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The Experience of Older Men with Heart Failure Who Are Receiving Palliative Care

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DEDICATION

To the Veterans and their families who willingly shared their experiences and time during their last phase of life. I am truly grateful for their sacrifices.

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THE EXPERIENCE OF OLDER MEN WITH HEART FAILURE WHO ARE RECEIVING PALLIATIVE CARE

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ABSTRACT

Purpose: The aim of this study was to describe the lived experiences of older men with heart failure who are managing symptoms near end-of-life, specifically to describe and learn how older men manage symptoms with those who support their care.

Significance: The care of older persons with heart failure is a national priority. It is a leading source of hospitalizations in a growing older population. Older adult's ability to self-manage is a fundamental aspect of the care of heart failure; this dissertation builds on how self-management is accomplished in the home environment of older adults with heart failure near end-of-life.

Design: An interpretive, qualitative design.

Participants: Older men (n=15), age 75 to 95, and their caregivers (n=15) living in northern California. Men were Veterans with late stage heart failure receiving palliative care from an interdisciplinary home based primary care team.

Methods: Semi-structured tape-recorded interviews and observation in the participant's homes. Data analysis consisted of thematic analysis influenced by interpretive interactionism and phenomenology. Emerging themes were analyzed to determine commonalities among participants. Data was collected over 2 years.

Results: The meanings of the home environment in management of symptoms and the importance of congruence of goals of care during the transition to hospice were major findings of this study. Men experienced difficulties with symptom recognition in the presence of high symptom burden. The home environment has a pivotal role in supporting their abilities to manage symptoms and their desire to stay at home. Hospitalizations occurred with a *watch and wait* approach to symptom management. When faced with the transition to hospice care, men and their caregivers resisted hospice with a preference for continued hospitalizations. The men's goals of care were *living while dying* contrasted with health professionals goals, who view hospice as a supportive option for these men whom they regard as *dying but still alive.*

Conclusion: The home environment plays a significant role in how older adults and their caregivers manage symptoms near end-of-life. Further research is needed to determine how best to provide concurrent palliative care based on the experiences of older persons with advanced heart failure.

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CHAPTER ONE: INTRODUCTION AND OVERVIEW OF THE STUDY

Introduction

In the United States, heart failure (HF) is the leading cause of death of those 65 and older (Go, et al., 2013). The illness carries a significant symptomatic, social, and functional burden for older adults and their families. Older adults with chronic HF have overwhelming unmet needs in the last several years of life. Symptoms and disability make remaining at home and providing for their needs complicated. Their burden of symptoms is highly unpredictable and may at times be greater than those dying from cancer (Gibbs, 2005; Bekelman et al., 2009).

Older adults who are at the later phases of HF receive care that is palliative in nature. Palliative care is the holistic approach to patient and family centered care that combines both life extending and supportive care for those with life-threatening illnesses (World Health Organization, 2011). The goals of palliative care are to alleviate distressing symptoms (physical, psychological, social and spiritual symptoms) and improve the quality of life of those persons whose illness cannot be cured (National Consensus Project for Quality Palliative Care, 2013; LeMond & Allen, 2011).

Palliative or supportive care is a continuum of care beginning at diagnosis to the end-of-life. Symptom management is one of the important reasons for older adults and their family to transition care to a palliative focus. The ability to self-manage symptoms is one of the key factors that determine whether older adults remain in their homes near end-of-life, yet little is known about the management of symptoms by the older adults and their family whose focus of care is palliative.

Within the context of their home environment and their illness, determining factors that are important and how older adults manage and communicate symptom experience during this time will provide further understanding of how to work and plan care with chronically ill older adults and their families near the end-of-life. This study is concentrated during the illness phase of heart failure during which symptoms are no longer responding as before to curative or life-prolonging medical treatment. This phase of interest is when a transition in the course of HF management changes to palliative or supportive care. It is a difficult time of care when hospitalizations increase; commonly avoidance of end-of-life issues affects care and patients and families must make difficult decisions about transitions to hospice care.

There is a need to understand how older adults interpret and assign meaning to the progression of HF in their everyday lives. Meanings determine what changes may be beneficial in the provision of care. Society, family and the health care system influence these meanings. In addition, the home is where the majority of HF management occurs. This study focuses on understanding the complexity of symptom management at home with family. Additionally the study explores how person/family beliefs affect symptom management and if remaining at home during the last phases of life can be accomplished.

Study Goals

The overall objective of the study was to elicit the meaning, beliefs, emotions and values surrounding the symptom experience of older adults whose approach to treatment of heart failure is palliative or supportive and who are near end-of-life. This research provides increased awareness of HF management strategies by older adults, the importance of hospitalization to older adults, and factors determining transitions to hospice.

Specific Aims

The aim of this interpretive qualitative study was to describe the lived experiences of older adults with heart failure who are managing symptoms near end-of-life, specifically to describe and learn how older adults manage symptoms with those who support their care. The University of California San Francisco School of Nursing Symptom Management Faculty Group defines symptoms “as subjective experiences reflecting changes in a person’s biopsychosocial function, sensation, or cognition of an individual” (Dodd et al., 2001, p. 669). The individual experience of symptoms is the “simultaneous perception, evaluation and response to a change in one’s usual feeling” (Humphreys et al., 2008, p. 147). Symptom management is a mutual interaction of symptom understanding, shaped by past and present experiences embedded in symptom language, meaning and assessment of the symptom and its impact on self, biography and body.

The following research questions were answered to achieve the aim of the study:

a). How do older adults understand the course or trajectory of their illness (past course of illness, transition to palliative care, future course of illness)?

b). What are the processes for symptom interpretation, communication and management by the older person and those who participate in the care?

c). How does the symptom management experience influence relationships of those whom the participant depends on for care and support?

Significance

"Heart failure is a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or eject blood" (Yancy, et al., 2013); at this time there is no cure for HF. It is a health care priority affecting 1-4% of the population over 65 years of age (Go et al., 2013). HF is a costly illness and is the leading cause of hospitalization for the aging adult (Blecker, Paul, Taksler, Ogedegbe & Katz, 2013). In the United States, there are approximately 5 million people with HF; annually 550,000 people are diagnosed with HF; estimated direct health care costs are $29.6 billion and HF is the main cause of 3.4 million hospital days of care (Go et al., 2013). The number of individuals with HF is increasing as a result of improved therapy and a growing aging population (particularly those 85 years and older), resulting in an increased number of deaths from HF despite advances in treatment. Today, the number of HF deaths annually is greater than all forms of cancer combined (Go et al., 2013).

The remarkable reality of HF is the revolving door of hospitalizations associated with the illness that have doubled in the past 10 years. Hospital readmissions related to HF are between 25% at 30-60 days and 50% at 6 months (Blecker, et al., 2013; Yancy, et al., 2013). There is a 42% mortality rate at 12 months after a hospitalization (Dharmarajan, et al., 2013). According to the Heart Failure Society of America (2000), the causes for readmissions to the hospital are the following: diet non-adherence 24%; medication non-adherence 24%; failure to seek care 19%; inappropriate medication 16% and other 17%. Although, there have been advances in treatment and patient education the statistics have remained unchanged for over the past decade (Go, et al., 2013).

An important aspect of management of HF is the affected person and their family's ability to self-manage aspects of HF care such as diet, medications, and seeking assistance when appropriate. Patient education has been a mainstay of HF management focused on prevention of hospitalizations. There have been advances with telehealth monitoring in the patient's home, patient education information, and telephone intervention programs along with other chronic illness models of care (Peikes, Chen, Schore & Brown, 2009). Chronic illness programs show promise in reducing or preventing hospitalizations (Sochalski, Jaarsma, Krumholz, Laramee, McMurray, Naylor et al., 2009; Ory, Smith, Kulinski, Lorig, & Zenker, 2013); however to date, HF hospitalizations have not declined (Go et al., 2013).

The patient's ability to self-manage is a central aspect of the care of HF. Specifically, "self-management requires that patients 1) engage in activities that promote health and prevent adverse sequelae; 2) interact with health care providers and adhere to recommended treatment protocols; 3) monitor physical and emotional status and make appropriate management decisions on the basis of the results of monitoring symptoms; and 4) manage the effects of their illness on emotions, self-esteem, relationships with others and their ability to function in important roles" (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997, p.1097). Self-management for the older adult becomes difficult when symptoms are increasingly harder to manage and differentiate; in the presence of cognitive impairment (>30% of HF patients have cognitive impairment), fragility and other commonly associated co-morbid illnesses of the aging adult (Gure., et al., 2011; Dickson, Buck, & Riegel, 2013; Saczynski, et al., 2013). The expectation is that older adults with significant symptom burden will manage their care, with the support of their families, who may be older themselves and are managing their own chronic illness.

Research directed at understanding the interaction between older adults experiencing HF and their families, while managing complex symptoms within the home environment, is essential to understanding self-management near end-of-life. Few studies have focused on what is happening in the home of the older adult and their families who are managing HF during the later stages of the disease and whose care is palliative in focus. Understanding the experience from the perspective of the older adult and their family is crucial when determining goals of HF care provision and particularly pertinent with the continuing increase in older adults and associated incidence of HF in the aging population. The goal of this research is to open new ways of seeing older adults, specifically to: identify possibilities for improvement in practice, heighten awareness of the current growing needs of older adults with HF, and identify values that will guide ways to prepare those with HF for end-of-life.

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CHAPTER TWO: REVIEW OF LITERATURE

Introduction

This chapter presents an overview of literature to provide an understanding of HF and older adults. A brief description of chronic illness and aging and an overview of HF are presented, followed by a review of literature organized by the aims of the study: a) living with HF, b) management of HF, c) influence of caregiver relationships, and d) transitions to palliative care. The chapter concludes with an analysis of identified gaps in the literature that this study intended to focus on with a qualitative study design. Table 2.1 presents the definitions used for this study.

Chronic Illness and Aging

The growth of the aging population is a serious social phenomenon during this century and represents an increase in chronic illness. The impact is felt in political and economic sectors and, therefore, that of health care. Chronic illness is defined as a condition characterized by a prolonged course, lasting longer than a year, and may require constant care from disability (Institute of Medicine, 2012). Chronic illness is the leading cause of death in the United States and the leading cause for older persons seeking health care. More than one chronic illness are common among older adults as 43% of older adults have 3 or more chronic illnesses and 24% of older adults have 5 or more chronic illnesses (Institute of Medicine, 2012; Hung, Ross, Bookvar & Siu, 2011),

During the past 30 years, research has provided evidence of complex care needs for chronically ill older adults (age 65 and older) and shared experiences across chronic illnesses. The research drew attention to the increasing urgency of understanding the impact of chronic illness as the *baby boomer* generation reaches older age. *Baby boomer* is the cultural term for those born post World War II during the years 1946-1964. As of 2011, the baby boomer generation has begun to contribute to the increasing numbers of older adults and likely those aging with chronic illness.

Living with chronic illness is a series of adaptations to the unpredictable nature of chronic illness. Making sense and acquiring meaning of the chronic experience is individual and multifaceted. Perhaps one of the most influential and important work is that of Charmaz (1991a); her work has continued to influence understanding of how individuals experience chronic illness.

Charmaz (1983, 1991a) describes chronic illness in the context of the debilitating nature of physical decline and periods of stability which may include periods of improvement. Chronic illness interrupts one’s ability to control what is happening within the body, this causes a destabilizing of the concept of self specifically surrounding concepts of autonomy or independence (Charmaz, 1991a, 1991b). When the course of illness begins progressive decline, underscored is the uncertainty of symptoms, ability to function and how to continue to maintain the interrelated sources of biography.

Charmaz (1983) identified four sources of suffering which lead to loss of control and action and finally the positive sense of self: a) living a restricted life, b) social isolation, c) discrediting definitions of self and d) becoming a burden. Her outstanding work with chronic illness heightened awareness of how individuals relate to the chronic illness experience and the losses faced during daily life with chronic illness.

The challenge of maintaining independence and remaining at home is a problem while aging with chronic illness (Haslbeck, McCorkle & Schaeffer, 2012). Independence depends on successful transitions; not only within the course or progression of the illness but between sites of care and health care professionals (i.e. acute hospitalizations, skilled nursing facility admissions) and may require different skills or knowledge for successful transitions. Transition is a perspective that occurs during aging and results in “change in lives, health, relationships and environments” (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher (2000, p. 13).

The symptom experience, as it relates to transition to palliative care for chronically ill older adults, is expressed through action and dialogue during a time when symptom management is difficult. It is also a time when persons and their families are developing an understanding and recognition that medical treatment may not improve their illness. The family as a social group develops its own concepts of self and identity through their interactions and symbols of language (Leeds-Hurwitz, 2006). Personal and family meanings are evolving as self and family identities change in the context of illness, symptoms and life transitions.

The occurrence of transitions or turning-points surrounding serious heart failure and symptoms requires a person and their family to reconstruct and transform the meaning given to themselves and their life (Fife, 1994). The response of the individual and their families to turning-points is reflected through their concepts of self and identity through interactions and symbols of language resulting in a response or behavior to the event (Leeds-Hurwitz, 2006). It is in capturing of meaning in the interactional process that reveals how a person or family emotionally and biographically fits the experience into the emerging definitions of self (Denzin, 2001).

Chronic illness trajectories influence independence, relationships and the environment. Advanced illness trajectory was first described by Glasser & Strauss

(1968) and Quint Benoleil (1967) while studying the care of the dying. Glasser & Strauss (1968) described a pattern of deterioration, hospital re-admissions, discharge and then a continuing series of re-admissions continuing until death.

Recognizing the impact of chronic illness from the increasing numbers of individuals with eventually fatal chronic illness, Lynn & Adamson (2003) described three trajectories of illness: a) short period of apparent decline (i.e. cancer), b) chronic illness with exacerbations and sudden dying (i.e. organ failure such as HF) and c) a long dwindling (i.e. frailty and dementia). Lynn (2004) describes care during chronic illness transition to end-of-life as an emphasis on the complexity of needs and goals with a shared treatment concentration of life-prolonging and palliative care.

Overview of Heart Failure

Heart failure (HF) is a progressive illness of the older adult developing over time with symptoms often mistaken for normal signs of aging. Advanced heart failure in older age does not exist solely; symptom management occurs with many co-morbid conditions and symptoms limit activity. The prognosis is poor with less than 50 percent surviving five years after initial diagnosis and less than 25 percent surviving ten years (Heart Failure Society of America, 2013). In spite of increased attention to HF management programs, much of the care depends on the older adult and their family and their ability to manage the increasing symptom burden.

HF is largely attributed to hypertension, diabetes, coronary artery disease, obesity and is found with other co-morbidities such as chronic obstructive pulmonary disease (COPD), sleep disorders, anemia, cognitive impairment and depression (Nagarjan & Tang, 2012). HF affects younger persons (age less than 65); although the risk for developing HF increases with age. During years 2007-2010, in the general population, the incidence of women between ages of 20-59 with HF is 0.2-0.7%; men in the same age group 0.4-1.5%; women between ages of 60-79 is 4.5% and men 7.8%. After the age of 80, HF incidence rises to 11.5% for women and 8.6% for men (Go, et.at. 2013). This change in incidence is influenced by the greater number of women than men living after age 80. Most HF research has been with those under 65 or a mixed age group of young and older participants; resulting in data being generalized to the older population (Lehman, 2006).

Advanced, serious or end-stage HF does not have a formal definition; the terms are commonly used for Stage D and Class III- IV HF (Table 2.2). HF is staged by the American Heart Association (AHA) and American College of Cardiology (ACC). The system stages are A-D with D being those who have advanced HF with symptoms that are difficult to manage with standard therapy. The purpose of the staging is to identify those at risk and to identify progression of illness. In contrast, New York Heart Association (NYHA) classification system identifies symptoms of HF based on functional capacity. Classification is I-IV with class IV being those who have symptoms at rest and severe functionally limits. If symptoms improve the functional class can change to a lower classification. Both the HF staging and classification systems work together to identify treatment strategies. Prognosis and treatment strategies are complicated by multiple co-morbidities modifying the presentation of symptoms (Martin-Pfitzenmeyer, et al., 2009).

Living with Heart Failure in Older Age

A number of qualitative review articles describe the experience of living with HF (Yu, Lee, Kwong, Thompson & Woo, 2008; Welstand, Carson, & Rutherford, 2009; Hopp, Thornton & Martin, 2010; Jeon, Kraus, Jowsey & Glasgow, 2010). These articles present convincing documentation that living with HF is difficult, requiring constant adjustments associated with uncertainty and frequent hospitalizations. Table 2.2 summarizes the four review articles.

Table 2.3 Review Article Comparison: Living with Heart Failure

First Author	Sample	Study Design	Significant Findings
Yu, 2008	14 studies Sample size: 4-62 Age:45-90 NYHA: (not stated)	Systematic Review of qualitative studies 1997-2007, Transactional Model of Stress used as guide for synthesis.	HF influenced roles, coping & social support. Ongoing adjustment & coping improved with self-care as did social support. Males interpret HF through lens of activity.
Welstand, 2009	18 studies Sample size: 5-36 Age:29-90 NYHA: I-IV	Integrative Review of qualitative studies 1985-2008, Examined common concerns, perceptions.	Identified 5 categories coping behavior, perceptions of daily life, role of others & concept of self; all categories mediated by the concept of self. Adapting to new “self” influences self-care success.
Hopp, 2010	15 studies Sample size: 1-40 Age:38-100 NYHA: (not stated)	Systematic Review of qualitative & mixed method studies 1990-2007, Common themes of HF lived experience.	Challenges identified were those of social isolation, health care access & living with symptoms that influence uncertainty of illness.
Jeon, 2010	30 studies Sample size: 1-87 Age & NYHA: (not stated)	Systematic Review of qualitative studies 1990-2008, Factors influencing HF lived experience.	Common themes of social isolation & need to be flexible to effectively cope with HF. Difficulty accessing health care common across studies.

In their review of 14 studies, Yu, Lee, Kwong, Thompson & Woo (2008) concluded older persons had limited self-management skills to respond to acute and chronic symptoms. Adjustment to HF was identified as a way of searching for meaning of symptoms, although this process was altered by frequent hospitalizations and symptom exacerbation. Only one study examined how adaptation to HF affected the environment; the results indicated the immense challenge of adjusting to changing life long patterns of living.

Welstand, Carson, & Rutherford (2009) reviewed 18 articles and found the concept of self-identity influenced all aspects of living with HF. Self-identity was negotiated by factors of diagnosis and manifestations of HF, perceptions of day to day life, role of others and coping behaviors. These factors influenced the need to reconstruct self-identity in the presence of HF. The authors conclude that strategies for improvement of HF care should include an individual’s changing identity and their coping abilities that affect self-management.

Hopp, Thornton & Martin (2010) evaluated findings from 15 articles which concentrated on the challenges of HF, the management of HF, social support challenges and coping with the dying process. The findings were not unlike experiences of other chronic illnesses, with the exception of the unpredictable nature of HF in which participants lived day by day. The associated uncertainty of HF interfered with developing end-of-life plans or goals.

Jeon, Kraus, Jowsey & Glasgow (2010) summarized three common themes from 30 articles: a) impact of HF on everyday life, b) common patterns of coping and c) factors influencing self-care and/or provision of quality care. As with previous reviews, social isolation is an ongoing problem, additionally living in fear of pain, death and the future was also a central component of the HF experience. Transitions between sites of health care promoted a sense of loss of control. This was associated with unpredictability of exacerbations and for some loss of control is associated with restrictions imposed on their life from advanced HF. Coping with advanced HF is improved through social support and being able to share HF experiences. Lastly, factors that influenced self-care include lack of HF knowledge and understanding which led to substandard care outcomes and non-adherence to self-management. Self-care was influenced by the relationship with family because of increasing reliance needs. Additionally, access and communication with health care services was limited across studies.

Management of Heart Failure Symptoms

Management of symptoms is essential to care provided by persons with HF and their family caregivers (CG) which includes symptom awareness and monitoring. Symptom identification and monitoring are critical to successful self-care; however they are challenging, especially in advanced stages, when hospital rates rise. Later stages of HF as seen in NYHA functional class III-IV, requires adherence to complex medication regimens, dietary restrictions and weight monitoring.

Self-care management requires the ability to take action when symptoms are worsening, and it is time consuming and difficult (Moser & Watkins, 2008). As older persons age, these processes include multiple steps and are influenced by many factors such as cognitive changes and overall energy requirements to complete management strategies. A recent systematic review of HF qualitative studies provided insight into the help-seeking processes (Clark, Savard, Spaling, Heath, Duncan & Spears, 2012). The first stage was that of unpredictable symptoms that were not understood by patients and associated with inadequate understanding was poor communication with health care professionals; the second stage is difficulty recognizing symptoms that required help and thirdly there was confusion about who to call for help (58 studies; n=990 patients, 274 female, 527 male, 189 gender not provided, 229 caregivers, 79 health professionals, class or stage of HF and age of patients was not provided). The evidence from these studies continues to confirm that communication and understanding of HF interfere with adequate reporting of symptoms between patients and health care professionals. Few studies in the review provided information of the caregiver (CG) role in help-seeking, although two studies reported CGs were not part of consultations with heath care professionals.

In spite of declining health, Zambroski, Mosher, Bhat, & Ziegler (2005) found patients with severe HF were able to identify worsening symptoms. This is in contrast to Riegel, et al. (2010) who found patients had trouble recognizing symptoms such as breathlessness. A previous qualitative study by Zambroski (2003) showed that the patients through self-assessment, planning and acting have developed unique problem-solving strategies. Participants described individual strategies were influenced by their intuition and experience with HF. Another qualitative study found patients with HF had serious commitment to maintain their daily routines and found ways to compensate for the HF symptoms which increased self-report time of increasing symptoms (Falk, Wahn & Lidell, 2007).

Lam & Smeltzer (2013) conducted an integrative review of symptom recognition, interpretation and response by HF patients. The review included 14 papers from 1997-2011. Lam et al. (2013) found breathlessness is the primary symptom reported between studies; however duration of breathlessness associated with gradual onset seems to be associated with delays in seeking help. Since none of the studies followed patients over time at home, symptom recognition is based on those patients who sought care, and it is unclear how symptom recognition is integrated into daily lives. Lastly, symptom perception may be impaired in older adults; only two studies explored the somatic implications of symptom recognition.

The frequency and severity of breathlessness reported by those with HF were similar to reports of those with COPD (Caroci & Lareau, 2004). A systematic review describing the experience of breathlessness found a majority of studies focused on breathlessness in the COPD population (Gysels, Bausewein & Higginson, (2007). A central finding from this review is breathlessness is a symptom which affects all aspects of ones' life, including function, ones' relationships, psychosocial, financial and that of immediate family members (Gysels et al., 2007).

A more recent study compared the experience of breathlessness with COPD, HF and motor neuron disease (MND) (Gysels & Higginson, 2011). Participants with COPD and HF had similar experiences. HF participants were less likely than COPD and MND patients to understand the nature of breathlessness. Instead, HF patients described the effects of breathlessness as disability and were likely to adapt to breathlessness daily.

Breathlessness and loss of energy is extremely difficult for individuals to manage and is the main reason to call a physician (Horne and Payne, 2004). In addition, caregivers often are older women who have difficulties with a sense of helplessness with symptoms such as breathlessness (Barnes, et al., 2006). Edmonds, Rogers, Addington-Hall, McCoy, Coats & Gibbs (2005) described breathlessness associated with HF through a narrative description (n=27, age 38-94; NYHA functional class II-IV). Breathlessness associated with HF is experienced in the context with physical functioning and is experienced daily. Participant descriptions of breathlessness differ from those descriptions associated with health care professionals' i.e. exertional breathlessness. When symptoms increased participants tended to rest or reduce activities and not call to report symptoms or ask for assistance.

Gender differences are noted in the experience of HF and that of self-care management. Women have been found to have greater positive feeling associated with the meaning of HF with men having more difficulty with adjusting to loss of functional limitations (Evangelista, Kagawa-Singer & Dracup (2001). Social support has a relationship to functional status, men perceived better social support than women and correlated with functional outcomes, men were less likely to experience a decline in health with more perceived social support (Berard, VanDenKerkhof, Harrison & Tranmer, 2012). Friedman (2003) found men had experienced less functional decline after hospitalizations than women.

Gender differences have been found with self-care activities. Men may take the primary role of self-care as a way to maintain control (Rodriguez, Appelt, Switzer, Sonel & Arnold, 2008; Dickson, Worrall-Carter, Kuhn & Riegel, 2011). Riegel, Dickson, Kuhn, Page & Worrall-Carter (2010) reported men had more confidence in symptom recognition, although men in the study had more illness co-morbidity. Social support was reported to be stronger for the men in this study and was associated with better symptom recognition (Riegel, et al., 2010).

Caregiver Relationships and Perspective

Caregiver support is a crucial aspect of the symptom experience. Older patients with severe HF may not be able to manage alone, and management of HF is difficult. Decisions must be made about the control of symptoms, in addition to understanding the symptom itself.

HF self-care in many respects is a misnomer as a person with HF has significant care demands that fall to family CGs in the late stages of HF. Often those family CGs are older adults who have poor physical and emotional health. (Pressler, et al., 2009). Compounding the impaired family CG health states, older persons with HF have a substantial presence of geriatric syndromes requiring higher levels of caregiving (Gure, Kabeto, Blaum & Langa, 2007).

HF requires multifaceted care, which is emotionally, physically and economically taxing (Pihl, Jacobsson, Friedlund, Stromberg, & Martensson, 2005; Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006). The ability of the CG to manage the care requirements is an important aspect in quality of life (QOL) and hospital admission reduction (Luttik, Jaarsma, Veeger, & van Veldhuisen, 2005). Education is a mainstay of HF self-care. Even with education of the person with HF and their CGs, there are delays in symptom reporting and failure to monitor symptoms (Evangelista, Dracup & Doering (2000), and lack of medication adherence (Wu, Moser, Lennie, & Burkhart, 2008).

Clark et al. (2007) found both the visible caring (bathing, medication regimens) and invisible caring that goes unnoticed by others leading to CG stress. Invisible caring includes decision making about symptoms, monitoring of symptoms and accurate assessment of the patient. Hwang, Luttik, Dracup & Jaarsma (2010) found 48% of partners of HF patients felt they had to be available 24 hours for care needs. This level of stress goes unnoticed by professionals and its impact can delay care and impact the spouse's health.

Martensson, Dracup, Frilund, Halmstad, & Goteborg (2001) using a descriptive qualitative design with critical incident technique found two main areas that influenced the spouses' support. The first main area is that of being valued which entailed their inclusion in care activities and reassurance in care decisions such as calling for assistance. Simply the aspect of others calling to check in was paramount. The next main area influencing support was that of social isolation. Social isolation occurred when patients kept their spouse at a distance about needed care requirements. This resulted in CGs not receiving the needed support from friends and family for extra care needs of the patient. The study highlights the importance of identifying family supports and understanding of the needs of the spouse.

Luttik, Jaarsma, Veeger, Tijssen, Sanderman, & VanVelduisen (2007) investigated the feelings of caregiver burden in partners of HF patients using a qualitative design. Caregiver burden was not associated with illness severity, although CG burden was dependent on the CG's mental health and impact of physical care of their spouse. CG burden was the same between men and women, women did report a higher burden due to lack of family support. This finding may indicate women caregivers receive less support than male caregivers. In contrast, Barnes et.al (2006) did report caregiver stress increased with disease severity and age of CG. This mixed methods study reported 76%

of the caregivers as older women (age 70 and greater was largest caregiver group). CG social isolation was found as disease severity increased. Social isolation can lead to resentment as reported by a focused interview research by Aldred, Gott, Gariballa (2005).

The Luttik, Jaarsma, Moser, Sanderson & VanVelduisen (2005) review article shows social support does influence hospital re-admissions, however they found less evidence to support an association between patient quality of life and their social support. The review concludes that current research on social support influences is inadequate and requires further study.

When HF patients do receive programmatic education, it is inconsistent and often not based on national recommendations. For example, two reviews examined HF program interventions for improving self-care. A systematic review and meta-analysis of 35 HF care intervention studies (n= 8071, age mean= 70.7, SD= 6.5 years) found all interventions were focused on individual patients and only 37% of the studies included a caregiver (Wakefield, Boren, Groves & Conn, 2013). Patient education with symptom monitoring by staff, symptom monitoring by the patient and medication management (adherence) were the most common topics. Paradoxically, less than 20% of the studies included weight management, dyspnea and fatigue management, coping skills, alcohol intake, tobacco cessation and diuretic modification. Only 1% of the studies included social support education and only 54% of the studies included symptom monitoring as an intervention component.

A second review of HF programmatic interventions represented by 19 studies (n=18-902, mean age 68.4 years) during the years of 2000-2010 (Barnason, Zimmerman & Young, 2011). Similar to the previous review by Wakefield et al. (2013), this review found limited description of the patient education provided in the intervention groups. It is unknown if the interventions included all of the standard components of recommended HF education (Heart Failure Society of America, 2010). Likewise, there were no long term data about the sustainability of self-care after the interventions. In addition, Yehle & Plake (2010) review found education alone did not directly impact self-efficacy in the care of HF.

These three reviews underline the variation of information provided to patients in HF educational programs. It is difficult to compare study outcomes without consistent educational interventions between studies. The inconsistency of educational interventions reported by HF programs suggests HF patients may not consistently receive the needed education required for successful self-care management.

Transition to Palliative Care

It is increasingly recognized that older adults with advanced or serious HF have needs similar to those with other terminal illnesses. The trajectory of HF is punctuated with acute exacerbations requiring hospitalization with older adults surviving the hospitalization and returning home with gradual deterioration of functional status (Lynn & Adamson, 2003). The late-stage trajectory of HF has been identified as a time when palliative care should become a primary focus of care, as the last several years of serious HF is often experienced with increasing disability, decreasing functional capacity and distressing symptoms that are palliative in nature.

Palliative care programs have been developed in acute, outpatient and home care programs. Palliative care is “an approach to care that improves the quality of life of patients and their families facing problems associated with life-threatening illness and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual" (World Health Organization, 2011).

The term palliative care continues to be confused with hospice care by patients and health care professionals. Palliative care is an umbrella term for both life-prolonging and supportive therapy from the beginning of diagnosis to advanced stages of illness with palliative care utilization increasing at advanced stages. Hospice is palliative care at the end-of-life; it is a Medicare benefit which specifies a 6-month prognostic category for the natural course of illness (Center for Medicare & Medicaid Services, 2013). HF does not easily fit hospice criteria because of a variable end course without a distinct terminal phase (Lynn & Forlini, 2001). LeMond & Allen (2011) call advanced HF a "perfect storm of factors that converge" (poor prognosis, lack of communication and high symptom burden) indicating the need for palliative care (p.170).

Doughterty, Pyper, Au, Levy & Sullivan (2007) found patients with advanced HF were aware of their limited future and they did not tend to put plans in place for end-of-life and instead tended to "drift" living day by day and hoping for the best. Interestingly, this study found prognostic information such as 5-year survival rate did not improve end-of-life decision making by HF participants.

Metzger, Norton, Quinn & Gamling (2013) conducted a study to describe the experience of HF patients referred to an inpatient palliative care consultation service. Most participants confused palliative care and hospice as being the same and expressed concern over a referral to hospice as not being able to access hospitalization. Along with concerns of denial of hospital care, additional concerns about hospice care were being discharged from hospice if they did not die in a specified time period and the loss of their usual health care professionals while on hospice.

A European study to explore patients attitudes and ideas about dying found those with advanced HF did not necessarily know that HF may cause an earlier death and most only thought about dying while in the hospital (Willems, Hak, Visser & Van der Wal, 2004). Dev, Abernaethy, Rogers & O'Connor (2012) used a systematic review to explore preferences at end-of-life for those with HF. Over 50% of patients wanted to die at home and there was no common consensus between studies whether patients would chose quality of life vs. longer survival time. An additional two recent European studies addressed preferences of quality of life vs. length of life of those with advanced HF. Kraai, Luttik, Hoekstra, Jaarsma & Hillege (2013) found patient preference for quality of life (61%) over longevity (n=100, mean age 70; SD 9 years, 71% male) while Brunner-LaRocca, Rickenbacher, Muzzarelli, Schindler, Maeder et.al. (2012) found the majority of patients (n=622, mean age 77; SD 8 years, NYHA class III-IV) wished for longevity (74%) over quality of life. Accounting for differences in culture, these preferences point to the challenges HF presents at end-of-life and transitions to hospice care.

A review by Green, Gardiner, Gott & Ingleton (2010) found the communication surrounding transitions to palliative care for HF patients inadequate. An ongoing wish to discuss feelings about end-of-life care was impeded by the unpredictability of HF trajectory and a distinct transition point to palliative care was not identified. Comparably, a review by Low, Pattenden, Candy, Beattie and Jones (2011) found patients report the need for stronger communication to support coping with advanced HF.

In addition they report poor coordination between health care settings, including poor control of symptoms and the challenge of the loss of social support.

Results from these studies suggest that approaching death may not be a primary emphasis of the experience of advanced heart failure; but when presented with options for hospice, they do not want to give up life-prolonging treatment. Howlett (2011) describes this as the care gap for those with advanced HF; in the presence of an unpredictable illness course and a poor understanding of their illness trajectory, those with advanced HF are less likely to participate in end-of-life care decisions. These decisions are influenced by communication with patients, HF trajectory and knowledge of advanced HF transition points.

Gaps in Literature

Understanding the symptom management experience of older adults who have HF will add to knowledge about the challenges, responses and processes of older adults and their caregivers around symptom management near the end-of-life. Heart failure research has focused on self-care management and strategies, which often provides information about non-adherence to medical regimens, prevalence of symptoms and is focused on medical treatment of symptoms. Few studies have looked at the impact of HF from the perspective of the patient and their caregiver, what strategies are used to manage symptoms and how these strategies are communicated to accomplish the work of HF.

Symptoms and a person’s self- identity are closely woven together, rooted in their personal history, their current understanding of HF and how the future is perceived. Exploring the symptom experience from this perspective to understand the influences of the home environment, relationships of those who assist with care and what is important to the older adult can lead to approaches to care which better support chronically ill near end-of-life. This research will focus on understanding what patients and their families do together (processes) to manage symptoms and their perspective of symptom management in the home. The complexity of the care of serious HF is challenging; currently we are expecting older adults to self-manage symptoms without an understanding of what this entails in the home environment.

During this time there are transitions associated increased symptom burden, decreasing functionality and increasing hospitalizations occurring in the presence of transitions between health care systems and home environments. There is limited information about the how older adults manage advanced HF and how they experience these transitions in light of the HF trajectory. Our closer understanding of these last few years of life can lead to improved care models and treatment.

Table 2-1 Study Definitions

Term	Definitions
Palliative or Supportive Care	Palliative care is the holistic approach to patient and family centered care that combines both life extending and supportive care for those with life-threatening illnesses (World Health Organization, 2011). Palliative or supportive care entails the continuum of illness from diagnosis to end-of-life. For the purpose of this study, palliative or supportive care refers to the care management focus in the last one to two years of life.
Holistic care	Holistic care defines care of the whole person, the well-being of a person's physical, psychological, social, and spiritual well-being. This includes the roles and relationships of the person and family and the meanings of the illness experience.
Symptoms	Defined "as subjective experiences reflecting changes in a person's biopsychosocial function, sensation or cognition" (Dodd, et al., 2001)
Symptom Management	A mutual interaction of symptom understanding, shaped by past and current experiences embedded in symptom language, meaning and assessment of the symptom and its impact on self, biography and body.
Self–Care Management	A complex cognitive process of identifying signs and symptoms, recognizing the need to take action, acting on the treatment strategy and evaluating the effectiveness of treatment (Riegel & Carlson, 2006; Adams, et.al. 2006).
Lived Experience	The lived experience is the experience that comes from immediate awareness of life. The pre-reflective experience can only be understood reflectively as past presence; it is actual experience (Van Manen, 1990; Denzin, 2001).
Meaning	Meaning is the relationship persons have with their world (body, self, biography) and their unique perceptions of their place in the world (Fife, 1984, p. 309).
Family	In palliative care, family is defined from a clinical perspective as those closest to the patient in knowledge, affection and most affected by the person's illness (Kristjanson & Aoun, 2004). Byock & Corbeil (2003) refer to the phrase "for whom it matters" which encompasses the network of a person's relatives and close friends. For this study family is defined as those who the older adult depends on for care.
Transition or turning points of illness	Those events that alter, shape, and transform the lives of those studied (Denzin, 2001).

Table 2.2 Comparison ACC/AHA and NYHA Staging and Classification Systems (Yancy, et al., 2013, p. 15)

American College of Cardiology (ACC)/ American Heart Association(AHA) Staging System for Heart Failure Stage & Definition	American Heart Association (AHA) Functional Classification System Class & Definition
A At high risk for heart failure, but without heart disease or symptoms of heart failure. .	None
B Structural heart disease but without signs or symptoms of HF.	Class I: No limitations. Ordinary physical activity does not cause ordinary symptoms of heart failure such as fatigue, breathlessness or palpation.
C Current or past symptoms of HF associated with structural abnormalities.	Class II: Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in symptoms of heart failure such as fatigue, palpitation, breathlessness or angina pectoris. Class III: Marked limitation of physical activity. Although patients are comfortable at rest, less than ordinary activity causes symptoms. **
D Refractory end-stage heart failure.	Class IV: Inability to carry out any physical activity without symptoms of heart failure. Symptoms of heart failure are present even at rest.

** For this study late Class III

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CHAPTER THREE: STUDY DESIGN AND METHODS

Introduction

Describing the human experience is a difficult undertaking. The qualitative approaches utilized were intended to describe both the lives of the participants and those who are central to their care and provide cultural context within the environment of their home. In this chapter, the research design and methods are discussed. Additionally, procedure limitations are discussed with potential concerns that may be found during the study, for example, conducting a study within one's own work culture and working with older men who are significantly ill.

Study Design

Rationale for the Study Design

This research is an interpretive qualitative study. A qualitative design is both inductive and descriptive and is focused on understanding the meaning a phenomenon has for the participant (Merriam, 2002, Denzin, 2001, Patton, 1990). An interpretive qualitative approach was selected because it draws from phenomenology and symbolic interactionism with a central purpose of understanding how individuals interpret their experiences, how they interpret their worlds, and the meaning they attribute to their lives and experiences (Merriam, 2002). Thus, an interpretive qualitative design was selected to understand how older adults with HF manage their symptoms and how these understandings shape their interactions with others who are supporting or providing care.

The Setting

Data was collected in the homes of Veterans who are enrolled at the Veterans Administration Northern California Health Care System (VANCHCS) Home Based Primary Care (HBPC) and/or the cardiology outpatient clinic at Sacramento, California.

The researcher negotiated access to the HBPC program and the Sacramento cardiology clinic where the proposed research was conducted January 2010 through November 2011. The HBPC team provides interdisciplinary support for the palliative care needs of men and their families at home. The program uses an interdisciplinary approach for older palliative care patients whose focus of care is supportive rather than curative. The team consists of a physician or nurse practitioner, pharmacist, registered nurse, psychologist, occupational therapist, social worker and registered dietitian. Team member home visits are dependent on the assessed needs of the men based on the team evaluations. This team with the exception of two physicians works only in the home setting.

An adequate sample by gender and age was expected as heart failure affects men and women equally and heart failure is primarily an illness of the older adult. The average age of those receiving care with the HBPC program is 74 and 65 years of age for VANCHCS: the VANCHCS population is 92% male and 8% female. Also, 67% of California Veterans are Caucasian, followed by Hispanic 15%, Black 9%, Asian/Pacific Islander 6 % and American Indian 0.8% (California Department of Veteran Affairs, 2013).

Protection of Human Subjects

The research study was approved by the University of California Committee on Human Research and the VANCHCS Institutional Review Board. Medical providers identified potential participants and provided the researcher with their medical referral data sheet. The researcher contacted potential research participants. An informational sheet and copy of the consent was given before the start of the interviews. This allowed time for the consent to be reviewed by the participants prior to the first appointment to ensure participants had time to understand the study description, risks and benefits.

At the first appointment, a thorough explanation of the study and written informed consent was obtained for those interested in participating. The consent from the VANCHCS was the primary consent. The consent was reviewed with participants and signed by participants including those whom the participant depends on for care and support.

Ethical Considerations

Palliative care literature is replete with articles discussing whether studying individuals with serious illness is ethical, particularly older adults who are frail and dependent (Dean & Clement, 2002; Hopkinson, Wright, & Corner, 2005; Locher, Bronstein, Robinson, Williams & Ritchie, 2006; Gysels, et al., 2013). The vulnerability of this population is complicated by physical decline and debilitating symptoms of discomfort and distress (Dean & McClement, 2002).

Benefits of research are never certain; considerations of the risks raise ethical questions for this vulnerable population. The frail, older adult was given choices and control over participation throughout the research. A qualitative research design works when palliative care issues are addressed such as energy depletion, ensuring the interview or participant observation is no longer than an hour or the length of time determined by the participants themselves. Cognitive status was assessed prior to consent and at the beginning of each interview.

Methods

Sample

Veterans are appropriate participants for this study. Veterans represent 1,600 deaths each day and account for 28% of all deaths in 2013 (U.S. Department of Veteran Affairs, 2013). Additionally, Veterans do not die in VA hospitals; they represent a significant percent of the aging population in the community (U.S. Department of Veteran Affairs, 2013).

Additional participants were those the participant primarily depends on for care and support. These participants are defined as those closest to the participant in the management of care required for HF. They could be related to the primary participant or have a close relationship with the participant based on care and support of the participant.

The age of the HF participants was determined by several factors. The average age of diagnosis of HF is 70 (Cleland, 2008), and since the study focused on class III-IV HF, participants were 75 and older. The age grouping eliminates the *baby-boomer* generation who have had a different socioeconomic and cultural experience than older Veterans. Veterans who are 75 and older are those who served in WWII, Korean War and early Vietnam era (different from Vietnam War era); this age group represents the second largest population of Veterans in the United States (U.S. Department of Veteran Affairs, 2013).

While each war experience is different, this age group shares a variety of major historical events such as the Great Depression, post WWII prosperity, the Cold War, and the Civil Rights Movement. Other factors that may influence end-of-life experiences include military culture, whether drafted or enlisted in the military, branch of service, rank, combat or POW experience (U. S. Department of Veteran Affairs, 2013). This includes the emergence of war memories at the end-of-life.

Sampling Strategy and Recruitment

An *a priori* purposeful sample strategy was planned to obtain participants who met the predetermined criteria and research objectives. Purposeful sampling is the selection of participants who will provide information rich cases for an in-depth study (Patton, 2002). This specific strategy was used to select a small homogeneous sample to describe the experience of HF participants. Selecting individuals of the same gender, background, age and who are experiencing similar symptom experiences allows the questions or issues to be covered at greater depth.

Sample Size

The number of participants selected was determined by data saturation. Data saturation is present when no further new data are found and the researcher is able to develop properties of the data category. Guest, Bunce & Johnson (2006) found by selecting a homogenous sample in terms of their experiences with respect to the research domain, data saturation is reached after 12 interviews. While there are limited published guidelines, this number fits in the range of published recommendations of 6-30 participants for qualitative studies (Guest, Bunce & Johnson, 2006).

Inclusion and Exclusion Criteria

The following Table 3-1 summarizes inclusion and exclusion criteria for this study:

Inclusion Criteria	**Rationale**
1. Adults ages 70 and older, English speaking, male	The aims seek to explore the experience of HF symptoms from the perspective of elderly. Selecting age 70 & older attempts to keep the sampling homogenous by age, experience and gender.
2. NYHA Classes III-IV & ACC/AHA Stage C or Stage D; estimated life expectancy of 1-2 years and medical therapy is primarily palliative.	The overall aim of the study is to understand those older adults who are near end-of-life. Late class III or class IV and late stage C or stage D represent participants whose illness is serious and are likely to be in their last one to two years of life. These classifications usually indicate that medical therapy is palliative in focus.
4. Those identified by the participant as closest to the primary participant who are providing care and support.	The aims focus on understanding the experience of HF symptoms and the how those who participate in the care influence the experience.
5. Cognitively competent with a SPMSQ score <5.	This study will require participants to sign an informed consent and participate in open-ended questions to provide an accurate description of their symptom experience.
Exclusion Criteria	**Rationale**
1. Co-existing terminal diagnosis such as cancer and other primary organ failure.	The inclusion of additional terminal illnesses may misrepresent the results of the study.

Sample Demographic Profile:

At the initial visit, the investigator obtained socio-demographic and clinical characteristics from interviews with the participant. The socio-demographic and clinical information provided a format to obtain general but consistent information about the participant.

Fieldwork: Data Collection Procedures and Management

Interviews and Observations

Prior to all interviews permission from the participant was verbally acknowledged and an appointment date and time was made to come to the participant's home. A semi-structured, open ended interview format was utilized. Prior to each interview, the participant was provided a briefing in which the interview situation was defined, including the purpose of the interview and the use of tape recording (Kvale, 1996). The semi-structured interview approach allowed for a sequence of themes to be covered, yet allowed for openness to changes in sequence and forms of questions (Kvale, 1996). The interview guide reflected the study aims and provided a reference or checklist of topics that was explored with the participants (Appendix A).

Participants were encouraged to express their experiences in the way they wanted. They were encouraged to utilize "self-stories" or narratives to illustrate their experiences. Observation of the family and or caregivers was used to further enhance data to comment on the context and its role in shaping the participant's symptom experience. Observation took place during the interviews and was documented in field notes after each participant visit and used to supplement the tape-recording of the interviews. A contact data summary was developed to briefly summarize the field contact (Miles & Huberman, 1994). After reading field notes, the contact form was useful for summarizing main points and to develop follow up questions for the next interview.

Descriptive Tools

Short Portable Mental Status Questionnaire (SPMSQ) and the Memorial Symptom Assessment Scale for Heart Failure (MSAS-HF) provided descriptive information about the participants (Appendix B & C). The demographic information, cognitive assessment and MSAS-HF provide quantitative data which enhances the qualitative data.

SPMSQ assessed the cognitive status of the participants with HF at each interview. SPMSQ is a 10-item examination that has been found reliable and valid in distinguishing intellectual impairment and determining the degree of impairment of elderly living in the community or in institutions (Pfeiffer, 1975). The SPMSQ examines primarily orientation, although two questions assess memory and has established standards for intact mental functioning, borderline or mild organic impairment, definite but moderate organic impairment and severe organic impairment (Pfeiffer, 1975). Participants are scored ≤ 2 errors as intact, those who made 3 or 4 errors as mildly impaired, those who made 5-7 errors as moderately impaired, and those who made 8-10 errors as severely impaired (Pfeiffer, 1975). There is a high incidence of cognitive changes in later stages of HF. The SPMSQ was used to determine the participant's cognitive status each visit. Participants were not interviewed if they receive a score of 5 or greater indicating moderate cognitive impairment.

MSAS-HF was used to used determine physical and emotional symptoms of participants. The MSAS-HF is a modified questionnaire from the Memorial Symptom Assessment Scale (Portenoy et al., 1994). The MSAS-HF has been determined reliable and valid (Zambroski, Moser, Bhat, & Ziegler, 2005). The participants verbally rate 32 symptoms to provide multidimensional information about a wide range of symptoms experienced with heart failure (Zambroski et al., 2005). It has three subscales: physical symptoms (PHYS), psychological symptoms (PSYCH) and heart failure symptoms (HFS). The score is the sum of symptoms present and the symptom burden is the mean of the frequency, severity, and distress of each symptom (Zambroski et al., 2005). The reliability for the PHYS, PSYCH and HFS as 0.87, 0.83, 0.73 respectively and the total score is 0.92 (Zambroski et al., 2005).

Analysis

An experienced transcriptionist assisted in the transcription of interviews from the interview tape recording. The interviews were transcribed verbatim, including pauses, repetition of words, intonations and emotion such as laughter and sighing. The researcher listened to all tape recordings and transcriptions, proofread and annotated the transcripts for accuracy.

Data analysis began immediately after data was obtained. The processing and analysis of data consisted of guidelines for a generic inductive analysis set by Hood (2008) and Miles and Huberman (1994). Additionally, the data analysis was influenced by interpretive interactionism as outlined by Denzin (2001). This general approach is influenced by ethnography, constructionist grounded theory and phenomenology approaches.

The processing of data included a) careful review of interviews and transcripts, b) analyzing data to identify aspects of the symptom experience that are of importance to the participants; c) analyze data to identify the family or support person's perspective. The emerging themes and interpretation were analyzed within case and then across case to identify commonalities among the participants.

Preliminary analysis of the interviews included reading the data as a whole, while listening to the tapes. This was followed by further in-depth analysis. Methods described by Kvale (1996) were used included noting of patterns and themes (units of analysis), seeing plausibility and clustering, making metaphors and making contrasts and comparisons. Narrative analysis was utilized with texts that include long accounts of the participant's experiences. These strategies worked towards generating the meaning of the HF experience by opening up relationships, challenging the researcher to connect and view the data in different ways.

At the early stages of analysis, the data was general and descriptive in nature reflecting the study aims. Early strategies outlined by Miles and Huberman (1994) include individual case summaries, illustrated narrative, general condensation and conceptual frame (sequential analysis). Line by line coding was broad and as the analysis process continued, revisions in categories and coded themes occurred. Lastly, emerging themes within categories were identified. An important aspect with any data strategy is to look for the relationships that connect statements and events within the context into a coherent whole (Maxwell, 2005).

Interpretive memos were an important element throughout the research process (Hood, 2008). Memos provide a means of communicating emerging thoughts about the research, the researcher’s positionality (how the researcher affects the research), analytical processes, theoretical discussion and record the research (Lempert, 2008). Memos provided an important link between data and the analysis.

Validity and Trustworthiness

A major concern of any research is demonstrating integrity and competence (Tobin & Begley, 2004). This is demonstrated throughout the research process in the way the research is situated in theory, the methodological approach, explicitness of how the data is collected, how the participants are represented and given voice, how data is interpreted and presented, and that the research provides recommendations for practice (Arminio & Hultgren, 2002). The importance of how and why the specific criteria and choices were made before, during and after the research must be made explicit to ensure soundness of the research.

To support the validity of the data, an audit trail was maintained: a) field notes and observations of the interview, b) memos reflecting analysis and issues such as researcher bias & reactivity, c) documentation of the coding/thematic process and d) documentation of any changes to the interview guide and rationale for changes.

Qualitative research uses the process of triangulation for confirming results. Denzin (1992, 2001) makes these distinctions of triangulation by data source, method, researcher, theory and Miles & Huberman (1994) add data type. The key is to use aspects of each triangulation source. Each have "different bias, different strengths and can complement each other" (Miles & Huberman, 1994, p. 267). This entails sharing the data with the participants (source) to obtain their interpretation, using data from several different methods; observation, interviews and narrative to gain different perspectives of the data and having other researchers review texts and interviews. Confidence in the data can be increased by replication of the data. Replication is done as additional data is collected from new participants, new settings and events. According to Denzin (2001) interpretive data should be evaluated by the following criteria:

a. Do they illuminate the phenomenon as lived experience?
b. Are they based on thickly contextualized materials?
c. Are they historically and relationally grounded?
d. Do they engulf what is known about the phenomenon?
e. Do they incorporate prior understandings of the phenomenon?
f. Do they cohere and produce understanding?
g. Are they finished? (p.81).

In addition, perhaps the most important aspect, data must be understandable to the subjects.

Procedure Barriers

There were few barriers in recruitment as the cardiology outpatient and HBPC palliative care team readily referred potential participants. Unrelated to this study, VANCHCS IRB approvals in years 2010, 2011 were delayed and thus inhibited the researcher's ability to collect data 3-6 months.

Adverse Events

Psychological distress may also occur in the older Veteran population, the plan was that if distress was identified and, if appropriate, the participant would be referred to the HBPC psychologist and their HBPC medical provider.

Researcher Bias

Reactivity is the influence of the researcher on the setting or individuals studied (Maxwell, 2005). The researcher is always a part of the setting in qualitative research. Researcher bias is a far greater threat than the researcher presence in the setting (Maxwell, 2005). Prior to the start of the study, the researcher identified measures to limit research bias. As the researcher was a member of the palliative care team, the researcher removed herself from team meetings and any discussion of the care of any participants. Additionally, researcher influence was reduced by minimizing leading questions.

Reflexivity is the understanding of one’s own values, experience, decisions and interpretations (Charmaz, 2007). Planned time was built into the research process to reassess personal bias and minimization of the researcher’s identity as a nurse practitioner that may influence interviews and analysis.

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CHAPTER FOUR: FINDINGS

This chapter provides qualitative data analysis results. The first section provides men's demographics and illness characteristics, followed by a second section comprising qualitative data results. The results reflect the overall aim of the study: to describe the lived experiences of older adults with heart failure who are managing symptoms near end-of-life, specifically to describe and understand how older adults manage symptoms with those who support their care.

Demographics and Illness Characteristics

A sample consisted of 15 older men recruited through an outpatient cardiology clinic and Home Based Primary Care (HBPC) palliative care program at Veterans Affairs Health Care System (VA), Sacramento, California. Men ranged in age from 75-96; all had late Class III and Class IV HF. Table 4-1 summarizes participant demographic and illness information.

The participants reside in a 40 mile radius of the Sacramento area. Sacramento is the 6th largest city in California; it is comprised of urban, suburban, farming and rural communities (City of Sacramento, 2013). The Sacramento area has a large population of Veterans located between two active military bases and two closed military bases. Nationally the State of California has the largest Veteran population in the United States (U.S. Department of Veteran Affairs, 2013). Therefore, this study sample was drawn from a large but understudied population of older men who share similar early life experiences in a military environment around particular and significant historical events.

With the exception of 2 men with paid caregivers, men were living with their spouse who provided supportive activities for the management of HF. Two men lived in facilities in which staff provided some of their care needs; a board and care facility and an independent senior living facility. One man lived in a multigenerational home; the other men resided only with their spouse in the community. All men required some assistance with activities of daily living (ADL) such as bathing, dressing, and with instrumental activities of daily living (IADL) such as food preparation, cooking and medication management.

Men lived in diverse residential areas. While income was not obtained directly from the men, their home location reflected a range of low income to high income housing. The home location did not reflect the quality or quantity of assistance in the home. In fact, several lower income men received more family support than those living in higher income housing.

All men were Veterans serving in one of the following wars/conflicts: World War II (1941-1945), Korean War (1950-1953) and pre-Vietnam (1951-1963). While, each man had different actual war experiences, each was receiving care through the VA which not only represents the bond of their military experience, but ensured that each man received the same approach to medical management and had access to similar resources. Each man had elected to enroll with the HBPC team at the VA.

The researcher is the program director for HBPC. To maintain objectivity, this researcher excused herself during routine care discussions, and when men were presented at patient care conferences during and after research activities. The men were not known to the researcher prior to the interviews. HBPC team members were not interviewed.

The number of interviews with each man and his caregiver ranged from one to four interviews over one month to eighteen months. Two men declined further interviews after the first visit, and several men were hospitalized for extended periods of time limiting access to the men. The frequency of hospitalizations and death of men influenced the number of interviews that could be completed.

Thematic Descriptions of Heart Failure Symptom Experience

The study questions are answered within broad categories relating to awareness of the HF experience. The following questions are addressed in the data analysis:

> a). How do older adults understand the course or trajectory of their illness (past course of illness, transition to palliative care, future course of illness)?
>
> b). What are the processes for symptom interpretation, communication and management by the older person and those who participate in the care?
>
> c). How does the symptom management experience influence relationships of those whom the participant depends on for care and support?

Awareness is defined as a person's perception and cognitive reaction to experience (Merriam- Websters Collegiate Dictionary, 2013). In this study, the concept of awareness is used to organize broad categories of thematic and descriptive data to highlight the experience of older men with HF while analyzing the contextual factors and the processes which influenced their symptom experience. The thematic descriptions here are not intended to develop theoretical concepts; rather the thematic descriptions allow the reader to follow a pattern of perspective involved with heart failure symptom experience. Results include the experience of men's spouses in the management as well as the influence of our health care system in the decisions that are made at end-of-life.

Awareness of Heart Failure

Individuals experiencing serious HF interpret and understand their illness progression from their perspective based on new information and understandings of illness over time (Prius, 1996). Understanding how to manage HF is contingent on an individual's perceptions or personal understanding about the illness guided by that individual's own experience. The context and the individual personal history of HF are important in understanding how men participate in the symptom management requirements of HF.

Initial awareness of HF is a *transition or turning point* in which men recognize their life was changed at some point, not always immediately by the diagnosis. The recall from men how they were told or learned of HF was most often told through an event such as WWII, hiking or a sudden hospitalization for another illness. Although all men had been diagnosed with serious HF, several reported that the onset was recent. The following accounts highlight their perception of when HF first started. The following text excerpts are men ages 85-92.

> *"I was trying to climb (hiking) and I didn't make it. I sat down and rested, when I got down, I went and saw my doctor and he turned around and sent me to a cardiologist…..and he put me in the hospital (received valve replacement, beginning of HF)". (Age 85)*

> *"And then I knew where I was (hospital) and they (doctors) said we think he has congestive heart and everyone sort of agreed with that and then as it progressed, several doctors try to decide and said no it's not heart failure….so it turns out that the heart is fine and then now they are trying to get rid of all that fluid…" (Age 92)*
>
> *"Well I don't remember exactly. But I didn't have much trouble breathing until fairly recently…..a month ago, something like that. I used to live in a senior mobile home park…..they moved me….and that's about the time I started having breathing problems"(age 94)*
>
> *"I don't know, but I didn't like it (diagnosis), I didn't have anything peculiar, a heart attack or anything. I think you are surprised when these things happen…but I have accepted it" (age 92)*
>
> *"It doesn't expand and contract like it used to, and therefore, it doesn't pump enough blood and doesn't get rid of the moisture in my body, the excess moisture" (age 88)*

Explanatory attributions are a way to understand the meaning of an event. One's perception of the onset of an illness can influence how we engage in health care activities in the future. Additionally, knowledge of the illness onset was influenced by the age of the men. Older men more than younger older men found it difficult to recall the exact onset of the illness. Three men age 91 and older summarized as follows:

> *"I think at 60 or 65, I started to have heart problems. It's hard to dig up (from memory). It's uh, if I recall I think it was rather subtle. I was okay one day and the next day I was flopping around…." (age 94)*
>
> *"I don't remember exactly what she (daughter) said, long pause, She just said, the doctor had told her I had congestive heart failure. I didn't think much about it. I thought they were wrong of course". (age 92)*

> *"Well I don't know, I don't worry about nothing, I learned that years ago…..I guess I made it to this point, 91, so I say that I don't worry about it".(age 91)*

In contrast younger older men in their 70s and early 80s could recall the onset of HF and provide an explicit history of the illness. The following text reflects the exactness of one of the younger older men:

> *"That was August 6, 2003. I didn't know none of us noticed I had a heart attack until I got to the hospital. But anyway prior to call you know 911…..I was having breathing problems.……it was the very first time to be diagnosed being uh you know, but it was heart failure"… (age 75)*

Awareness of Decreasing Activity

Men describe a second *transition or turning point*, usually quite some time later, when the illness had an effect on their ability to continue their usual activities. The men's use of language "*it was subtle*" highlights how the illness did not gain prominence or had little consequence in their lives until the illness affected their daily function, at which time their perceptions of their level of daily function were intertwined with aging and effects of HF and other illnesses. The meaning of HF during this *turning point* was primarily focused on their ability to retain independence. They described HF through the lens of functionality:

> *"Don't have the get up and go, just lethargic" (93)*
>
> *"Disability not being able to do things I did before, the limitations" (88)*
>
> *"Well it's the mental thought of not being able to do the things you use to do……" (age 88)*

> *"Well, I used to be pretty active. Now I don't go fishing, I don't go hunting, and when I go to the store across the street I take my kiddy car (scooter)" (age 95)*

The oldest men experienced difficulty differentiating between their concepts of what aging entails versus the effects of HF and other chronic illnesses on their overall health. In other words, there is a general resignation of growing old. A man asked about his main worry responded: *"I don't know…I never really thought about it…you know a lot of people say I don't worry about nothing except home….I have been through two wars, I don't know how many (economic) depressions that I went through…".* HF is not a main concern in his day to day life.

Symptom Understanding

Men were seldom able to articulate the severity of symptoms when asked about their symptoms using the MSAS-HF. It was common for men to give up in frustration as they were asked about the 32 symptoms on the assessment scale. The frustration resulted from fatigue and for some irritability of not being able to provide an exact answer to the scale. They were not able to determine the frequency, severity or how much a symptom bothered them. The use of the MSAS-HF scale during the interviews was discontinued after the first six interviews. Questions were then asked about their worst symptoms; the most common response was breathlessness and the associated fatigue of HF:

> *"Shortness of breath is my problem" (age 91)*
>
> *"I get so tired and it's hard to breathe at times, can't do nothing else" (age 91)*
>
> *"Not breathing. When I went out of here I couldn't get my breath (911 call)" (age 82)*

Other men identified the worst symptom around functional status as the following reflects:

> *"Disability, not being able to do the things that I used to do, the limitations" (age 88)*
>
> *"I don't have any "get and go" I'm lethargic and when I go to bed I wonder if I'll wake up in the morning, but otherwise I'm perfect…." (age 94)*
>
> "*Bouncing around symptoms" between fatigue, breathlessness and limited physical ability" (age 88)*
>
> *"I don't have any energy at all" (age 90)*

On a day to day experience perspective, the level of function was of higher concern than the identification of actual HF symptoms. For three men measuring whether symptoms were controlled was represented by their being able to walk to the mailbox and back without stopping to rest. Prior to a hospitalization *"it used to be sort of a chore to walk to the mail box across the street and now (post hospitalization) I am not having as many problems".*

In spite of observable fatigue or breathlessness many men did not reflect a specific concern about these HF symptoms. The dyad of common HF symptoms breathlessness and fatigue are also associated with other chronic illnesses making differentiation of symptoms difficult if not impossible to determine as reported by men:

> *"It's the number of illnesses" (age 84)*
>
> *"When I get discharged from the hospital each time, at the top of the discharge papers it says "you have been treated for "x" number of illnesses" They got it up to nineteen now" (age 88)*

"Ya, I've had so many diagnoses it doesn't matter" (age 94)

Many of the common HF symptoms had become a *normal* part of their life and men failed to discern breathlessness although they were clearly breathless by appearance and speech. A way to compensate for some symptoms was to integrate symptoms into their daily activities and the activity was not associated with a symptom. For example, men with Stage IV HF took several naps during the day to compensate for breathlessness and fatigue. Insight into worsening symptoms seemed to diminish with the progression of illness and age.

Chronic illness and adaptation to illness and disability have been well studied (Charmaz, 1991). Other researchers have found that symptoms are normalized and often not recognized by the chronically ill (Gallacher, May, Montori & Mair, 2010; Jurgens, Hoke, Bymes & Riegel, 2009). Aging and chronic illness bring into focus a new perspective in which symptoms and attempts to define symptoms become what is considered a new normal. All men confirmed the finding of more than one chronic illness, further complicating discernment between HF and other illnesses. For example, two men describe difficulty in distinguishing the symptoms of HF and COPD:

> *"….it's hard to tell the difference, whether the lungs or heart…It's a sudden thing, no warning" (age 75).*
>
> *"I have shortness of breath now, but that's from this morning I kind of overdid it and then I was out of breath, that from the COPD…they are not sure if that shortness of breath is from the heart or the lungs" (age 84).*

In addition to other chronic illnesses that share similar symptoms, geriatric syndromes further complicate the symptom experience. Many of the common HF therapies such as the use of diuretics increased the potential for urinary incontinence and nocturia, thus increasing these men's already identified risk for falls and poor sleep as well as increasing deconditioning and dysmobility. These syndromes, particularly incontinence which is heavily stigmatized, influenced their ability to maintain a social life and attend events. As one man stated *"we go anyway"*, refer to attending social events. This same man was upset by the visual and material reminder of incontinence*: "I came home from the hospital and they (VA) had a case of Depends ® here…"* (age 88)

Struggle to Preserve Identity

Chronic HF as with other chronic illnesses challenge concepts of self through adaptations the illness progression presents such as indignation of seeing a box of Depends ® at home. One's identity is achieved through interaction between one's self, others, society and is developed over time and in various situations (Prus, 1996). How we "define and interpret" actions influences our identity formation" (Charon, 2004, p. 134). Identities also take into account how we desire to be seen, forcing one to take into account our present and future identities (Charmaz, 1987).

The incapacitating nature of breathlessness and fatigue are highlighted when men shared those identities that they once experienced. Interviews provided men an opportunity to influence how they were defined and seen by the investigator. It seemed important for men to provide a historical context of their past life with details of their current life living with HF.

Men by virtue of their age and the serious stage of HF appeared frail. Daily activity was difficult and intertwined with difficulty breathing and debilitating fatigue.

Maintenance of daily activities required assistance of their spouses or caregivers and other family members. A consistent pattern elicited by men during the interviews was spending time reviewing their military experience, a photo album or a treasured hobby. Descriptions of activities of their younger years were displayed in pictures and items on walls and shelves of their home. During several interviews, the main singular topic for the entire the time spent with the men was about their past.

A comparison was evident by their notable breathlessness and pictures of their military experience and past activities such as sports, hobbies that were predominantly displayed. This strikingly contrasted with evidence of illness: the table with multiple medications, medical equipment and home arrangements to accommodate their physical limitations.

Military Identity

Each man was asked if his military experience influenced how he managed or thought about this current experience with HF. None of the men saw a connection between the proximity of death in a war zone while in the military in contrast to the certainty of end-of-life as an older adult. A common response was that there was hope to survive during the war. This made an unstated comparison with HF in old age: HF will inevitable result in death. This perspective is not surprising as it is the difference between youth and older age.

Several men related HF to the stress of war:

> *"My heart is too weak. My kidneys are too weak to digest liquid intake….This thing (HF) has been going on since WWII….You can't abuse the body that much". (age 94)*

One man contrasted the influence of military experience and HF:

> *"Well I don't know. It must have taught me something about all the serious situations that you face in life….I was in the military 22 years…"(age 92)*

Another man discussed worry about past war activity as increasing breathlessness:

> *"I am inclined to think that. It (worry about the war) brought it (breathlessness) on noticeable" (age 94)*

These men had experienced Battle of the Bulge, the Normandy landing (Omaha Beach), Bataan Death March and Pacific war theaters. Although all men demonstrated a certain stoicism about HF, several were overcome with emotion and at times tears flowed when talking about their war experiences. These experiences were very much present in their current lives.

With the exception of four men, all had met their spouses during or shortly after their war experience. The maintenance of their military identity has been strengthened by either their military spouses or spouses who were there to re-begin life after the war. Spouses who had married the men later in life also maintained a sense of military identity and history by encouraging participation in the VA health care system.

These men are culturally rooted in a generation that survived a great depression, major wars (WWII, Korean) and came home to raise families (Brokaw, 1998). Many of the men described their hard work to find success in their career life, their families and significantly their pride of these accomplishments. With aging their roles have changed in light of breathlessness and fatigue. It was common to find spouses performing roles the men previously undertook, for example: driving to appointments and taking over yard duties such as mowing the lawn, tending to the fruit trees. There is an overall frustration expressed by many men about their helplessness in not being able to support activities in the home: *"I need to do things, I need to help her. She could use help lifting and doing things around here" (age 78).* In another situation, in spite of significant breathlessness, a man was preparing meals for his spouse who had increasing cognitive impairment. The roles of men changed to meet individual and family goals and centered on the goal to remain at home.

Awareness of Increasing Symptoms

Symptom Management

Symptom management of HF by men is pivotal to preventing hospitalization and preserving their functional capacity. It requires not only the ability to recognize symptoms, but also the ability to know what to do when the symptoms worsens, to communicate the symptoms to others involved in the care of HF and how to manage a complex medication regimen.

The men's identity, recognition of self, is reinforced by spouse/caregivers who outwardly appeared to leave control of the symptoms to the men. This seemly respectful approach recognizes the traditional roles in their relationships. It is also another indication why symptom intervention is not sought sooner. Spouses tend to leave much of the decision making to the men, along with medication management. Several spouses indicated that they want to provide the men with independence around their care. Initial symptom management is performed by the men; that may include monitoring activities such as recognizing worsening breathlessness, diet, weight and medications.

When symptoms or repeated hospitalizations occur, the men's spouse/caregiver increasingly becomes involved in the HF management activities. The involvement of the spouse/caregiver maintains a state of *watchful waiting* with the men continuing to semi-independently manage symptoms and medications. Now, the caregiver watched over the process, but did not override the decisions of the men until was apparent that a call to 911 was warranted. This preservation of role is seen across all men.

In late stages of HF the men's day revolves around rest, medications and treatments. Activities are limited to primarily the men's home with social isolation ensuing. The following texts reflect how men manage increasing breathlessness:

> *"I get into trouble breathing and I come into the house and do nothing much" (age 82)*
>
> *"I spend anywhere for 9-12 hours in bed and I get up every 2 hours to use the restroom, so my sleep is interrupted" (age 94)*
>
> *"I usually come in here and sit down and rest. And when it (breathlessness) quiets down a little bit, I come in here and take a nap. Let my heart rest…happens just about every day" (age 93)*
>
> *"I get tired real easy. Sometimes I lay there and I get real sleepy and tired and I just want to lay down. I lay down and rest for an hour or two hours. …Today I got up early and then I went back to bed. And then I go in and lay down again" (age 82)*
>
> *"I don't want to move. I want to just sit. Once in a while, in the evening I will read for an hour or hour and a half. But I don't sleep too good. I can go to bed and lay down and not fall asleep until 2 in the morning" (age 93)*

On one occasion an interview that had been planned with one of the men and his spouse had been forgotten by the couple. I was suddenly at their door and found the man in his underwear with a urinary catheter hanging at his side and his wife disheveled and unable to get out of bed. He was fatigued and breathless. The couple had always been immaculately dressed and groomed at the previous three interview occasions. I soon realized that they had previously “dressed for me” and what I was seeing was the results of their usual rest/activity routines and lack of energy to dress and groom. It provided me with a glimpse that many of these couples were preparing for me not only with picture albums set out but with special attention to dressing for having a visitor in the home. Had they not forgotten my visit, I would have never known the reality of what lack of energy means and what the interviews meant to them in terms of energy expenditure.   The interviews were an opportunity to present themselves as normal, regular older adults who are still actively engaged in life and capable of sustaining social interaction with a visitor.

Managing Breathlessness

Several men were able to articulate increasing breathlessness as a cause for hospitalization. Typically, a first response to increasing breathlessness was to rest or go to bed to see if the episode would pass. Men did not notify a health care provider for assistance based on increasing breathlessness; nor did they link breathlessness with other factors such as weight gain and increasing fatigue. Very few men weighed daily and weight gain was not reported. Instead this self-care activity was balanced with other priorities and energy.

Hospitalization occurred when the constellation of symptoms persisted and were not improving; making it clear to the men they should call 911 and go to the hospital. The actual decision to call 911 happened when symptoms were too overwhelming to manage alone at home; often times after the spouse had allowed the man to determine if he needed to go in to the hospital. Men tend to describe a period of time prior to the 911 call in which their activity level decreases and more time was spent in bed. The preservation of roles continued although the men may have been too ill to recognize and report the symptoms sooner.

A man age 83 described daily weighing, strict recording of his weights and changes he had made with his diet resulting in weight loss after his diagnosis of HF. Although, he was performing all the tasks of HF symptom monitoring including responding to a HF monitoring system, he and his spouse did not see the connection between changes in these activities such as noticing a weight gain and reporting to a health care provider sooner rather waiting until 911 was required:

> *I: "What do you do if he gets short of breath, what are the kinds of things that you do for him?"*
>
> *M/Spouse: Well all I can do is tell him to sit down and take deep breaths if he can…..But if he does run into problems, then yeah I'll get on the phone and call 911 immediately" (spouse age 78, man age 82)*

The persons who care for these men are crucial in determining outcomes, however in their wanting to allow for independence, control of symptoms measures such as calling the palliative care team occur later. This does not seem to be related to denial of the seriousness of the illness by men, but is more related to the inability to judge when to call the health care providers. In addition, the *watchful waiting* by the caregiver delayed taking action. Particularly for those at the end-of-life, the cycle of severe symptoms, hospitalizations and return to home was frequent even with a palliative home care team visiting the men at home.

The relationship between the palliative care team goals to prevent hospitalizations and the men's view of living with breathlessness reveals meanings men attach to symptoms and their approach to controlling symptoms particularly breathlessness. Men are living the experience of breathlessness which carries the anxiety and fear of not breathing. This experience has multiple realities for the men. A hospitalization provides one more opportunity to feel better in spite of the knowledge that symptom relief may not last.

> *"I have been in the hospital a couple of times taken on water uh enough so that it created a congestive heart failure and we went to the hospital to get rid of it and the last time I was in there I was in there for over a week because I got rid of 10 pounds of water…I feel good in the hospital because I feel better when I get home" (age 85)*
>
> *"And well I was just gasping for air and I couldn't breathe and finally after a few hours, I thought I was going to die because it was getting worse and worse. And finally I got a doctor in there (ED) to look at me and they gave me…pills…stuff they'd give to go to the bathroom all the time" (age 88)*

A secondary factor in delays in calling 911 was expressed by two men. A 911 call resulted in costs which caused them to rethink when to call for assistance. One man had thought about alternatives to 911, for example, calling a taxi and not telling the taxi driver why he was going to the hospital:

> *"So what I am thinking about doing the next time when I think I am in trouble. I'm going to pretend I'm not and I'm not going to call them (911). Because I found out that they go to Community Hospital and I can go there by cab. By the condition of what would be anywhere from $14 to $18 cab fare to go to the same place. Or it could be thousands of dollars if you call 911" (age 94)*

The second man expressing financial concerns stated that they were paying 50 dollars monthly for the cost of their 911 call and *"hospital bills"*. This additional monthly payment caused great stress and concern about finances and the spousal couple ability to remain in their home.

Another interesting factor was most men had "clickers" a medical alert call button when they needed help. Several men referred to this as being their back-up for help:

> *"I have my clicker, if I run into any problems" Spouse: "that's what they sent, the VA, they said it's what they have on TV, you push the button and emergency comes"…Yeah it's a medical alert, in case I am not home and he's out there by himself, then he could push the button if he needs some help.." (age 82)*

Medication Management

Medication management is left to the men to order, organize and take at the correct times. Medication difficulties abound. The management difficulty is reflected by the counting of the number of pills:

> *"I take them (medications) in three doses, like 15(pills) in the morning, 5(pills) at noon, then the balance at night….right now I take 43 pills a day" (age 94)*
>
> *"It's the number of pills…57 a day" (age 89)*
>
> *"You know you count those pills up; I must take 70 pills a day, maybe 80"; spouse says "not that much, but a lot" (age 95)*

In the later stages of HF, medications may maintain or support heart function and provide a reduction of symptoms and increase activity tolerance, however in the final stage (Class IV) symptoms are refractory despite medical therapy. It is only when assistance is needed to manage the medications that spouses step in. The involvement of the caregiver occurs late in the illness when it becomes apparent management assistance is required (i.e. hospitalizations, men are overwhelmed by symptoms). The assistance of medication management may begin with oversight by his spouse by checking the medication boxes after the men have filled them:

> *"…when he does his medicine, he's got the pill boxes and he actually puts the pills in the box and I keep a card and I mark it when he's finished each pill in the box and make sure that all the pills are there" (age 84)*

The task of remembering when to take the medication was difficult for many, even with more sophisticated medication boxes that had a recorded reminder to take the medication. The decision to have the men continue with administration seemed to be a decision that was made by the men. As a man becomes more impaired by fatigue and breathlessness, the caregiver, family member or the nurse from the palliative care team begins to fill medication boxes. The medication boxes can be a source of frustration. Because of the sheer number of medications, missing several medication dose times does not take on significance:

> *I: "I know your son was doing your medicine box the last time I was here, it sounds like your son has taken over that.*
>
> *M: "Yah, he has. No matter how hard I try, I goof up somehow. I don't get the right pills in the right box.*
>
> *I: "Well 43 pills is quite a number"*
>
> *M: "Well I take them in 3 doses, like 15 in the morning, 5 at noon, then the balance at dinner, then he (son) was pretty abrupt. I missed a couple of days and he (son) came around and said you miss your pills you die, just like that…*
>
> *M: "I thought about it for a while….I missed 2 morning sets of pills, but I don't think that it was too bad when you have 14 doses of each quantity and I only missed 2 of them…..that little black box announces it is pill time, "take your morning pills, take your noon*

> *pills"...it actually talks…it gets a little frustrating, it says take your pills maybe 3 or 4 times a day and it will repeat maybe 7 or 8 times….we still miss it, we don't feel like getting up and getting the medicine" (age 94).*

Another man expressed medication management this way:

> *"So I got to get somebody like a nurse to order them for me or I won't get them and that's alright too because I'm tired of taking pills anyway" (age 82)*

The ordering of medications and filling of medication boxes has long been a part of the role of home healthcare nurses. Homecare nurses have experienced the complexity and time requirements to safely set up medication boxes. The actual filling of the medication boxes can take up to an hour, depending on the number and complexity of the regimen. It also becomes problematic when there are not enough doses of one medication, the nurse then needs to remember or mark the box as incomplete until the medication is obtained. Taking on the role of filling medication boxes is not automatic, once the role is taken it places responsibility on the nurse to return immediately to the home for medication changes and box fills. For this reason, families are left to manage medications until it is apparent that they are unable to do so. Medication boxes are an invisible consumption of time for men and their families and ultimately if done incorrectly may cause hospitalizations.

Education about Symptom Management

All men had received education utilizing a home HF monitoring program and/or in person by registered nurses on the HBPC palliative care program. The results of the education were more apparent with the younger older men (age 75-82). Older men (age 88-96) were generally less vigilant in monitoring activities such as weight, diet, and symptom recognition. Older men were more likely to check one aspect of HF monitoring activities but they were not likely to take action on the results, for example reporting weight gain, an important preventative to exacerbation of breathlessness.

Learning response based skills requires understanding the illness, understanding the importance of a sustained response to changing symptoms and these skills are generally learned through trial and error. For these men, these skills were absent in light of the required time and energy to perform these activities.   It is also a challenging endeavor in the presence of increasing HF symptoms and increasing symptoms not always associated with HF, for example, pain, difficulty concentrating, impaired appetite, anxiety (Lehman, 2006). These increasing symptoms often require adding medications to an already complex medication regimen, a very difficult enterprise for men with serious heart failure.

A common finding describing HF was about *“fluid buildup”* and the great difficulty their body was having managing *“fluids”*. The language used to describe HF was *“kidneys too weak to digest liquid intake”* and *“my heart is fine…trying to get rid of all that fluid”*. Two men had developed renal failure as a consequence of HF. They seemingly did not connect the fluid and renal failure as a progression of the illness and so their focus was to eliminate fluid in their body. The term *“congestive heart”* is reference to the knowledge of fluid accumulation, but does not involve knowledge of actual heart failure; rather the fluid accumulation is about a *“weak heart”* or a *“fluid”* problem. This distinction has potential ramifications about their knowledge and perception about the seriousness of their illness.

Family Experience

Relationships developed through activities helped form the men's perspectives, identities and commitments (Prius, 1996). Each man's identity, recognition of self, is reinforced by his spouse caregiver, who leaves control of the symptoms to the man. This seemingly respectful approach recognizes the traditional marital roles in their relationships. It is also another indication why intervention is not sought sooner. Spouses tend to leave much of the decision making to the men, along with medication management. Several spouses have indicated that they want to provide the men with the independence with their care.

As the men's functionality decreases, the spousal role begins to evolve to meet the growing need for additional supportive care. Their spouse recognizes that their social life too has become limited in order to provide supportive for their husbands increasing needs. Several caregivers discussed the decrease of social activities over time:

> *"We haven't taken as many trips lately; we have family calling daily to check on us" (man age 89)*
>
> *"We were in Tai Chi class which I loved and it just started making him nervous, so when he quit, I quit too" (man age 80)*
>
> *"He does relatively little around here. He gets up, he eats breakfast. He sits out in his chair in the garage and falls asleep then he doesn't stay awake very long until it's time to eat another meal. He spends more time asleep than he does awake anymore" (man age 92)*
>
> *"He can't hear well. For 25 years we had tickets to the music circus. We were right in the front row, but now we erased it because he can't comprehend what they are saying (hearing). But really it was his only outlet. He is around other people that way. It makes him feel like he's doing something as opposed to just sitting" (man age 92)*

Roles change as the spouse begins to be the central person for organizing and performing daily activities. Spouse activities include ensuring medical appointments are coordinated; driving to medical appointments which in some cases were located over 40 miles away, cooking/housekeeping activities, medication oversight and coping with disturbed sleep with the men getting up frequently at night. The increasing work for the caregiver or the inability to manage both the illness and home environment precipitated decisions about moving to a more supportive environment. These changes impacted men's idea of independence. For one man it means moving from independent senior apartment to assisted living; this change in location at his senior complex resulted in having to recognize the decreasing ability to manage his illness. For another man it meant transitioning to a senior apartment:

> *"Once we get into one of those things (senior apartment) they don't give us much independence…At 1200 they ring a bell and ...schedule…they cost about $5,000 a month…and it's not a medical facility, that's only assisted living…They check on them (residents) and make sure you are still breathing" (age 88)*

This personal loss of control begins with changes in man's role in the home, "*taking care of the outside*", while the caregiver maintained the *"inside"* of the home. As breathlessness and fatigue increase these roles become difficult if not impossible for the men. Caregivers transitioned to increased work around the home by either working together outside, taking over the work or hiring the work done. While men had grown children in the area, there was a reluctance to include them in the work of the home.

Several spouses comment:

> *"I am old and he trimmed the lawn 5 years ago….we had an electric mower, but he was able to, now I mow it" (man age 80)*
>
> *"We both work out in the yard together watering the fruit trees" (man age 82)*
>
> *"He used to take care of our pool and yard…now we have hired someone to take care of the outside"(man age 81)*

Simple social outings for the spouse such as having dinner out or having a haircut may be interrupted by the side effects of a diuretic medication:

> *"If we want to go out to dinner we go. We go to the grocery store. I have never, the only time I have trouble is..she got her hair cut. And I really didn't have a big problem, cause I went to find her because she had a bathroom, her assistant, so other than that I didn't have much of a problem…since 70, maybe be bought two cases (Depends ®, a brand of adult incontinence underwear)"(man age 88)*

Men in this HF population, presented many situations where they made a concerted effort to maintain a fairly high level of social activity. The majority of men had caregivers who were able to drive which provided a means to leave the home. One man with Stage IV HF, who met hospice criteria, required a wheelchair to leave home and wore oxygen continuously. On one occasion when he arrived home from a hospitalization his caregiver was planning how to get him to a bridge game until she encountered the barrier of 3 steps:

> *"Saturday night, we had people here last week come over and play bridge and we're going and we're going to try to go to their house this next Saturday...its three steps into their place so that's the problem……but it's good for you" (man age 83)*

Another man and his spouse were not able to drive but found acquiring scooters allowed them to leave their senior apartment and do their own shopping. Spouses even found ways to continue enjoyable activities such as fishing. One spouse drove up the edge of a fishing area which facilitated her husband to sit in the car and continue a favorite pastime of fishing. Another spouse took her husband on walks with their beloved dog. The man would walk for 5 minutes then sit and rest until his spouse had returned from her 30 minute walk. The spousal couple remained active together.

An 88 year old man sums up their decreasing social activities and support:

> *"Most of our friends are our age and they have been dropping like flies. A couple of them visit. I go to our previous town and gosh, we are surprised every time we get back (home)"*

Many caregiving spouses spoke of living with major health issues themselves which influenced how much support they provided to their spouse. In one situation, the spouse was in treatment for terminal breast cancer, she states that she had her husband dress himself as a way to get exercise:

> *"It takes an hour for him to get dressed, but that's his exercise"*
> *(age 84)*

The goal was to keep him independent, so that they both might remain at home. For another man whose spouse had mild cognitive impairment, but physically remained functional, the roles of caring for each other became focused on each other's strengths. This man could not walk any distance due to breathlessness but they both were able to get out with the cognitively impaired spouse pushing the wheelchair while the man sat and directed getting to their desired destination. These activities were not without challenges:

> *"Well we had another fall the other day, went over the curb with a walker and we piled up in the driveway and she (caregiver) hasn't been the same….I had trouble walking so I sat on a walker and she was pushing and all of a sudden we piled up"…and she was worse than I was, but I had an ankle pain, pain in my butt and my wrist was a little flexible. Jeez that was last Thursday, so I should be recovered by now" (age 94)*

In these cases where the effort of activity was coordinated between strengths of both the men and their spouses, their ability to remain at their current independent state counted on this interdependence. One could not live alone without the other. The companionship of having a partner near and supporting the men made a difference in the quality of their lives and the ability to remain at home.

Men talked with pride about their children and grandchildren, pointing to pictures, artwork and experiences that included their families. In one home portraits of grandchildren were painted by the man's spouse and hung prominently in their living room. Another man had a formal head portrait of his grandson's dog poised as if another grandchild. Lastly, men spent time telling with satisfaction the accomplishments and activities of their children and grandchildren.

Involvement on a daily or weekly basis varied; however, the actual involvement with symptom management by family members was limited. One daughter visited her father daily at his board and care facility to do puzzles and word games together. In this way she kept a watchful eye on his overall care. Other examples of watchfulness were also encountered. The move to the board and care had been difficult a 94 year old, as he had lived many years in a mobile home park which afforded him with friendship and companionship. His friends who visited him at his new location brought in "salt pills" to correct his low sodium that was mentioned after recent lab work. This created a conflict at the facility and with his daughter who did not want these visitors back. This man's wishes prevailed, however, and his friends were given a warning not to provide him with food or supplements. While the additional sodium could have been harmful to his overall symptom management, it was not commented on extensively. Rather, the potential loss of visitation by his friends caused an emotional upset that he talked about for some time. The balance between one's own health determination and the influence of family and facility requirements illustrates conflicts that can occur within the caregiving role.

Many grown children talked of the responsibilities to their own immediate family, their own retirement activity goals, and the increasing need of support by their parents. One son walked into his parents' senior apartment and spoke to his father in an angry tone about forgetting to take medications and about his mother's difficulty in managing the finances. The son's frustration appeared to be around the increasing amount of time required of him to assist his parents to remain at home and possibly his inability to recognize the increasing difficulty of both parents to manage care requirements.

Relationships and roles between the men and their children begin to change as the men become more dependent on "family" outside the home. Resistance to their children participating in care can be seen by increasing reliance on friends and neighbors rather than their children:

> *"When I went to the hospital, my neighbor never missed a day and he was out there visiting me…..If they don't see one or both of us every day, they are right at the door bell to check" (age 89)*

The utilization of friends and neighbors can be a way to delay the changing roles with children and maintain a level of independence apart from children. Neighbors recruited to witness the consent, for this study, were very concerned about the men and asked many questions prior to witnessing the consent, demonstrating their protectiveness of the man.

Two men with extended families intermittently living with them appeared to manage the growing dependence in a different way. Their families (children and grandchildren) depended on them for a place to reside. This situation allowed the men to retain a role as "head of household" while their family provided extra support to the man and his spouse by *"being there"*. Extended family members did not visibly participate in management of HF. Although, it appeared that additional persons in the home added a sense of support and a window into the outside world. One of the difficulties of aging in place is the social isolation, particularly for these men for whom getting out is an effort and challenge.

Awareness of End-of-Life

As breathlessness increases and becomes difficult to manage, it forces discussion around treatment options i.e. further hospitalizations and transition to hospice. A first step towards these discussions is admission to palliative care.

Palliative Care Options

The goal of home palliative care is to maximize men's quality of life through frequent assessment and appropriate deployment of interventions through education and therapy management. One part of care is to work with men through planning the goals of care. Activity revolves around “exploring and assessing options” and “formulating plans” (Prius, 1996, p. 158). Admission to palliative care services for ongoing care in the home is generally part of supportive care in the last one to two years of life. For the men it may bring ease of care by having providers come to the home and thus easy access to medical and nursing care.

A palliative care referral occurs when a health care team determines that the patient would be best served with care in the home; symptoms require more frequent interventions, it is increasing difficult for the patient to come to the clinic for primary care. Persons with late stage HF are referred for interdisciplinary care management. The goal is to improve quality of life and to reduce hospitalizations through symptom management at home.

Symptom management is difficult because “most symptoms are denied, normalized, or evaluated as having little importance” (Mechanic, 1992, p.1347). The difficulty is not in reaching consensus in goal setting by the men and the palliative care team; it is in operationalizing goals. For most men their wish is to remain at home, but when breathlessness becomes uncontrolled, they call 911 for relief of breathlessness. The following men describe the situation in this way:

> *“When I have difficulty breathing… Yeah that’s really difficult to put up with because you imagine all sorts of things. I am not afraid of dying, I am not afraid of dying, every body’s got to do it, but when it approaches you that close where you can’t catch your breath, no matter what you say about dying, it gives you a creepy feeling. Sometimes I wake her up, I say wake up come on wake up stay out here with me” (age 92)*

> *"There were times…like I wake up in the night and I couldn't get my breath….that's pretty scary when you can't get enough breath in, it's like somebody choking you"(age 90)*

In spite of frequent hospitalizations and a limited quality of life, allowing for a natural death is unthinkable in the presence of breathlessness, especially when it is uncertain if this episode of breathlessness will in fact be sufficient to cause death. Regardless of the availability of medications and equipment to support management of breathlessness at home, men found it difficult to do what they considered *"nothing"*:

> *"My cardiologist now, the couple of visits he said I have done everything I have done for you now and ah, just bide your time. He says if I was you I would stick to the DNR and once you are down, you're down and out…But the nurse and somebody else said, when I give you the last chance, if you fall and pass out, give them 24 or 48 or 72 hours to see if they can do anything to prolong you…my wife doesn't want me to (DNR)" (age 94)*

Transition to Hospice Care

The last *turning point* is when men's symptoms become uncontrolled in the sense that hospitalizations are increasing in frequency. Referral to hospice requires a different perspective of the illness, its significance and of one's present and future quality of life in order to accept the transition. Additionally, it requires that the relationship with the referring team (home palliative or inpatient palliative care) is reflective of the experience of the men.

The general medical perspective for referral to hospice is that the medical therapies, including benefits from hospitalizations, have been maximized and have become futile with respect to improvement in condition. The men's perspective of the severity of their heart failure was not entirely influenced by health professionals, health facilities or caregiver opinions; their perspective was based on the need to obtain relief from breathlessness and the place where the symptoms could be improved was the hospital.

For most men, a hospitalization meant returning home and feeling better for a short period of time. When hospice was accepted, it was readily apparent that there are no further second chances. For example, one man and his spouse interviewed while in the hospital stated that dialysis for renal failure was not something he would survive and therefore he wanted to go home to die. He went home with hospice services, understanding he would be kept comfortable during his last week of life. For those men who had periods of stability between exacerbations of symptoms, hospice carried a fear that medications, need for hospitalizations and other services will be discontinued. Instead, for advanced HF, the goal of hospice is, at least in the beginning, "maximal management of HF with medications that may also be life-prolonging" (Tanner, Fromme & Goodlin, 2011, p. 239). Instead of a collaborative approach to management of HF, men understood this as "nothing more could be done", but did not understand what this referred to. "Nothing more" meant no further improvement in condition could be expected.

At times health care providers were perceived as providing uncertainty in how to proceed with care:

> *"The doctors don't know. They don't have a clue right now. I went to the cardiologist about 6 weeks ago, and he said "I think I have failed you". Very seldom you hear a statement like that from a doctor. He felt that we were not going the right direction of what I needed. But who knows, everyone makes mistakes. …….I had 3*

> *cardiologists in my room down there for 3 weeks. They can't agree with each other" (age 92)*

Men whose heart failure had progressed to Stage IV resisted the idea of hospice care. This resistance was in spite of multiple hospitalizations over a short period of time. After each hospitalization limited improvement occurred and severe breathlessness reoccurred making it difficult to remain at home.

The discussion of a referral to hospice often began with the men and the palliative care team at a hospital visit. Then discussions occurred again during hospitalizations for HF exacerbation. Several men stated they were told they could not go home from the hospital unless they agreed to receive hospice services. This was a common finding from both community and VA hospitalizations.

For some men, they spoke of not being able to have further hospitalizations if they accepted hospice care. Hospitalizations represented relief from difficult, overwhelming breathlessness; hospice meant the inability to receive hospital interventions. The decision to forgo immediate hospitalizations was difficult for men to accept in the presence of symptoms that were difficult to control. One man indicated when he was discharged from hospice it was a second chance, this same man had been admitted to hospice three times.

> *"…who knows maybe the next time there would be any second chance, but good thing I have been getting second chances you know all this time, but I really don't know, the doctors say it could be any time, no one knows except God…"*
> *(age 75)*

One man resisted hospice care resulting in over 20 hospitalizations the year prior to his death. Hospice care at end-of-life was provided when he was no longer able to make decisions for himself. He died 8 days of discharge from an acute care hospital to a skill nursing facility. Up to his last hospitalization, he remained at home *struggling* to remain independent with paid caregiving in place. In spite of the complexity and difficulty of care, his choice was to remain at home without the support of hospice services. He lived with almost certainty that he was dying, his desire to protract the dying process was likely influenced by feeling better for a short period of time after the hospitalization.

> *"I don't mind going into the hospital…..It isn't the total number of days that I spend there. It's the repetitiveness" (age 89)*

After his death his spouse spoke about her anger of being told that her husband had to agree to no further hospitalizations to qualify for hospice care. This interpretation of the hospice benefit prevented him from accepting the hospice program sooner. Hospice programs are cost effective when patients choose to remain at home for treatment, particularly when acute hospitalizations are futile (Story &Knight, 1997). The overall goal of hospice programs is to manage symptoms at home; a hospice patient is advised to call their hospice program instead of 911for symptom management. If an acute hospitalization is needed for symptom management, it is approved and directed by the hospice program. If a patient independently calls 911 and is hospitalized, this may result in a discharge from hospice, hence hospice services are reluctant to admit patients who state they wish hospitalizations.

A 75 year old man was told during a hospitalization that he would not be discharged from the hospital without hospice. He describes the discussion as a positive pitch on why he should transition to hospice: a) he will not have to come back to the hospital, b) the bipap (breathing) machine will be just like the one at the hospital and c) he will have 24 hour access to medical and nursing staff. Hospice is “just like taking him to the hospital”. He was previously admitted and discharged from a hospice program three times when he failed to meet consistent decline, and for calling 911 which resulted in a hospitalization. Finally he refused hospice care. His primary hospice diagnosis of HF was complicated with serious chronic obstructive lung disease (COPD). He experienced repeated hospitalizations in spite of the availability of hospice care. Through his experience of repeated admissions to hospice, he understood that there was not anything that prevented him calling 911 and re-admission was possible if he was discharged.

A common theme about concern of electing hospice services is the ability to receive symptom intervention when symptoms require it. Many of the men manage their symptoms by self-treatment methods such as increasing naps or time spent in bed when breathlessness or fatigue begins increasing. This process of “waiting to see” delays contacting a healthcare provider and results in frequent hospitalizations. Hospitalizations act as a reprieve from symptoms and result in a temporary improvement in symptoms. The process of recognizing a change of function and taking action at that point seems to be difficult to recognize.

One 92 year old man during an intensive care unit (ICU) stay for three weeks, described the struggle between hospice and going home: …*"It's morning in the swamp surrounded by crocodiles"….* The statement provides a perfect visualization of his dilemma. Morning indicates a new beginning, the swamp is the ICU, it is isolating in the ICU room, life has become mucky (swamp) without a clear picture of surviving or knowing what is coming next….and the crocodiles….well, it is the perception of hospice swarming, swimming around, snapping at him with death at arm's length.

Biding Time

Biding time accurately reflects the separate realities of the notion of time between palliative care members and men's HF goals of care. Biding means to *wait for or withstand, an old word meaning to remain in place* (Merriam-Websters' collegiate dictionary, 2013). According to the men, this means to give up, to do nothing. For these men whose lives reflect a "never give up" perspective, this is a challenge to meet. As one man states *"I can still do anything I want to do. It's just mind over matter" (age 89).*

All men are very aware their life is coming to a close; however they are not willing to give up the option for relief of symptoms at the hospital, which is a *safety net* for breathlessness that cannot be managed at home. As reported by men, the communication from palliative care teams whether at a community or VA hospital was one of the terminality of their illness, to essentially go home and "*bide time*"; to passively do nothing; not actively receive comfort care.

Hospitals are increasingly under pressure to reduce HF related re-hospitalizations. Hospice referral represents one option to assist men to remain at home. Men with HF consistently report living *"day by day, no long term future"*, although they are not willing to give up what they consider options for emergent care. None of these men saw palliative care as an option for care as hospice meant doing nothing.

The blurring of being older, HF and other illnesses made it difficult for men to accept or acknowledge the seriousness of HF *per se* and end-of-life concepts. This seems to contradict what we may expect from men in their 80s or 90s who have already outlived their life expectancy. Those men with frequent hospitalizations were likely to anticipate any future hospitalization as one more opportunity to gain relief from symptoms and a "do not resuscitate" order (DNR) represented an inability to have that opportunity for care.

Time itself commonly is seen in a linear sense and connected by "sequence of moments" (Miller & Johnson-Laird, 1976 p. 415). This sequence of moments is part of a past, present and future perception and is connected by events (Miller & Johnson-Laird, 1976). In the context of this study, the pattern of awareness of illness is commonly put into the context of physical abilities with the present related to the past in the accounting of activities that can no longer be accomplished. It is common for men to talk about the considerable contrast from young to old in terms of activities. However, activities disappear slowly, subtly, and gradually declining over time, with small incremental changes that one may not notice at all at once. In the case of medication management, the understated change from managing medications, to your spouse providing watchful monitoring, and finally someone else is filling the medication box. All of the decreasing activity happens over time, not all at once, and is hardly noticeable until one looks back to the beginning. And all of this taking place in a smaller shrinking world.

The notion of *biding time* reflects a future without obvious movement or activity towards a goal; in this case the undesired outcome of death. It provides an impression of marking time or time standing still and a visual picture of sitting and waiting with progressive decreasing physical abilities. Yet time is not standing still, the habitual or usual routine of management of HF is perpetually present. Time stands still during activities of sleep and then suddenly an increased activity momentum associated with meals and medications occurs. One no sooner takes a nap then it is time to take medications again; there is a sense of time waiting and time accelerating around necessary activities of managing HF symptoms. This momentum can also be associated with re-hospitalizations and changes in medication:

> *"And then I went through the same old thing again. And then I wanted pills. I was taking one a day, from one pack an hour. I take two. The next day I take four. The next day I take two, the next day I take four. It keeps me busy" (age 94)*

For the one man living alone, struggling with multiple symptoms, and much of his time was spent sleeping or resting, had short bursts of energy to remain on task for activity and the sense of time itself had become less significant:

> *"I eat whenever I feel like I'm hungry. Many days go by where I never turn the TV on. I don't wear a watch anymore, because I don't want to know what time it is. When I feel hungry, I go and make myself something to eat. They don't understand how I can live that way" (age 89)*

Spatial relationships in the environment change as symptoms worsen, reflecting the increased time it takes to perform activities. Medications, equipment, and recliner chairs are in proximity to the bathroom and bedroom although the recliner chair functions for some as a bed (within 3-10 feet). These changes reflect the time and energy it takes to manage their symptoms. Environments are set up for ease of time and constraints of mobility. The following description from my field notes of a man's home was similar to many other homes visited; "his home was cocoon like, surrounded by bookshelves, paintings done by his wife, table filled with his stamp collections, all things of great meaning to him and represented a snapshot of his life in one small area of the home, an area where he spent his days and many nights".

Walking takes energy and uses oxygen, so decreasing the actual area lived in reflects a way to manage both breathlessness and fatigue. Another man's day to day life involved managing his care from 3 feet by 3 feet space around his recliner chair. The area:

> "*contained medications, oxygen equipment, food, logs for weight and blood pressure, his scale and blood pressure monitor all surrounded by his scrapbook of family pictures and woodwork designs that he had once completed. His time/distance from bed to chair was condensed to a very small space with everything he should need at an arm's length*" (memo)

This ease of care in the careful positioning of objects in the environment and their relationship to the men may be another indication for the delay in hospice services or perhaps a move to a place with more support. Their environment is set up in a way that preserves their ability to perform self-care, having additional care in the home may mean a disruption of their surroundings. Furthermore, a hospitalization preserves their space without interruption. Upon their return home, they resume their spatially constricted life once more.

Acceptance of End-of- Life: "Whatever will be, will be"

There were many reflective moments about their life and overall satisfaction about their lives in general. One man clearly with limited life expectancy found a brief moment of pleasure when talking about his life with his spouse. This overall recall of satisfaction helped to diminish the burden of illness for many men:

> *"Ya, I've had a good life. Growing up through the depression, times when my father made great big wages and then down to nothing. My father made big money when things were good and when the market crashed….I was lucky. I got a wonderful life" (age 84)*
>
> *"I always try to be happy. I think the one thing that has brought me the most happiness in my life has been my wife" (age 82)*

Post-Script

This study entailed interviewing men near end-of-life. At the conclusion of the study 12 of 15 men died, many shortly after an interview visit. There were no reported adverse events. All deaths were expected and not associated with the study.

Reflections on the Process

As an employee of the VANCHCS, an understanding of the HBPC palliative care program was beneficial in understanding the experience of many of the participants. Even so, some fresh, unexpected yet important aspects of self-management of HF were revealed through careful observations and wide ranging conversations during home visits. For example, adaptive use of environmental constraint around a central recliner chair to maximize the man's energy and avoid undue fatigue was revealed. So, too, was the effort required to preserve identity and carefully represent the self through immaculate grooming when a visitor was expected versus the more casual semi-dressed state of a daily life replete with breathlessness, fatigue and frequent naps.

Self-reflection required recognition that data is grounded in both the participant and researcher social context and biography. Personal memos were useful to keep the participants perspectives in the forefront, additionally critically reading interview texts assisted in recognizing perspectives around questions and language when interviewing participants.

Self-awareness became more evident as to understand my own feelings and ideas about near end-of-life. Working with participants are near end-of-life is both a privilege and work that inspires. During the study time of data collection (2010-2012) 80% of the participants died, as of this writing, three Veterans are living who participated in the study.

Table 4-1 Demographics and Illness Characteristics

	Mean	Median	Minimum	Maximum
Participant Age (years)	92	89	75	95
Caregiver Age (years)	81	80	67	92
HF Hospitalizations (last 12 mos.)	3.6	2	1	5
		(n)	(%)	
Participant Gender	Male	15	100%	
Caregiver Gender	Male	1	6%	
	Female	14	94%	
Caregiver Status				
Married		10	70%	
Widowed		2	12%	
Living with Significant other		1	6%	
Separated		0	0%	
Divorced		2	12%	
Single, never married		0	0%	
Residence				
Home		13	86%	
Board and Care Facility		1	7%	
Senior Independent Apartment		1	7%	
Race				
Caucasian		12	80%	
Black/African American		2	13%	
Pacific Islander		1	6%	
NYHA Class/AHA Functional Class				
Class III/Stage D		5	30%	
Class IV/Stage D		10	70%	
War Era Served				
World War II		12	80%	
Korean		2	13%	
Pre-Vietnam		1	6%	
Other Chronic Illnesses				
>5 secondary chronic illnesses		15	100%	
Heart Failure Education				
Home Care Education		15	100%	
Telehealth monitoring/education		6	40%	

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CHAPTER FIVE: DISCUSSION

This chapter discusses findings in the central category of *living while dying* which includes three thematic subcategories a) *symptoms: maintenance and management,* b) *biding time: meaning of place, space, time and activity*, and c) *societal influences: being old with HF*. The discussion will compare and contrast existing studies with research findings, discuss theoretical perspectives, the importance and limitations of the study, describe practice relevance and future research. Major findings of this study are meanings of home environment in management of symptoms and the importance of congruence of goals of care during the transition to hospice.

Living While Dying

Three thematic subcategories emerged which constitute the main theme of *living while dying: awareness of symptoms, biding time* and *societal influences*. The concept of *living while dying* is not new; the concept has recently gained prominence in chronic illness literature (Nicholson, Meyer, Flatley, Holman & Lowton, 2012; Sinuff, Giacomini, Shaw, Swinton, & Cook, 2009; McWilliam, Ward-Griffin, Oudshoorn & Krestick, 2008). The overall concept realigns the focus of how living continues during the uncertainty of being near end-of-life. This basic social process of living while dying normalizes end-of-life. End-of-life for those with HF may occur over several years and is a generally accepted term for the last phase of illness.

Prior phases of HF (living the trajectory of illness) should provide the foundation for the last phase of illness. Communication about HF and its progressive nature ideally starts at diagnosis so individuals and families are prepared for the last phase of illness.

Data suggest men associated their initial understanding of HF in different time frames related to age; middle older men (age 75-84) identified an early event, while oldest older men (age 88-94) did not put the onset of illness to a time or event and some “just learned” about the diagnosis of HF. The focus during the time in-between (beginning and end of trajectory) is a complicated timeframe for men to express, most likely that life did not seem to change until symptoms imposed physical limitations. In other words, HF trajectory understanding only seemed to get importance in the present when disability imposed restrictions to everyday life and becomes obscured by overwhelming symptoms.

Transition to home palliative care indicates HF has progressed to advanced stages. Older adults with advanced or serious HF have maximized their medical treatment; their prognosis is poor, although predicting when end-of-life will happen is uncertain. This is one of the critical challenges of HF, while there may be a slow dwindling from progressive symptoms; end-of-life is unpredictable with periods of acuity requiring hospitalization. For men, a matter of living while dying with HF replaces the notion of transitioning to hospice and having the opportunity for prolonging treatment when needed.

End-of-life, for the men in this study, occurred over time with progressive slow decline, although 24-48% of HF patients die suddenly due to arrhythmia or other types of cardiac events (Ezekowitz, Kaul, Bakal, Armstrong, Walsh & McAlister, 2009). End-of-life becomes complicated by other chronic illnesses, geriatric syndromes and perceptions of aging. Time passes with frequent hospitalizations, increasing frailty and associated limitations from a distressing symptom burden. Men who participated in this study were given an opportunity to discuss how they lived with HF and for their spouse to discuss their role in HF management. Ultimately, the findings are their combined experience living with HF near end-of-life.

Symptoms: Maintenance and Management

Maintenance and management are fundamental elements of self-care. Maintenance is customary symptom monitoring and following medical regimens and management reflects decisions that include symptom recognition and actions taken for symptom treatment (Chriss, Sheposh, Carlson & Reigel, 2004). The standard for HF self-care management is recognition of signs and symptoms (i.e. weight gain, lower extremity swelling, and breathlessness) and prevention of HF exacerbation through diet, exercise and medications. Compounding HF symptom management is the increased complexity of illness management skills as HF becomes increasingly unpredictable and refractory to previously successful therapies. Awareness of symptoms requires understanding of the meaning of symptoms and the ability to recognize and interpret symptoms.

Symptom Recognition

Consistently, symptom recognition was a challenge for older men with serious HF. The confluence of symptoms during later stages of HF with those from other chronic illnesses made individual symptom recognition difficult. Instead, symptoms converged as an experience of expectation of older age. Symptoms become the fabric of their daily lives; thus recognition and interpretation of individual symptoms is commonly not identified.

Men found it difficult to answer or complete MSAS-HF (Zambowski, 2004), an assessment scale of 32 symptoms associated with HF.   The length of the assessment scale frustrated men.   This was due in part to fatigue and inability to remember specific symptoms and then rank the severity. Instead, when asked their worst symptoms they consistently stated breathlessness and fatigue. Zambroski, Moser, Bhat, & Ziegler (2005) and McMillan et al., (2007) identified these same two symptoms as the most frequently identified by their older HF participants. The recognition of the degree of breathlessness and fatigue was less notable until these symptoms required urgent intervention. Intolerable breathlessness was the primary impetus for an urgent emergency call.

Symptoms were most likely to be associated with activity level and men did not report their recognition of inability to maintain previous levels of activity. Instead, men instituted rest and/or increase naps, as a symptom management method. For this reason, delayed reporting occurred that resulted in an urgent hospitalization. Uncertainty and slow onset of symptoms (duration) has been found to delay reporting (Jurgens, 2006).

This aspect of symptom interpretation is similar to Horowitz, Rein & Leventhal (2004) who found patients did not link a symptom to a specific illness. Consequently, measures to stop the symptom exacerbation process did not occur. Further, Reigel, Dickson, Cameron, Johnson, Bunker, Page & Worrall-Carter (2010) found older patients had difficulty detecting shortness of breath after a 6-minute walk test as compared to shortness of breath observed by a registered nurse. It is a common finding among men interviewed in the study to state they were “not short of breath” in spite of prominent breathlessness at rest and with speech. Friedman (1997) found older adults waited an average of three days with increasing breathlessness before an acute hospitalization, leading to the conclusion that their perception of increasing symptoms was not acute.

Men reported five or more comorbid conditions. Comorbid conditions contribute to delays in symptom reporting and hospitalizations (Chen, Normand, Wang & Krumholz, 2011). Dickson, Buck & Riegel (2013) found multiple comorbid conditions interfered with self-efficacy and self-care maintenance and lowered confidence of the older adult with self-care activities. One man from this study reported he had not thought about the difference between COPD and HF symptoms; after thinking about it for a few moments he provided his individual idea of the differences. It is unlikely his idea of the differences would provide earlier reporting, however this may be a starting point in assisting patients to recognize how each illness contributes to symptom burden.

The findings of this study reflect a resignation by men; “what will be, will be”. The significance of symptoms is not appreciated as the symptoms became normalized. In light of advancing age, many expressed surprise they had lived to late age and surprised that their lives were ending in this manner. In many ways, the act of responding to symptoms (primarily breathlessness) had little importance until breathlessness could no longer be controlled through a set of consistent processes of rest/naps and activity. Many men report calling emergency services when breathlessness involved immediate relief and was no longer controlled through rest/naps.

All participants had received HF education through the palliative care interdisciplinary team and several men monitored symptoms daily with a home electronic program. None of the men talked about calling the palliative team to report symptoms prior to requiring an emergency response team at home, demonstrating that symptoms were not worrisome enough to report. Reasons for these delays have been related to not wanting to ‘bother’ the health care team (Horowitz, Rein, & Leventhal, 2004), nor wanting to impose on their family (Patel, Shafazand, Schaufelberger & Elkman, 2007). Delays in reporting symptoms have also been found to be related to the gradual onset of increasing symptoms such as worsening fatigue (Jurgens, Hoke, Byrnes & Riegel, 2009).

Additionally, to conserve energy a report to the palliative care team was more bothersome to men than waiting to see if the symptoms improved. Reporting requires cognitive assessment, talking and explaining; all of which take energy, the very thing they are trying to conserve. There was a reported fluctuation in symptoms particularly breathlessness and fatigue resulting in a *wait and see* approach. Much of the time this approach was successful for men, reinforcing this ongoing behavior. *Wait and see* approaches have been reported as a way for perceived control of a variable course of symptoms by patients (Edmonds, Rogers, Addington-Hall, McCoy, Coats & Gibbs, 2005). The interpretation from this study was that of practicality and a history of some success with this approach by both men and their spouses.

Preserving energy meant setting priorities for which HF care activities would be performed in order to complete all of their daily activities. More importantly, the level of symptom burden prohibited extensive self-care. Perceived importance influenced decisions for a self-care activity, for example continuing a nap or getting up for timed medications. The perception of missing one medication dose time (which included multiple medications) during the day was not significant in the context of multiple dosing times during the day and the sheer numbers of reported pills.

A consistent finding was a reported frustration of living with HF and the associated disability of the illness. This study provides examples of older men's ingenuity of finding ways to continue an activity. For example, when walking was no longer a possible means of getting out of the house, a scooter substituted for transportation to the grocery store. Basic activities such as dressing in the morning constituted exercise, as was walking to a mailbox. Noting the degree of disability with men in this study, the continued activities are remarkable in spite of high levels of fatigue and functional limitations. Exercise is part of self-care activities for HF and studies frequently report older persons have difficulty following exercise regimens (Evangelista, Doering, Dracup, Westlake, Hamiliton & Fonarow, 2003; Corvera-Tindel, Doering, Gomez & Dracup, 2004; Tully, Morgan, Burke & McGee, 2010).

A surprising finding was that of continued "exercise for their heart". The palliative team occupational therapist provided exercise bands for strengthening exercises. Men in their 90s performed exercises on "good" days. After observing a 94 year old man proudly demonstrate a full exercise set, it is convincing that activity levels may be a more powerful hallmark to men than recognition of symptoms. While men expressed frustration with having others perform household chores for them; they demonstrated with pride their ability to use the exercise bands. Consistently, as functional abilities declined, they demonstrated resilience in accepting other forms of exercise.

The challenge for these men to manage HF was to do so in spite of fatigue, breathlessness, increasing frailty, and the challenges of maintaining other activities such as their home and social life. Priorities competed with their perceived necessity of reporting symptoms in the presence of other beneficial activities. Results from research have identified problems with adherence to self-care activities and found knowledge deficits, cooperation and active participation as reasons for low levels of adherence (Evangelista & Shinnick, 2010). For the older HF population, it may not be a matter of behavioral change as much as setting priorities in the midst of competing activities each of which may be overwhelming singularly (i.e. home maintenance, social activity, and symptom management).

Caregiver Relationship

The family relational experience included their unique family history, culture and roles. Few studies have examined the role of spousal caregiving in the sociocultural context of the home environment at end-of-life (Ward-Griffin, McWilliam & Oudshoorn, 2012). For these men, their spouses provided support and means to remain at home.

Men managed their HF care needs with oversight from their spouses; two widowed men received support from paid caregivers. Spousal oversight meant following time consuming activities of self-care and preservation of their husband’s role in the family. The main approach for spouses was to support independence and provide as much social activity possible. A consistent report of concern over their spouse’s illness was present; however most spouses positively verbalized their role was to support their spouse. The stress reported about their role was that of worry and concern about their spouse. There was one exception to this response, a spouse with a terminal illness reported stress associated with the complexity of HF medical and personal care while balancing care of herself. The presence of the men during most interviews may have influenced the results.

Support by family members results in less delay time with symptom reporting (Friedman, & Quinn, 2008). Results from this study indicate spouses did not report symptoms sooner and supported their husbands decisions associated with delay in seeking of care. This may be a result of a combination of wanting to support existing roles and supporting decisions by men on when to report symptoms. Clark, Freydberg, McAllister, Tsuyuki, Armstrong & Strain (2009) found a low level of knowledge about HF among patients and their caregivers. This lack of knowledge about symptom management was in the presence of significant overwhelming HF symptoms.

Experiences of family members of cancer patients found the focus of managing and prioritizing multiple responsibilities by the caregiver lead to their feeling isolated (Ward-Griffin et al., 2012). While men in this study are dealing with multiple symptoms and decreasing function, their spouses were trying to keep “multiple balls in the air”. Men expressed their appreciation of their spouses care through emotional and often teary dialogue, recognizing the sacrifice by their spouses. The men’s sense of helplessness over rising care needs and burden to their spouses influenced symptom management. The *wait and watch* approach is also influenced by not wanting to burden their spouse with symptom reports (Rectrum, Nowels & Bekelman, 2013).

The positive nature of the spouses provided a foundation for maintaining lives in the context of the home and living while dying. Their calm, within uncertainty, provided cohesion to care. The consequences of emotionally and physically supporting their husbands were not explored.

Biding Time: Importance of Place, Space, Time and Activity

The concept of biding time implies time waiting for something to happen or biding one's time waiting for further developments (Merriam-Websters' Collegiate Dictionary, 2013). In the course of *living while dying,* older men are not simply waiting for the next hospitalization or for death; they are creating a home which accommodates the needs of smaller space and time sequences for the environmental activities that they continue to undertake. In spite of limited energy, breathlessness and frequent hospitalizations, men continue to find pleasure in social environment and interaction and continuing activities as permitted by physical limitations. While not wanting to bother family for care needs, there was significant evidence of engagement with family including children and grandchildren.

Place, Space and Time

The meaning of place, space and time captures the setting in which the HF symptom experience is occurring. It represents home that includes physical, social, time within an environment where everyday experience occurs (Chippendale & Bear-Lehman, 2010; Roush & Cox, 2000). It is also the location of where health care requirements are performed around the routines of maintaining home. Receiving care at home has several considerations that influence health: it is a "familiar place", it is the "center of everyday experience" and it can serve as a "protector" (Roush & Cox, 2000, p. 391). Tuan (1977) interprets space as a series of images; for these men space and time represents the snapshots of a lifetime of lived experience through immediate images of their past and present life in a small confined space. Symbolically, place represents security and space represents freedom (Tuan, 1977). Similarly, this study found men and their spouses created a place of security while their decreasing lived space provided freedom to manage time and limited activities.

Home can be a therapeutic environment which reinforces notions of self, or life story and serves to support failing bodies. The development of home occurs over time through reconstructions of self, biography and body. The sense of home is healing as it provides a relationship of "feeling at home" and an experience of "being at home" (Gillsjo, & Schwartz-Barcott, 2011, p. 6). As symptom burden increases and influences everyday activities, one aspect of comfort for unpredictable symptoms is the relationship with and experience of home. Time at home takes on an independent rhythm, it slows with sleep/rest and then seemingly increases for activities such as medications and meals.

The meaning of home changes again when it becomes the place for health care. These men received regular health care visits from the palliative care team; their home environment reflected their health care needs through the visibility of medical equipment and medications. For several, receiving health care at home provided a way to maintain independence and autonomy. Wiles, Leibing, Guberman, Reeve & Allen (2012) found older adults concept of independence was formulated either "through family" providing support or "from family" meaning not requiring family support for care (p. 363). Home also means the autonomy of time management; freedoms to determine when to eat, sleep, dress and take medications. For several men moving to a senior apartment meant the loss of autonomy and control of how symptoms would be managed.

The home as an environment where health care is delivered re-immerged over the last 30 years through the growth of home care, house call and palliative/hospice programs. Particularly for end-of-life care, home represents an emotional relationship where most men would like to die. These bonds are connected by the psychological, social and cultural significance that is attached to place, space and time (Rubinstein, 1989; Dovey, 2005).

When dying occurs over years with intermittent hospitalizations, it changes the ideal natural dying process. The home is set up to accommodate immediate needs, family needs and support coherence during a time of uncertainty. Homes may not be set up to accommodate increasing health care professional visits that may influence the arrangement and rituals of home life. Hospitalization may not only symbolize immediate relief of symptoms; hospitalization may be a way to preserve the men's concept of home.

Activity

As activity becomes more difficult, actual lived space is arranged to meet the growing demands of breathlessness and fatigue. Within decreasing lived space and the rhythm of time; home represents security, a sense of emotional connection with past and present, and a space that is thoroughly known providing a sense of comfort while living with serious HF. A study of well-being and attachment to space identified that "shrinking" space is not necessarily negative response to aging (Wiles, Allen, Palmer, Hayman, Keeling, & Kerse, 2009). Wiles, et al. (2009) found that older adults had strong attachments to home and expected diminishing space over time. Participants identified home as a central point for living with a focus on comfort and practicality.

The frequent hospitalizations during the last months of living with HF immediately improved activity level upon arrival back at home, such as once again walking to the mailbox. Hospitalizations have been known to decrease functional ability. Recently, Brown, Roth, Allman, Sawyer, Richie & Roseman (2009) found older adults (mean age: 74.6 SD: 6.3) after hospitalizations with various medical diagnosis' including HF did not recover life-space mobility even 2 years after hospitalization. The focus on activity highlights the important perspective of those with HF and their evaluation of their illness through activity level.

The growing confinement to home has been associated with significant social isolation experienced by those with serious HF and their caregiver (Alred, Gott & Garballa, 2005; Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Imes, Dougherty, Pyper & Sullivan, 2011). Men and their spouses identified ways to keep connected socially through family and neighbors. While, fewer activities occurred outside of home, there was great effort in spite of difficult symptoms to continue usual social activities until men were unable to participate or, if able, bring the activity to their homes.

Bekelman et al. (2011) report caregivers found the most difficult part of living with HF was the physical limitations often related to increasing symptoms of NYHA class III/IV participants. Men and their spouses found many ways to continue activities together. For one man, continuation of walks with his spouse meant walking a short way in the neighborhood and sitting and waiting for his spouse to finish her complete walking route. Another spouse drove up to a river bank so her husband could continue fishing while sitting in the car. Spouses were creative in the ways they found to support activities outside the home. These findings are similar to Pihl, Fridlund & Martinsson (2010) who reported spouses became the primary person taking initiative for activities. However, being the primary person responsible for activity was considered stressful for spouses (Pihl, et al. 2010).

The arrangement of the home could have unintentional consequences. The limited living space also decreases mobility as found by Cress, Orini & Kinsler (2011). Yeom, Fleury & Keller (2008) also found that over protective caregivers may inhibit mobility. In this study, spouses and caregivers continued attempts to maintain social connections, thus promoting physical activities and allowing for social support. Men's utilization of neighbors and friends before calling adult children, many of whom did not live nearby, emphasized the important role of proximity, independence and the role of community in protecting identities and social connectedness.

Life was not unchanging, interests and health goals continued in the midst of protracted dying. Findings compared with Nicholson, Meyer, Flately, Holman & Nowton (2012) who found frail older persons work actively to retain balance and sustainment even in the advancement to death. Nicholson et al. (2012) challenge current "cultural notions of binary modes: social or health; independent or dependent; living or dying" (pg. 1432). To this end, men demonstrated end-of-life does not mean giving up, it means life can be meaningful in spite of limitations.

Men were reluctant to continually focus on their illness. A frequent finding among all the men was their desire to talk about their past and their family, reinforcing this notion of normalizing their life without a constant focus on HF. The act of normalizing their environment during this last phase of HF is likely the key component in their ability to cope and accept their current realities.

Societal Influences: Being Old with Heart Failure

Symptom management of serious HF in older age is influenced by the meaning of aging in the presence of increasing fragility and significant symptom burden near end-of-life. The timing of this study (data collected between 2010-2011) reflects the current challenges of cost containment for HF services (Centers for Medicare and Medicaid Services, 2013), the influence palliative care teams at hospitals (Green, Gardiner, Gott & Ingleton, 2010)) and the desire of older HF participants for access to acute care when needed. The communication between health care teams (hospital, clinic & home teams) led to inability to reach mutual goals.

While hospitalized, several men perceived they were told they must transition to hospice; three men recounted that they were told they could not return home without hospice. Men and their spouses report resistance to hospice care transition to be associated with the inability to receive acute care (hospitalizations) once accepting the hospice care benefit. This finding is consistent with the findings of Metzger, Norton, Quinn & Gramling (2013) whose HF participants described hospice as a *“deal breaker”* because of the limitations of aggressive management of symptoms available on hospice (p.6).

Hospice was interpreted as a change in focus for the men, from *living while dying to dying yet still alive* and was a major source of stress for older HF men. These older men wanted to remain at home with intermittent hospitalizations for symptom management. They did *not* want the focus of their care to be around activities of dying but rather activities of living.

An outsider view of older men with advanced HF may see frail, symptomatic men with limited life and view that they should receive hospice in the presence of advancement of both age and HF. This view may lead one to believe transition to hospice is the optimal level of care, although, symptom control when receiving hospice care is not always obtained. A study of hospice HF patients (n=90, mean age 85) showed that while most symptoms could be managed through hospice, 24% of patients required in-patient admission and 2% needed emergency services for symptom management (Zambroski, 2005).

There is individualization of how men react and work around the "rules" of hospice care. Some agree to hospice with the knowledge that they will continue to call emergency services, not hospice service if symptoms are not well controlled. Several men aware of the cost of emergency services have worked out plans to get to emergency services without calling 911. Still others continue with hospitalizations in spite of the increasing frequency of hospitalizations and the associated financial costs. Metzger, Norton, Quinn & Gambling (2013) found HF participants wanted the opportunity to utilize hospitalizations for symptom relief (described as *tune-ups)* and return home consistent with their goals of care.

Men indicated they wanted to remain at home near end-of-life consistent with other findings as home being the preferred site of death (Vig, Davenport, & Pearlman, 2002; Fried, Pollack, Drickamer & Tinnetti, 1999). A retrospective cohort study of a random 20% sample of Medicare beneficiaries who died during the years 2000, 2005 & 2009 found a decreasing proportion of all patients dying in the hospital (Teno, et al., 2013). The decrease in hospital deaths resulted from an increase rate of transitions at end-of-life with shorter hospice stays and referrals to and from home, hospice and acute care (Teno et al., 2013). It is unclear if the transitions, Teno and colleagues (2013) report are patient preference or mandated by the system, although results from this study show patient preference as a reason for frequent hospitalizations in the last one to two years of life.

Summary

The men in this study provided insight to the adaptations of HF that form the reconstruction of men with HF's self and identity in older age. Living with chronic illness forces a “shift and change” as the illness disrupts body and self through new changes, obstacles and complications (Charmaz, 2006, p. 27). With these shifts and changes, new constructions of self and identity occur. For older men with HF, their identity and concept of self is measured by activity and as Charmaz (2006) states those with chronic illness use pursuits from past and present as markers of self. Men consistently used past activities to provide history of a younger past and yet rudiments of this active past remained in present through adaptation to other forms of activity. For example, one man who was a professional athlete, progressively adapted exercise from the use of exercise equipment in the home, to use of a scooter for trips outside his home, to use of a walker and now walking alternating with wheelchair loaded with oxygen. So his awareness of transition to older age is associated with activity.

The concept of self can only exist with interaction with others; this intersubjectivity is created through action and shared meanings (Prus, 1996). The spouses of men provide an important role in maintaining the man's self, biography and body through the maintenance of place. The sense of identity can diminish when others impose their own set of attributes associated with end-stage HF for example the experience with hospital palliative care teams. Thus home and sense of place provide a refuge from shifting changes of illness and others perspective.

Death is anticipated by these older men, however how dying is expected to occur has changed in the presence of HF. For those with serious HF, dying may occur over years and requires an intact identity and continuation of social life. Dying trajectories have different societal consequences and transition to the dying role changes concepts of identity (Seale, 1998). Hospice is socially constructed offers "resistance to a social death of institutionalization" and provides a "revivalist transcript" for a good death (Seale, 1998, p.7). When the death event is predictable, in the case of those dying from cancer, hospice provides a sense of community and support for the last shift of self, that of a dying person (Seale, 1995). Seen from this perspective, it is understandable that men resist hospice (who are *living while dying*) and it is understandable that health care professionals see hospice as a supportive option for these men whom they view as *dying but still alive*.

The experience of these men is one of inner strength or resilience. In spite of challenges of managing competing illnesses, this research provides insight into the processes of men in relation to their environment. These sources of self (strength) are of interest in understanding person-environment interaction and coping resources as persons adapt to adversity (Wild, Wiles & Allen, 2013).

Study Significance

The findings provide a privileged look at the lives of men with HF near end-of-life. This study provides additional insight into difficulties of symptom recognition and management in the presence of high symptom burden near end-of-life. The study also highlights the difficulty of transitions of care between palliative, acute and hospice care with those near end-of-life.

This study provides further evidence of how older HF men manage during this time at end-of-life with high symptom burden. Studies in the past decade have described the HF symptom experience through the perspective of overwhelming symptom burden and social isolation (Gott, Barnes, Parker, Payne, Gariballa & Small, 2006; Luttik, Jaarsma, Moser, Sanderman, & vanVeldhuisen, 2005). The present study confirms these findings, however this study’s findings extend knowledge by identifying that men’s wishes for symptom control are high. Older men do go to the hospital for uncontrolled symptoms after attempting to self-manage symptoms through rest and waiting to see, albeit accessing this level of care with what health care professionals would call significant delay.

Their decisions to manage symptoms prior to hospitalization include developing a home environment that supports their abilities and provides energy conservation. This contrasts with the purely clinical approach to symptom management and emphasizes symptom management is multifactorial. Reinke, Ulman, Udris, Moss & Au (2013) found similar priorities in Veterans with chronic obstructive pulmonary disease.

HF in later stages requires both acute and palliative approaches to prevent frequent hospitalizations. The fear of losing this option resulted in resistance to hospice transition. From the perspective of men and their spouses the choice of comfort and relief of symptoms at the hospital was determined when staying at home with unrelieved symptoms was intolerable. The unknown of remaining at home with unrelieved symptoms made this either/or decision impossible to make when experiencing overwhelming symptoms such as breathlessness.

Older men lives are arranged to meet the need to maintain independence and to remain at home. This is their center point, arranged to accommodate their increasing limitations. Their preference is to remain at home at end-of-life with acute interventions (hospitalization) to alleviate increasing symptom exacerbations, and once again feel better for a period of time. This contradicts one of our societal implications of a good death at home without the intrusions of the technical world of the hospital. Here we see a convergence of priorities between reduction of hospitalization, cost of hospitalizations and older persons need to gain relief of symptoms and maintain control over location of life, which involves continued care, and death.

Older persons should not only be able to “live well even until death”; they should be able to “choose or refuse certain treatments and therapies that may improve their lives and ultimately their deaths” (McNamara, 2004, p. 932). Decisions for care should not be whether to accept hospice or continue to utilize the hospital for acute treatment of symptoms. Hospice care is associated with lower hospitalizations and intensive care use although the costs associated with hospice are not less than the costs associated with hospitalizations (Blecker, Anderson, Herbert, Wang & Brancati, 2011). Cost reduction for HF will come when hospice care extends the borders of home and hospital (Jennings, Ryndes, D’Onofrio & Bailey, 2003). Dobratz (2005) reports on a pilot project in which a model of care provided both life extending and supportive or palliative services, specifically the model provides both “aggressive, life-prolonging treatment and hospice care in the home setting” (p.123). HF with its uncertain illness trajectory would benefit from this expansive model of end-of-life care where patients continue to have options for what is considered life-prolonging care.

Study Limitations

The study sample size was small with follow up interviews limited because of illness burden, frequent hospitalizations and death. The results are similar to other studies inclusive of older adults with HF. Inclusion of their caregiver’s perspective without the participant being present did not occur regularly, often interviews took place in both of their presence and information was obtained jointly. The participant group was comparatively homogeneous; all were male Veterans, with little variation by race. All men received care from the same palliative care team and lived in the same geographical region. Men had a wide variation with number of years of education from fourth grade to graduate education. These factors may limit generalization beyond study findings.

Practice Relevance

Palliative care principles assimilate both acute and hospice principles of care that can be provided simultaneously. As seen in this study, transitions of care between home, hospital and hospice occur with unnecessary struggle when care does not include the goals and views of those most impacted by HF. This study illustrates the further need for education about end-of-life occurring in the home environment.

Education should incorporate the values and rituals of the home environment. Additionally, education needs to take into account the symptom burden level and abilities of the older adult and family to monitor all the parameters of HF. For some older adults management may be as simple as reporting change of activity levels. Older adults are interested in exercise, although it needs to be tailored to activities that can be performed in the home environment.

Palliative care teams are aware of dying trajectories of non-cancer and cancer patients. Chronic illness (non-cancer) dying trajectories have similarities between each illness; however recognition of the differences in each illness trajectory would enable teams to provide illness specific information to prepare for end-of-life. Additionally, patients should be aware that palliative and/or hospice care does not mean *no* care. Teams need to reinforce what palliative and hospice can do in terms of symptom management.

Lastly, all team members require specialized education for symptom management and the principles of palliative care. This includes HF competency training and individual assessments of abilities in the field. The goals of care need to center on how to live well.

Implications for Future Research

There is recognition at the national health care levels that hospice today does not work well with many non-cancer diagnoses (Casarett, 2011). Congress has approved a three year Medicare plan to test concurrent payment for both hospice and acute care at 15 sites throughout United States (Center for Medicare and Medicaid Services, 2013). Previous work by Aetna with private insurance has shown liberalization of the hospice benefit does not increase costs and in some instances reduces costs of care (Center for Medicare and Medicaid Services, 2013). In contrast, Teno et.al (2013) indicates longer hospice length of stays may be more costly than acute care. Further research and or demonstration projects to determine how best to provide concurrent care is needed. Importantly, demonstration projects should be based on the “meanings, interpretations, and experiences of the person they intend to serve” (Denzin, 2001).

The home environment and implications for end-of-life care have not been well-studied (Ward-Griffin, McWilliam & Oudshoorn, 2012). Unless health care professionals have visited the homes of their patients, the home environment and its relationship to management of care is an unknown. Research is needed that furthers the concept of home, and end-of-life care including the relational relationships of family providing care in the home.

The activity of monitoring symptoms has significant impact on the caregiver’s ability to adapt to environmental changes, social isolation, and increasing functional decline of the aging patient. Studies are needed that extend our knowledge of symptom monitoring between patient and caregiver to improve recognition of illness exacerbation with the goal of reduction of hospitalizations. Many of our HF programs focus on one aspect of HF care such as symptom monitoring through telehealth or patient report, few programs offer a multifactorial approach recognizing the evolving importance of specific caregiver support.

Further programmatic studies that develop specific interventions for caregivers are needed to explore how caregiving support may ultimately reduce hospitalizations through early recognition of symptoms. Caregivers of patients with NYHA class III-IV should be a focus of intervention studies that incorporate caregiver support, ongoing education and identifies additional support i.e. home telephone support groups for caregivers as illness progresses.

Conclusions

This study demonstrates the symptom experience for those with advanced HF is complex and can be overwhelming in the presence of aging. Symptom reporting for older adults living in the community is delayed and appears to result in increasing hospitalizations near end-of-life. This study provides understanding of how older HF men preserve their lives and thus their identity through arrangement of their environment to support remaining independent and at home. There is a need for better understanding of home and how older adults and their caregivers manage near end-of –life.

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Appendix A

Interview Guide

This study will include the following collection strategies: a) participant-observation and b) semi-structured interviews. The interview will begin with historical questions to understand what the diagnosis of chronic illness has meant to the patient and lead to the patient’s current experience of symptoms while on the palliative care program. The semi-structured protocol will be divided into the following subsections: a) history of living and managing with a chronic illness, b) transition to palliative or supportive care, c) experience of symptoms.

Introduction:

The interview will begin with an introduction to the content of the interview: “Thank you for agreeing to talk to me about your chronic illness and palliative care. The purpose of the interview is to learn more about how patients experience chronic illness and symptoms. I would like to begin with asking questions about your chronic illness and then discuss your current perceptions of your chronic illness and symptom management. I believe the interview may last an hour, if you need to stop at any time please let me know”.

Interview Questions:

History of living and managing with a chronic illness:

- Can you tell me when you first noticed or were told you had a chronic illness? What were you told about the chronic illness (state actual illness)? Did this change your feeling about your life? (probe for How chronic illness has changed your life, future plans, your family?).

Transition to palliative or supportive care

- What happened to you to bring about the shift to palliative or supportive care? Tell me about that process? (probe for insidious process or some specific event? When did it happen, where were you at the time (i.e. home, in the hospital).
- Did you have a sense you needed palliative care before you were told? What difference has palliative care service made to your daily life? In your spouse's life?
- How was the decision to move you to palliative care communicated to you? What was said? Who was involved in the decision to make this shift?

Experience of symptoms:

- What symptoms are you currently experiencing? Tell me about them: (probe for what are they like? When do they occur, how often, how do they make you feel?) Tell me how you manage your symptoms? (probe for What do you do? Who helps? How? When? How often?)
- Tell me more about your experience with breathlessness? How has this symptom affected your life? (probe for any difference from other symptoms, What do you do? Who helps? How? When? How often? How is it described? What helps?)
- Do you talk to anyone about managing your symptoms? (probe for Who? What do you say to them? What do they say to you? Why do you talk to this person? Do you always talk to this person? Why?)
- What difference has it made? What interventions work best?
- How do symptoms affect your family? (probe for changes in family roles, time spent with elder)

Appendix B

THE SHORT PORTABLE MENTAL HEALTH QUESTIONNAIRE (SPMHQ)

1. What are the date, month, and year?
2. What is the day of the week?
3. What is the name of this place?
4. What is your phone number?
5. How old are you?
6. When were your born?
7. Who is the current president?
8. Who was the president before him?
9. What is your mother’s maiden name?
10. Count backward from 20 by 3’s

Scoring:

0-2 errors: normal mental functioning
3-4 errors: mild cognitive impairment
5-7 errors: moderate cognitive impairment
8 or more errors: severe cognitive impairment

•One more error is allowed in the scoring if a patient has a grade school education or less.
•One less error is allowed if the patient has had education beyond the high school level.

Appendix C

MEMORIAL SYMPTOM ASSESSMENT SCALE-HEART FAILURE

SECTION 1:

INSTRUCTIONS: We have listed 26 symptoms below. Read each one carefully. If you have had the symptom during this past WEEK, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED OR BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK, **Did you have any of the following symptoms?**	**DID NOT HAVE SYMPTOM**	**IF YES,** **How OFTEN did you have it?**				**IF YES,** **How SEVERE was it usually?**				**IF YES,** **How much did it DISTRESS or BOTHER you?**				
		Rarely	**Occasionally**	**Frequently**	**Almost constantly**	**Slight**	**Moderate**	**Severe**	**Very severe**	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
Difficulty concentrating	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Chest Pain	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Other Pain	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Type/ Location of pain: ______________________														
Cough	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/tingling in hands/feet	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping	☐	1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated	☐	1	2	3	4	1	2	3	4	0	1	2	3	4

DURING THE PAST WEEK, Did you have any of the following symptoms?	DID NOT HAVE SYMPTOM	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost constantly	Slight	Moderate	Severe	Very severe	Not at all	A little bit	Somewhat	Quite a bit	Very much
Problem with urination		1	2	3	4	1	2	3	4	0	1	2	3	4
Palpitations		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Waking up breathless at night		1	2	3	4	1	2	3	4	0	1	2	3	4
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

SECTION 2:

INSTRUCTIONS: We have listed 6 symptoms below. Read each one carefully. If you have had the symptom during the past week, let us know how SEVERE it was usually and how much it DISTRESSED OR BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK, **Did you have any of the following symptoms?**	**DID NOT HAVE SYMPTOM**	**IF YES,** **How SEVERE was it usually?**				**IF YES,** **How much did it DISTRESS or BOTHER you?**				
		Slight	**Moderate**	**Severe**	**Very severe**	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
Change in the way food tastes		1	2	3	4	0	1	2	3	4
Weight loss		1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	0	1	2	3	4
Swelling of arms or legs		1	2	3	4	0	1	2	3	4
Weight gain		1	2	3	4	0	1	2	3	4
Difficulty breathing when lying flat		1	2	3	4	0	1	2	3	4
***IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.**										
Other:						0	1	2	3	4
Other:						0	1	2	3	4
Other						0	1	2	3	4

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M. Janelle Culjis 09-04-2013

M. Janelle Culjis Date