that guided this study include:

- Participants in the study provided honest answers to the HF Somatic Perception Questionnaire and to follow-up questions regarding self-symptom recognition.
- Participants have been accurately diagnosed with a life expectancy of less than two years using the Seattle HF Model.
- The researcher and trained data collectors bracketed any of their own biases to avoid influencing participant responses (Creswell, 2009 & Houser, 2008).

**Limitations**

Limitations to the study are based on the methodological design and include the following:

- The small sample size and limited racial and ethnic diversity limit the ability to generalize results to a broader HF population.
- Changes over time were not captured since participants were only surveyed once.
- Although the researcher and trained data collectors bracketed any of their own biases, unintentional influence may still have impacted the participants’ responses (Creswell, 2009 & Houser, 2008). Examples of bracketed influences included previous experiences
with HF patients and the belief that HF patients should be able to recognize their symptoms.

**Significance of the Study**

This study examined the process of somatic awareness and self-symptom recognition in the realm of advanced HF patients, concepts that have not been studied together with this patient population or with length-of-time from diagnosis as a variable that might affect patient perceptions. Unfortunately, the concepts, somatic awareness and self-symptom recognition are often confused in the literature by being applied interchangeably to signify related but distinctly different concepts, limiting the ability to draw inferences across studies. In relation to Stage D HF patients, a better understanding of the patients’ somatic awareness and self-symptom recognition-based on more explicit definitions of those concepts than is common in the literature-and a better understanding of whether and how time from diagnosis may influence them may open a path for future research to explore better patient interventions, better patient outcomes, and better health care systems and costs.

**Chapter Summary**

HF is clearly a major public health problem. Research findings indicate that Stage D HF patients are very ill individuals and without proper somatic awareness and self-symptom recognition, these patients are more likely to experience challenges to: self-care management (Richard & Shea, 2011; Riegel & Dickson, 2008), coping skills, self-regulation (Riegel & Carlson, 2002), and quality of life (Jaarsma et al., 2012; Riegel, Jaarsma, & Stromberg, 2012). Thus, a better understanding of somatic awareness and self-symptom recognition in these patients has the potential to improve interventions and outcomes in a number of important areas. In addition, a better understanding of how length-of-time from diagnosis impacts somatic
awareness and self-symptom recognition can point the way to better design of studies pursuing interventions tailored to these patients’ needs.

The parameters for length-of-time from diagnosis was informed by earlier research by Evans and colleagues (under review), who compared life descriptions of newly-diagnosed versus chronic Stage D HF patients. The patients shared life descriptions along a continuum: recently diagnosed patients described naïve expectations with hope for improvement, while the chronic group appeared resigned to their fate and the reality of the limitations of living with Stage D HF. Four themes illustrated differences between the groups: outlook on life, activity adjustments, understanding of HF, and mood. Results revealed that somewhere along this continuum Stage D HF patients came to a realization that HF was permanent. Although it appears those living with HF greater than 2 years were resigned to the permanency and limitations, the typical point when the realization and resignation occurred could not be determined; most of the patients had HF for years but had only recently been diagnosed with Stage D (Evans et al., under review). This study continues the earlier investigation by looking more closely at the possible relationship between length-of-time from Stage D HF diagnosis and patient somatic awareness and self-symptom recognition with the goal of contributing to related interventional studies in the future.
Chapter 2: Review of Literature

Introduction

Heart failure is a chronic disease resulting in the heart’s inability to pump enough blood to meet the body’s demands. This causes a variety of symptoms including, but not limited to: cough, fatigue, dyspnea, pulmonary edema, dependent edema, and ascites. Without proper medical management, patients with HF require hospital visits or hospitalization for emergency treatment. With proper treatment, including diet modifications, medication adherence, smoking cessation, fluid intake monitoring, weight loss, and physical activity, patients can often maintain some stability (National Institutes of Health: National Heart, Lung, and Blood Institute [NIH: NHLBI], March, 2014). Unfortunately, HF is a progressive disease and even with proper treatment and strict adherence to self-care guidelines, patients will eventually progress to more advanced stages of HF, requiring more intensive treatment (NIH: NHLBI, March, 2014).

According to the AHA (2015c), HF can be staged in four classes:

- Stage A: At risk for HF but without evidence of HF.
- Stage B: Evidence of structural damage but without signs or symptoms of HF.
- Stage C: Evidence of heart damage with prior or current signs or symptoms of HF.
- Stage D: Refractory or advanced HF requiring specialized treatments.

In addition, HF may also be classified by using the New York Heart Association (NYHA) stages, which includes:

- Stage I: Physical activity is not limited, nor does it cause HF symptoms.
- Stage II: Ordinary physical activity causes symptoms of HF but they are alleviated at rest.
- Stage III: Considerable limitations in physical abilities but still comfortable at rest.
• Stage IV: HF symptoms at rest. Any physical activity results in HF symptoms (AHA, 2015c).

Patients in this study were classified with AHA Stage D or NYHA Stage III to IV HF. Their predicted survival rate was less than two years, based on the Seattle HF Model (a calculator that provides healthcare providers with a projected survival rate for patients) (Levy, 2006; Seattle Heart Failure Model, n.d.). If such very ill patients do not have appropriate somatic awareness and self-symptom recognition, less than optimal interventions and outcomes are likely.

This study enrolled patients with a less than two year predicted survival rate based on the Seattle HF Model (a calculator that provides healthcare providers with a projected survival rate for patients) (Levy, 2006; Seattle Heart Failure Model, n.d.). These patients were classified with Stage III to IV NYHA class and/or AHA Stage D HF. If these very ill patients do not have appropriate somatic awareness and self-symptom recognition, poor health outcomes can result.

This chapter presents an analysis of relevant literature on HF and other areas associated with the study’s purpose: somatic awareness, symptom recognition, healthcare utilization, and length-of-time from HF diagnosis. After conflation of the key terms of somatic awareness and symptom recognition is identified in the literature, definitions of those terms are clarified for the purposes of this study. Finally, theoretical foundations and the study’s conceptual framework are described.

Search Strategies

The purpose of the literature review was to determine the current state-of-the-science regarding somatic awareness and self-symptom recognition in HF patients. For the literature review, all known databases related to the health sciences were searched to locate all possible
scholarly evidence sources. Search tools included: Penn State’s LionSearch; Cumulative Index to Nursing and Allied Health (CINAHL); ProQuest Nursing and Allied Health Source; The Cochrane Library; Academic Search Complete; PubMed; PsycINFO; Web of Science; and, Google Scholar. Search terms included somatic awareness, somatic awareness and heart failure, self-symptom recognition, and self-symptom recognition and heart failure. A search for risk assessment tools for HF patients included the Seattle Heart Failure Model and others. Inclusion criteria were peer reviewed literature, focused on adult research participants, and published in English. Exclusion criteria consisted of children and adolescents as research participants, non-peer reviewed publications, participants with cognitive impairment (dementia; mini-mental status exam of less than 24, etc.), and any literature that looked at self-symptom recognition and acute illnesses, such as influenza.

A practical screen, as described by Garrard (2014), was applied to results of the initial search, to remove duplicate articles and to review all titles and abstracts for relevancy. The practical screen yielded 30 relevant articles; reference lists in these articles yielded an additional 10 articles for consideration. Of these 40, five articles were excluded due to methodological limitations or lack of relevance to the research questions, resulting in a total of 35 articles for detailed analysis. Figure 2 provides a diagram of this process. Publication years ranged from 1990 to 2015. Disease entities included heart failure, diabetes, cancer and schizophrenia. Study designs ranged from qualitative and quantitative research studies to theoretical articles and integrative reviews.
Figure 2 - Flowchart of Search Strategy

CINAHL
n=93

PubMed
n=911

ProQuest: Nursing & Allied Health Source
n=4336

The Cochrane Library
n=10

The Web of Science
n=384

LionSearch
n=3822

Academic Search Complete
n=802

Google Scholar
n=196,000

Combined Search Results
n=206,358

Removal of Duplicates and research not related to the study
n=109

Practical Screen–Titles and abstracts reviewed related to research questions
n=30

Reference lists analyzed for additional articles
N=10 (n=40 total)

5 Studies excluded due to age, methodological limitations, and/or lack of relevance to the research questions

Methodological Screen–Studies critiqued using appropriate guidelines
n=35
Heart Failure Symptoms

Most individuals with HF as well as healthcare providers are aware of the common symptoms of HF, such as shortness of breath and weight gain (AHA, 2013), but the reviewed research revealed that they need to be more cognizant of other symptoms experienced by this group of patients. Dyspnea (shortness of breath), while still the most common reported symptom (Lam & Smeltzer, 2013), is only one of many reported symptoms experienced by patients. Altice and Madigan (2012), Friedman and Quinn (2008) and Song, Moser, Rayens, and Lennie (2010) identified fatigue, anorexia, nausea, difficulty sleeping, decrease in functional ability, edema, tight clothes, increased urination, coughing, paroxysmal nocturnal dyspnea, tachycardia, and chest discomfort as symptoms associated with HF.

A more recent focus in the study of HF symptoms is symptom clustering. A descriptive study by Hertzog, Pozehl, and Duncan (2010) identified three different sets of symptom clusters in study participants. They also found that the higher the New York Heart Association (NYHA) level of HF among patients at levels III and IV, the more symptoms participants reported, including: shortness of breath at rest and when lying down, difficulty sleeping, forgetfulness, dizziness, bloating, heart palpitations, and depression. In addition, this group of participants also had lower formal education and greater functional impairment, which could impact decisions regarding seeking treatment (Hertzog et al., 2010). Lee and colleagues (2010) found no difference among symptom clusters between men and women, but they did find that the emotional/cognitive symptom cluster (worrying, feeling depressed and cognitive problems) was associated with higher risk of a cardiac event (i.e., death, re-hospitalization, or emergency department visit). Lee et al. (2010) found the physical symptom cluster of dyspnea, fatigue, low energy, and sleep disturbances was very similar to the findings by Hertzog et al. (2010). Findings
from a more recent study indicate that educating patients and healthcare providers about the lesser known symptoms of HF can result in increased self-care and improved patient outcomes (Jurgens et al., 2013).

**Healthcare Utilization**

Heart failure is the number one principal diagnosis for hospitalized adults over the age of 65 in the U.S. (Longjian, 2011). However, research suggests that hospitalization rates would likely be lower if individuals with HF did not delay treatment or self-care. The majority of studies defined healthcare utilization as calling a healthcare provider, (i.e., family doctor, cardiologist), having an appointment with a physician, or going to an emergency department. Studies indicate that the average delay in time for seeking treatment for HF exacerbations was two to three days from the onset of symptoms (Evangelista, Dracup & Doering, 2002; Gravely-Witte, Jurgens, & Tamim, 2010; Nieuwehuis, Jaarsma, Van Veldhuisen, & Van Der Wal, 2011). This delay has important implications for this study, as it may imply that patients are not recognizing their symptoms or are not recognizing that their symptoms are part of worsening HF.

Research has also identified several motivators for utilizing healthcare services, including the urging of healthcare providers and family members (Riegel, Dickson, & Topaz, 2013) and a history of myocardial infarction or stroke (Nieuwehuis et al., 2011). Symptoms most commonly reported in patients seeking healthcare services include dyspnea, edema, and fatigue (Evangelista et al., 2000). This study will add to the literature on healthcare utilization by helping healthcare providers understand if newly-diagnosed and/or chronic Stage D HF patients are perceiving symptoms associated with HF and whether they relate those symptoms to their HF, factors related to potentially harmful delays in seeking or self-administering treatment.
Another contributor to delayed healthcare treatment was the advice patients with HF received from their healthcare provider(s). Friedman and Quinn (2008) found that healthcare providers advised those with chronic HF to call 911 more frequently than those with acute HF. Acute HF patients were more likely to be told to make an appointment or to come to the office (Friedman & Quinn, 2008). This is a concerning finding as it could delay needed emergency services for those with acute HF. It is clear that HF patients are not accessing proper healthcare services when an exacerbation occurs. It is possible that this study will help us better understand Stage D HF patients’ somatic awareness and self-symptom recognition, which could lead to further studies involving this public health issue.

Newly-Diagnosed versus Chronic

Limited research was found that compared newly-diagnosed to chronic HF patients in terms of somatic awareness and self-symptom recognition. However, there is evidence that length-of-time since the diagnosis of HF influenced how patients perceived and acted upon exacerbations and general symptoms. Friedman and Quinn (2008) found that patients with chronic HF were more likely to have self-administered diuretics, attributing their symptoms to HF, compared to new onset patients who more often attempted symptom relief with nitroglycerin, cold and cough remedies, or pain relievers. Reasons for the differences in symptom recognition and treatment were not completely understood, but are possibly related to differences in disease comprehension, symptom confusion, perceived impact on daily life, or adaptation to illness that occurs over time (Friedman, & Quinn, 2008). These results are relevant to this study because length-of-time from diagnosis is a variable, and symptom confusion would lead to decreased self-symptom recognition.
Symptom confusion is also relevant in a qualitative descriptive study by Decker, Peden, Lennie, Schooler, and Moser (2009), which found that chronic HF patients diagnosed with NYHA class III-IV HF described experiencing emotional and somatic symptoms of depression. However, many of the somatic symptoms, such as change in appetite, sleep disturbances, and lack of energy, were also indicative of HF (Decker et al., 2009). Therefore, it is not clear if this group of patients was experiencing somatic symptoms of depression or symptoms of their chronic HF. These patients may have been experiencing symptom confusion as described by Friedman and Quinn (2008).

Though not directly related to somatic awareness or self-symptom recognition, a descriptive quantitative study by Quinn Griffin et al. (2007) provided information relevant to subjects of this study. This study found that elderly patients with classes II-IV NYHA HF have significantly lower physical quality of life but more spiritual well-being than younger patients (Quinn Griffin et al., 2007). Finally, a qualitative study by Zambroski (2003) described the process of patients experiencing turbulence due to living with chronic HF. The participants described physical turbulence as having too much fluid and difficulty breathing (Zambroski, 2003), which is typical of symptoms reported in the literature of chronic HF. The participants in the study had a mean age of 67 and had lived with chronic HF on average for three years.

Other studies yielded other findings about the perceptions of advanced HF patients. Friedman and Quinn (2008) demonstrated that patients with chronic HF were more likely to administer their own self-care, but for reasons that were unclear. Finally, a study by Evans et al. (under review) found that patients with chronic Stage D HF were more resigned to their fate and the reality of the limitations that living with HF brings, while newly-diagnosed Stage D HF patients still had naïve expectations and hoped for improvement.
While there is limited research related to somatic awareness and/or symptom recognition in terms of length-of-time from diagnosis in advanced HF patients, existing studies nevertheless help shed light on the perceptions and behaviors of those patients. Better understanding in these areas may lead to better interventions and outcomes. This study may provide additional clarity by helping us to understand whether advanced HF patients perceive their symptoms, whether they recognize them as related to HF, and whether perceptions appear to vary based on length of time from diagnosis. These are important questions because somatic awareness and self-symptom recognition impact care and outcomes, and because the possibility of length-of-time from diagnosis as a significant variable may point to an additional area for future study.

**Somatic Awareness and Symptom Recognition**

In the published literature, confusion exists between somatic awareness and symptom recognition as well as among similar concepts (see Table 1 below). Therefore, a concept analysis and more specifically a concept clarification as described by Morse, Hupcey, Mitcham and Lenz (1996), was done as the concept appeared mature within the literature with a large body of scholarly information available but lacked clarity when scientifically examined.

The epistemological principle guided the review of how clearly somatic awareness and symptom recognition were defined within the scientific literature (Hupcey & Penrod, 2005; Penrod & Hupcey, 2005). Concepts that were found in the literature included symptom recognition, symptom perception, symptom experience, body awareness, and somatic awareness. These concepts are defined in Table 1.
<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
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<tr>
<td>Symptom Recognition (Patel et al., 2007)</td>
<td>Becoming aware of, identifying, and distinguishing symptoms of heart failure from other potential causes</td>
</tr>
<tr>
<td>Symptom Perception (Sethares et al., 2014, p. 431)</td>
<td>“Patient recognition of a change from a usual state of health often due to a change in the number or intensity of symptoms”</td>
</tr>
<tr>
<td>Symptom Experience (Posey, 2006)</td>
<td>Includes perception of the symptom</td>
</tr>
<tr>
<td>Body Awareness (Bass et al., 2004, p. 33)</td>
<td>“The ability to recognize subtle body cues and identify the physiological manifestations”</td>
</tr>
<tr>
<td>Somatic Awareness (Jurgens, 2006, p. 75)</td>
<td>“Sensitivity to physical sensations and bodily activity secondary to physiological change”</td>
</tr>
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</table>

From the above definitions, it is clear that somatic awareness and symptom recognition are similar, yet distinct concepts. Somatic awareness and body awareness are antecedents to symptom recognition and thus need to be treated as such and appropriately defined and measured. This study employs the concept of somatic awareness because it has been used previously in HF research (Jurgens, 2006). Symptom recognition and symptom perception are very similar concepts as well. However, symptom recognition was chosen for this research as it too has been used in HF research (Patel et al., 2007; Riegel & Dickson, 2008). In addition, it is an appropriately narrow concept for this work, and it fits within the evaluation sub-concept of Symptom Experience, as described in the Theory of Symptom Management (Dodd et al., 2001).
In other studies, symptom monitoring was used but not defined; it seemed to replace symptom recognition in the article “Nurses’ Strategies to Address Self-Care Aspects related to Medication Adherence and Symptom Recognition in Heart Failure Patients” (Jaarsma et al., 2012). Oddly, although the term symptom recognition was used in the title, it often was not operationalized in the study and it was also confused with similar terms. Other terms used in the literature and not clearly differentiated from symptom recognition included symptom self-assessment and symptom attribution (Artinian et al., 2002; Posey, 2006). Finally, a study by Friedman (1997) used the term symptom reporting, but it was not defined and appeared similar to symptom recognition.

As noted earlier and as demonstrated in the research reviewed, somatic awareness and symptom recognition are two factors that can potentially impact the self-care process of patients with advanced HF. The concepts were employed within multiple contexts, including studies on heart failure (Artinian et al., 2002; Bass et al., 2004; Dickson et al., 2007; Evangelista et al., 2002; Friedman, 1997; Jaarsma et al., 2012; Jurgens, 2006; Jurgens et al., 2013; Lam & Smeltzer, 2013; Moser et al., 2011; Patel et al., 2007; Posey, 2006; Riegel & Carlson, 2002; Riegel et al., 2000; Riegel & Dickson, 2008; Riegel et al., 2010; Sethares et al., 2014; Vellone et al., 2013; White et al., 2010), diabetes (Kirk, Grzywacz, Chapman, Arcury, Bell, & Quandt, 2011), cancer (Brian et al., 2014; Lam, Tsuchiya, Chan, Chan, Or, & Fielding, 2008; Low, Walter, Menon, Jones, Reid, Simon, 2013; Mor, Masterson-Allen, Goldberg, Guadagnoli, & Wool, 1990), and schizophrenia (Kennedy, Schepp, & O’Connor, 2000). Although these studies have employed the concepts of somatic awareness and symptom recognition, the lack of clear conceptual definitions makes it difficult to fully understand their findings.
In qualitative studies, symptom recognition was often identified as a theme and described as symptoms experienced by the patient (Patel et al., 2007; Riegel & Carlson; 2002). This is problematic as the studies did not differentiate symptom recognition from somatic awareness; thus, it is not known whether participants understood that their symptoms were related to HF or whether they were aware only of the symptoms themselves, which is more indicative of somatic awareness. One study suggested that patients become accustomed to having symptoms over time (Friedman, 1997), suggesting duration of time with diagnosis may be an important variable to study in relation to somatic awareness and symptom recognition.

So, it is clear that the concepts of symptom recognition and somatic awareness are epistemologically immature, as they are poorly differentiated and nurses are left to determine which concept to use in everyday language and research, which further confuses the science. Clarity is needed to advance the state of the science and improve research in this area. In addition, the word “self” is never part of the concept symptom recognition and absolutely needs to be to avoid confusion with the term symptom recognition used by nurses and other healthcare providers to attribute a symptom to a particular disease.

The pragmatic principle was used to determine how well the concepts of symptom recognition and somatic awareness fit or is useful in describing some aspect of nursing phenomena (Hupcey & Penrod, 2005; Penrod & Hupcey, 2005). The analysis of research literature makes evident that symptom recognition and somatic awareness very useful concepts within nursing. They have been used in various types of publications, including theoretical articles, concept analyses, quantitative and qualitative research studies, and integrative reviews.

Researchers who focused on somatic awareness and symptom recognition found that patients with cancer, diabetes, and schizophrenia have difficulty recognizing symptoms of the
disease, even when their condition worsened (Brian et al., 2014; Kennedy et al., 2000; Kirk et al., 2011; Low et al., 2013; Mor et al., 1990; Patel et al., 2007; Riegel et al., 2000; Riegel et al., 2010; Sethares et al., 2014). Low and colleagues (2013) conducted a survey research study on women living in the United Kingdom and found that symptom awareness was low for identifying symptoms related to ovarian cancer. Results showed that pain in the abdomen was the most frequently recognized symptom (Low et al., 2013), and research by Brian and colleagues (2014) supported that finding. In a survey study using randomized sampling methods for women over the age of 50, Brian et al. (2014) found that most women were only able to identify three (post-menopausal bleeding, persistent pelvic pain and persistent abdominal pain) of the 11 most common symptoms of ovarian cancer (Brian et al., 2014). Mor and colleagues (1990) conducted survey research with newly-diagnosed lung, breast, and colorectal cancer patients to determine if they could recognize the symptoms of those cancers. Results showed that individuals had difficulty recognizing the symptoms of the disease process until advanced symptoms were present, leading to treatment delays (Mor et al., 1990). Kennedy and others (2000) conducted a descriptive study and discovered that adults with schizophrenia were unable to recognize the symptoms of the illness and beneficial self-management strategies. Kirk and colleagues (2011) conducted a qualitative study to determine if older rural adults could recognize symptoms of high or low blood glucose levels. While individuals could perceive change, such as lightheadedness and eyesight differences, they could not determine whether changes were related to high or low blood glucose levels (Kirk et al., 2011). This research shows that poor somatic awareness and self-symptom recognition are not limited to those individuals with HF, but they also impact other chronic conditions. However, a major limitation to all such studies is that somatic awareness and
symptom recognition are not conceptually clarified, leading to uncertainty about what was truly measured.

HF patients also had difficulty recognizing symptoms of their illness. Riegel and colleagues (2000) developed a tool to measure self-management of HF. A category in the tool was “recognizing a change,” intended to explore whether patients with HF could readily identify episodic changes related to HF; results indicated they could not recognize signs and symptoms of the disease (Riegel et al., 2000). Sethares and colleagues (2014) conducted an exploratory, descriptive, cross-sectional study examining factors associated with patients delaying care for HF symptoms. One hundred and thirty one participants were recruited for the study, and only 37% of participants were able to notice a change in symptoms as measured using the HF Somatic Awareness Scale (Sethares et al., 2014). Riegel and colleagues (2010) conducted a cross-sectional study with qualitative interviews and found that symptoms associated with HF were not easily detectable as part of a HF exacerbation and were often linked to other co-morbid conditions instead. As was true for studies discussed above, these studies did not conceptually discriminate between somatic awareness and self-symptom recognition, again leading to confusion over what was truly studied.

It was also found that older patients had a harder time with symptom recognition (Brian et al., 2014; Bass et al., 2004; Friedman, 1997; Mor et al., 1990; Riegel et al., 2010). Bass and colleagues (2004) conducted an exploratory study of body awareness in persons with HF and found that younger patients scored higher on the Body Awareness Questionnaire. This meant that they were able to better perceive symptoms of HF. Friedman (1997) conducted an exploratory, correlational study and found that dyspnea was the most commonly reported symptom of older adults with HF but other symptoms were not often recognized.
Variability of symptoms (fluctuation of improving and worsening symptoms) was found to have a greater impact on symptom recognition than symptom severity. Moser and colleagues (2011) conducted a longitudinal study and found that in community dwelling adult HF patients, symptom variability, not severity, resulted in increased hospitalizations and higher mortality rates. This could be due to the fact that patients with severe HF symptoms become accustomed to living with them, while those patients who have fluctuating symptoms are more likely to perceive a problem and seek treatment. One study found that race may relate to symptom recognition. Evangelista et al. (2002) conducted a retrospective study to determine if race impacts treatment delays in HF patients and found that African Americans with heart failure had longer treatment delays. It is not clear why this is, and it may be an area deserving further investigation.

In addition, symptom recognition and somatic awareness are often described as part of a larger self-care process, such as: self-care management (the ability to recognize and respond to symptoms as they occur) (Artinian et al., 2002; Jaarsma et al., 2012; Jurgens et al., 2013; Kennedy et al., 2000; Riegel et al., 2000, Riegel & Dickson, 2008); self-monitoring process (recognition that a change has occurred) (Lam & Smeltzer, 2013; Low et al., 2013; Riegel et al., 2012); and symptom experience (perception of symptom) (Dodd et al., 2001; Richard & Shea, 2011; Sethares et al, 2014). Symptom recognition and somatic awareness have even been described as one process, with symptom recognition as the main concept and symptom interpretation, symptom progression, and social messages as sub-concepts (Lam et al., 2008).

The linguistic principle guided the analysis of how consistently and appropriately the terms symptom recognition and somatic awareness were used within the scientific literature (Hupcey & Penrod, 2005; Penrod & Hupcey, 2005). The analysis showed that each concept was
always used as a noun to describe a process of recognizing symptoms or the actual symptom experiences. In addition, the concepts were often part of a larger self-care process such as self-care management, self-monitoring process, symptom experience—or even described as a discrete process itself (Artinian, et al., 2002; Dodd, et al., 2001; Jurgens, et al., 2013; Jaarsma, et al., 2012; Kennedy, 2000; Lam, et al., 2008; Lam & Smeltzer, 2013; Low, et al., 2013; Richard & Shea, 2011; Riegel & Dickson, 2008; Riegel, et al., 2000; Riegel, et al., 2012; Sethares, et al, 2014). In addition, it remains unclear whether symptom recognition and somatic awareness should fit into models as unidirectional or bi-directional concepts or should have their own situation-specific theory or middle-range theory based on the number of pre-conditions and measurable outcomes available. With such confusion, it is difficult to advance the logical principle as it is evident that the concepts do not hold their boundaries.

The lack of consistency in how symptom recognition and somatic awareness are defined and used in the literature limits the validity of research in this area. It is evident that conceptual clarity is needed to advance the state-of-the-science and the concepts’ utility; they are two similar but distinct concepts and must be accurately defined and separately measured to advance the science. In addition, the word “self” has never been part of the concept, causing confusion between the symptom recognition used by healthcare providers to note a change in a patient’s condition versus a patient’s ability to recognize symptoms. Thus, self-symptom recognition is being proposed as one concept being measured in this study.

**Mediating factors for somatic awareness and symptom recognition.** An analysis of the literature revealed that appropriate somatic awareness and symptom recognition is enhanced by good decision making skills (Dickson et al., 2007; Jurgens et al., 2013; Riegel et al., 2012; Richard & Shea, 2011; Sethares et al., 2014). Dickson and colleagues (2007) found that HF
impacts the area of the brain needed for decision making and therefore could alter patients’ ability to make decisions regarding self-care. Jurgens and colleagues (2013) conducted a randomized controlled trial and found that a HF training program could positively impact one’s decision-making abilities regarding changes in their HF symptoms. Riegel and colleagues (2012) discussed the need for good decision-making to recognize signs and symptoms of a disease process early enough to take action before the disease worsens. Similarly, Richard and Shea (2011) conducted a concept delineation and discussed the need for intact cognitive abilities as a necessary antecedent for taking proper self-care actions (a point incorporated in Riegel’s Middle Range Theory of Self-Care of Chronic Illness). Finally, Sethares and others (2014) conducted an exploratory, descriptive study and found that interventions directed towards decision-making in HF patients may be an effective method to prevent HF patients from delaying seeking care.

Vellone and colleagues (2013) conducted a secondary analysis of data from a cross-sectional study and found that individuals with increased confidence and experience with HF had better symptom recognition (Vellone et al., 2013). Also, current health status (the healthier the better) was found to affect patients’ perception of their deteriorating status. In this qualitative study, 50% of participants in the study with multiple co-morbidities were unsure of what was causing the deterioration in their condition (Patel et al., 2007).

Age was also found to be an important factor in predicting the ability to accurately recognize symptoms, but the research was inconclusive as to whether younger or older age predicted better somatic awareness and self-symptom recognition. In an exploratory study, Bass and colleagues (2004) found that individuals less than 60 years of age had lower body awareness scores and thus either did not have or did not recognize that they were having symptoms. Friedman (1997) conducted an exploratory, correlational study and found that age was
negatively correlated to the duration of acute symptoms, meaning that younger patients had more acute symptoms longer before hospital admission. In 2006, Jurgens found that as age increased, so did the duration of symptoms before seeking care. This is a concerning finding as elderly patients often have difficulty with self-care. Finally, Riegel and colleagues (2010), conducted a cross-sectional mixed methods study and found that older patients (>73 years of age) had a harder time detecting and interpreting dyspnea than younger patients. This delay may be due to a decrease in somatic awareness and symptom recognition. In addition, increased adaptation to the disease process, motivation, hope, self-efficacy, technology based tools, and social support all can lead to improved symptom recognition (Dodd et al., 2001; Jaarsma et al., 2012; Jurgens, 2006; Riegel & Carlson, 2002; Riegel & Dickson, 2008; Riegel et al., 2000).

In summary, somatic awareness and symptom recognition were influenced by: decision-making abilities (Dickson et al., 2007; Jurgens et al., 2013; Riegel et al., 2012; Richard & Shea, 2011; Sethares et al., 2014); symptom severity or variability (Artinian et al., 2002; Jurgens et al., 2013; Moser et al., 2011); confidence and/or experience (Vellone et al., 2013); one’s current health status (Patel et al., 2007); the number of co-morbidities; age; psychological state; education; training; technology based tools; social support; adaptation; motivation; hope; and self-efficacy. In addition, fear and misconceptions were found to negatively impact symptom recognition (Bass, 2004; Brian et al., 2014; Dodd et al., 2001; Friedman, 1997; Jaarsma et al., 2012; Jurgens, 2006; Kirk et al., 2011; Lam et al., 2008; Lam & Smeltzer, 2013; Low et al., 2013; Mor et al., 1990; Riegel & Carlson, 2002; Riegel & Dickson, 2008; Riegel et al., 2000; Riegel et al., 2010). This study will add to our knowledge by examining length-of-time from diagnosis, symptom severity, and age as variables with somatic awareness.
Outcomes. According to reviewed literature, outcomes of appropriate somatic awareness and symptom recognition can lead to better self-care management. Dodd and colleagues’ (2001) concept paper on the Symptom Management Model, suggested that without proper symptom evaluation (self-symptom recognition), poor treatment decisions could be made leading to poor outcomes. Further, Richard and Shea (2011) detailed an outcome of appropriate self-care, including better symptom control, as the desired result. Jurgens (2013) conducted a randomized control trial and found that HF symptom awareness training in patients with chronic HF may lead to improved HF self-care, such as increased weight monitoring and other symptom monitoring interventions. Sethares and colleagues (2014) conducted an exploratory, descriptive, cross-sectional study on 131 community residing adults with HF and found that only 37% of participants in the study recognized that their changes in symptoms were related to HF and only 10% attempted to get help from a healthcare provider. Vellone and colleagues (2013) found through their testing of the Situation–Specific Theory of HF Self-Care that symptom monitoring, symptom recognition, and treatment implementation and evaluation were all positively correlated, meaning each process relies on the next for appropriate self-care. Finally, using the same theory, Riegel and Dickson (2008) found that participants delayed treatment when they were unable to recognize symptoms of HF.

In addition, Riegel and colleagues (2012) proposed in their theoretical paper on the Middle-Range Theory of Self-Care of Chronic Illness that through proper self-care monitoring, which involves somatic awareness and symptom recognition, individuals can have enhanced treatment, quality of life, and health outcomes. Using a diary analysis, White and colleagues (2010) found that patients with HF who kept weight monitoring diaries did not have improved self-care; only one of sixteen patients contacted the healthcare provider when he/she gained more
than 3 pounds in a day. However, diaries may help patients realize the symptom is happening (somatic awareness) and possibly other interventions need to be explored to help them recognize the importance of the weight gain. Riegel and Carlson (2002) conducted a qualitative analysis and found many HF patients struggle with symptom recognition and thus delay self-care treatments.

In 2002, Artinian and colleagues conducted a descriptive, correlational study with 110 participants and found that most participants scored poorly on self-care behaviors associated with symptom monitoring and management, which involves somatic awareness and symptom recognition. In 2006, Jurgens conducted an exploratory, descriptive study and found that uncertainty is positively correlated with somatic awareness, which could lead to delayed self-care and increased hospital admissions.

In summary, appropriate somatic awareness and symptom recognition can lead to better self-care management (Dodd et al., 2001; Jurgens et al., 2013; Kennedy et al., 2000; Kirk et al., 2011; Richard & Shea, 2011; Riegel & Dickson, 2008; Sethares et al., 2014; Vellone et al., 2013), enhanced treatment and quality of life (Jaarsma et al., 2012; Riegel et al., 2012), positive health outcomes (Mor et al., 1990), increased coping skills, better self-regulation, and decreased anxiety (Bass et al., 2004; Lam et al., 2008; Riegel & Carlson, 2002; Riegel et al., 2012; White et al., 2010).

**Measurement of somatic awareness and symptom recognition.** Many tools are available to help measure somatic awareness and symptom recognition, including the Heart Failure Somatic Awareness/Perception Scale (Jurgens, 2006); Body Awareness Questionnaire (Bass et al., 2004); Revised Heart Failure Self-Care Behavior Scale (Artinian et al., 2002); Self-Care Heart Failure Index (Vellone et al., 2013); 10-item Heart Failure Data Collection Tool
(Friedman, 1997); Self-Management of Heart Failure Instrument (Riegel et al., 2000); Ovarian Cancer Awareness Scale (Brian et al., 2014); Early Signs Scale (ESS) for Schizophrenia (Kennedy et al., 2000); and other investigator developed instruments. There are multiple tools available to measure somatic awareness and symptom recognition, but without adequate theoretical and operational definitions, it is unclear what is actually being measured. The tools that are relevant to HF include The HF Somatic Awareness Scale, The Body Awareness Questionnaire, The Revised HF Self-Care Behavior Scale, The Self-Care HF Index, The 10-Item HF Data Collection Tool, and The Self-Management of HF Instrument. A review of each follows.

**The HF somatic awareness/perception scale.** The HF Somatic Awareness Scale was originally developed by Jurgens (2006) to measure “somatic awareness of and perceived severity of symptoms specific to HF” (p. 78). At the time, no such scale existed. Instruments for measuring somatic awareness, such as the modified somatic perception scale, were developed for patients with back pain. Jurgens’ original HF Somatic Awareness Scale was a 12-item Likert scale, with higher scores indicating higher somatic awareness. The scale had a theta reliability of 0.78 (Jurgens, 2006), which was an acceptable measure of its accuracy and precision (Houser, 2008). Content and construct validity was also established for the scale (Jurgens, 2006). Version three, the latest, is an 18-item Likert scale, with scores for each item ranging from 0-5; higher scores continue to indicate greater somatic awareness. (V. 2 did not appear in the literature.) Based on patient feedback and research findings, the scale’s third version included additional symptoms (Sethares, 2014). Current items on the scale include items about: heart rate, chest pain, dyspnea, upset stomach, cough, fatigue, edema, weight gain, activity intolerance, and appetite (C. Jurgens, personal communication, March 10, 2014). Cronbach’s alpha reliability of the
revised scale was 0.83 (Altice & Madigan, 2012). Jurgens et al. (2016) reported the internal consistency of the scale, v. 3, to be 0.90. Also convergent (r = 0.54, \( p < 0.01 \)) and divergent (r = 0.18, \( p > 0.05 \)) validities were supported. An additional change in the third version was a revision of its name, now the HF Somatic Perception Scale (Jurgens et al., 2016).

**The body awareness questionnaire.** The Body Awareness Questionnaire is a generic questionnaire, not specifically designed for HF patients (Bass, 2004). It is an 18-item Likert scale of “reported attentiveness to normal nonemotive bodily processes…” (Bass et al., 2004, p. 35). The questionnaire is designed to determine such things as the ability of a person to: tell if he/she is running a fever without taking his/her temperature; know in advance that he/she is getting the flu; and determine his/her energy levels at various times of the day (Bass, 2004). The generic items on this scale are not appropriate to measure somatic awareness specific to HF patients.

**The revised HF Self-Care Behavior Scale.** The Revised HF Self-Care Behavior Scale is a 29-item Likert scale that measures self-care behavior of patients with HF. The tool was not developed to measure somatic awareness or symptom recognition, although some items assess somatic awareness. The scale is organized around three areas: complying with medical regime, asking for help, and adapting activities (Artinian et al., 2002).

**The self-care HF index.** The Self-Care HF Index was used in a study by Vellone et al. (2013) to operationalize symptom recognition, such as ankle swelling and problems breathing, as HF symptoms. While results of the study showed that HF patients recognized these symptoms 56% of the time (Vellone et al., 2013), it does not capture the array of symptoms that a patient with HF may experience. The tool has been shown to be effective in measuring self-care and in testing the effectiveness of interventions (Barbaranelli, Lee, Vellone, & Riegel, 2014).
The 10-item HF data collection tool. The 10-item HF Data Collection Tool was developed by Friedman (1997) to collect data on HF patients’ symptoms and the duration of those symptoms before hospital admission. The items on the scale included dyspnea, acute dyspnea, paroxysmal nocturnal dyspnea, edema, orthopnea, fatigue, palpitations, chest pain, nausea, and cough. Items were determined based on a literature review, and content validity was established by having two critical care nurses review the items (Friedman, 1997). This is the oldest tool uncovered that measured symptoms experienced by HF patients, but it has not been adopted for use in research nor has it been reported on in peer-reviewed literature. The newer HF Somatic Perception Scale is a better fit for measuring somatic awareness due to its more accessible and specific phrasing. For example, the HF Somatic Perception Scale, v.3, asks if a patient had difficulty breathing rather than asking if he/she had dyspnea.

The self-management of HF instrument. Finally, the 65-item Self-Management of Heart Failure Instrument was developed by Riegel and colleagues (2000) to measure the following six categories: recognizing a change; evaluating a change; implementing a treatment strategy; evaluating a treatment strategy; ease of evaluating the treatment strategy; and self-efficacy. The category “recognizing a change” measures concepts similar to somatic awareness and symptom recognition, attempting to determine if patients could readily identify episodic changes and relate them to HF. However, the instrument combines the two concepts, although they are distinctly different, and measures them in the context of the larger self-care process. In addition, the “recognizing a change” category included only six HF symptoms, so it is not all inclusive of the symptoms experienced by HF patients (Riegel et al., 2000).

In summary, it is clear that confusion exists between somatic awareness and symptom recognition, along with other similar concepts as discussed here. These terms and others have
been used extensively in the literature and have shown that patients with HF have difficulty recognizing and interpreting their symptoms. The concept clarification showed the need for a new concept, self-symptom recognition, and future research to add clarity to the science. Several tools exist that measure somatic awareness and symptom recognition, but the reviewed literature indicates that the HF Somatic Perception Scale, v. 3, is the most reliable and valid tool for measuring somatic awareness. No tools were found to effectively measure self-symptom recognition.

**Conceptual Framework**

**Theoretical Foundations**

The concepts of somatic perception and self-symptom recognition were examined from the dispositional view, which means that concepts were viewed as habits or specific mental or physical acts (Rodgers & Knafl, 2000). An additional theoretical orientation is the philosophical approach of moderate realism, which posits that one can obtain an objective view of reality (Hupcey & Penrod, 2005; Penrod & Hupcey, 2005). However, concepts are not static, but rather represent definitions at particular points-in-time that will continue to evolve as the state of science evolves (Bonis, 2013). Finally, the author strongly embraces hermeneutics, a philosophy suggesting that readers’ create their own understanding of information (Rodgers & Knafl, 2000).

Finally, as an individual living with type one diabetes, the author has long had an interest in somatic awareness and self-symptom recognition.

**Conceptual Model**

The Theory of Symptom Management (Figure 1 in Chapter 1, p. 6) is a middle-range theory that was first introduced to the nursing arena in 1994 by the School of Nursing faculty at the University of California, SF (UCSF). Originally called the Symptom Management Model,
the theory was used as a framework in symptom research and clinical practice. The model and current theory evolved when the UCSF nursing faculty identified a need for a universal model that could guide both direct care and research across a broad spectrum of symptoms resulting from a range of diseases and health statuses. Earlier, social science researchers had been using frameworks reflecting a one dimensional approach to symptom management, often focusing on a single symptom, strategy, or outcome; they did not focus on the patient’s experience (UCSF School of Nursing, 2014). The Symptom Management Model was developed from other self-care research, such as the Orem’s Self-Care Model and the Model of Self-Care by Sorofman, Tripp-Reimer, Lauer, and Martin, as well as models from anthropology, sociology, and psychology fields (Humphreys et al., 2008).

The model has undergone two revisions since its inception. A first revision in 2001 was detailed in “Advancing the Science of Symptom Management”; concepts were altered slightly and the nursing metaparadigm of person, environment, and health/illness was clarified (Dodd et al., 2001). In 2008, the model was again revised and renamed the Symptom Management Theory. Despite the expansion from a model to a theory, the three major concepts of symptom experience, symptom management, and outcomes remained the conceptual basis. The theory has been applied to address not only specific areas of research (such as symptoms in patients with cancer or HIV), but also to broader areas of nursing (such as pain management) (Humphreys et al., 2008) that cut across numerous chronic and acute health conditions. It has not, however, been used with HF patients.

*Concepts of the theory.* The Symptom Management Theory contains three major concepts: symptom experience, symptom management strategies, and symptom outcomes, as shown in Figure 1. All three are directly related to each other, as indicated by the bidirectional
arrows in the figure, and they are all framed by the nursing metaparadigm of person, environment, and health/illness. Figure 1 illustrates the interrelated concepts of the theory, the constant interaction of the person with the concepts, and the overlap among the three concepts. The person element of the metaparadigm encompasses psychological, sociological, physiological, demographic, and developmental characteristics. The environment element includes physical, social, and cultural differences. And finally, the health and illness element is comprised of risk factors, health status, and disease and injury (Humphreys et al., 2008).

**Symptom experience.** The first major concept of the Symptom Management Theory is symptom experience. The symptom experience is an individual’s subjective perception of the symptom, his or her evaluation of the symptom, and his or her response. Perception of the symptom means the way that a particular symptom has caused a change in the way a person normally feels. Evaluation of the symptom refers to the meaning individuals assign to their experience and the judgments they make, as when they attribute a cause to the symptom. Finally, response to the symptom refers to the resulting action/, which might be physical, psychological, sociocultural, and/or behavioral. Bidirectional arrows in the model link the three areas of symptom perception, evaluation and response, suggesting that an individual’s perception of a symptom may have a direct impact on the how the symptom is—or is not—handled (Dodd et al., 2001).

**Symptom management strategies.** The second major concept of the Symptom Management Theory is symptom management strategies. Symptom management strategies include the: who, what, when, how, to whom, how much, and why factors relevant to effective response. This dimension represents the role of individuals in preventing or delaying a negative outcome by taking some type of action (Dodd et al., 2001).
**Outcomes.** The third and final major concept of the Symptom Management Theory is outcomes, where eight variables can impact adherence to the symptom management strategy. These variables are functional status, emotional status, mortality, morbidity and co-morbidity, quality of life, costs, and self-care. All of these variables can impact the symptom status and are interrelated (Dodd et al., 2001).

**Adherence.** The minor concept of adherence emerged during the 2001 revision. Adherence was defined as “whether the intended recipient of the strategy actually receives or uses the strategy prescribed” (Dodd et al., 2001, p. 674). Adherence is shown in Figure 1 by the broken arrow between symptom management strategies and outcomes. Humphreys et al. (2008) identifies non-adherence in instances where symptom management strategies are too demanding, are inconsistently applied, or simply are not used.

**Assumptions.** The Symptom Management Theory is based on six assumptions. These include:

1. The gold standard for the study of symptoms is based on the perception of the individual experiencing the symptom and his/her self-report.
2. The symptom does not have to be experienced by the individual to apply this model of symptom management. In other words, the individual could be at risk for the symptom and intervention strategies could be initiated to lessen or prevent the symptom from occurring.
3. Nonverbal patients may experience symptoms and the interpretation by the parent or caregiver is assumed to be accurate for purposes of intervening.
4. All troublesome symptoms need to be managed.
5. Management strategies may be targeted at the individual, a group, a family, or the work environment.

6. Symptom management is a dynamic process. It can be modified by individual outcomes and/or the influences of the nursing domains of person, health and illness, and/or environment (Dodd et al., 2001, pp. 669-670).

**Research on The Symptom Management Theory.** The Symptom Management Theory is commonly used as a framework for research studies (Baggott, Cooper, Marina, Matthay, & Miaskowski, 2012; Bay & Bergman, 2006; Coleman et al., 2006; Fuller, Welch, Backer, & Rawl, 2005; Hardie, Janson, Gold, Carriero-Kohlman, & Boushey, 2000; Hearson, McClement, McMillian, & Harlos, 2011). Researchers have also used the Symptom Management Theory to broaden the description of symptom experiences and management strategies to improve patient care. Studies have included mixed-methods designs using interviews and survey tools (Hearson et al., 2011), quantitative descriptive designs utilizing standardized tools (Humphreys et al., 1999; Kris & Dodd, 2004), cross-sectional designs (Bay & Bergman, 2006) and a secondary cross sectional design utilizing a convenience sample (Heilemann, Coffey-Love, & Frutos, 2004). The Symptom Management Theory has also been modified for use in the study of nurse practitioners who care for children with asthma (Newcomb, 2010).

Humphreys et al. (2008) conducted a systematic review and found 20 research studies which had the Symptom Management Theory as their conceptual framework. The theory has also been subjected to theoretical analyses (Henley, Kallas, Klatt, & Swenson, 2003; Maag, Buccheri, Capella, & Jennings, 2006). In addition, it has been compared and contrasted with other frameworks for continued research (Brant, Beck, & Miaskowski, 2010; Voss, Dodd, Portiollo, & Holzemer, 2006). The theory has also been used to guide large federally funded
studies by the National Institute of Health (Aouizerat, 2006; Dodd, Cho, Cooper & Miaskowski, 2010; Lee, 2004 & 2006) and in studies of diverse populations such as battered women living in shelters (Humphreys, Lee, Neylan, & Marmar, 1999) and people with Acquired Immune Deficiency Syndrome (AIDS) (Tsai, Holzemer, & Leu, 2005).

**Research on the symptom experience concept.** Within the theory, the symptom experience concept guiding this research has been the most often studied (Humphreys et al., 2008), and it has been used in both quantitative and qualitative studies. In a study dealing with women’s perceptions of the cause of their depression, the theory was used to guide an exploration of the depressive symptom experience, which identified six causal categories: partner issues, family issues, feelings of being alone, inability to provide for material needs, bodily symptoms, experiences, and vague nonspecific reasons (Heilemann et al., 2004). In two other studies, battered women’s symptom experiences were explored using descriptive correlational approaches, yielding the additional symptom experience of disturbed sleep and daytime fatigue (Humphreys, 2003; Humphreys & Lee, 2005). Hardie and colleagues (2000) studied the sensation of bronchoconstriction experienced by asthmatic patients from different ethnic groups using the Symptom Management Theory as a guiding framework. They were able to identify differences between White and African American participants. Bay and Bergman (2006) used the theory as a conceptual framework for a cross-sectional study that examined symptom experience and emotional response in traumatic brain injury patients. A positive correlation between post-injury symptom frequency and tension/anxiety, anger/hostility, and perceived chronic stress was found (Bay & Bergman, 2006). Finally, the Symptom Management Theory was utilized as a framework in a mixed methods study exploring the experience of family members providing palliative care at home, which found that many fail to attain quality rest.
(Hearson et al., 2011). So, while the symptom experience dimension of the Symptom Management Theory has not been used in the HF population, it has been successfully used in diverse populations to explore multiple diseases as well as in both quantitative and qualitative designs—thus demonstrating that the Symptom Management Theory is a robust tool appropriate for guiding this study.

**Research on symptom experience and management strategies.** Studies focusing on the symptom experience and related management strategies have been the next largest area of research with the Symptom Management Theory. Many of these studies have used diverse populations and the influence of the nursing metaparadigm as key variables, demonstrating the theory’s flexibility and applicability (Humphreys et al., 2008). Tsai, Hsiung, and Holzemer’s (2002) work with HIV patients and healthcare providers found that patient care strategies are an under-explored area of research and that patients acquire knowledge from a variety of sources. Another research study found that middle-aged African American women use passive rather than active management strategies when learning and choosing management strategies (Hudson, Kirksey, & Holzemem, 2004). Finally, another study explored the relationship between symptom experience and the use of prayer as a management strategy in a community based population of HIV positive patients. The researchers found that African American women were much more likely than men to use prayer as a symptom management strategy (Coleman et al., 2006).

**Research on all three major concepts.** Studies that incorporate all three major concepts of the Theory of Symptom Management have also been completed. Fuller et al. (2005) studied constipation in women with pelvic floor disorders and found that the symptom experience of these women was very distressing and that their symptom management strategies were ineffective—and so more effective strategies were needed to improve outcomes (Fuller et al.,
2005). Newcomb (2010) utilized the Symptom Management Theory to explain how nurse practitioners care for children with asthma, concluding that the concepts of communication and feedback should be added to the theory when dealing with children (Newcomb, 2010).

**Conclusions about Symptom Management Theory.** The Theory of Symptom Management is the best fit for this research study. The major concept of symptom experience with the sub-concepts of perception of symptoms and evaluation of symptoms fits perfectly with the concepts of somatic awareness and self-symptom recognition targeted in this study. Perception of symptoms—when a person feels differently from normal due to a symptom—will be operationalized in this study as somatic awareness. Evaluation of symptoms—the judgment an individual makes about the symptom, as when they assign cause—will be operationalized in this study as self-symptom recognition.

In addition, this theory fits this research in depicting the symptom experience as an iterative process impacted by person and environment as well as health and illness. The researcher agrees that participants in this study will be impacted by forces of person (i.e., age and psychological state), environment (i.e., home environment and caregiver support), and health and illness (i.e., other co-morbidities). Also, somatic awareness and self-symptom recognition do overlap each other and can occur together depending on the number of symptoms involved. Finally, the theory fits well with this research as it has been used as framework for a variety of studies focused on multiple chronic health conditions using either qualitative or quantitative designs.

While length-of-time from diagnosis is not directly addressed in the Theory of Symptom Management, it can be addressed in the person domain through the psychological, physiological, and developmental variables (Humphreys, et al., 2008). In adapting the theory to address
length-of-time from diagnosis, a measure of time had to be selected. The selected measure was clock-calendar time, a widely accepted common measurement tool (Henly et al., 2003). Clock-calendar time in years was used to separate the newly-diagnosed from the chronic group of participants, allowing for comparisons of somatic awareness and self-symptom recognition based on the variable of length-of-time from diagnosis.

**Other considered theories.** Two other theories were considered to guide this research study, the Theory of Self-Care of Chronic Illness and the Situation-Specific Theory of Heart Failure Self-Care. The following will review both theories and detail why they were not selected.

**The middle-range Theory of Self-Care of Chronic Illness.** First, the middle-range Theory of Self-Care of Chronic Illness, developed in 2012 as a framework to help practitioners and researchers care for individuals with chronic illnesses, was considered (Riegel et al., 2012). This theory has several major concepts, including self-care maintenance, self-care monitoring, and self-care management. However, before one can understand the major concepts, it is critical to understand how the theorists define self-care. In the middle-range Theory of Self-Care of Chronic Illness, self-care is defined “…as a process of maintaining health through health promoting practices and managing illness” (Riegel et al., 2012, p. 195). The theorists go on to explain that everyone engages in some form of self-care (e.g., brushing teeth, taking medications); however, those with chronic illnesses often require more self-care and the self-care required of them is critical for avoiding complications. In addition, self-care is not the same for everyone and thus, the middle-range Theory of Self-Care of Chronic Illness is vital to helping individuals with chronic illnesses maintain their highest degree of wellness (Riegel et al., 2012).

The first major concept defined in the middle-range Theory of Self-Care of Chronic Illness is self-care maintenance. According to the researchers, “Self-care maintenance refers to
those behaviors performed to improve well-being, preserve health, or to maintain physical and emotional stability” (p. 196). Minor or sub-concepts related to self-care maintenance include reflection, adaptation and adherence. Reflection involves the individual reflecting on the usefulness of the behaviors he or she is engaging in to determine helpfulness and effectiveness of the activities. Adaptation is critical because patients with chronic illness(es) often need changes in their self-care maintenance as their chronic condition(s) evolves. Finally, adherence is critical to self-care maintenance to ensure the best patient outcomes. (Riegel et al., 2012).

The next major concept described in the theory is self-care monitoring, which is “….a process of routine, vigilant body monitoring, surveillance, or body listening (Riegel et al., 2012, p. 196). The theorists explain that self-care monitoring is part of normal behavior, as when individuals commonly monitor their weight. However, for those individuals with chronic illness it becomes even more critical to maintain their health(Riegel et al., 2012). In fact, “The goal of self-care monitoring is recognition that a change has occurred” (Riegel et al., 2012, p. 196). Sub-concepts to self-care monitoring include the following three criteria: “First, clinically significant changes in the condition must be possible over time. Second, a method of reliably detecting these changes must exist. Finally, a reasonable action must be possible in response” (Riegel et al., 2012, p. 196). The concept of self-care monitoring is the link between self-care maintenance and the next concept, self-care management (Riegel et al., 2012).

Self-care management “involves an evaluation of changes in physical and emotional signs and symptoms to determine if action is needed” (Riegel et al., 2012, pp. 196-197). An important sub-concept associated with the self-care management concept is situation awareness, which involves “…alertness to bodily sensations (somatic awareness) and the ability to reliably
determine how these sensations change in response to treatments implemented” (Riegel et al., 2012, p. 197).

The relationship of the concepts from the Theory of Self-Care of Chronic Illness is depicted below:

![Figure 3. A depiction of the middle-range theory of Self Care of Chronic Illness by Riegel, Jaarsma, & Stromberg, 2012, p. 199, copyright permission obtained (see Appendix B).](image)

As one can see, the figure depicts the concepts as semi-circles with arrows leading from self-care maintenance to self-care monitoring to self-care management with the circles never reconnecting, thus implying a linear process. However, Riegel, Jaarsma, and Stromberg (2012) point out in their theory that the concepts are not linear and may not all occur.

The major concepts of self-care monitoring and self-care management would fit best from this theory with this research. If this theory were chosen, self-care monitoring could be operationalized as somatic awareness, while self-care management could be operationalized as self-symptom recognition. However, this theory was not chosen as it does not show the process
as an iterative one, which the researcher believes it truly is. It also does not take into account outside forces, such as person, environment, and health and illness, as does the Theory of Symptom Management—a clear limitation, because these outside forces clearly can impact individuals and need to be considered. In addition, this theory was recently developed and thus does not have research support to inspire confidence.

**The situation-specific Theory of Heart Failure Self-Care.** The other candidate for theoretical guidance was The Situation-Specific Theory of Heart Failure Self-Care. This theory was developed by Riegel and Dickson in 2008 to help clinicians and scientists better understand the self-care process of HF patients. This theory, like the middle-range Theory of Self-Care of Chronic Illness, uses self-care as the overarching domain to guide the theory. Below that, as shown in Figure 4, the first major concept is self-care maintenance, which includes behaviors used to maintain physiologic stability. Sub-concepts linked to self-care maintenance are symptom monitoring and treatment adherence. The next major concept is self-care management, which involves the decision-making response to symptoms when they occur. Sub-concepts here include: symptom recognition, symptom evaluation, treatment implementation, and treatment evaluation. Confidence is shown below the model as a mediating factor that could impact all phases of HF self-care.
Figure 4. A depiction of the Self-Care of Heart Failure Model by Riegel & Dickson, 2008, p. 192, copyright permission obtained (see Appendix C).

If this theory were chosen to guide this research, then self-care management would be the major concept evaluated, and symptom recognition would be the sub-concept studied. Symptom recognition (recognizing a change, e.g., ankle swelling) would be operationalized as somatic awareness and symptom evaluation (deciding whether the change required action or not)—which does not fit with this study’s concept of self-symptom recognition. This self-care theory does not separate the two concepts of research interest, somatic awareness and self-symptom recognition, but rather groups them under the one concept of symptom recognition. Because it does not discriminate between the two variables of interest, this theory was a poor theoretical fit. Also, like the Theory of Self-Care of Chronic Illness, outside forces are not taken into account. Finally, the self-care process depicted in this theory is linear, while the researcher feels somatic awareness and self-symptom recognition interact in an iterative process as depicted in the Theory of Symptom Management.
Chapter Summary

A review of the literature was conducted to provide a strong foundation for this research study and to add clarity to the concepts of interest: somatic awareness and self-symptom recognition. The review of the literature revealed that the phenomena of interest have not been studied using length-of-time from diagnosis (newly-diagnosed versus chronic) as a variable, but it did show that chronic HF patients are more likely to suffer from depression (Decker et al., 2009) and to be resigned to their fate and the reality of the limitations of living with Stage D HF (Evans et al., under review).

The literature review also showed that there is much confusion between the concepts of somatic awareness (sensing that something is different due to a symptom) and self-symptom recognition. In fact, self-symptom recognition (a patient’s recognition of bodily changes and linking these changes to a cause) does not exist as a concept in the literature and needs to be identified separately from symptom recognition, which currently exists as a catch all concept for self and healthcare provider recognition of symptoms. The clarity provided during the review of the literature and subsequent concept analysis has provided the needed precision advance this research, allowing the concepts to be accurately measured and helping advance the state-of-science in this area. In terms of instruments, the HF Somatic Perception Scale was found to be a reliable and valid tool that could be used to accurately measure somatic awareness in HF patients (Jurgens, 2006). No tools were found that captured the true essence of self-symptom recognition.

Finally, the Theory of Symptom Management was reviewed and chosen to provide theoretical guidance. This theory provides a clear framework that allows the concepts of somatic awareness and self-symptom recognition to be clearly operationalized. It is a middle-range
theory, frequently employed in diverse research; and, finally, it incorporates outside forces, such as person, environment, and health and illness, which impact individuals with advanced HF.
**Chapter 3: Research Design and Methods**

**Introduction**

The purpose of this study was to determine whether length-of-time from initial diagnosis were linked to differences in somatic awareness and self-symptom recognition in Stage D HF patients with less than a two year predicted survival time. These concepts were examined using a mixed methods approach with both quantitative and qualitative methodologies. Quantitative research methods allowed for comparison of the somatic awareness scores of newly-diagnosed Stage D HF patients with the scores of chronic HF patients who had recently progressed to Stage D HF. Quantitative methods were also used to explore a possible association between somatic awareness and length-of-time from diagnosis, and also possible associations with demographic data, such as age, gender, and so on. Since no tool was found that adequately measured self-symptom recognition, qualitative research methods were employed to determine whether patients recognized their symptoms as being related to HF. After the HF somatic awareness scale was administered, the participating patients were interviewed to determine how they themselves attributed symptoms.

**Design of the Study**

The data for this study were collected during the author’s time as a research assistant on the larger parent study (described below). Data analysis for that study indicated that patients with Stage D HF differ in various ways depending on time since HF diagnosis. While working on the parent study, the author also became interested in how somatic awareness and symptom recognition might affect these patients. A literature review revealed much information relevant to those concepts and yielded an appropriate tool to measure somatic awareness, The HF Somatic Perception Scale, v. 3. Since no tool was found to measure self-symptom recognition, a mixed
methods approach seemed most likely to generate data relevant to the research questions. The approach was shaped by concurrent triangulation design (Creswell, 2009), in which both quantitative and qualitative data are collected together to provide rich data. Each method will be explained in detail below.

**Quantitative Methodology**

A prospective cross-sectional survey design was used to determine whether newly-diagnosed and chronic Stage D HF patients exhibited a difference in somatic awareness. Collecting information via a survey-the HF Somatic Perception Scale, v. 3-allowed the research team to collect data quickly, with little burden on research participants. Jurgens (2006) originally developed the scale as part of her doctoral work and has subsequently revised it (C. Jurgens, personal communication, March 10, 2014). More detail on the scale appears in Chapter Two and later in this chapter. A PhD or MSN educated nurse conducted interviews either via telephone or in-person, since the participants were already enrolled in the parent study and were being interviewed monthly by phone.

The major threat to internal validity was sample selection: “participants can be selected who have certain characteristics that predispose them to have certain outcomes” (Creswell, 2009, p. 163). This threat to internal validity cannot be controlled in this study as participants were drawn from a larger parent study conducted by Hupcey and Kitko, based on their HF survival risk of less than two years. The total sample from the parent study could not be included since some patients had died, some had completed their two year participation in the parent study, or had an intervention that changed perceptions of heart failure symptoms (e.g., mechanical support device or heart transplant) prior to data collection for this study.
Threats to external validity include selection effects, the overgeneralization of results based on the sample in a study. This study had a relatively small sample size (n=20; newly-diagnosed n=9; chronic n=11) from mainly rural Pennsylvania. In addition, the sample was predominately White. Both of these factors will limit the ability to generalize results beyond this population of patients. This threat could have been reduced through stronger sampling approaches (i.e., from more ethnically diverse areas and multiple data collection sites) (Houser, 2008).

**Qualitative Methodology**

Explorative qualitative descriptive research methods, appropriate to pursuing an understanding of phenomena (Miles, Huberman, & Saldana, 2014; Sandelowski, 2000), were employed to better understand symptom recognition of newly-diagnosed versus chronic Stage D HF patients. According to Sandelowski (2000), such research allows data to be categorized in a less interpretive form than other types of qualitative research, such as phenomenology (Sandelowski, 2000). This seems a good fit, since an intent of the research was to understand how patients interpret their experience.

Before qualitative data collection began, the data collectors bracketed their feelings to avoid biasing participants during interviews; data analysts did the same to prevent bias during data analysis. During the administration of the somatic perception scale, data were collected via a semi-structured interview format. To help determine if participants linked their symptoms to HF, they were asked follow-up questions for each symptom they identified as problematic. For example, if a participant complained of weight gain on the somatic perception scale, he/she was then asked if he/she felt that the weight gain was related to his/her HF. This technique was intended to yield a greater understanding of self-symptom recognition of HF symptoms in this
population as no measurement scales exist to measure self-symptom recognition. Interviews were audio-recorded and professionally transcribed verbatim. Transcripts were de-identified and checked for accuracy by one of the team members prior to analysis by the research team (Creswell, 2013; Miles et al., 2014).

Reliability of qualitative data was ensured by having two doctorally prepared nurse scientists who specialize in qualitative methodologies check the codes identified by the author. This helped ensure the confirmability of the findings, while their credibility was ensured through bracketing and peer debriefing. Trustworthiness was promoted by the fact that the data collectors were involved in the parent study and had genuine relationships with the participants, allowing them to feel comfortable and provide more honest and meaningful responses. In addition, semi-structured interview protocols were used for data collection to ensure that all participants were asked similar questions. Triangulation was also used in relation to the concept of self-symptom recognition, as both quantitative and qualitative methods were used to examine this concept. This is explained further below (Creswell, 2013; Macnee, 2004; Miles et al., 2014).

Sample and Setting

The sample participants for this research study were recruited from Drs. Judith Hupcey and Lisa Kitko’s (multiple principal investigators) National Institute of Nursing Research of the National Institutes of Health funded study (5-RO1-NRO13419). The aims of this parent study were:

- **AIM 1**: To identify whether there are critical variations in palliative care needs of patient-caregiver dyads between patients with a 1-year predicted survival and a 2-year predicted survival.
Sub Aim: Compare and contrast variations in patient-caregiver dyads’ palliative care needs based on:

- Predicted survival
- Various patterns of medical instability and medical stability across the terminal heart failure trajectory
- Care settings (rural versus inner city)
- Populations (age, gender, ethnic/racial groups) (J. Hupcey, personal communication, February 8, 2015).

**AIM 2:** Based on data from Aim 1: to develop an algorithm that specifies type and timing of individualized palliative care interventions to meet the needs of the patient-caregiver dyads across the terminal heart failure trajectory (J. Hupcey, personal communication, February 8, 2015).

Participants in the parent study were enrolled during an acute care hospitalization at The Penn State M.S. Hershey Medical Center or Pinnacle Health System (Harrisburg) Hospital. Participants were also enrolled in the nurse-run HF clinic at Pinnacle Health. Initial interviews took place upon enrollment in the hospital or the clinic and subsequent interviews were conducted over the phone or in the hospital if the patient was admitted.

**Participants**

Participants for this study were recruited from the above mentioned R01 funded study. For the parent study, 100 heart failure patient-family caregiver dyads (total sample, n=204; 100 patients/104 caregivers) were recruited. Enrollment continued through the middle of year 2 to allow for a 24-month follow-up for the 2-year predicted survival group (or the 1-year predicted survival group if the patient survived beyond the model’s prediction). There was no exclusion
for, gender, race, ethnicity, or any other demographic factors. Inclusion criteria for all participants included:

- Age 18 or over
- English speaking
- No evidence of psychiatric disorder or cognitive impairment that preclude insightful reflection
- Patient: Have a diagnosis of end-stage refractory heart failure (50 patients with a 1-year predicted survival and 50 patients with a 2-year predicted survival as measured by the Seattle Heart Failure Survival Model) and have an identified primary family caregiver
- Caregiver: family member (spouse, parent, child, sibling) or significant other identified by the patient as the primary caregiver
- Provide written informed consent (J. Hupcey, personal communication, February 8, 2015).

From that sample, this study sought participants with Stage D HF still participating; data from caregivers were not relevant to the questions researched here.

Purposive sampling methods (selection based on a specific characteristic: here, HF patients with a predicted survival rate of less than two years per the Seattle HF model) were used to identify and recruit participants (Creswell, 2013; 2014; Houser, 2008; Miles, et al., 2014). Demographic data from the parent study were analyzed to identify those participants with Stage D HF and their length-of-time from diagnosis with HF. Participants were categorized in two groups: those newly-diagnosed with Stage D HF less than two years earlier, and those with a chronic diagnosis of HF for two years or longer who had recently progressed to Stage D. The two year demarcation was determined based on earlier research results (Evans et al., under review; Friedman & Quinn, 2008). Institutional review board (IRB) approval had already been
obtained for the researcher as he assisted on the parent study, and so additional IRB approval was obtained solely to ask participants the additional survey and follow-up questions. After IRB approval was received (See Appendix D), participants were asked during their monthly follow-up interview if they would be interested in completing the HF Somatic Perception Scale and answering follow-up interview questions (See Appendix E). Participants were asked to complete the scale only once, so retention of subjects was not an issue.

**Study Measures**

The two main outcome measures of interest in this study were somatic awareness and self-symptom recognition. They are defined and operationalized as follows:

- Somatic awareness is the ability of an individual to know a physiological change is occurring. It was operationalized using the HF Somatic Awareness/Perception Scale, v. 3, discussed in detail in the following section.

- Self-symptom recognition is the ability of an individual to link a physiological change to a specific disease condition. It was operationalized through semi-structured interview questions, which are described in the section below titled self-symptom recognition.

**Somatic Awareness**

As noted earlier, somatic awareness was measured using the HF Somatic Perception Scale, v. 3 (C. Jurgens, personal communication, March 10, 2014), originally developed in 2006 as a tool to measure somatic awareness—the presence and perceived severity of symptoms—in adult HF patients. The original scale was a 12-item Likert scale consisting of a symptom list derived from a review of the HF scholarly literature. The original scale had a Theta reliability of 0.78 and had good construct and content validity (Jurgens, 2006). Theta reliability scores that are
closer to 1.0 are indicative of greater reliability and a score of 0.7 is typically used as the lower limit criterion for a reliable measurement (Ott & Longnecker, 2010).

For this study, version 3 of the tool was used (see Appendix F). Based on participant feedback and insights gained from subsequent research literature, version 3 was expanded to an 18-item Likert scale, with items scored 0 to 5 and with possible scores ranging from 0-90. Higher scores indicate more severe symptoms, while a zero indicates a participant reported not a single symptom. Internal consistency reliability for this scale was demonstrated with a Cronbach’s alpha of 0.80 (Sethares et al., 2014). A previous study found reliability reported at 0.83 (Altice & Madigan, 2012). Jurgens et al. (2016) reported the internal consistency of this version to be 0.90. Also convergent ($r = 0.54$, $p < 0.01$) and divergent ($r = 0.18$, $p > 0.05$) validities were supported (Jurgens et al., 2016).

**Self-Symptom Recognition**

Self-symptom recognition was measured using semi-structured interview questions, as no scales were found to measure this concept. Following each item that a participant answered positively, indicating somatic awareness, the data collector asked the participant if he/she felt that symptom was definitely related to HF or might have been related to something else. For example, if a participant complained of nausea and rated it a 3 on the HF Somatic Perception Scale, the data collector would then follow-up and ask the participant if he or she felt as though the nausea was related to HF or perhaps something else, i.e., medication side effects, gastrointestinal illness, or other causes. Based on the participant’s response, the interviewer had the freedom to ask further questions to allow the participant to clarify and/or expand his or her answer.
Data Collection

MSN or PhD prepared data collectors administered the perception scale via telephone or in-person if the participant was admitted to a hospital or at an appointment at the HF clinic. Each interview began with an ice-breaker comment; “Good Morning/Afternoon/Evening Mr./Mrs. last name. Thank you for taking the time to talk with me today.” A final thank you statement concluded the interview to thank the participant for their time (Creswell, 2014). The scale and the follow-up semi-structured questions took between 20 and 40 minutes. An interview protocol for this qualitative work was developed as described in Creswell (2014). Per the protocol, the initials of the interviewer, code number of the participant, and date were recorded on the top of the document. Following were instructions to ask the participant if he/she felt any symptoms that he/she responded yes to on the HF Somatic Perception Scale were related to HF. If the participant answered yes to this, then the data collector used a probing question, such as “tell more about that?” allowing the participant to expand on the answer if he/she chose to. Pre-testing of the scale showed that the time consumed by the three trial interviews accurately predicted length of interviews during the study.

Each participant meeting inclusion criteria was asked to complete the scale once. All participants who were approached consented to participate. Each interview was audio recorded and transcribed verbatim by a trained transcriptionist, and three of the audio recordings were compared to the transcription to ensure accuracy. All data were de-identified during the transcription process. All of the cleaned data (Perception Scale responses and corresponding interviews) were then uploaded into an encrypted password protected computer. These methods helped to ensure the anonymity of the participants and the trustworthiness of the data as described by Creswell (2013; 2014).
IRB approval was already obtained for the researcher as he has assisted on the parent study. Therefore, only an IRB modification was needed. This was requested and obtained to ask participants the additional survey and follow-up questions for this research. Data collection for this study began only after the IRB modification was approved.

**Data Analysis**

Data analysis for this study involved qualitative and quantitative methods. These will be explained below.

**Descriptive Analysis**

Participants’ demographic data are presented in tables (See Chapter 4), which were formulated by running descriptive statistics on the data. For each of the two groups analyzed (newly-diagnosed and chronic), tables include the number and mean age of participants. In addition, measures of variability are used to show the range of time and the standard deviation for demographic variables that produce interval level data (i.e., age and duration of diagnosis). Frequencies are reported for gender, marital status, and race of participants (Jones & Kottler, 2006). Finally, frequencies are reported for the 18-items in the HF Somatic Perception Scale, v. 3, ranked in descending order from the most frequently reported symptom to the least.

**Analysis of Research Questions**

The following describes how data relevant to each research question was analyzed.

*Research question #1.* Does somatic awareness differ in newly-diagnosed versus chronic Stage D HF patients?

The independent samples $t$-test-appropriate for analyzing mean score differences between two groups was the inferential statistical test used to analyze the perception scale score differences between the newly-diagnosed and chronic HF groups. A conservative $p$ value of 0.05
was set to determine if a significant difference existed between scores for the newly-diagnosed and chronic groups (Jones & Kottler, 2006)

**Research question #2.** Is there a difference in self-symptom recognition between newly-diagnosed and chronic Stage D HF patients?

To answer this question, quantitative methods were used to determine whether the groups differed in self-symptom recognition. The original research plan called for analyzing the mean number from each group who associated symptoms with HF using an independent samples Mann-Whitney U test. A $p$ value of 0.05 was planned to be set to determine whether difference existed or were the result of chance; however, since none of the participants recognized their symptoms as part of their Stage D HF, the analysis was not necessary (Jones & Kottler, 2006).

**Research question #3.** To what disease(s) do Stage D HF patients with high somatic perception scores attribute their symptoms?

Qualitative methods were used to analyze the final research question. To begin the analysis, the researcher read all data to gain an overall sense of the available information. During this stage, the researcher began to write notes in the borders of the transcripts, about the general sense of the data. Following this, coding of the data began (See Appendix G). All qualitative data were coded to align with the relevant question from the HF Somatic Perception Scale. Each interview response to each “yes” answer on the perception scale was analyzed to determine whether the participant felt that the symptom was related to HF. Any other information provided by the interviewee was also analyzed for important information. These data were coded and then analyzed (Creswell, 2013; 2014).
Reliability and Validity

The following text discusses reliability and validity of this study in both quantitative and qualitative terms. While it is impossible to control every aspect of a study, it is essential for the researcher to conduct the study with as much rigor as possible to ensure confidence in the data.

Quantitative

Reliability (a measure that can be relied on to give the same result consistently [Macnee, 2004]) of the current version of the HF Somatic Perception Scale (v. 3) was assessed at 0.80 by Sethares et al. (2014) when they reported on the tool’s internal consistency. Altice and Madigan (2012) reported the reliability (type of reliability not discussed) of the tool at 0.83. Jurgens, Lee, and Riegel (2016) reported its internal consistency to be 0.90. Also convergent \( r = 0.54, p < 0.01 \) and divergent \( r = 0.18, p > 0.05 \) validities were supported (Jurgens et al., 2016). In addition, version one of the tool (v. 2 not found in the literature) had good content validity, which was established by two nursing experts in HF (Jurgens, 2006). Construct validity was also discussed by Jurgens (2006). She reported that the scale had a low to moderate correlation with general somatic awareness (Spearman’s rho – 0.48), meaning that the scale has something in common with the general somatic awareness, but that the HF Somatic Awareness Scale does in fact measure a different construct (Jurgens, 2006). Version three of the scale is the same as version one with six additional items that were added due to participant feedback and a review of current HF literature (Altice & Madigan, 2012). Thus, the current version of the HF Somatic Perception Scale is reported to be a reliable and valid tool, one that the researcher deemed appropriate to analyze somatic awareness in Stage D HF patients.

Reliability and validity were not an issue in terms of research question three as the researcher is only looking at “yes” and “no” answers. However, it always possible that the
researcher could have miscoded the data during data entry and an obvious limitation to this question was participant self-report (Creswell, 2014; Houser, 2008).

One threat to the external validity of the study was selection effects (Houser, 2008). Due to the limited characteristics of the participants in the study, the researcher cannot generalize the findings to other populations (Creswell, 2014). For example, the findings from this study cannot be generalized to individuals with advanced HF with different racial and ethnic backgrounds.

**Qualitative**

A discussion of the rigor employed in the researcher’s qualitative data collection and analysis follows. The three methods that helped the researcher maintain rigor in his study were trustworthiness, confirmability, and credibility. Trustworthiness—the honesty of the data collected from the participants (Creswell, 2014; Macnee, 2004)—was promoted by the data collectors’ already meaningful relationship with the participants in the parent study. This meaningful relationship likely encouraged participants to share more meaningful information with the data collectors without feeling pressured or a need to censor their responses (Macnee, 2004). Trustworthiness was also maintained through the use of semi-structured interview protocols during data collection, which helped ensure that all participants had a similar experience (Macnee, 2004). In addition, the researcher reviewed all interviews for any obvious errors to increase the trustworthiness of the results (Creswell, 2014).

The next method that helped the researcher maintain rigor in his study was confirmability. Here, the researcher developed an audit trail, an ongoing process documenting decisions made during data analysis. This audit trail helped provide consistency as data was categorized data and shared (Creswell 2014; Macnee, 2004). Another process that the researcher used to enhance confirmability was regular, coordinated meetings with his advisors, which
included two experienced qualitative researchers, both of whom were the multiple principal investigators for the parent study (Creswell, 2014).

Another method enhancing credibility was triangulation, which involves using more than one approach to look at the phenomenon of interest (Macnee, 2004). Triangulation was evident when the researcher looked at self-symptom recognition using both qualitative and quantitative methods. Quantitative methods involved calculating the mean total “yes” and “no” answers from the participants on the HF Somatic Perception Scale, v. 3. Qualitative methods involved coding the response to each “yes” answer on the HF Somatic Perception Scale when the participant was asked whether the symptom was related to HF. Any other information provided by the interviewee was also analyzed for important information. These data were coded by each question from the HF Somatic Perception Scale (v. 3) and then analyzed to see whether the participant attributed the symptom to HF (Creswell, 2013; 2014). In addition, the researcher used intercoder agreement, as described by Creswell (2014)—having another researcher cross-check the codes described by the original researcher. The researcher asked his advisors (Drs. Hupcey and Kitko) to independently analyze several of the qualitative interviews and develop their own codes. Individual analysis followed by the team of three meeting face-to-face to review their analysis and ascertain if coding was consistent. If coding was not consistent, a collegial discussion occurred that allowed for the researcher to make a decision about which codes to use (Creswell, 2014).

Also, as noted earlier, the researcher and data collectors bracketed their biases, which helped ensure the credibility of the findings. In addition, the researcher used peer debriefing to enhance the accuracy of the account (Creswell, 2014). This was accomplished by asking a peer to review this study and ask questions that may have resonated with him or her. Finally, the
researcher used an external auditor, Patricia Hinchey, Ed.D., an individual who is not familiar with the researcher’s work but who has expertise in the area of research, to review the entire research project (Creswell, 2014). This enhanced the credibility of the research, as the external auditor provided an objective review of the study and asked relevant questions.

Chapter Summary

This research study measured somatic awareness and self-symptom recognition using both quantitative and qualitative methods. This is important as it provides research about two often conflated but distinct concepts, somatic awareness and self-symptom recognition, in Stage D newly-diagnosed and chronic HF patients. Participants for the study were accessed from Drs. Hupcey and Kitko’s NIH-funded parent study. All participants had Stage D HF. Somatic awareness was measured using the HF Somatic Perception Scale, v. 3; immediately after administration of the scale, self-symptom recognition was measured using follow-up semi-structured interview questions. Quantitative data were analyzed using both descriptive and inferential statistics and an analysis was performed on the qualitative data to determine where the symptoms were attributed to HF. Appropriate measures were taken to ensure the rigor of the study and thus the reliability and validity of the results.
Chapter 4: Results

This chapter will present the study results. First, the sample is described, along with frequencies of each symptom from the HF Somatic Perception Scale, v.3. Second, an analysis of the HF Somatic Perception Scale (v. 3) is presented, followed by the results of each research question.

Sample

Twenty-nine participants (10-newly-diagnosed and 19-chronic) were recruited for this study. The original 29 participants were distributed almost evenly between male and female and were primarily White, married individuals with an average age of 61 (See Table 2).

<table>
<thead>
<tr>
<th></th>
<th>FREQUENCY (n=29)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE n=29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>61</td>
<td></td>
</tr>
<tr>
<td>Standard Deviation</td>
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<td></td>
</tr>
<tr>
<td>Minimum</td>
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<td></td>
</tr>
<tr>
<td>Maximum</td>
<td>79</td>
<td></td>
</tr>
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<td></td>
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<td>45</td>
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<tr>
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<td>16</td>
<td>55</td>
</tr>
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<td></td>
</tr>
<tr>
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<td>90</td>
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<tr>
<td>Black</td>
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<td>10</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
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<td></td>
</tr>
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<td>65</td>
</tr>
<tr>
<td>Divorced</td>
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<td>21</td>
</tr>
<tr>
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<td>7</td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>DIAGNOSIS TIME</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newly</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Chronic</td>
<td>19</td>
<td>65</td>
</tr>
</tbody>
</table>
One participant was excluded from the study because of missing data. Eight additional participants were excluded from the study for invalid HF Somatic Awareness Scale scores: seven were found to have left ventricular assist devices in place, and one was found to have had a heart transplant. No significant differences were found among the excluded LVAD/heart transplant patients ($p_s > 0.31$). As shown in Table 3, the final sample (n=20) had an average age of 63 and were distributed almost evenly between male and female and were primarily White, married individuals.

<table>
<thead>
<tr>
<th>Table 3-INCLUDED PARTICIPANT DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE n=20</td>
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<tr>
<td>Mean</td>
</tr>
<tr>
<td>Standard Deviation</td>
</tr>
<tr>
<td>Minimum</td>
</tr>
<tr>
<td>Maximum</td>
</tr>
<tr>
<td>FREQUENCY (n=20)</td>
</tr>
<tr>
<td>GENDER</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>RACE</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>DIAGNOSIS TIME</td>
</tr>
<tr>
<td>Newly</td>
</tr>
<tr>
<td>Chronic</td>
</tr>
</tbody>
</table>

The two groups (newly-diagnosed and chronic) were differentiated at the two year mark because previous research suggested that the two groups vary in their perception of the disease at
this time (Evans et al., under review). Table 4 presents the demographic profile for these two groups. Examination of demographic differences (i.e., t-test) failed to indicate any significant demographic differences between the two groups ($p$s $> 0.11$).

Table 4-DEMOGRAPHIC DATA OF NEWLY-DIAGNOSED AND CHRONIC GROUPS

<table>
<thead>
<tr>
<th>AGE</th>
<th>NEWLY-DIAGNOSED</th>
<th>CHRONIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
<td>53</td>
<td>Minimum</td>
</tr>
<tr>
<td>Maximum</td>
<td>75</td>
<td>Maximum</td>
</tr>
<tr>
<td>Mean</td>
<td>63</td>
<td>Mean</td>
</tr>
<tr>
<td>Std. Deviation</td>
<td>6</td>
<td>Std. Deviation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
<th>PARTICIPANTS</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENDER</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>44</td>
<td>Female</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>56</td>
<td>Male</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>RACE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>7</td>
<td>78</td>
<td>White</td>
<td>11</td>
<td>100</td>
</tr>
<tr>
<td>Black</td>
<td>2</td>
<td>22</td>
<td>Black</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>5</td>
<td>56</td>
<td>Married</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>44</td>
<td>Divorced</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>0</td>
<td>Widowed</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Single</td>
<td>0</td>
<td>0</td>
<td>Single</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

Table 5 presents frequencies from the 18-items on the HF Somatic Perception Scale, v. 3 ranked in descending order, with the most commonly reported symptom reported first. The commonly reported symptom was “I woke up at night because I had to urinate.” In addition, this symptom was the most commonly reported symptom in both the newly-diagnosed and chronic groups. However, the most bothersome symptom to all participants was “I was tired.”
<table>
<thead>
<tr>
<th>Symptoms (in descending order, ranked according to most commonly reported symptom)</th>
<th>Total Percentage and Number Reporting Symptom</th>
<th>Percentage and Number Reporting Symptom as Quite a Bit or Extremely Bothersome</th>
<th>Percentage and Number of Newly-Diagnosed (n=9) Reporting Symptom</th>
<th>Percentage and Number Chronic (n=11) Reporting Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>I woke up at night because I had to urinate</td>
<td>85% (n=17)</td>
<td>20% (n=4)</td>
<td>89% (n=8)</td>
<td>82% (n=9)</td>
</tr>
<tr>
<td>I was tired</td>
<td>75% (n=15)</td>
<td>35% (n=7)</td>
<td>67% (n=6)</td>
<td>82% (n=9)</td>
</tr>
<tr>
<td>I had a cough</td>
<td>60% (n=12)</td>
<td>15% (n=3)</td>
<td>33% (n=3)</td>
<td>82% (n=9)</td>
</tr>
<tr>
<td>I had to rest more than usual during the day</td>
<td>55% (n=11)</td>
<td>15% (n=3)</td>
<td>44% (n=4)</td>
<td>64% (n=7)</td>
</tr>
<tr>
<td>I did not feel like eating</td>
<td>55% (n=11)</td>
<td>5% (n=1)</td>
<td>44% (n=4)</td>
<td>64% (n=7)</td>
</tr>
<tr>
<td>I had an upset stomach</td>
<td>50% (n=10)</td>
<td>20% (n=4)</td>
<td>56% (n=5)</td>
<td>46% (n=5)</td>
</tr>
<tr>
<td>My feet were swollen at the end of the day</td>
<td>40% (n=8)</td>
<td>20% (n=4)</td>
<td>33% (n=3)</td>
<td>46% (n=5)</td>
</tr>
<tr>
<td>I gained weight in the past week</td>
<td>40% (n=8)</td>
<td>25% (n=5)</td>
<td>11% (n=1)</td>
<td>64% (n=7)</td>
</tr>
<tr>
<td>I could not do my usual activities because I was short of breath</td>
<td>40% (n=8)</td>
<td>20% (n=4)</td>
<td>22% (n=2)</td>
<td>55% (n=6)</td>
</tr>
<tr>
<td>My clothes felt tighter around my waist</td>
<td>40% (n=8)</td>
<td>15% (n=3)</td>
<td>22% (n=2)</td>
<td>55% (n=6)</td>
</tr>
<tr>
<td>I could feel my heart beat get faster</td>
<td>35% (n=7)</td>
<td>5% (n=1)</td>
<td>22% (n=2)</td>
<td>46% (n=5)</td>
</tr>
<tr>
<td>I could not catch my breath</td>
<td>35% (n=7)</td>
<td>15% (n=3)</td>
<td>22% (n=2)</td>
<td>46% (n=5)</td>
</tr>
<tr>
<td>My shoes were tighter than usual at the end of the day</td>
<td>35% (n=7)</td>
<td>20% (n=4)</td>
<td>11% (n=1)</td>
<td>55% (n=6)</td>
</tr>
<tr>
<td>It was hard for me to breathe</td>
<td>35% (n=7)</td>
<td>15% (n=3)</td>
<td>11% (n=1)</td>
<td>55% (n=6)</td>
</tr>
<tr>
<td>I could not breathe if I lay down (flat)</td>
<td>30% (n=6)</td>
<td>0% (n=0)</td>
<td>11% (n=1)</td>
<td>46% (n=5)</td>
</tr>
<tr>
<td>I woke up at night because I could not breathe</td>
<td>25% (n=5)</td>
<td>5% (n=1)</td>
<td>22% (n=2)</td>
<td>27% (n=3)</td>
</tr>
<tr>
<td>Getting dressed made it hard to breathe</td>
<td>25% (n=5)</td>
<td>0% (n=0)</td>
<td>22% (n=2)</td>
<td>27% (n=3)</td>
</tr>
<tr>
<td>I felt discomfort or pain in my chest</td>
<td>20% (n=4)</td>
<td>5% (n=1)</td>
<td>11% (n=1)</td>
<td>27% (n=3)</td>
</tr>
</tbody>
</table>
Statistics on the HF Somatic Perception Scale, v. 3

Cronbach’s alpha of the revised scale was 0.89, showing that the tool is a reliable measure of somatic awareness. Pearson Product and Spearman’s Rank-Order correlations analyses were conducted to examine correlations between HF Somatic Awareness total score and the variables of self-reported years-of-age, gender, race, marital status, and diagnosis time. Diagnosis time was found to be significantly correlated with the HF Somatic Awareness total score ($r_s = 0.53, p = 0.02$). All other correlations were non-significant.

Research Question 1 Results

An independent samples $t$-test was used to analyze and interpret the results for the first research question.

Research Question: Does somatic awareness differ in newly-diagnosed versus chronic Stage D HF patients?

Analysis indicated a difference between the newly-diagnosed and chronic groups, $t(18) = -2.45$, $p = 0.03$. As shown in Table 6, the chronic group had significantly higher somatic awareness scores when compared to the newly-diagnosed group.

<table>
<thead>
<tr>
<th>Table 6-GROUP STATISTICS HEART FAILURE SOMATIC AWARENESS SCORES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DIAGNOSIS TIME</strong></td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Newly-Diagnosed</td>
</tr>
<tr>
<td>Chronic</td>
</tr>
</tbody>
</table>
Analyses also sought correlations (see Table 7) among items in the scale (See Appendix F). No negative correlations were found; the number of positive correlations is not surprising, given the high reliability of the scale and the scale’s exclusive focus on HF symptoms.
<table>
<thead>
<tr>
<th>HFSPS</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>9</th>
<th>10</th>
<th>11</th>
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<td>HFSPS3</td>
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<td>HFSPS4</td>
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<td>.457*</td>
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* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Next, a multivariate analysis of variance (MANOVA), Wilk’s Lambda, was conducted to determine if HF Somatic Awareness Scale, version 3, individual item responses differed between chronic and newly-diagnosed participants. As shown in Table 8, the MANOVA failed to indicate any significant difference between the two groups for each scale item.

<table>
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<th>EFFECT</th>
<th>WILK'S LAMBDA</th>
<th>F</th>
<th>HYPOTHESIS df</th>
<th>ERROR df</th>
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Table 8-MANOVA TEST TO DETERMINE SIGNIFICANCE OF DIAGNOSIS TIME TO HF SOMATIC AWARENESS SCALE

Research Question 2 Results

No inferential statistics were used to determine the results to this question because no patients recognized their symptoms as part of their HF disease.

Research Question: Is there a difference in self-symptom recognition between newly-diagnosed and chronic Stage D HF patients?

As stated above, the chronic group had significantly higher somatic awareness scores when compared to the newly-diagnosed group as shown in table 5, \( t(18) = -2.45, p = 0.03 \). However, none of the participants in either group was able to recognize their symptoms as being part of advanced HF.
**Research Question 3 Results**

Explorative qualitative descriptive research methods were used to gain a better understanding of participants’ ability to self-recognize symptoms of HF.

Research Question: To what disease(s) do Stage D HF patients with high somatic perception scores attribute their symptoms?

Qualitative analysis showed that none of the participants recognized symptoms from the HF Somatic Perception Scale as part of their HF. However, it cannot be said with confidence that patients were not accurately attributing the symptoms to other co-morbid condition, which most participants experienced. The following text provides examples of the qualitative analysis of the semi-structured interviews by item from the HF Somatic Perception Scale, v. 3.

Item 1: I could feel my heart beat get faster.

None of the participants related this to their advanced HF. Instead, participants most commonly recognized this symptom as being part of their atrial fibrillation or being short of breath. For example:

- “Maybe two or three times because I do have A-fib.”
- “Only when I get out of breath.”

Item 2: I could not breathe if I lay down (flat).

One participant blamed this symptom on his/her acid reflux, stating:

- “You know I have acid reflux and I’ve gotten into the habit that I never lay down very much. I’ll prop myself up more in a sitting position and that’s just because of that you know.”

No other participants linked this symptom with any other disease processes.

Item 3: I felt discomfort or pain in my chest.
Two of the participants provided feedback as to why they feel they have this symptom but neither related it to advanced HF. The symptom was linked to indigestion or unknown causes:

- “Once in a while but they tell me it’s not my heart. It’s indigestion or something like that.” I get the symptom “when I eat.”
- “I feel different things but I’m not sure what it is.”

Item 4: I had an upset stomach.

None of the participants related this symptom to advanced HF but instead attributed it to having an upset stomach, indigestion, medication, and previous gastric bypass surgery. Quotes from the participants included:

- “One time that I got up and I had a belly ache and I went and had a good bowel movement and it went away.”
- “Oh I had indigestion the other day I didn’t take my Prilosec.” “… I have acid reflux and it wasn’t because of my heart.”
- “Oh my stomach is upset all the time. I don’t know if it’s the medicines that bother me or what but I have heart burn almost every day.”
- “Well that’s hard to detect because I get upset stomachs with my gastric bypass. Like I just threw up the other day. But I don’t think it was due to my heart. I think it was due to the gastric bypass.”

Item 5: I had a cough.

Participants did not associate this symptom with advanced HF disease but to being congested, having a sinus infection, having a cold, his/her fluid being up, and/or having phlegm. Past interviews from the parent study were analyzed to determine whether a participant
complaining of “fluid being up” ever related those terms to advanced HF, but the answer was unclear. Comments on this symptom included:

- “Yeah I cough off and on, not all the time. Right now I feel a little congested in my bronchial tubes or whatever you want to call them but it’s not in my lungs. It’s hard to explain. I never cough anything up.”
- “That’s my sinuses.”
- “It’s all due to the cold.”
- “Sick with a cold.”
- “There again when I get the fluid up, I get the wheezing and a little bit of cough but not much.”
- “Yeah I’ve got that. I’ve been coughing up phlegm for I don’t know a month now I guess. I wouldn’t say it’s extreme but just below that because if I cough too much and I have to wind up using the nebulizer. I get shortness of breath then from trying to cough up the phlegm.”

Item 6: I was tired.

Once again, participants did not relate being tired to their advanced HF, but instead related being tired to how well he/she slept at night, activity level, medications, and back issues:

- “Oh I’m always tired but it all depends on my night of sleep you know.”
- “Yeah I feel tired off and on. Sometimes I don’t know it just hits me in weird times.”
- “Because this chemo makes me tired.”
- “If I do a lot of going up and down the steps then I get tired, but like on Monday it’s my wash day so I’m downstairs most of the time and then if the wash basket needs to be
carried upstairs I just put it at the door and then when my husband goes up he just takes it up for me.”

- “Yeah I’m usually always like that. I don’t know if it’s all the medicine I’m on or what.”
- “Yeah but it doesn’t come from my heart. I hurt my back. I fell.”

Item 7: I could not catch my breath.

No participants attributed this symptom to their advanced HF. Responding participants blamed the symptom on coughing and hot air:

- “… it’s when you first get into the tub and that hot steam hits you it will do it then sometimes and I’ll take 3, 4, or 5 really deep big breaths and I can make it go away.”
- “Yeah when I’m doing the coughing and that.”

Item 8: My feet were swollen at the end of the day.

Participants attributed this symptom to swelling, but did not link the swelling to advanced HF. Because of this response, past interviews from the parent study were analyzed to determine if at any time the participants who attributed swollen feet to swelling ever linked swelling to advanced HF. Analysis indicated they did not. Responses included:

- “Well they’re always kind of like swelled. I can’t really feel them because of being diabetic.”
- “I was swollen – my ankles were until I took that water pill.”

Item 9: I woke up at night because I could not breathe

The single participant who reported this symptom attributed it to snoring.

- “I woken up because I snore. I’m pretty sure that has woken me up because I notice when I’m taking a nap and if I’m not lying flat on my back I gasp. It’s like I can feel my throat is closed.”
Item 10: My shoes were tighter than usual at the end of the day.

Again, only one participant complained of this symptom but did not relate it to a disease process:

- “Oh I always have a little swelling at the end of the day, yeah. Just slightly.”

Item 11: I gained weight in the past week.

Participants who recognized this symptom as part of a disease process mentioned taking medication to control it and also discussed water build up:

- “Well I had gained a little bit, I had a little bit of water buildup and the cardiologist gave me a pill that I’m supposed to take if I get too much. I took one this week one time and that brought my weight back.”
- “It fluctuates the whole week you know up and down. I take extra Bumex.”

With these quotes, past interviews from the parent study were analyzed to determine if anywhere the words “water buildup” and/or “Bumex” could be associated with their HF and this determination could not be made.

Item 12: I could not do my usual activities because I was short of breathe.

Only one participant related this symptom to a disease process:

- “Well my cold.”

Item 13: Getting dressed made it hard to breathe.

The two participants that answered positively to this symptom related the symptom to activity and fluid levels:

- “Maybe bending down to put my shoes on. Things like that.”
- “I get awful tired. When my fluid is up again I get awful tired taking a shower and getting dressed, yes.”
Once again past interviews from these two participants were analyzed to determine if they ever participants attributed the word “fluid” to advanced HF, and no evidence was found that they did.

Item 14: My clothes felt tighter around my waist.

The only participant who answered this item did not relate it to a specific disease process but rather stated:

- “Yeah progressively you know what I mean. I refuse to go above a 34 waist so I will stay in these pants.”

Item 15: I woke up at night because I had to urinate.

Four participants who responded that they had this symptom elaborated on this during the semi-structured interview process, relating it to growing older, taking water pills, and water intake:

- “Yeah I usually do that sometimes. I get up during the night. It all depends on how much water I go till I go to bed that I pee a lot. Sometimes I don’t pee a whole lot maybe two or three times.”
- “I do that at least twice a night with all my water pills.”
- “Yes I have that every night. Part of the elderly routine let’s put it that way.”

Past interviews from the participant that used the words “water pills” were analyzed from the parent study to determine if the words “water pills” could be attributed to their advanced HF.

This distinction could not be made.

Item 16: I had to rest more than usual during the day.

Only one participant responded that this symptom was related to a disease process, stating
• Yeah but that’s not because of the heart either. It’s because of the back.

Item 17: It was hard for me to breathe.

No participants linked this symptom to a disease process.

Item 18: I did not feel like eating.

Four participants recognized that this symptom was related to a disease or something in particular, such as heartburn, not wanting to eat, not liking meat, or being tired

• “Sometimes I’m just too tired to get up and go do it. Sometimes especially if my back is bothering me I just don’t feel like eating.”

• “Well I’ve been having some issues with eating. I’m not a real big meat eater anymore. I used to eat meat a lot but I’m just not big about meat. I can eat it or I can leave it go. I don’t know sometimes if I eat meat I kind of like I look at it and turns my stomach and I can’t eat. But I make up on other stuff. I eat like my potatoes and whatever.”

• “Yeah. Sometimes I wouldn’t care not to eat. With the diabetes you know I have to eat something.”

• “I get like that. It’s usually at supper time. I don’t want anything to eat or I eat very little. I have heartburn usually.”

None of the participants related this symptom to their advanced HF.

Chapter Summary

The final sample for this study (n=20) had an average age of 63 and were distributed almost evenly between male and female and were primarily white, married individuals. Data analysis revealed no significant demographic differences between the two groups (ps > 0.11). Statistics on the HF Somatic Perception Scale, v. 3, revealed a Cronbach’s alpha of 0.89, showing that the tool is a reliable measure of somatic awareness. Analysis of the scale also
revealed many positive correlations among various items, which will be further discussed in chapter 5. Pearson Product and Spearman’s Rank-Order correlations analyses were conducted to examine correlations between HF Somatic Awareness total score and the variables of age, gender, race, marital status, and diagnosis time. Diagnosis time was the only variable significantly correlated with the HF Somatic Perception total score ($r_s = 0.53$, $p = 0.02$). An independent samples $t$-test was used to determine if somatic awareness scores differ in newly-diagnosed versus chronic Stage D HF patients. Analysis indicated a difference between the newly-diagnosed and chronic groups, $t(18) = -2.45$, $p = 0.03$, with the chronic group having a mean somatic awareness score of 28.82 and the newly-diagnosed group having a mean somatic awareness score of 12.33. In addition, frequency analyses of the scale by item showed that the symptom of “I woke up at night because I had to urinate” was the most commonly reported symptom in both groups. Next, explorative qualitative descriptive research methods were used to gain a better understanding of participants’ ability to self-recognize symptoms of HF to their HF disease process. Qualitative analysis showed that none of the participants recognized symptoms from the HF Somatic Perception Scale, v. 3. However, it cannot be said with confidence that patients were not accurately recognizing symptoms to another co-morbid condition.
Chapter 5: Discussion

This chapter presents significant findings from the data analyses and application of the middle-range Theory of Symptom Management. In addition, study limitations and strengths are discussed, along with clinical implications and recommendations for future research.

Overview of Significant Findings

Research question 1. An independent samples t-test was used to analyze and interpret the results from the first research question: Does Somatic Awareness differ in newly-diagnosed versus chronic Stage D HF patients?

Analysis indicated a difference between the newly-diagnosed and chronic groups, $t(18) = -2.45$, $p = 0.03$, with the newly-diagnosed group ($n=9$) having a mean HF Somatic Awareness score of 12.33 and the chronic group ($n=11$) having a mean HF Somatic Awareness score of 28.52. In addition, Pearson Product and Spearman’s Rank-Order correlations analyses were conducted to examine correlations between HF Somatic Awareness total score and the variables of age, gender, race, marital status, and diagnosis time. Diagnosis time was found to be significantly correlated with the HF Somatic Awareness total score ($r_s = 0.53$, $p = 0.02$). All other correlations were non-significant.

These findings are both statistically and clinically significant. This is the first study that investigated somatic awareness in advanced HF patients. It supports the work of Friedman and Quinn (2008), who found chronic HF patients were more likely than newly-diagnosed patients to attribute their symptoms to HF. However, caution is in order in noting the linkage. Friedman and Quinn (2008) used the term symptom recognition but did not clearly define it, so exactly which of several closely related concepts they actually measured is unclear.
Findings here appear unrelated to the findings of Bass and colleagues (2004), who conducted an exploratory study of body awareness in persons with HF and found that younger HF patients (less than 45 years-of-age) scored higher on the Body Awareness Questionnaire (i.e., were better able to perceive HF symptoms) than older patients. Comparisons of the two groups in this study do not apply, because the ages of the participants were not significantly different—a mean age of 63.22 years for newly-diagnosed patients and of 62.82 years for chronic patients.

**Research question 2.** The second research question was: Is there a difference in self-symptom recognition between newly-diagnosed and chronic Stage D HF patients? Data analysis indicated that no patients recognized their symptoms as being part of HF.

While the chronic group had significantly higher mean somatic awareness scores than the newly-diagnosed group, no participant in either group recognized symptoms as related to advanced HF. While this was surprising, it should be noted that 74% of patients with HF have at least one other co-morbid condition (van Deursen, 2013), which may make it difficult for HF patients to properly attribute their symptoms. As a result, a definitive conclusion cannot be derived from this study: it is unclear whether or not participants who reported experiencing a symptom were correct in attributing it to something other than HF, such as having a cold, another disease, previous surgeries, or other feasible explanations.

**Research question 3.** Evidence related to the third research question shed light on patient attribution of symptoms. This question was: To what disease do Stage D HF patients with high somatic perception scores attribute their symptoms?

Simply stated, none of the participants in this study related the symptoms from the HF Somatic Perception Scale, v.3, to HF disease. In fact, they appeared to relate symptoms to almost anything but advanced HF.
For example, participants in the study related their hearts beating faster (item 1) to atrial fibrillation. In addition, many of the participants related their symptoms to acid reflux, previous surgeries, and other co-morbid diseases. Explanations for feeling the symptom of chest discomfort included “Once in a while but they tell me it’s not my heart. It’s indigestion or something like that,” or to experiencing the symptom “when I eat.” Clearly this participant relates his/her chest discomfort to indigestion rather than advanced HF disease—but, unfortunately, whether or not this attribution is accurate is unknown. Future longitudinal and physiological studies need to be conducted.

Participants had a variety of explanations for their experience of the fourth symptom on the scale, “I had an upset stomach.” These included: “Oh I had indigestion the other day I didn’t take my Prilosec.” “I have acid reflux and it wasn’t because of my heart.” “Oh my stomach is upset all the time. I don’t know if it’s the medicines that bother me or what but I have heart burn almost every day.” “Well that’s hard to detect because I get upset stomachs with my gastric bypass. Like I just threw up the other day. But I don’t think it was due to my heart. I think it was due to the gastric bypass.” It is clear that none of the participants who responded that they had an upset stomach in the last week related the symptom to advanced HF. Instead, they correlated the symptom to a previous surgery, indigestion, and medications. For item 5, which targeted having a cough, participants offered such explanations as: “That’s my sinuses.” “It’s all due to the cold.” “Sick with a cold.” Again, none of the participants related the symptom to advanced HF, instead relating it to having a cold and/or sinus issues.

For item 6, which asked about being tired, participants offered many explanations—none of them being advanced HF. Examples included: “Oh I’m always tired but it all depends on my night of sleep you know.” “Because this chemo makes me tired.” “Yeah I’m usually always like
that. I don’t know if it’s all the medicine I’m on or what.” “Yeah but it doesn’t come from my heart. I hurt my back. I fell.” Explanations included chemotherapy, medication use, back pain, and quality of sleep. Again it is not possible to tell whether these attributions were accurate—but it does appear telling that participants did not ever consider a possible relationship between fatigue and advanced HF.

For item 11 regarding weight gain, participants tangentially related the symptom to advanced HF disease by mentioning “water build up” and “Bumex.” However, when earlier interviews were analyzed, no evidence appeared that participants’ linked those words to HF; therefore, no HF attribution could be identified. For item 15 asking about urination at night, participants offered aging, water pills, and water intake as causes: “Yeah I usually do that sometimes. I get up during the night. It all depends on how much water I go till I go to bed that I pee a lot. Sometimes I don’t pee a whole lot maybe two or three times.” “I do that at least twice a night with all my water pills.” “Yes I have that every night. Part of the elderly routine let’s put it that way.” Once again, past interviews from the participants who responded to this question were analyzed to determine if the words “water pills” had been linked to HF, but no evidence appeared for the correlation; thus, it cannot be confidently said that participant(s) linked frequent urination to HF. Future research might ask more probing questions during interviews to better clarify terms used by the participants.

Finally, for item 18: I did not feel like eating. Participants related the symptom to fatigue, not liking meat, not wanting to eat, or another disease process as the following quotes demonstrate: “Sometimes I’m just too tired to get up and go do it. Sometimes especially if my back is bothering me I just don’t feel like eating.” “Well I’ve been having some issues with eating. I’m not a real big meat eater anymore. I used to eat meat a lot but I’m just not big about
meat. I can eat it or I can leave it go. I don’t know sometimes if I eat meat I kind of like I look at it and turns my stomach and I can’t eat. But I make up on other stuff. I eat like my potatoes and whatever.” “Yeah. sometimes I wouldn’t care not to eat. With the diabetes you know I have to eat something.” “I get like that. It’s usually at supper time. I don’t want anything to eat or I eat very little. I have heartburn usually.” None of the participants related this symptom to advanced HF.

Previous research showed that most individuals are aware of symptoms such as shortness of breath and weight gain (AHA, 2013). While advanced HF patients may be aware of the symptoms, the bigger issue that this study shows is that some patients may be having these symptoms, but they are not identifying the symptoms as part of their HF disease process.

In addition, Hertzog, Pozehl, and Duncan (2010) discovered three different sets of symptom clusters in the participants in their descriptive study. They found that the higher the New York Heart Association level (levels III and IV) of HF, the more symptoms participants reported including shortness of breath at rest and when lying down, difficulty sleeping, forgetfulness, dizziness, bloating, heart palpitations, and depression. Moreover, Lee et al. (2010) found the physical symptom cluster of dyspnea, fatigue, low energy, and sleep disturbances, which was very similar to the findings by Hertzog et al., (2010). The participants in this study displayed many of these symptoms; however, again they are not recognizing that their symptoms are related to their advanced HF.

So, why is this an issue? If patients are not relating their symptoms to their advanced HF, then proper self-care and treatment can be delayed or missed all together. The literature review indicated that the main reasons for a delay in healthcare utilization included patients: being unsure that their health was deteriorating; having a desire to “wait and see” what would happen;
and, lacking trust in the healthcare system (Patel et al., 2007). This study supports the findings by Patel et al. (2007) as participants in this study were unsure that their health was deteriorating in relation to their advanced HF.

**Correlations of items in the tool.** Analyses to identify correlations (see Table 7, p. 69) among items in the HF Somatic Perception Scale, v. 3 (See Appendix F) produced no negative correlations. The number of positive correlations was not surprising based on the high reliability of the scale; Cronbach’s alpha of the revised scale was 0.89 in this study, and all questions directly focused on HF symptoms.

Positive correlations for the tool included:

- Item 4 with items 1 and 3
- Item 5 with item 3
- Item 6 with item 5
- Item 7 with item 1 and 5
- Item 8 had no correlations
- Item 9 with item 7
- Item 10 with items 4 and 8
- Item 11 with items 1, 2, 4, 8, and 10
- Item 12 with items 2, 8, 10, and 11
- Item 13 with items 7, 8, 9, 11, 12, and 13
- Item 14 with items 1, 4, 7, 8, 10, 11, and 13
- Item 15 had no correlations
- Item 16 with item 1, 3, and 6
- Item 17 with items 1, 3, 4, 7, 10, 11, and 14
• Item 18 with item 6

It is interesting to note which items clustered together in these correlations. For example, item 11 “I gained weight in the past week” was positively correlated with item 1, “I could feel my heart beat get faster”; item 2, “I could not breathe if I lay down (flat)”; item 4, “I had an upset stomach”; question 8, “My feet were swollen at the end of the day”; and item 10, “My shoes were tighter than usual at the end of the day.” In this cluster of items, fluid volume overload is the obvious theme that emerges.

The next item with correlations reflecting a common theme was question 13, “Getting dressed made it hard to breathe.” That statement was positively correlated with item 7, “I could not catch my breath”; item 8, “My feet were swollen at the end of the day”; item 9, “I woke up at night because I could not breathe”; item 11, “I gained weight in the past week”; item 12, “I could not do my usual activities because I was short of breath”; and item 13, “Getting dressed made it hard to breathe.” Respiratory distress is the theme that emerges from this cluster.

The next item that showed a positive correlation with several questions was item 14, “My clothes felt tighter around my waist.” This question was positively correlated with item 1, “I could feel my heart beat get faster”; item 4, “I had an upset stomach”; item 7, “I could not catch my breath”; item 8, “My feet were swollen at the end of the day”; item 10, “My shoes were tighter than usual at the end of the day”; item 11, “I gained weight in the past week”; and item 13, “Getting dressed made it hard to breathe.” Here, a common theme of weight gain emerges.

The final item that positively correlated with several items was item 17: “It was hard for me to breathe.” This item was positively correlated with item 1, “I could feel my heart beat faster”; item 3, “I felt discomfort or pain in my chest”; item 4, “I had an upset stomach”; item 7, “I could not catch my breath”; item 10, “My shoes were tighter than usual at the end of the day”;
item 11, “I gained weight in the past week”; and item 14, “My clothes were tighter around my waist.” A specific theme does not emerge as clearly from this group of questions because they suggest both fluid overload and respiratory issues. However, the correlations do illustrate that HF impacts not just one but multiple body systems.

Like the work of Hertzog et al. (2010) and Lee et al. (2010), this study provides support for the appearance of symptom clusters do in HF patients—although this study identified different clusters than the other works. Still, this study offers further support for symptom clusters as a relevant research area that needs further attention.

**The Symptom Management Theory and Advanced Heart Failure**

The Symptom Management Theory has been commonly used as a framework in healthcare related research studies (Baggott, Cooper, Marina, Matthay, & Miaskowski, 2012; Bay & Bergman, 2006; Coleman et al., 2006; Fuller, Welch, Backer, & Rawl, 2005; Hardie, Janson, Gold, Carrieri-Kohlman, & Boushey, 2000; Hearson, McClement, McMillian, & Harlos, 2011). It has been used as a framework to support research on battered women, HIV, asthma, traumatic brain injury, and palliative care, but not HF research. This study supports the use of The Theory of Symptom Management in the advanced HF population as it served as an appropriate framework for this research. In addition, this theory has been used to support various research designs including descriptive survey research and qualitative research and thus this study further supports the use of this theory as a framework for this quantitative and qualitative research designs.

**Study Limitations and Strengths**

Limitations to this study include the small sample size with limited ethnic and racial diversity, so that findings cannot be generalized to the larger advanced HF population. The
parent study’s total sample could not be included because before data collection for this study began, patients had died, or completed their two year participation in the parent study, or had an intervention that changed perceptions of heart failure symptoms (e.g., mechanical support device or heart transplant). In addition, since an explorative cross-sectional survey design was used, along with an explorative qualitative descriptive research design, data were not collected over time. Finally, many of the participants had co-morbid conditions with symptoms similar to those of HF, which may have decreased the accuracy of participants’ self-symptom recognition.

Strengths of the study include using a reliable and valid tool to measure the concept of somatic awareness. The HF Somatic Perception scale, v. 3, was found to have a Cronbach’s alpha 0.89 in this study and in other studies, Sethares et al. (2014) found the internal consistency reliability of the tool at 0.80 and Altice and Madigan (2012) reported the reliability (type of reliability not discussed) of the tool at 0.83. In addition, a recent study by Jurgens et al., (2016) reported the internal consistency of the HF Somatic Awareness Scale, v. 3, to be 0.90. Also convergent \( r = 0.54, p < 0.01 \) and divergent \( r = 0.18, p > 0.05 \) validities were supported.

In addition, trustworthiness of data was promoted by the fact that data collectors already had a meaningful relationship with the participants, developed during Drs. Hupcey and Kitko’s parent study. These personal relationships encouraged participants to share meaningful information with the data collectors without feeling pressured or feeling a need to censor their responses (Macnee, 2004). Trustworthiness was also enhanced through the use of semi-structured interview protocols during data collection, which helped ensure that all participants had a similar experience (Macnee, 2004). In addition, the researcher reviewed all interviews for any obvious errors (Creswell, 2014).
To help ensure confirmability, the researcher developed an audit trail, involving ongoing documentation of decisions made during data analysis. The audit trail helped ensure consistency as data was categorized and shared (Creswell 2014; Macnee, 2004). Confirmability was also promoted by regular, coordinated meetings of the researcher and his advisors, including two experienced qualitative researchers who were the principal investigators for the parent study (Creswell, 2014).

Triangulation, which involves using more than one approach to look at phenomenon of interest (Macnee, 2004), promoted credibility. In this case, self-symptom recognition was investigated using both qualitative and quantitative methods. In addition, the researcher used intercoder agreement, as described by Creswell (2014), to cross-check the codes described by the original researcher. The researcher’s advisors independently analyzed several of the qualitative interviews and developed their own codes, which were compared to the researcher’s in three face-to-face team meetings. Analysis revealed that coding was consistent among all reviewers.

Finally, the researcher and data collectors bracketed their biases to ensure the credibility of findings, and the researcher used peer debriefing to enhance accuracy (Creswell, 2014). Finally, Patricia Hinchey, Ed.D., served as an external auditor to review the entire research project, enhancing credibility by providing an objective review and asking relevant questions. (Creswell, 2014).

**Clinical Implications**

Although this study does not allow for findings to be widely generalized, it does provide useful clinical implications. By understanding that chronic advanced HF patients have higher mean somatic awareness scores, healthcare providers can work with this population of patients more aggressively to help them understand and control their symptoms. Also, since the study
indicates that advanced HF patients are not recognizing that their symptoms may be caused by that disease, it suggests that healthcare providers might do more to implement educational interventions designed to help this population better understand signs and symptoms of the HF disease process.

In addition, this study has palliative care health policy implications. Results of this study show those patients with Stage D HF who have less than two years life expectancy are having troublesome symptoms and are not recognizing the symptoms as part of their HF disease process. Therefore, these patients are unable to implement proper self-care or reach out for needed healthcare resources. Palliative care interventions, which focus on symptom relief and improving the quality of life, would be ideal for this patient population. Even though palliative care teams continue to grow in the U.S., more needs to be done to ensure all patients with a serious chronic illness and a limited life span have access to these services. Therefore, further policies need to be put into effect to continue the growth of palliative care services in the U.S. (Center to Advance Palliative Care, 2012).

**Recommendations for Future Research**

Based on the findings in this study, future research needs to focus on a more diverse population of advanced HF patients. In addition, a longitudinal design would allow researchers to examine changes over time (Creswell, 2009) and to better understand if time is a variable that impacts changes in somatic awareness and self-symptom recognition in the advanced HF population. The benefits of longitudinal study were demonstrated in the Framingham study, which is seminal in the study of heart disease (Framingham Heart Study, 2015).

Also, additional quantitative measures might be used to help validate both the quantitative responses to the HF Somatic Awareness Scale, v. 3, and the qualitative responses
from the semi-structured interviews. For example, participants might be provided with non-invasive pulse-oximetry devices, electronic scales to measure weight, and a researcher-designed log to document weights. These quantitative measures could help confirm qualitative responses, as such measures are generally more accurate than other forms of data collection (Nieswiadomy, 2012). For example, if a participant complained that his or her heart rate was faster than usual during the last week, downloaded data could be checked to confirm the self-report.

In addition, although the version 3 HF Somatic Perception Scale was found to have good reliability and validity (Jurgens et al., 2016), further scale development should be explored. The findings of this study raise concern about the validity of the scale. How can it be a valid measure of HF somatic awareness if none of the participants related their symptoms to HF? It is plausible that the scale is measuring only general somatic awareness. Another possible issue might be the scale’s use of the word “bothersome.” If someone living with HF for many years has become accustomed to having the symptoms, he/she may not find the symptoms “bothersome” any longer. The scale used in this study might be revised, for example, to ask how many days in the last week a patient had the symptoms listed in the scale (e.g., 0, 1-2, 3-4, 4-6, or every day). Another possible revision is to add follow-up questions to the Perception Scale, so that somatic awareness and self-symptom recognition could be studied using a single tool. Finally, perhaps a scale might be developed based on recent literature exploring symptom clusters (Hertzog et al., 2010; Lee et al. 2010).

Finally, the concepts of somatic awareness and self-symptom recognition in advanced HF patients and their response to symptoms need to continue as focus of future research. Response to symptoms refers to what actions an individual takes in response to the symptoms being experienced (Dodd et al., 2001). Through such investigation, researchers can improve
understanding of self-care practices around healthcare utilization among this population of patients, building on previous research that indicates an average delay of two to three days between HF exacerbations and patient response (Evangelista, Dracup & Doering, 2002; Gravely-Witte, Jurgens, & Tamim, 2010; Nieuwehuis, Jaarsma, Van Veldhuisen, & Van Der Wal, 2011). This delay is critical to note as it can imply that patients are not recognizing their symptoms or are not recognizing that their symptoms are part of worsening HF. Therefore, research on the entire symptom experience concept can provide important insights. In addition, the Theory of Symptom Management offers multiple concepts that can guide interventional research studies; more specifically, its concepts of management strategies and outcomes can be employed to improve understanding of which interventions best improve outcomes in advanced HF patients (Dodd et al., 2001).

**Chapter Summary**

Results from the study showed that chronic Stage D HF patients had higher mean somatic awareness scores than newly-diagnosed patients. In addition, results showed that none of the participants recognized any of the symptoms from the HF Somatic Perception Scale, v. 3, as possibly linked to advanced HF disease. However, this finding must be viewed cautiously as many of the participants had other co-morbid conditions that may present with symptoms similar to HF, making it difficult to determine the true accuracy of the participants’ self-symptom recognition. Also, due to the small homogenous sample, results cannot be generalized to the general advanced HF population. Future longitudinal studies with physiological measures are needed to better measure somatic awareness and self-symptom recognition. In addition, interventional and outcome research needs to be conducted to better improve self-care and healthcare utilization of patients with advanced HF. However, this study provides a strong
foundation for future studies as researchers work to improve the lives of patients living with Stage D HF.
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124.


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## Appendix D-IRB Approval

### APPROVAL OF SUBMISSION

**Date:** October 19, 2015  
**From:** Susie Walmer, IRB Compliance Specialist  
**To:** Judith Hupcey

<table>
<thead>
<tr>
<th>Type of Submission:</th>
<th>Modification and Continuing Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study:</td>
<td>Comprehensive Palliative Care for Patients with Heart Failure and Their Family Caregivers</td>
</tr>
<tr>
<td>Principal Investigator:</td>
<td>Judith Hupcey</td>
</tr>
<tr>
<td>Study ID:</td>
<td>PRAMS22307EP-</td>
</tr>
<tr>
<td>Submission ID:</td>
<td>MODCR00001872</td>
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<tr>
<td>Funding:</td>
<td>National Institutes of Health (NIH)</td>
</tr>
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<td>IND, IDE, or HDE:</td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>

**Documents Approved:**  
- 22307EP_ABSTRACT (3-18-14), Category: IRB Protocol  
- Pinnacle APPROVAL_LETTER_12-9_14 (0.01), Category: Collaborating Approval Materials  

**Review Level:** Expedited
On 10/19/2015, the IRB approved the above-referenced Modification and Continuing Review. This approval is effective through 10/18/2016 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 10/18/2016, approval of this study expires on that date.

To document consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu). These requirements include, but are not limited to:

- Documenting consent
- Requesting modification(s)
- Requesting continuing review
- Closing a study
- Reporting new information about a study
- Registering an applicable clinical trial
- Maintaining research records

This correspondence should be maintained with your records.
Appendix E-Consent for Research

CONSENT FOR RESEARCH

Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: Comprehensive Palliative Care For Patients with Heart Failure and Their Family Caregivers

Principal Investigator: Judith E. Hupcey, EdD, RN
Associate Professor of Nursing

Participant’s Printed Name: __________________________

This is a research study. Research studies include only people who want to take part. This form gives you information about this research, which will be discussed with you. It may contain words or procedures that you don’t understand. Please ask questions about anything that is unclear to you. Discuss it with your family and friends and take your time to make your decision.

1. **Purpose of the Research:**
   You are being offered the opportunity to take part in this research because you are presently hospitalized or were recently hospitalized with a diagnosis of heart failure. The purpose of this research is to enroll persons with heart failure and discuss this illness so that we may get a better understanding of what it is like to live with this diagnosis and the needs of patients and their family caregivers.
   Approximately 375 participants will be enrolled.

2. **Procedures to be Followed:**
   We will ask you to participate in an audio-recorded interview about living with heart failure and/or complete a short survey rating your experiences with heart failure and its treatment. If you agree to participate this is what you can expect:
   - You will be asked to read and sign this consent form.
   - A member from the research team will meet you to set up a time and place for the interview/survey
• completion.
• If you are hospitalized at the time the interview is scheduled, and if you are stable and agree, we will come to your room and do the interview.
• If you are out of the hospital and want us to come to your home, we will conduct the interview in a quiet, private area of your home.
• You will be interviewed and audio-recorded about your experiences in living with heart failure and/or asked to complete a short survey. You do not need to answer any question that makes you uncomfortable.
• You may be asked if we may contact you monthly for up to two years by phone (or in-person if you are in clinic or hospitalized) to see what has gone on since our last conversation and how you are feeling health-wise.
• All interviews, face-to-face or by phone will be audio-recorded.
• Your name or any other identifying information will be removed from the recorded interview during transcription and not be recorded on the survey form.

3. **Discomforts and Risks:**
   As you talk about your illness, you may feel emotional as memories and situations are relived. Or you may tire and need to stop the interview sooner than expected. If these situations occur you may:
   • Stop the interview.
   • Restart the interview when you are ready and agree to continue.
   • Be asked to make another appointment to continue the interview at a later time.

   Potential loss of confidentiality.

4. **Possible Benefits:**
   • **Possible benefits to the participant:**
     • You will not benefit directly from taking part in this research study.
   • **Possible benefits to others:**
     • Information from this research may help develop interventions to help other patients and families in similar situations.
5. **Other Options that Could be Used Instead of this Research:**
   - You do not have to take part in this research study.

6. **Time Duration of the Procedures and Study:**
   - If you agree to participate in the study, the audio-recorded interview and survey completion will take about 30-60 minutes.
   - After the first interview, we may ask to call you every month for up to two years.
   - If you agree to participate in the two year study, this would include monthly contacts with a short interview that should take approximately 10 minutes with longer interviews (30-60 minutes) every three months.

7. **Statement of Confidentiality:**
   - **Privacy and confidentiality measures:**
     - You will be interviewed (audio-recorded) by a member of the research team.
     - Your audio-recording will be labeled with a code, date, and time.
     - The principal investigators and co-investigators will have access to the list that links the code number to your name, which will be kept separate from the audio-recorded interviews, transcripts, and surveys.
     - Any information in the data that can identify you will be removed once the audio-recordings are transcribed.
     - The person who transcribes the audio-recording will not have access to your name, but will have access to the audio-recording with potentially identifying information.
     - The transcripts will be reviewed and analyzed by the research team only.
     - Your audio-recorded interviews will be encrypted and placed on a password-protected computer and transcripts will be secured in a locked office at The Pennsylvania State University, College of Nursing.
     - The audio-recorded interviews will be erased from the recorder once uploaded on the computer and erased from the computer upon completion of the study.
     - In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

   - **The use of private health information:**
     - Health information about you will be collected if you choose to be part of this research study. Health information is protected by law as explained in the HMC Privacy Notice. If you have not received this notice, please request a copy
from the researcher. At The Milton S. Hershey Medical Center (HMC) and Penn State College of Medicine (PSU) your information will only be used or shared as explained and authorized in this consent form or when required by law. It is possible that some of the other people/groups who receive your health information may not be required by Federal privacy laws to protect your information and may share it without your permission.

- If you choose to participate, you are free to withdraw your permission for the use and sharing of your health information at any time. You must do this in writing. Write to Dr. Hupcey and let her know that you are withdrawing from the research study. Her mailing address is:
The Pennsylvania State University
College of Nursing 90
Hope Drive Hershey,
PA 17033

- To participate in this research you must allow the research team to use your health information. If you do not want us to use your protected health information, you may not participate in this research.

- Your permission for the use, retention, and sharing of your identifiable health information will expire at the completion of the study of the study or within five years. At that time the research information identifying you will be removed from such research results at HMC. Any research information in your medical record will be kept indefinitely.

- If you withdraw your permission:
  - We will no longer use or share medical information about you for this research study, except when the law allows us to do so.
  - We are unable to take back anything we have already done or any information we have already shared with your permission.
  - We may continue using and sharing the information obtained prior to your withdrawal if it is necessary for the soundness of the overall research.
  - We will keep our records of the care that we provided to you as long as the law requires.

- The research team may use the following sources of health information
  - Information collected during the audio-recording and transcribed interviews
- Age
- Medical diagnosis
- Address and phone number
- Representatives of the following people/groups within HMC/PSU may use your health information and share it with other specific groups in connection with this research study.
  - The principal investigator, Dr. Judith Hupcey
  - The HMC/PSU Institutional Review Board
  - The HMC/PSU Human Subjects Protection Office
  - The Co-Investigators, Dr. Kitko, Dr. Boehmer, Ms. Palese, and Ms. Pinto.
- The above people/groups may share your health information with the following people/groups outside HMC/PSU for their use in connection with this research study. These groups, while monitoring the research study, may also review and/or copy your original PSU/HMC records.
  - The Office of Human Research Protections in the U. S. Department of Health and Human Service

8. **Costs for Participation:**
   - **Cost:** There will be no cost for participating in this study. You are not waiving any legal rights you may have by signing this form.

9. **Compensation for Participation:**
   You will receive a $10.00 gift card for each interview in which you participate.

10. **Research Funding:**
    - The investigators are receiving a grant from the National Institutes of Health, National Institute of Nursing Research to support this study.

11. **Voluntary Participation:**
    - Taking part in this research study is voluntary. If you choose to take part in this research, your major responsibilities will include being available at the agreed upon location, at a specific time, to be interviewed and audio-recorded by a member of the research team for approximately 30-60 minutes every three months with monthly contact lasting approximately
10 minutes and be available for follow-up interviews which may include face to face or phone interviews. You do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are entitled.

12. Contact Information for Questions or Concerns:
- You have the right to have all of your questions and concerns addressed.
- You may contact the PI, Dr. Judith Hupcey, at (717) 531-4211 if you have further questions, complaints or concerns about the research.
- If you have questions regarding your rights as a research participant or you have concerns or general questions about the research or about your privacy and the use of your personal health information, contact the research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687. You may also call this number if you cannot reach the research team or wish to talk to someone else.
- For more information about participation in a research study and about the Institutional Review Board (IRB), a group of people who review the research to protect your rights, please visit the HMC IRB’s Web site at http://www.hmc.psu.edu/irb. Included on this web site, under the heading “Participant Info”, you can access federal regulations and information about the protection of human research participants. If you do not have access to the Internet, copies of these federal regulations are available by calling the HSPO at (717) 531-5687.

Signature and Consent/Permission to be in the Research
Before making the decision regarding enrollment in this research you should have:
- Discussed this study with an investigator,
- Reviewed the information in this form, and
- Had the opportunity to ask any questions you may have.

Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.
**Participant:** By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

__________________________  __________________________
Signature of Participant       Date   Time
Printed Name

**Person Explaining the Research:** Your signature below means that you have explained the research to the participant/participant representative and have answered any questions he/she has about the research.

__________________________  __________________________
Signature of person who explained this research       Date   Time
Printed Name

(Only approved investigators for this research may explain the research and obtain informed consent.)

**Witness to Consent for Limited English Speaking Subjects (Using a “Short Form” written in the subject’s own language)**

**Witness Statement:** As someone who understands both English and the language spoken by the subject or subject representative, your signature indicates that the English version of the consent form was presented orally in the language of the subject or subject representative, and that he/she was given the opportunity to ask questions.

__________________________  __________________________
Witness Signature       Date       Time       Printed
Name

**Witness to Consent of Subjects Who Cannot Read or Write**

**Witness Statement:** Your signature indicates that you were present during the informed consent discussion of this research for the above named subject, that the information in the consent form and any other
written information was presented orally to the subject or subject representative, that he/she was given the opportunity to ask questions, that the

informed consent decision was freely made by the subject or subject representative who indicated his/her consent and authorization for participation by (check the box as applicable):

☐ Making his/her mark
☐ Other means: ____________________________ (fill in above)

________________________  __________  ______  __________________________
Witness Signature        Date       Time       Printed
Name
### Appendix F- HF Somatic Perception Scale, v. 3

Heart Failure Somatic Perception Scale

Date: __/__/____ / Assessment #: ______________

Please read each statement. Check the number that closely measures how you felt in the past week. Please respond to each statement.

<table>
<thead>
<tr>
<th></th>
<th>I did not have this symptom</th>
<th>Not at all bothersome</th>
<th>Slightly bothersome</th>
<th>Moderately bothersome</th>
<th>Quite a bit bothersome</th>
<th>Extremely bothersome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I could feel my heart beat get faster.</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>2.</td>
<td>I could not breathe if I lay down (flat)</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>3.</td>
<td>I felt discomfort or pain in my chest</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>4.</td>
<td>I had an upset stomach</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>5.</td>
<td>I had a cough</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>6.</td>
<td>I was tired</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>7.</td>
<td>I could not catch my breath</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>8.</td>
<td>My feet were swollen at the end of the day</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>9.</td>
<td>I woke up at night because I could not breathe</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>10.</td>
<td>My shoes were tighter than usual at the end of the day</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>11.</td>
<td>I gained weight in the past week</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>12.</td>
<td>I could not do my usual activities because I was short of breath</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>13.</td>
<td>Getting dressed made it hard to breathe</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>14.</td>
<td>My clothes felt tighter around my waist</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>15.</td>
<td>I woke up at night because I had to urinate</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>16.</td>
<td>I had to rest more than usual during the day</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>17.</td>
<td>It was hard for me to breathe</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>18.</td>
<td>I did not feel like eating</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
</tbody>
</table>
# Appendix G - Sample Coding

<table>
<thead>
<tr>
<th>Patient 21</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>When asked if patient experienced HF symptoms in the last week patient says: “No, not in the past week.”</strong></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Experienced Symptom</td>
<td>Related Symptom</td>
</tr>
<tr>
<td>Could feel my heart beat</td>
<td>No</td>
</tr>
<tr>
<td>I could not breath if I lay down flat</td>
<td>No</td>
</tr>
<tr>
<td>I had discomfort or pain in my chest</td>
<td>Yes</td>
</tr>
<tr>
<td>I had an upset stomach</td>
<td>Yes</td>
</tr>
<tr>
<td>I had a cough</td>
<td>Yes</td>
</tr>
<tr>
<td>I could not catch my breath</td>
<td>Yes</td>
</tr>
<tr>
<td>My feet were swollen at the end of the day</td>
<td>Yes</td>
</tr>
<tr>
<td>My shoes were tighter than usual</td>
<td>Yes</td>
</tr>
<tr>
<td>My weight loss in the past 6 months</td>
<td>No</td>
</tr>
<tr>
<td>Getting dressed made it hard to breathe</td>
<td>Yes</td>
</tr>
<tr>
<td>My clothes felt tighter around my waist</td>
<td>Yes</td>
</tr>
<tr>
<td>I woke up at night because I had a cough</td>
<td>Yes</td>
</tr>
<tr>
<td>I had to rest more than usual during the day</td>
<td>Yes</td>
</tr>
<tr>
<td>I slept less than usual</td>
<td>Yes</td>
</tr>
<tr>
<td>I did not feel like eating</td>
<td>No</td>
</tr>
<tr>
<td>13</td>
<td></td>
</tr>
<tr>
<td>FLA symptoms</td>
<td></td>
</tr>
<tr>
<td>HF patient symptoms or caused by something other than</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>User</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/5/2006</td>
<td>6:39 PM</td>
<td>132</td>
<td></td>
</tr>
</tbody>
</table>

*Note: This is a screenshot of a spreadsheet with data entries.*
VITA

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Education

2016  PhD in Nursing
The Pennsylvania State University, University Park, PA
2012  Master of Science in Education
Capella University, Minneapolis, MN
2008  Master of Science in Nursing
Misericordia, Dallas, PA
2003  Bachelor of Science in Nursing
Penn State Worthington Scranton, Dunmore, PA
2002  Associate of Science in Nursing
Penn State Worthington Scranton, Dunmore PA

Professional Experience

2013-Present  Assistant Chief Academic Officer, Penn State Worthington Scranton
2008-Present: Instructor of Nursing, Penn State Worthington Scranton
2002-2013  Staff Nurse, Medical/Surgical/Oncology & Pediatrics, Moses Taylor Hospital, Scranton, PA

Publications


Presentations

Evans, M. (April 11, 2015). Comparison of Life Descriptions of Newly Diagnosed Versus Chronic Stage D Heart Failure Patients. Podium presentation at Sigma Theta Tau International Beta Sigma Chapter Research Day at Penn State University, State College, PA.