

Living with End-Stage Heart Failure: An Interpretive Phenomenological  
Study

by

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## ABSTRACT

A qualitative phenomenological study incorporating Photovoice was conducted to gain insight into the lived experience of patients with end-stage heart failure (ESHF). Seven participants were recruited and in-depth open-ended interviews were conducted with all participants. Three of the seven informants also opted to take part in the Photovoice portion of the project. “Working to preserve a sense of self” emerged as the essence of living with ESHF and was supported by three themes: i) the work of managing a failing and unreliable body, ii) the work of choreographing daily living; and iii) the work of charting the final chapter of one’s life. The findings from this study provide healthcare professionals with empirically grounded information and insights about the needs and everyday challenges individuals living with ESHF experience, and how clinicians can best support them. Such information is essential in order to plan meaningful, holistic, evidence-based care for ESHF patients.

*Keywords:* end-stage heart failure, lived experience, qualitative research, phenomenology

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## CHAPTER 1: INTRODUCTION

### Introduction

Aging of the population, technological advances, and improved options for managing heart failure (HF) have contributed to increasing numbers of Canadians suffering from end-stage disease. Current statistics demonstrate that HF afflicts at least 400,000 Canadians, with more than 50,000 newly diagnosed cases each year and an annual mortality rate of 25% to 40% (Turriss & Rauscher, 2005). Despite numerous recent medical advances, no cure exists for HF; consequently, it is progressive and irreversible. As a result, the present goal in the medical management of HF is to control the patients' symptoms and delay the progression of the disease.

Living with HF and its associated management strategies is a reality for many individuals, and research has demonstrated that living with HF dramatically changes one's life. However, despite knowing that HF is progressive and lethal, research identifying what it is like to live with end-stage heart failure (ESHF) is limited. A phenomenological research design is optimally suited to better understand the experiences of those living with ESHF. Phenomenology strives to develop a rich understanding of what living that specific experience is like for the individual (Speziale & Carpenter, 2007). For this study an interpretive phenomenological approach was employed to discover insights into what it is like to live with ESHF on a daily basis.

### Significance of the Problem

The progression of HF results in an illness trajectory encompassing a substantial degree of physical and psychological suffering, and a reduced quality of life (QOL) (Coats, Clarck, Piepoli, Volterrani, & Poole-Wilson, 1994). Once these patients reach

end-stage disease, they require specialized cardiac and palliative care (PC) to manage their symptoms, maximize their QOL, and to assist them and their family through the terminal stages of HF. Unfortunately, the vast majority of ESHF patients do not receive specialized PC services (Gaudette et al., 2002; Murray et al., 2002).

Studies are lacking that detail the subjective experience of individuals living with ESHF. If nurses hope to optimize the care that they provide to these patients, they must first be knowledgeable about how patients perceive and deal with living with advanced end-stage heart disease. In order to understand how the ESHF experience is expressed and represented by patients, healthcare professionals need to provide these individuals with the opportunity to share the stories of their experiences in their own words. Giving a voice to ESHF patients' experience of their illness and the meanings they ascribe to it could make a difference in the way members of the healthcare team understand and respond to patient care needs, and how they support patients in the end stages of their illness trajectory.

#### Purpose of the Study

The purpose of this phenomenological study was to develop an understanding of the lived experience of ESHF through eliciting detailed descriptions of patients' lived experiences of ESHF. The focus was on discovering what it was like for an individual to live with ESHF on a daily basis and how living with ESHF impacted the individual's life overall.

#### Research Question

Consistent with a phenomenological approach to inquiry, the overarching research question guiding this study was 'What is it like to live with ESHF?' The major sub-

question addressed was: What are the meanings those living with ESHF assign to their experience.

### Assumptions

All individuals conducting research bring with them varying degrees of previous understanding of the topic of interest. Phenomenological research recognizes that the investigator as research instrument inherently contains preconceived unconscious beliefs, attitudes and assumptions that influence the collection and analysis of data (Creswell, 2007; Giorgi, 2009; Holloway & Wheeler, 2002; Lobiondo-Wood & Haber, 2009; Speziale & Carpenter, 2007). Within interpretive phenomenology one is required to appreciate that prior/expert knowledge builds the foundation of the study and influences the research question and study design (van Manen, 1997). As a result, prior to initiating an interpretive phenomenological research project it is imperative that the researcher identify his/her thoughts, beliefs and ideas related to the phenomena of interest. The ultimate goal of this activity is to increase one's awareness of preconceived beliefs that may potentially influence data collection, analysis and the interpretation of the data.

This researcher has gained many rich experiences in providing nursing care to individuals living with ESHF from an intensive care unit (ICU) perspective. Within the ICU, numerous patients admitted with HF were provided specialized medications and life saving/sustaining interventions during acute episodes of HF. Some patients did not survive their hospital admission, while others were transferred from the ICU with permanent cardiac damage and in some cases a diagnosis of ESHF. However, each and every one of these patients suffered severely from symptom distress during their ICU admission. This researcher also completed a clinical rotation in the St. Boniface Heart

Failure Clinic as a component of his Master of Nursing degree and witnessed firsthand the everyday challenges and degree of suffering that individuals living with ESHF in the community face on a daily basis. It was during these clinical experiences that this researcher became cognizant of the fact that individuals who were diagnosed with ESHF were not receiving optimal, holistic end of life care. From an ICU and HF Clinic perspective, there were no further interventions that could be offered. As a result, how future care could or should be provided to individuals living with ESHF, and by whom, was unclear. Patients were thus referred back to their general practitioner who was supposed to attend to their end of life care needs. Furthermore, a review of the literature surrounding ESHF revealed that a gap existed in identifying the lived experience of ESHF and the idea for this study was born.

Currently, this researcher is a nurse manager of a medical unit within a community hospital where many elderly patients are admitted with ESHF. As a result of an active role that this researcher takes in assisting with patient care, the challenges of living with ESHF continue to be witnessed on a daily basis.

These previous experiences caring for ESHF patients notwithstanding, the task of the researcher is to allow the study participants to openly and honestly discuss the topic of interest, and capture the nature of it without influencing or biasing their descriptions of the phenomena. The following assumptions were acknowledged by the researcher of this study based upon previous professional and personal experience prior to and during this study:

- 1) Individuals living with ESHF are the experts in describing their experience of living with this chronic illness on a day to day basis.

- 2) Individuals living with ESHF are able to articulate their daily experience of what it is like to live with ESHF.
- 3) Individuals living with ESHF are specialists in their own care and are able to articulate their care needs.
- 4) Living with an end-stage illness is an extremely challenging situation and not all individuals will have the desire or strength to partake in research.
- 5) The researcher interacts with the informants in the research study. This mutual interaction influences both the researcher and informant.
- 6) Based upon the researcher's previous experiences of providing nursing care to individuals living with ESHF the researcher assumed that a minimum of one participant would discuss PC as an important strategy for end of life care in ESHF.

#### Definition of Major Constructs

Within this study a number of major constructs were employed and they are defined as follows:

##### *Heart Failure (HF)*

Heart Failure is “a complex syndrome in which abnormal heart function results in, or increases, the subsequent risk of clinical symptoms and signs of low cardiac output and/or pulmonary or systemic congestion” (Arnold et al., 2006, p.23).

##### *Advanced Heart Failure*

Individuals diagnosed with HF, who continue to suffer limiting symptoms despite medical management and continue to remain candidates for invasive treatment options, such as cardiac transplantation (Nohria, Lewis, & Warner Stevenson, 2002).

### *End-Stage Heart Failure (ESHF)*

Individuals diagnosed with HF who, despite maximal/optimal medical management, continue to experience distressing symptoms at rest or with minimal effort (Arnold et al., 2006; Hunt et al., 2001). For the purposes of this study, individuals were considered to have ESHF if they fit the aforementioned definition and were deemed not to be candidates for a heart transplant.

### *Essence*

Essence is the ideal or true meaning of a phenomenon representing the concepts (basic units) that give common understanding to the phenomenon being investigated (Speziale & Carpenter, 2007).

### *Interpretation*

Interpretation is the process that strives to discover the meaning of an experience (van Manen, 1997). Through interpretation the meanings buried within the phenomenological texts are unveiled and a description of the overall experience becomes possible. Each individual interprets a situation or experience uniquely.

### *Lived Experience*

The individual lives the specific experience in his/her everyday life, and thus should be able to describe the meanings associated with the specific experience (van Manen, 1997).

### *Meanings*

Identifies how an individual experiences and understands the aspects of their world as real and meaningful (van Manen, 1997). Each individual who experiences a situation is able to describe the aspects that make the situation unique.

However, in most cases the meaning of a situation is hidden and must be revealed through description of the situation or experience.

#### *Palliative Care (PC)*

Is the provision of interdisciplinary biopsychosocial care to patients who have an end-stage or terminal illness, where death is the expected outcome with the goal of relieving physical, mental and spiritual suffering ultimately improving ones quality of life in a dignified manner (Cohen, Boston, Balfour, & Porterfield, 2001).

#### *Photovoice*

Photovoice is “an innovative participatory action research (PAR) method based on health promotion principles and the theoretical literature on education for critical consciousness, feminist theory, and nontraditional approaches to documentary photography. Photovoice enables people to identify, represent, and enhance their community through a specific photographic technique” (Wang & Burris, 1997, p. 185).

#### *Quality of Life (QOL)*

Quality of life (QOL) is “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1993, p.153). QOL is a multidimensional, subjective and dynamic construct all of which make it difficult to measure.

#### *Understanding*

Understanding is the process of comprehending what has been interpreted in a text (van Manen, 1997).

## Chapter Summary

Chapter one provided an overview for the rationale for this study concerning the lived experience of individuals living with ESHF. Although vast amounts of information have been published pertaining to HF, the management of HF and the lived experience of HF, comparatively little work has been conducted examining what it is like to live with ESHF on a daily basis. With more Canadians surviving cardiac events, developing HF and progressing to ESHF, a more fulsome empirical understanding of the experiences of this patient population is required in order to develop interventions and provide care that meets their needs. The next chapter will provide a review of the literature that informed this study.

## CHAPTER TWO: LITERATURE REVIEW

### Introduction

This chapter reviews select bodies of literature relevant to this study. Within phenomenological research the literature review is not meant to be an exhaustive review of the literature surrounding the topic of interest. But rather, provides the researcher with a context to guide the development of the research study (Morse & Field, 1995). First, a brief overview of the age and health of Canadians is presented. Second, literature concerning HF, its associated management, and the diagnosis of ESHF is described. Third, existing research examining living with HF is presented. Lastly, a discussion pertaining to PC, its potential benefit within the ESHF population along with the challenges associated with implementing PC in the ESHF population is provided.

### The Canadian Population and Chronic Illness

The Canadian population is aging. As of the year 2006, 3.7% of the population was older than 80 years and 13.7% of the population was older than 65 years; representing an increase of 11.5% since 2001 (Statistics Canada, 2007a). Manitoba also has seen an increase in the age of its population, with 14.1% of people being greater than 65 years of age, and 4.4% being older than 80 years.

Medical advances have now resulted in many aged Canadians living longer with, and suffering from, the consequences of a chronic illness. Currently, the majority of Canadians older than 65 years old have at least one chronic medical condition (81%) and 33% have three or more (Gilmour & Park, 2003). Statistics Canada (2007b) estimates that by the year 2020 there will be 40% more deaths annually than in 2003 and that 90% of deaths will occur as a result of prolonged illness.

The leading causes of death in Canada in 1994 were cardiovascular disease (38%), cancer (28%), respiratory disease (9%) and accidents/poisoning/violence (6%) (Public Health Agency of Canada, 1997a,b,c). Within cardiovascular disease, the leading cause of death was myocardial infarction (28%), with HF accounting for 5.5% of all deaths. Overall, cardiovascular disease accounted for the most hospitalizations (13%), the largest proportion of healthcare costs (15.2%) and the highest mortality. As of 2008, heart disease and cancer account for 51% (238,617) of all deaths in Canada; however, for the first time ever cancer has become the leading cause of death accounting for 30% of all deaths and heart disease 21% of deaths (Statistics Canada, 2011). Differences exist in the leading causes of mortality by age group, where for individuals between 35 and 84 years of age, the leading cause of death is cancer and for those Canadians over the age of 85 heart disease. Cardiovascular disease continues to account for the most hospitalizations (17%) (Public Health Agency of Canada, 2009) and the second largest economic burden (11%) following musculoskeletal injuries (11.2%) within Canada (Public Health Agency of Canada, 2008).

### Heart Failure (HF)

HF is defined by the Canadian Cardiovascular Society (CCS) as “a complex syndrome in which abnormal heart function results in, or increases, the subsequent risk of clinical symptoms and signs of low cardiac output and/or pulmonary or systemic congestion” (Arnold et al., 2006, p.23). A number of cardiac and noncardiac disorders interfere with the normal function and structure of the heart, resulting in a reduced ventricular filling and ejection of blood, which ultimately initiates neurohormonal compensatory mechanisms that further reduce cardiac function. This cascade of events

leads to cardiac remodeling due to cardiac myocyte apoptosis, hypertrophy, and myocardial necrosis along with the retention of salt and water and resultant edema (Jackson, Gibbs, Davies, & Lip, 2000; Jessup & Brozena, 2003). Unfortunately, 70% of HF cases are due to coronary artery disease, which in many cases is preventable and manageable if diagnosed and treated early (Camici, 2004).

Presently, in Canada the management of HF consists of lifestyle modifications, medications, and mechanical devices that attempt to provide relief from symptoms, slow the progression of HF, prolong life and improve the patients' overall QOL (see Appendix A) (Arnold et al., 2006). However, management of HF has yet to be perfected. The implementation of medications, such as angiotensin converting enzyme (ACE) inhibitors aimed at slowing the progression of HF do not improve the QOL of the patient (Mejhert, Kahan, Persson, & Edner, 2004; Smith et al., 2005).

Cardiac resynchronization therapy has been demonstrated to reduce mortality, decrease hospital admissions and improve the QOL of HF patients with intraventricular conduction delays; unfortunately, 30% of recipients do not respond to this therapy and continue to suffer severe symptoms of HF (Abraham et al., 2002; Bradley et al., 2003). The insertion of implantable cardioverter defibrillators (ICD) may change the HF patient's mode of death from sudden cardiac death to progressive debilitating HF and has also been associated with an actual reduced QOL in ESHF patients. The reduced QOL is related to discomfort from debilitating symptoms of ESHF, the uncertainty and unpredictability of receiving shocks, (both appropriate, and inappropriate) and device malfunction, all of which contribute to patients experiencing anxiety, anger, and depression (Shaffer, 2002). Lewis and colleagues (2006) discovered that in ESHF

patients who had a functioning ICD (n=43) 21% and 28% received a shock within 30 and 90 days of death respectively.

The only cure available for ESHF is cardiac transplantation; however, first year mortality rates remain as high as 20% followed by a 4% per year increase thereafter, resulting in a 50% survival rate at 10 years and 15% at 20 years (Hertz et al., 2002).

Despite medical advances and improved quality of care, the prognosis for HF remains poor. Mortality within the first year of diagnosis is as high as 33.1%, increasing to 40.1% if the patient is over the age of 75 years, and to 60.7% if the senior has other comorbid conditions (Jong, Vominckel, Liu, Gong, & Tu, 2002). Furthermore, HF carries a 50% mortality rate within the first five years of diagnosis (Levy et al., 2002) and of the most common cancers (lung, large intestine, prostate, bladder, breast and ovarian) only lung cancer is associated with a higher mortality (Stewart, MacIntyre, Hole, Capewell & McMurray, 2001).

Canada categorizes HF based upon the individual's functional capacity utilizing the New York Heart Association's (NYHA) functional classes that can vary over a period of time and with treatment measures (see Appendix B ) (Arnold et al., 2006). This classification system is currently utilized to define the patient's degree of functional limitations in relation to HF and to guide treatment options.

The American College of Cardiology and the American Heart Association have adopted a staging system for HF that complements the NYHA functional classes and is similar to that used in the staging of cancer (Hunt et al., 2005). This system of staging considers HF as a progressive, irreversible and lethal condition, thereby incorporating early screening for and treatment of risk factors, with the goal of preventing HF. Upon

diagnosing HF, progressive treatment is outlined for each stage, and back steps between stages are not permitted (see Appendix C).

#### End-Stage Heart Failure (ESHF)

Currently, ESHF patients are defined as those individuals who, despite maximal/optimal medical management, continue to experience distressing symptoms at rest or with minimal effort (Arnold et al., 2006; Hunt et al., 2001). These individuals are classified as NYHA functional class IV and stage D HF. ESHF patients suffer greatly from cardiac pump failure leading to distressing symptoms, such as dyspnea, pain and fatigue resulting in a severely impaired functional level and a reduced QOL (Coats et al., 1994).

#### Living with Heart Failure

Incorporating HF as a part of oneself is a challenging process initiated by one's initial experience with an acute episode of HF. This is followed by the individual having to find a way of incorporating the diagnosis of HF into one's self-identity, adjusting to the diagnosis, and the overall challenges associated with its management (Stull, Starling, Haas, & Young, 1999). A qualitative study conducted by Zambroksi (2003) examining the experiences of patients living with HF (n=11) suggests that living with HF and its associated management strategies is akin to "living at sea" where one must navigate "too much water" and "not enough wind." Physical, emotional and social turbulence occur as a result of living with HF and its associated challenges, ranging from side-effects of treatments, symptom distress and life threatening emergencies to boredom or frustration. The goal of the individual becomes finding strategies to navigate the turbulence, which include individual problem-solving methods, such as self-assessment, planning, and

acting in order to find safe harbor. Living with the challenges of HF leads to a severely reduced QOL, especially in those individuals who are unable to navigate successfully on their own, requiring these individuals to send out a “mayday” for assistance from health care providers to “pilot” them to safety. Conversely, for those who are in the terminal stages of HF, piloting to safety is not possible and other measures must be implemented to provide these patients relief from symptoms and mental and emotional anguish as they face death.

Research demonstrates that ESHF patients suffer severely from symptoms in their final months of life. The Study to Understand Prognosis and Preferences for Outcome and Risks of Treatments (SUPPORT) was a two phase study involving 9,105 hospitalized patients in five teaching hospitals in the United States, aimed at assessing how decision making between physicians and patients occurred in regards to probable outcomes and patient preferences, and to develop an understanding of the end of life experience for seriously ill hospitalized patients. Patients enrolled in the SUPPORT study were in advanced stages of one or more of nine illnesses, including 1,404 with a diagnosis of HF and 236 that died in hospital from ESHF (Callif, Vidaillet, & Goldman, 1998). The findings from the study demonstrated that 65% to 80% of participants died in hospital versus 15% to 20% who died at home (The Support Principal Investigators, 1995). This study also discovered that the end of life care provided to patients was suboptimal. Management of reported symptoms was lacking, and half of all do not resuscitate orders were written only within 24 hours of death.

In relation to ESHF, the SUPPORT study found that over 70% of ESHF patients rated their QOL as “fair to poor” during their last month of life (Califf et al., 1998) and as

death neared, one's illness worsened and the frequency of specific symptoms increased (Levenson, McCarthy, Lynn, Davis, & Philips, 2000). The most distressing and frequently reported symptoms were dyspnea (35%) and pain (20%), being reported most frequently 3-6 months prior to death. These symptoms increased in incidence to 63% and 41% respectively within the patients' final 3 days of life. Despite the documented suffering and unstable condition in these HF patients, a 54% six month model-based survival rate was estimated, even within 3 days of death. Also, as a result of a lack of communication between healthcare professionals and patients, 40% of the ESHF patients had at least one major therapeutic intervention within their last 48-72 hours of life, including cardiopulmonary resuscitation, mechanical ventilation or tube feeding. These interventions were implemented, despite patients' preference for comfort measures versus aggressive treatment.

It has also been reported that more than 70% of ESHF patients would trade any or all of two years of their poor QOL to feel better and obtain improved symptom control (Quaglietti, Atwood, Ackerman, & Froelicher, 2000).

Nordgren and Sorensen (2003) also documented the degree of suffering hospitalized ESHF patients endure. This European review of 80 medical charts of patients hospitalized for HF in 1995 found that in the last 6 months of life, ESHF patients suffer on average 7 symptoms, with dyspnea (88%), pain (75%) and fatigue (69%) being the most commonly reported. Unfortunately, these researchers also discovered that despite documentation by nurses and physicians reporting the existence of symptoms, rarely were symptom-controlling measures documented as having been provided.

Research with HF patients living in the community also indicates that these individuals suffer severely from symptoms leading to a reduced functional level and diminished QOL. Burns and colleagues (1997) studied the effects of HF in 519 patients after discharge from hospital and discovered that despite receiving medical care; 35% remained dyspneic, preventing them from walking more than one block; 32% received formal care, including nursing, healthcare aide or homemaker services; 62% perceived their health as fair, or poor, and 46% were rehospitalized within one year. The literature also suggests that as HF progresses to end-stage disease, the individual's mobility becomes severely limited and those living in the community become progressively restricted to their homes, and finally their chairs or their beds, leading to social isolation, anxiety, and depression (Willems, Hak, Visser, Cornel, & van der Wal, 2006).

Boyd and associates (2004) also discovered that healthcare professionals did not discuss end of life care with ESHF patients, unsuccessfully managed distressing symptoms of HF, and did not recognize psychosocial problems, such as social isolation, low mood, and anxiety. Numerous other studies have further demonstrated that psychological distress and depression are expected as the result of uncertainty and a perceived loss of control associated with HF (Gottlieb et al., 2004; Hawthorne & Hixon, 1994; Scott, Setter-Kline, & Britton, 2004; Zambroski, Moser, Bhat, & Ziegler, 2005) and fewer than 10% of HF patients living in the community are treated for depressive symptoms (Gottlieb et al., 2004).

The previously described studies indicate that ESHF patients suffer greatly within their final months of life and would benefit from the implementation of PC services aimed at alleviating distressing physical symptoms and addressing psychosocial and

existential concerns. The next section of the literature review will examine the nature of PC and how it might inform the care of ESHF patients.

### Palliative Care (PC)

Major medical and technological advances occurred during the 1940s through to the 1960s resulting in a shift from medical care that accepted death as a natural course of illness, to the cure seeking system that prevails today, where death is equated with failure (Saunders, Summers, & Teller, 1981). As a consequence of these advances, the site of care and place of death for patients has shifted from the home to hospital setting. This shift has been characterized in the literature as leading to immense suffering and loss of QOL (Ditillo, 2002; Gottlieb, 2003; Saunders et al., 1981). In response both to the suffering endured by patients in their final months of life, and the demand from patients and their loved ones to receive care aimed at alleviating symptoms versus seeking the unrealistic and unattainable goal of cure, the PC movement was born. In 1967, Dame Cicely Saunders opened St. Christophers hospice in the United Kingdom to provide care to the terminally ill, most of whom were individuals actively dying from cancer (Saunders, 1996). Within North America, the first specialized PC units were opened in 1974 by Dr. Balfour Mount at the Royal Victoria Hospital in Montreal, followed shortly thereafter by the establishment of a unit by Dr. Paul Henteleff at St. Boniface General Hospital in Winnipeg. These units had the expressed goal of providing specialized end of life care to dying cancer patients and aiding the assimilation of PC into medical programs and general healthcare settings (Fassbenber et al., 2005).

PC has developed into the provision of interdisciplinary biopsychosocial care to patients who have an end-stage or terminal illness, and their families, where death is the

expected outcome. The provision of care is aimed at the goal of relieving physical, mental, and spiritual suffering, supporting patient dignity, and ultimately improving QOL (Cohen et al., 2001; Ferris et al., 2002; Gottlieb, 2003; Zerwekh, 2006).

The shift to PC in end-stage disease allows for healthcare professionals to alter the goal of care and actively seek measures that relieve discomfort and promote QOL for patients and their loved ones. Previous studies evaluating QOL have occurred in advanced cancer patients in PC programs via retrospective evaluations from bereaved family members. One Canadian study assessed QOL directly by interviewing 88 palliative hospitalized cancer patients. The findings of that study demonstrated that the QOL of advanced cancer patients receiving specialized PC was enhanced; reflecting improved physical, emotional, and interpersonal status, and preparation for death (Cohen et al., 2001). Research examining the impact of implementing PC services for oncology patients in community settings has also demonstrated positive impacts including, an increase in the amount of time patients remained at home, improved symptom control, and improved likelihood of dying where one wished to die (Hearn & Higginson, 1998).

#### Palliative Care (PC) in End-Stage Heart Failure (ESHF)

The predictable steady decline in health associated with terminal cancer allows for clinicians to prognosticate life expectancy and assists the individual in planning one's end of life care. However, the variable and unpredictable course of HF, accompanied by the desire of individuals living with HF and their cardiac clinicians to continuously treat their HF with the hopes of prolonging life and optimistically finding a cure, has resulted in those suffering with ESHF being considered unsuitable candidates for PC.

In the past ten years the focus of relieving suffering in ESHF has begun to return to the forefront. In 2001, the American Heart Association/American College of Cardiology for the first time included PC as a recommendation for the management of stage D HF (Hunt et al., 2001). The Canadian Cardiovascular Society (CCS) followed suit in 2006 (Arnold et al., 2006). Furthermore, in 2008 the CCS highlighted the importance of transitional care in ESHF (Arnold et al., 2008). Transitional care is defined as “care and services that promote the safe and timely transfer of patients from one level of care to another (eg, acute to subacute) or from one type of setting to another (eg, hospital to home)” (Naylor, 2000, p.1). Within ESHF, the transition must occur from active aggressive medical care to optimal end of life care. Transitional care may include continued involvement of the patient’s primary care physician, and the early incorporation of psychiatry, geriatrics, and specialized PC services for adequate symptom control and assisting the patient in meeting their goals of end of life care (Arnold et al., 2008). Finally, in 2011 for first time ever, the CCS HF management guidelines included a significant section pertaining to the end of life care needs of ESHF patients. This section addresses the necessary and important role that PC plays and provides recommendations and suggestions to manage the distressing symptoms associated with ESHF (McKelvie et al., 2011).

Love and Sawatzky (2007) discussed the current barriers to ESHF patients receiving specialized PC in Canada. These challenges include stringent admission criteria to PC programs, such as life expectancy of six months or less, and an inability of healthcare professionals to accurately predict life expectancy in ESHF of less than six months. Inadequate communication between healthcare professionals, patients and their

families pertaining to prognosis, resuscitation preferences/recommendations and patient care wishes when achieving cure was futile, and the failure of patients and/or family members to recognize or accept the terminal phase of illness also pose significant challenges, and contribute to the difficulty transitioning from care with a curative focus to a palliative perspective. Furthermore, HF patients commonly choose maximal medical therapy throughout their illness and up until the time of their death, despite a poor prognosis (Stewart, Moser & Thompson, 2004). Patient preference for interventions that restore health versus obtaining comfort are not congruent with the philosophy of PC, thereby further reducing the likelihood of being enrolled in a PC program and the initiation of PC strategies aimed at ensuring comfort.

Research also demonstrates that patients dying from ESHF suffer severe symptoms that are similar to, and in many cases greater, than those of cancer patients; nevertheless, ESHF patients do not receive specialized PC services to the same degree as cancer patients (Lynn et al., 1997; McCarthy & Addington-Hall, 1996). The unpredictable trajectory of HF and the goals of the medical model to aggressively treat periods of decompensation and prolong life prevent healthcare professionals from discussing end of life care with ESHF patients. Consequently, patients who die from HF receive more life-sustaining treatments than those dying from cancer (Tanvetyanon & Leighton, 2003).

Research, though extremely limited, suggests that PC services can improve the experience of ESHF patients living in the community. Brannstrom and colleagues (2006) published the first study assessing the effectiveness of palliative homecare for ESHF patients. They conducted a hermeneutic phenomenological study that examined the lived experience of four patients living with severe HF who were receiving specialized

palliative homecare services. The findings of this European study suggest that ESHF patients who received specialized palliative homecare suffered from thirst, dyspnea, feebleness, and shifts in feeling better or worse. However, despite the severity of their illness and degree of suffering, all participants stated that receiving advanced palliative homecare increased their independence and facilitated a life at home. Furthermore, the participants felt privileged to remain in their homes and developed feelings of security related to the 24 hour availability of health professionals, which ultimately reduced their need for hospital visits and admissions.

### Chapter Summary

This chapter provided an overview of select bodies of literature relevant to the purpose of the study. First, Canada's aging demographic, and the landscape of chronic illness among the elderly was discussed. Next, literature examining the diagnosis and management of HF and ESHF was presented. The aims and goals of PC, its potential role in informing the care of ESHF and the current challenges in integrating a PC approach into the care of ESHF patients was described. It was clear from the literature reviewed that empirical work examining the experiences of those with ESHF is extremely limited, underscoring the importance of further research in this area. The next chapter will describe the sensitizing framework that informed this study.

## CHAPTER THREE: THERORETICAL FRAMEWORK

### Introduction

Chapter three describes the Human Response to Illness (HRTI) Model in relation to its function as a sensitizing theoretical framework in guiding this study.

### The Human Response to Illness (HRTI) Model

The HRTI Model was used as a sensitizing theoretical framework to guide this study. This model has its foundation in nursing and considers human responses to illness from four interrelated perspectives; thereby, ensuring that the patient receives holistic care to promote their well-being (Mitchell, Gallucci & Fought, 1991). The model provides nurses and other healthcare professionals with a framework to assess the physiological, pathophysiological, behavioral, and experiential perspectives of a specific response to an illness or threat to one's health (see Appendix D). The physiological domain encompasses the body's normal physiological responses and functioning, whereas the pathophysiological response is the disruption of the normal functioning of a system(s), which ultimately results in dysfunction within the body. The behavioral perspective includes observable and measurable behaviors, most frequently symptoms that occur in response to the pathophysiological alterations within the body. The final perspective, the experiential considers the lived experience of the individual patient and encompasses the verbal expression of living with the illness itself and its associated symptoms. The experiential perspective is considered one of the most important components of the HRTI model due to the fact that the patient perspective often describes what he/she perceives as most relevant in the illness response.

The HRTI model also considers person and environmental factors as variables that have the potential to interact and influence all four perspectives of the model, leading to variations in responses to illness and patient outcomes. Person factors are considered those variables that are inherent within the individual and influence their responses to illness states. Nonmodifiable person factors are variables that influence one's response to illness and can not be altered, such as age. Modifiable risk factors are those variables that have the potential to alter one's health or illness state and can be influenced to minimize the negative illness response or maximize the positive health response, including sleep, exercise, and smoking. Environmental factors are external variables that have the potential to alter one's response to health or illness.

#### *The Appropriateness of the HRTI Model for This Study*

The HRTI model has been utilized as a framework for nursing care in the management of breast biopsy anxiety (Deane, 1997), anxiety associated with the diagnosis and treatment of breast cancer (Pedersen, Sawatzky, & Hack, 2010), dysphagia in advanced oropharyngeal cancer patients (Penner, McClement, & Sawatzky, 2007), stress related to lung cancer (Hansen & Sawatzky, 2008), altered level of consciousness in patients with subdural hematomas (Nesbitt & Sawatzky, 2009), and urinary incontinence post radical prostatectomy (Yu Ko & Sawatzky, 2008). Within all of these publications, the HRTI model was used as a way of guiding nurses to attend to the holistic care needs of a given patient population.

In quantitative research, theoretical frameworks are utilized to aide the researcher in identifying the variables being studied and the relationship among them (Morse & Field, 1995; Polit & Beck, 2008). In qualitative research; however, variables typically

have either not yet been identified, or their dimensions and properties are not well understood. Thus, the goal of this study was not the testing of the HRTI model. Rather, the model was used to sensitize the researcher to attend not only to one specific response to an illness, but rather the totality of the response of the individual living with ESHF. Use of the HRTI model also ensured that the researcher remained grounded in a nursing focus and provided direction regarding some of the facets of ESHF to be explored with patients as they recounted their experiences of living with this disease. For example, in regards to patients' symptom experiences, the researcher made efforts to explore not only dyspnea, but the entire cascade of symptoms that individuals living with ESHF experience and the impact that the symptoms collectively have on every day life. The HRTI provided a sensitizing framework for this study in that the researcher needed to understand normal cardiac physiology, pathophysiology, and how symptom distress and burden are understood and experienced by the individual living with the disease. Being sensitized to these various dimensions of patient responses to ESHF helped to clarify the need to adopt a research approach that would lend itself to explicating and understanding patients' lived experiences in a holistic way. It also helped to inform the development of the questions driving the study, and the topics to be explored during participant interviews.

### Chapter Summary

This chapter has described the HRTI Model and its function in ensuring that the researcher remained focused on discovering the holistic meaning of what it is like to live with ESHF on a daily basis. When one considers a human response to any illness from a multi faceted perspective the potential of understanding the experience is heightened and

the discovered knowledge becomes a significant tool in the development of interventions aimed at obtaining desired patient outcomes.

## CHAPTER FOUR: METHODOLOGY

### Introduction

Chapter four identifies the research design that was used to conduct this research, and provides justification for selecting a phenomenological approach to answer the study questions. Information concerning the sample, setting, recruitment procedures, study procedures, data collection and data analysis methods, and ethical considerations are also detailed in this chapter. The chapter concludes with a discussion about the strategies that were employed to achieve trustworthiness in this research project as it is understood from a qualitative paradigm. The research design outlines the overall approach that the researcher developed and instituted to perform this research.

### Research Design

#### *Interpretive Phenomenology*

Researchers strive to discover knowledge that is accurate and interpretable, which thereby aides us in making sense of reality and explaining the world as we know it (Morse & Field, 1995). The approach one uses in discovering knowledge is driven by the nature and quality of existing work about the topic of interest. Given the lack of research examining the experience of living with ESHF, a qualitative research approach was warranted. Qualitative research has been defined by Creswell (2007) as a research methodology that:

Begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data

in a natural setting sensitive to the people and places under study, and the data analysis that is inductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the problem, and it extends the literature or signals a call for action. (p.37)

Qualitative research provides a rigorous, yet flexible means to develop or advance an understanding of the meaning of a human experience.

Phenomenology, a specific type of qualitative research, enables researchers to discover what it is like to live an experience from an individual's perspective, which is termed the 'lived experience' (Speziale & Carpenter, 2007). Phenomenology seeks to discover the essential truth about reality by exploring subjective phenomena through the lived experience that is presented by the individual participant. Given the stated aim of this study, phenomenology was an appropriate research design to use.

#### *The Philosophical Underpinnings of Interpretive Phenomenology*

Interpretive phenomenology, which is also termed hermeneutics, was founded by Martin Heidegger in 1916 as a philosophy to guide researchers in unveiling otherwise concealed meanings in the phenomena and has since been frequently refined (Spiegelberg, 1975). Heidegger, a student of Husserl's did not agree with Husserl's principle of phenomenological reduction (bracketing), which requires the researcher to consciously reflect on and eliminate past experience, knowledge and assumptions to ensure that the research is not influenced or biased (Annells, 1996; Dowling, 2004; Koch, 1995). Heidegger believed that because all humans live in the world, and both influence, and are influenced by it, they cannot make sense of the world by detaching (bracketing) from it. Heidegger sought to uncover the meaning of 'being' for humans. He alleged that

being itself is time and that understanding is the realization of 'being-in-the world' (Dasein) (Gadamar, 1989). Furthermore, Heidegger viewed hermeneutics as a research philosophy that discovers 'being-in-the world' (presence in the world) through interpretation of the world. As a result, interpretive phenomenology was established.

Within the literature discussing interpretive phenomenology, Heidegger's two essential principles of historicity of understanding, and the hermeneutic circle are frequently discussed (Annells, 1996; Koch, 1995). The two concepts are intertwined and are based upon Heidegger's ideas of background, pre-understanding, co-constitution and interpretation. Background is what culture instills within a person at birth and is considered a fundamental part of who a person is and becomes the individual's source of understanding the world. Due to one's background, all individuals come to a situation with previous cultural knowledge and understanding, which is termed pre-understanding or fore-conception. This fore-conception is the result of one's culture, which incorporates language and practices that are occurring in the world prior to one's understanding. Therefore, pre-understanding is rooted within the individual and not amendable to bracketing. Furthermore, to ensure that pertinent questions are asked to gain a further understanding of the world one must have fore-conception (prior knowledge). Co-constitution is the belief that one cannot separate person from world. The world in which we live is a part of us and we construct and influence the world through our own experience and background. Interpretation is considered necessary for humans to understand their being-in-the world and this understanding is dependent upon one's background. As a result, when we try to understand the world we are employing interpretations of interpretations of previous interpretations. The researcher interprets the

data, which has already been interpreted by the participant both of whom have incorporated their pre-understanding of the situation.

The hermeneutic circle of interpretation is a term that has been devised to describe the analysis of the interaction that occurs between researcher and participant (Conroy, 2003). This analysis consists of a reflection and interpretation of the interview itself and the data (text) produced by all involved; considering each individual's background. The reading and rereading of the narrative leads to the development of further questions that influence the researcher's view of the text and the collection of future data.

Heidigger founded interpretive phenomenology as a philosophy and had no intention of providing rules or methodological procedures to govern the use of interpretive phenomenology as a research methodology (Annells, 1996). However, scholars, such as Max van Manen (1997) have developed interpretive phenomenology into a research method that incorporates a guide for study development, data collection, analysis, and interpretation. van Manen's approach, which includes the six methodological themes of: (a) turning to a phenomenon of interest; (b) investigating experiences as it is lived; (c) reflecting on the essential themes; (d) describing the phenomenon through writing and rewriting; (e) maintaining a nursing relation to the phenomenon; and (f) considering the parts and the whole, was utilized to guide this study.

#### *The Appropriateness of Interpretive Phenomenology for This Study*

Interpretive phenomenology requires that the researcher becomes totally immersed in the phenomena of interest. This immersion requires: developing an understanding of the phenomena by actively listening to the narrative of the lived

experience of the individual participants; analyzing the individual reports to discover the essence of the phenomenon by identifying individual and reemerging common themes; and communicating the identified distinct and critical elements of the phenomena of interest (Creswell, 2007; Speziale & Carpenter, 2007). As a result, the participant is provided the opportunity to portray what it is like to experience the phenomena on a daily basis as they perceive it in their very own life, and describe this experience through their own words. The researcher then interprets this text and presents these words in a written report in an attempt to summarize and describe the lived experience of the phenomenon under investigation. Overall, the byproduct of the research project is a textual interpretation that reduces the individual experiences of the participants to a description of the universal essence of the experience of living with the specific phenomenon being researched. Furthermore, due to the fact that the primary researcher of this study has experience working with individuals living with ESHF and has gained knowledge pertaining to the challenges that the individuals face on a daily basis living with ESHF, it would be impossible to bracket this pre-understanding out of the research process. Based upon these facts interpretive phenomenology was an appropriate research method for this research project.

### *Photovoice*

Photovoice, previously termed photo novella, is an approach developed by Wang and Burris (1994) in an attempt to offer vulnerable populations, most notably oppressed women, an opportunity for empowerment and influence in health policy decisions. Photovoice is defined by Wang and Burris (1997) as “an innovative participatory action research (PAR) method based on health promotion principles and the theoretical

literature on education for critical consciousness, feminist theory, and nontraditional approaches to documentary photography. Photovoice enables people to identify, represent, and enhance their community through a specific photographic technique” (p. 185). This specific research method provides participants with cameras and offers them the opportunity to express, reflect and communicate their everyday lives by capturing the lived experience through photography and by discussing what the picture means to them. As a result, Photovoice has three main goals: “(a) to enable people to record and reflect their community’s strengths and concerns; (b) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs; and (c) to reach policymakers” (Wang & Burris, 1997, p. 369). Photovoice as a methodology has successfully been utilized in numerous research studies to evaluate and highlight the health needs of varying groups of individuals and communities (Moffitt & Robinson Vollman , 2004; Ornelas et al., 2009; Wang, 1999; Wang, Burris, & Xiang 1996; Wang & Burris, 1994; Wang, Cash, & Powers, 2000, Wang & Redwood-Jones, 2001).

#### *The Appropriateness of Photovoice for This Study*

Within this study Photovoice provided the participants with an opportunity to capture images of what it means to them to live with ESHF, and then during an interview describe the images in the context of their everyday lives. As a result of incorporating Photovoice into this research study participants were encouraged to express, reflect upon, and communicate their everyday lives with ESHF by capturing their daily experiences in photographs and by discussing what the picture meant to them.

### *Sample*

Qualitative research seeks to obtain “rich” data that aids in creating a deeper understanding of a phenomenon. Therefore, participants must be selected based upon their experience with, and ability to describe the experience of living with the phenomenon being studied. Criterion based purposeful sampling was used to select the participants for this study. Purposeful sampling, a type of convenience sampling, allows the researcher to consciously select participants who can share their particular knowledge about the phenomena of interest (Creswell, 2007; Speziale & Carpenter, 2007). As a result, the researcher deliberately selects participants who are intimately familiar with the topic being investigated and can provide rich information about it.

### *Inclusion Criteria*

In order to be eligible to participate in this study, participants were required to meet the following inclusion criteria: i) aged 18 years or older; ii) able to read and speak English; iii) a primary documented diagnosis of HF, as confirmed by transthoracic echocardiogram, coronary angiography, radionuclide angiography and magnetic resonance imaging; left ventricular ejection fraction <40%; left ventricular diastolic HF/preserved systolic function (left ventricular ejection fraction > 40%), right sided HF or biventricular HF. Participants also needed to iv) be receiving optimal medical therapy; for their ESHF; v) continue to be suffering from refractory symptoms; including, a combination of pulmonary and/or peripheral edema, dyspnea, orthopnea, abdominal distension/discomfort, anorexia, fatigue and a reduced activity tolerance equating to NYHA functional class III & IV; vi) be willing to provide written informed consent; vii) have access to a telephone; and ix) consent to participate in an interview(s).

### *Exclusion Criteria*

Individuals were excluded from the study if they: i) chose not to participate; ii) did not have access to a telephone; iii) did not read or speak English; iv) were cognitively impaired as per the judgment of the clinical staff; v) had a secondary end-stage illness, such as stage IV cancer, renal disease requiring dialysis, pulmonary disease that required oxygen; or vi) were being considered for organ transplantation.

### *Sample Size*

In qualitative research the exact sample size for the study cannot be known a priori. To study a phenomenon in depth and detail, a small sample size of five to 20 participants is most commonly utilized (Kuzel, 1999). Sampling occurs one participant at a time and continues until the researcher recognizes no new data is forthcoming or nothing new is heard during interviewing, which is a condition known in qualitative research as ‘information redundancy’ or ‘data saturation’ (Morse & Field, 1995; Munhall, 2007). Data saturation is recognized when reoccurring themes occur and no new themes/experiences are described by the participants. Data saturation within this study occurred at seven participants, thus further recruitment efforts were terminated.

### *Recruitment Setting*

The participants for this study were recruited from the specialized HF clinic at St. Boniface General Hospital in Winnipeg, Manitoba, Canada. The 2006 CCS guidelines for the diagnosis and management of HF recommend that all individuals with recent or recurrent hospital admissions for HF should be referred to specialized HF clinics (Arnold et al., 2006). These specialized multidisciplinary clinics provide evidence-based medical therapy; including, patient and family education, lifestyle modification therapy, titration

of HF medications, psychological support, and electrophysiological and surgical interventions.

At the time of this study within Manitoba, all patients who were considered potential candidates for surgical intervention, including cardiac transplantation were screened by the St. Boniface Heart Failure Clinic and follow-up care was provided by the clinic post surgical intervention. When a HF patient who attends a specialized HF clinic is receiving maximal medical therapy, including optimally titrated medications and has received or is deemed not a suitable candidate for surgical interventions or mechanical devices and remains severely symptomatic with a drastically reduced QOL they are diagnosed as “true” ESHF and become suitable candidates for PC services.

#### *Study Procedures*

Prior to recruiting participants for this study, ethical approval was received from the Education and Nursing Research Ethics Board at the University of Manitoba (see Appendix E) and access approval was obtained from the St. Boniface General Hospital Research Review Committee (see Appendix F).

Upon receiving ethical and site access approval, recruitment of participants was initiated through the St. Boniface HF Clinic. Information pertaining to the purpose of the study and inclusion/exclusion criteria for screening participants was provided to the physicians, clinical nurse specialist and nurses associated with the HF clinic during a regularly scheduled staff meeting by the researcher. The HF clinic was also provided with a laminated poster (see Appendix G) that outlined the highlights of the study and the inclusion/exclusion criteria. The poster was hung in a location that was easily visible by patients and staff. Clinic staff were also encouraged to consider all ESHF patients

attending the clinic for their appropriateness for the study. In the development of the recruitment poster staff associated with the HF clinic suggested that the wording be changed from ESHF to something less fatalistic, such as advanced HF or progressive HF. However, to preserve the reality that HF is progressive and lethal the decision was made to continue to use ESHF within the recruitment poster. The researcher also did not want initial discussions surrounding the fact that HF is a terminal illness to occur during the research interviews. The expectation was that discussion surrounding the lethality of HF would occur between the HF clinic staff and the patient.

Individuals were classified as ESHF by a cardiologist associated with the HF clinic. Either a cardiologist or nurse associated with the HF clinic informed patients, that there was a study being conducted for which they were eligible, and provided them with a information sheet that described the project, and contained the researcher's contact information (see Appendix H). Potential participants were provided the opportunity to take the information sheet home with them, review it, and then contact the researcher if they were interested in hearing more about the study using the contact information provided on the sheet. If a patient requested that the clinic staff contact the researcher on their behalf, then a staff member of the HF clinic contacted the researcher and provided him with the potential participant's name and phone number.

The researcher was present in the HF clinic at St. Boniface General Hospital a minimum of one day a week in order to facilitate the recruitment process, and provided timely information to those patients who were visiting the clinic, and expressed interest in hearing more about the study. Prior to contacting all potential study participants, the researcher verified with a cardiologist that the patient met ESHF classification criteria.

The researcher then contacted the potential study participant, and at a time convenient for the individual provided him/her with information about the study and answered questions about participation in it.

Potential participants were contacted by the researcher within one week of signaling their interest in taking part in the study. At this point of contact, the researcher set up an appointment to obtain written informed consent and conduct an interview. Prior to obtaining consent for participation in the study the researcher reviewed with all individuals the purpose of the study, and the nature of their involvement in it. The fact that participation was voluntary and that the individual could withdraw from the study at any time without influencing the care provided by the HF clinic staff or other health professionals was reinforced. Once the researcher was satisfied that the individual understood the purpose of the study and the implications of their participation in it, the consent form was signed, and each participant was provided with a signed copy of the consent form for their records (see Appendix I).

#### *Data Collection Methods*

Data was collected through: i) a demographic form; ii) open-ended face to face audio-recorded interviews; iii) field notes; and iv) photographs taken by participants that they believed captured what it is like to live with ESHF.

#### *Demographics*

A demographic form was used to collect information that helped to describe the characteristics of the sample (see Appendix J). Demographic data was collected after the consent form was signed and prior to beginning the interview. The researcher also accessed the participant's HF clinic medical chart to obtain further demographic data

after he received permission from the study participant. The data collected from the participant's HF Clinic chart included; date of diagnosis of ESHF, ejection fraction, documentation pertaining to discussion of the patient's resuscitation preference/wishes, co-morbidities, and the utilization of community or homecare services.

### *Phenomenological Interviews*

The primary source of data collection was open-ended, face to face audio-recorded interviews. In order to obtain rich data, unobstructed dialogue had to occur between the study participant and the researcher. Open-ended interviews are traditionally used in phenomenological research and are considered unstructured purposeful conversations that utilize an interview guide to assist the discussion process (Speziale & Carpenter, 2007). The use of this technique provided the participant with the latitude and opportunity to completely describe the lived experience of living with ESHF in their own voice and terms. An interview guide consisting of 5 to 7 questions is recommended to navigate the researcher, most notably a novice researcher, through the interview process and to ensure that rich data is collected to assist in describing the phenomenon being researched (Creswell, 2007). The interview guide (see Appendix K) was revised on an ongoing basis as descriptions and interpretations of the phenomena revealed new data, and suggested the need to explore additional facets of participants' lived experience.

Data collection in qualitative research typically occurs in a natural setting sensitive to the people and places under study (Creswell, 2007). This natural setting allows the researcher to talk directly to the participants and observe how they behave and act in their context. As a result, the researcher is provided with an opportunity to enter the participant's world. Furthermore, an environment that minimizes distractions and allows

for confidential discussion to occur is recommended to facilitate ease of interaction (Creswell, 2007; Lobiondo-Wood & Haber, 2009; Speziale & Carpenter, 2007).

All interviews were completed in the individual participant's home, which provided a natural, private, safe, quiet, and comfortable environment. Handwritten field notes were composed during and after each interview to capture the contextual features of the interaction, and aided the researcher in achieving a comprehensive and accurate description of the collected data and the interview itself.

At the end of the interview the researcher asked each study participant for their permission to be contacted at a later date in order to offer them the opportunity to partake in a follow-up interview aimed at validating the accuracy of the researcher's interpretations of their descriptions of living with ESHF. It was explained to participants that the follow-up interview would allow them the opportunity to clarify or add any additional information they may have omitted. Participation in the follow-up interview was voluntary. Five participants agreed to partake in follow-up interviews with the researcher. These interviews were also conducted in the participant's home.

Given the poor health status of participants, the researcher had determined in advance that if at any time during an interview process the participant displayed troublesome physical symptoms and/or emotional/psychological distress, the interview would be halted and the researcher would provide support to the individual. If the participant required further assistance it was preplanned that the researcher would seek permission from the study participant to contact the HF clinic. No participants required further assistance from the HF Clinic.

### *Photographs*

Though interview data was the primary data source for the study, the project also provided participants the opportunity to take photographs of anything that they felt captured what it was like to live with ESHF. Wang's (1999) procedures for Photovoice research informed and guided this part of the project. The general consent form included a discussion about the intent, benefits, and risks of Photovoice, and clarified that photographs may be utilized for research or educational purposes. Upon completion of the interpretive interview, the researcher explored with each participant their desire to partake in the Photovoice portion of the project. Participants consenting to be part of the Photovoice portion were provided with three disposable cameras from the researcher, and a demonstration of how to use the cameras. The participant was encouraged to take photographs of anything that they felt portrayed what it is like to live with ESHF. They were informed that it was acceptable to have someone else photograph them if they so desired and that they were not to take photos of other humans. A time frame by which the picture taking was to be completed was negotiated with each participant. The cameras were then collected by the researcher, and the photos developed. At the time of retrieval of the cameras, an appointment was made two weeks hence for an interview in which the researcher would discuss the photographs with the participant.

#### *Interviews about the photographs.*

During the Photovoice interview, the participant was asked to select and talk about five photographs that he/she felt were the most significant in identifying the lived experience of ESHF. The discussion about the photographs was facilitated by incorporating the Freirean-based critical dialogue technique, consisting of a series of

questions and referred to as SHOWED (Wallerstein & Bernstein, 1988). These questions guided the discussion from a personal level to social analysis and action steps. The questions included: (a) What do you see in this photograph?; (b) What is happening in this photograph?; (c) How does this relate to our lives?; (d) Why do these issues exist?; (e) How can we become empowered by our new social understanding?; and (f) What can we do to address these issues? An interview guide based upon SHOWED was developed for this study (see Appendix L). All interviews about the photos were audio-recorded.

### *Ethical Considerations*

#### *Ethics / Review Board Approval*

Ethical review and approval of the study was obtained from the Education and Nursing Research Ethics Board at the University of Manitoba (see Appendix E) and the St. Boniface General Hospital Research Review Committee (see Appendix F) preceding commencement of the study.

#### *Vulnerable Populations*

Individuals who are in their final stages of life are considered a vulnerable population (Dean & McClement, 2002; Polit & Beck, 2008) and may enter research with the hope of receiving new curative treatment modalities or with the hope of influencing the future management of individuals with similar conditions (Addington-Hall, Bruera, Higginson, & Payne, 2007). As a result, the consent form clearly stated that no treatment was being offered and that the goal of the research project was to reduce the gap in the currently available knowledge pertaining to ESHF by developing an understanding of the experience of living with ESHF.

### *Confidentiality*

Confidentiality is the guarantee to the study participants that any information provided by them will not be accessible by others or publicly reported in a manner that would identify them (Speziale & Carpenter, 2007). To ensure confidentiality all collected data was and continues to be stored in a password protected computer and/or a locked filing cabinet at the researcher's residence. Furthermore, only the researcher and research supervisor had access to the collected data and all data collected will be destroyed within five years of completion of the study, and treated as confidential waste.

### *Anonymity*

Anonymity entails the protection of the study participant's identity (Lobiondo-Wood & Haber, 2009; Polit & Beck, 2008). Anonymity was protected by not placing names or other identifying information on study documents. All participants were assigned a unique code number and pseudonyms were used to replace actual names when interviews were transcribed (Dean & McClement, 2002). The information and consent form clearly stated that photographs may be incorporated within publications and educational presentations, once again using pseudonyms instead of participants' names. However, because it was possible photographs of participants may be recognizable by others, absolute anonymity could not be guaranteed. This was communicated to participants in the consent form.

### *Data Analysis*

#### *Demographic Data*

Descriptive measures, such as percentages and averages were employed to summarize and describe the demographic data.

### *Analysis of the Interviews*

Data collected during the interview process was transcribed verbatim by a hired transcriptionist employed within the Winnipeg Regional Health Authority. To ensure accuracy of the transcription, the transcripts were read simultaneously by the researcher while listening to the recorded interview. The transcribed data included: line numbers, numbered pages, and a cover page that contained the date, location, and time of the interview and the unique code number assigned to the participant. Consistent with a phenomenological approach, analysis of the data occurred continuously and simultaneously with data collection.

Qualitative data analysis of participant interviews is a complex nonlinear process that is time-consuming, creative, dynamic, flexible, and iterative (Creswell, 2007; Holloway & Wheeler, 2002; Speziale & Carpenter, 2007). The ultimate goal of data analysis entails preserving the uniqueness of each participant's lived experience while developing an understanding of the phenomenon under investigation. Analysis of the data occurs throughout the research process beginning with active listening during each interview and is followed by the reading and rereading of the transcribed interviews and other sources of collected data.

#### *Thematic analysis – interpretive phenomenology.*

van Manen's guide to interpretive inquiry was utilized to analyze the data collected during the main portion of the study. Phenomenological reflection assisted the researcher in producing an understanding of the essential meaning of an experience by employing thematic analysis to determine essential themes (van Manen, 1997). The discovery of the essential meaning of an experience occurred as a result of uncovering

thematic aspects, isolating thematic statements, and composing linguistic transformations. Thematic aspects were identified by reading and reviewing the transcripts a number of times assessing for significant statements, which further offered insight into the themes that identified the meaning and understanding, also known as the experiential structure that identified what it means to live with ESHF. Thematic statements were isolated using van Manen's selective highlighting approach where statements or phrases that appeared to be essential or revealing about living with ESHF were highlighted. All of the highlighted statements and phrases were then reduced into essential and incidental themes using free imaginative variation. Essential themes included those statements whose meanings were unique to the phenomenon and without which, the phenomenon would not be what it is; thereby, losing its fundamental meaning. The question: "Is living with ESHF still the same if I imaginatively change or delete this theme?" was used as a guide to identify essential themes. Incidental themes were identified as those statements or themes that were incidentally related to the phenomenon.

Once the essential and incidental themes were identified, linguistic transformation was employed to identify the essence of the themes (van Manen, 1997). This process involved capturing the thematic statements in phenomenologically sensitive paragraphs that were written and reflected upon numerous times. Reflection occurred by alternating the focus between the whole and parts of the transcripts, between individual and group transcripts and by sharing the text with the thesis chair. Each reflection considered the question: "Is this what the experience really is like?" In the case of this study the question: "Is this what living with ESHF really is like?" was used to guide the researcher's reflection. The paragraphs written describing the essential themes were used

to develop the interpretation of the experience of living with ESHF and examples were incorporated to illustrate how the description evolved. The result was a possible description of the experience of living with ESHF, due to the fact that meaning is multi-dimensional and multi-layered and thereby phenomenon are not applicable to a single complete full description (van Manen, 1997).

*Content analysis - photovoice.*

Content analysis was utilized to analyze the transcripts from the interviews discussing the meaning of the photos for each participant in relation to ESHF. Content analysis entailed breaking the transcribed interview data down into topic categories utilizing codes to identify the content within the interview and category names to identify the data groups (Morse & Field, 1995).

The first step in content analysis is termed 'coding' and included reading the entire transcript a number of times and then identifying repetitive words, sentences, paragraphs or themes within the data. This process allowed the researcher to become familiar with the data and to initiate data organization. Categories were then developed to identify groups of content that shared commonalities and each category was given a descriptive name to identify the group of data. A total of 11 categories were developed and each code belonged to one or more category. Throughout the data analysis process the categories were refined, revised and validated and subcategories were formulated. The final step included within content analysis was theme development where the integration of categories occurred.

### *Methodological Rigor - Trustworthiness*

Phenomenological research seeks to gain an understanding of a lived experience from an individual concerning a specific phenomenon through visiting personally with the participants. As a result of this interactive flexible process, the standards of validation and evaluation developed for quantitative studies to ensure reliability and validity do not accommodate the qualitative researcher (Creswell, 2007; Holloway & Wheeler, 2002; Lobiondo-Wood & Haber, 2009; Speziale & Carpenter, 2007). Therefore, measures of rigor, termed trustworthiness have been developed to recognize the uncertainty within qualitative research, reinforcing that all outcomes of research are tentative and will vary based upon the time reference and study participants. Measures of trustworthiness include; credibility, dependability, confirmability, and transferability.

#### *Credibility*

Credibility encompasses activities that increase the probability that credible findings were produced (Creswell, 2007; Holloway & Wheeler, 2002; Speziale & Carpenter, 2007). Prolonged engagement with the subject matter and member checking, the act of returning to the participants involved to receive verification of the accuracy of one's findings, are frequently utilized to ensure credibility. The participants must recognize the meanings that they themselves provided within the findings of the study; thereby, reinforcing the truth within the findings. This study employed member checking through the use of follow-up interviews to ensure the accuracy of the researcher's interpretations of the participants' descriptions of living with ESHF. During the follow-up interviews the participants confirmed the accuracy of the interpretations of the researcher and no revisions were recommended by the participants.

### *Dependability*

Dependability is the transparency of the researcher in outlining their decision making processes utilized during the analysis of the data and development of their conclusions or findings. Clear documentation of these decision points provides an audit trail (Creswell, 2007; Holloway & Wheeler, 2002; Speziale & Carpenter, 2007). The context, participants, and the process utilized within the research project are also described in detail, and in combination with the audit trail, help to ensure that the study findings are consistent and accurate (Holloway & Wheeler, 2002). In attending to issues of dependability, the researcher provides a map of the thought processes and decisions that were made throughout the study allowing other researchers the opportunity to repeat the study with similar participants and under similar circumstances. Dependability within this study was ensured through the implementation of an audit trail, which included field notes that described the context of the interviews and notes that identified methodological changes and revisions to the interview guide as concepts/themes began to emerge. Furthermore, personal reflections along with prior thoughts and assumptions were recorded. The thesis chair, who has expertise in qualitative research and PC also analyzed the interview transcripts and confirmed the interpretations of the researcher.

### *Confirmability*

Confirmability is the degree to which the analysis and conclusions reflect the aims of the study and are supported by the data, versus reflecting the researcher's prior assumptions or preconceptions (Creswell, 2007; Holloway & Wheeler, 2002; Speziale & Carpenter, 2007). Once again the audit trail provides a means of tracing the data back to

the sources and outlines the way that the researcher arrived at the codes, themes and interpretations/findings.

Phenomenological research recognizes that the researcher as the measurement tool inherently contains preconceived unconscious beliefs, attitudes, and assumptions that influence the collection and analysis of data (Creswell, 2007; Giorgi, 2009; Holloway & Wheeler, 2002; Lobiondo-Wood & Haber, 2009; Speziale & Carpenter, 2007). Included within the audit trail is reflexivity, where researchers critically reflects on their own preconceptions and monitors their relationship with the participants and their own reactions to the accounts and actions of the participants (Holloway & Wheeler, 2002). Qualitative researchers must recognize and identify how their preconceptions and knowledge may influence data collection, analysis and the interpretation of the data. However, within interpretive phenomenology one is not required to bracket prior knowledge, but rather to appreciate that prior/expert knowledge builds the foundation of the study and influences the research question and study design (van Manen, 1997). Journaling assists the researcher in documenting one's own values, attitudes, prejudices, knowledge, and expertise prior to the initiation of the research and provides a record about why decisions were made in the development of the study.

Prior to and throughout the data collection process, the researcher documented his own beliefs and assumptions about what it may be like to live with ESHF, as well as any factors related to the participants or the research process that may have potentially influenced the collection and interpretation of the data.

### *Transferability*

Transferability refers to the probability that the study findings have meaning to others in similar situations (Creswell, 2007; Holloway & Wheeler, 2002; Speziale & Carpenter, 2007). The researcher's maintenance of an audit trail and a clear description of the study procedures helped to ensure transferability of the study findings, and provides the necessary information for those reading and analyzing qualitative research studies about the extent to which the findings from this study might be transferred to other ESHF populations in similar situations.

### *Triangulation*

Triangulation is the use of a combination of research strategies within an investigation to maximize the variation in employed perspectives and data obtained about a phenomenon (Speziale & Carpenter, 2007). One form of triangulation is investigator triangulation where researchers with two or more divergent backgrounds and expertise are involved throughout the research process within the same study. Within this study triangulation occurred as a result of varying specialties of the researcher's thesis committee, including that of nursing and medical perspectives. Furthermore, the incorporation of Photovoice also provided a means of data triangulation.

## Chapter Summary

Chapter four has identified the research design that was employed to investigate the lived experience of the phenomena of ESHF. The methodology, sample, recruitment setting, study procedures, data collection methods, and data analysis strategies were discussed. The processes and procedures for ensuring ethical conduct of the project were

described. Measures used in this study to enhance the rigor of qualitative work were detailed. The next chapter will describe the study findings.

## CHAPTER FIVE: FINDINGS OF THE STUDY

### Introduction

The purpose of this research project was to explore and interpret the lived experience of ESHF from the perspective of the individual living the phenomena on a daily basis. Chapter five describes the demographic characteristics of the study participants and details the findings of this interpretive phenomenological study. The overarching essence that captures the lived experience of ESHF, and its supporting themes and sub-themes will be presented, supported by data exemplars. The findings from the Photovoice interviews are also discussed and sample pictures are provided.

### Description of the Study Participants

Recruitment for this study occurred from June 2010 until June 2011. A total of 11 individuals diagnosed with ESHF who met the study inclusion criteria were invited to take part in the project. Seven people consented to participate in the study. The four individuals who declined to participate identified that they were too exhausted and did not have the strength or energy to participate in a research study in their final phase of life. Three of the seven participants also chose to participate in the Photovoice portion of the study.

The seven participants in this study had a mean age of 79 years and an age range from 57 to 86 years. All participants were male except one, and all but two of the participants lived alone. Three participants were widowed, two separated/divorced and two were married. Of the seven participants five were retired, one remained self employed, and one was on long term disability. Three of the participants did not complete high school, three completed post secondary education, and one received a graduate

degree. Six participants were Caucasian, with one of Jewish ethnicity and five of European decent. The remaining participant was Métis. Five of the participants lived in the city of Winnipeg and two resided within 60 km of Winnipeg. One participant lived in a condominium, one in an apartment, one in a senior citizens complex that did not provide support services, and one in an intermediate care environment where support services, including access to nursing care were available. Three participants lived in their own homes.

Cardiac ischemia was the cause of HF in five of the participants. Of the remaining two participants, the suspected cause of HF in one case was alcohol induced cardiomyopathy. In the other case cardiac ischemia was suspected, but no confirmatory diagnostic testing had been conducted. One participant had an ejection fraction within the normal range and the remainder of the participants had ejection fractions of less than 25%. One participant had a pacemaker, three had a combination of cardiac resynchronization therapy and ICD, and three participants were not candidates for the insertion of specialty devices. All devices were active at the time of the interviews.

All of the participants lived with at least one other chronic illness and the number of coexisting illness ranged from one to six. The most common co-morbidity was diabetes mellitus with three participants being insulin dependent and two being non-insulin dependent. Two participants also lived with chronic renal insufficiency. Three participants lived with cerebral vascular disease, of which two had suffered cerebral vascular accidents and one had experienced transient ischemic attacks. Four of the participants were alive at completion of this study. One other participant passed away post completion of this study. Time from interview completion to death varied within the

sample from one month post interview to over one year with an average time from interview to death of 6.8 months. To date three participants remain alive.

Three of the participants received homecare services to assist with medication administration, meal preparation, bathing and light house keeping duties, such as dish washing and laundering of clothes. Four participants hired private cleaning services and six hired private transportation services. Two participants utilized oxygen at home, with one relying on oxygen continuously and the other only using oxygen at night to assist in settling to sleep in bed. Table 1 presents a summary of the participant demographics.

Table 1 Participant Demographics

Characteristic	Number (%)	n=7
Sex		
Male	6 (86%)	
Female	1 (14%)	
Age		
51-60 years	1 (14%)	
61-70 years	--	
71-80 years	1 (14%)	
81-90 years	5 (71%)	
Highest Level of Education		
Less than High School	3 (43%)	
College / University	3 (43%)	
Graduate Studies	1 (14%)	
Home Care Services		
Receiving	3 (43%)	
Not Receiving	4 (57%)	
Private Care		
Transportation	6 (86%)	
Cleaning Services	4 (57%)	
Ethnic / Racial Background		
European Caucasian	5 (71%)	
Jewish	1 (14%)	
Métis	1 (14%)	
Home Oxygen		
Not Required	5 (71%)	
Continuous	1 (14%)	

At Bed Time	1 (14%)
<b>Living in Urban / Rural Area</b>	
Urban	5 (71%)
Rural	2 (29%)
<b>Employment Status</b>	
Self Employed	1 (14%)
Retired	5 (71%)
Disability	1 (14%)
<b>Marital Status</b>	
Married	2 (29%)
Widowed	3 (43%)
Separated / Divorced	2 (29%)
<b>Chart Note About Resuscitation Preference</b>	
Yes	4 (57%)
No	3 (43%)
<b>Source of Heart Failure</b>	
Ischemic	5 (71%)
Idiopathic	2 (29%)
<b>Specialized Devices Inserted</b>	
Implantable Cardiac Defibrillator (ICD)	--
Pacemaker	1 (14%)
Cardiac Resynchronization Therapy (CRT)	--
ICD & CRT Combination	3 (43%)
No Devices	3 (43%)
<b>Ejection Fraction</b>	
≤ 25 %	6 (86%)
26 – 54 %	--
≥55 %	1 (14%)

### Main Findings

This section presents the researcher's interpretation of the essence of the lived experience of ESHF and the themes that were discovered in the interpretive interviews and Photovoice portion of the research project. The research question driving the study was, "What is it like to live with ESHF?"

### *Summary of the Overall Participant Experience*

The participants described the interview process as a positive and rewarding experience where they conveyed that they felt grateful for being provided the opportunity to discuss their experience. They hoped that their involvement in the study would help others with the same condition to receive improved care in the future. Two participants requested that family members be present during their interviews to help ensure that they understood the questions. One participant, though he could read and speak English felt more comfortable having a family member present because English was an additional language for him. In the other case, the participant was very hard of hearing, and the family member helped to restate or clarify the researcher's question so that the participant could hear it clearly. In these two cases although the family members were not the focus of the interview, they were provided an opportunity to discuss their experience as a loved one of an individual living with ESHF as it was apparent to the researcher that they had much to say about this issue. The presence of family members aided to enhance the participants' responses to the interview questions, but did not supplant patient interview data. Data provided by family members was not analyzed or interpreted within this study. Initial interviews ranged in length from approximately 40 to 80 minutes. Follow-up interviews ranged in length from 40 to 60 minutes.

#### *The Essence of Living with ESHF: Working to Preserve a Sense of Self*

The essence of living with ESHF was that each participant was fervently "working to preserve a sense of self". This work involved balancing and adapting to disruptions in the physical, psychological, and social dimensions of one's life, while striving to meet one's basic needs and desires. These disruptions became dislocating to

the individual's sense of self in terms of who they were in the past, who they had become and what their life would entail into the future. The majority of individuals living with ESHF had suffered from HF for many years. The experience of living with HF required that they develop and employ strategies to assist them to function on a daily basis. However, as their HF progressed to end-stage disease, life for every individual became substantially more taxing. ESHF is an illness that disrupted the physical, psychological, and social dimensions of the participants' lives. These disruptions arose because the illness challenged the taken for granted assumptions about the individual's body and the world in which they lived. Every individual living with ESHF faced daily challenges as a result of their failing and unreliable bodies. ESHF was associated with a host of symptoms, including but not limited to: dyspnea, fatigue, dizziness, and edema. These symptoms fluctuated in severity and the extent to which they impacted the individual in their daily life. As a result of the varying degree and impact of symptoms, individuals did not know what a given day would hold for them in terms of severity of symptoms and the extent to which their activities of daily living would be impacted. Consequently, life became living day by day and learning to listen carefully to what one's body was telling them.

Furthermore, all individuals living with ESHF had recognized the need to adjust their daily routines to align with their physical capacity on any given day. They accomplished this through the processes of anticipating possible physical responses to activity and developing routines to accommodate the limitations caused by their illness. Although routines were important and necessary, they also varied from day to day and at

times had to be abandoned or revised, depending on how the person was feeling in any given moment. Energy conservation became necessary for those living with ESHF.

Each individual discovered methods to mitigate these challenges and remain as independent as possible. Every individual invested substantial amounts of energy and effort on a daily basis while struggling to live with ESHF. Giving up was not the answer, but remaining active and involved in one's own care was.

Living with a diagnosis of ESHF equated to a life that encompassed increasing debilitation and an associated number of losses; including, the loss of physical vitality, loss of ability to socialize freely, loss of ability to live spontaneously, and a loss of one's independence. Overall, the inability to do things as one had in the past required that the individual accept help and support from external sources. It was paramount that the individual recognize their limitations and accept available assistance as required to meet their basic needs in a safe manner. A multitude of available sources of support and assistance were identified as being extremely beneficial and crucial in aiding individuals in living with ESHF. The required supports varied by the individual's situation and degree of symptom severity. Sources of identified help and support included: information and support from the healthcare team; practical assistance from one's family and friends to run errands, assist with transportation to appointments and provide emotional support; assistance from homecare personnel to aide in personal care, meal preparation and light housekeeping tasks; and physical aides, such as canes, walkers, scooters and motorized lift chairs to assist one with safe mobility within and outside of their home environment. In an attempt to manage the symptoms of ESHF each individual took a number of

prescription medications on a daily basis, many of which caused undesired side effects that further challenged the individual in living with ESHF.

Living with ESHF includes a number of accommodations and adaptations to one's life. The fact that one must accept help and support from others resulted in some individuals developing a sense of being a burden on others, most notably family members. The reality of having to be reliant and dependent on others and physical aides also led some individuals to form a belief that they were helpless, worthless, and useless.

Conversely, and somewhat paradoxically, the support and assistance that was relied upon permitted the individual living with ESHF to remain independent and active, which aided them in engaging in activities that they found pleasurable and meaningful, although in a limited capacity. The ability to continue to care independently for oneself to some degree was viewed by all participants in this study as a source of pride and satisfaction.

It was also possible and necessary for those living with ESHF to discover sources of pleasure and happiness, despite the impact of their disease. Each individual determined for his/her self what was significant in their life and provided them with a sense of comfort throughout their battle of living with ESHF. The desire to continue to live depended upon one's sense of purpose and sources of happiness. When purpose and happiness no longer existed a comfortable death was desired. Death was not feared, but rather expected as one appreciated that their illness was progressive and terminal and that they had reached end-stage disease.

Participants all acknowledged that they were living on borrowed time. Upon receiving the diagnosis of ESHF, planning for one's future became paramount.

Participants demanded that their autonomy be maintained and that they be involved in choreographing their future plan of care. Planning for end of life was viewed as a collaborative effort that occurred with assistance and guidance from one's family and medical team with the goal of developing a plan of care that respected the individual's wishes and prevented undesired painful medical interventions, such as mechanical ventilation and cardiopulmonary resuscitation. Participants' preferred way to die was that they comfortably slip away from the world while sleeping.

In summary, the disruptions that individuals living with ESHF experienced undermined their sense of self. Consequently, the essence of the experience of living with ESHF involved the constant and unending work of preserving a sense of self.

#### *Themes Supporting the Essence*

Three themes and a number of sub-themes emerged from the data that support the essence of living with ESHF, "working to preserve a sense of self." These themes included: (1) the work of managing a failing and unreliable body, (2) the work of choreographing daily living, and (3) the work of charting the final chapter of one's life.

#### *The Work of Managing a Failing and Unreliable Body*

The reality of living with ESHF was that each individual suffered from numerous symptoms that varied in degree over any given day and from day to day. What further complicated living with ESHF was that each person also had at least one other illness, and was most often dealing with the challenges of age related changes. The combination of living with age related changes, co-morbidities, and symptoms of ESHF resulted in a reduction in one's physical and mental capabilities. Participants reported having 'good days and bad days,' which were characterized according to the degree of symptoms and

functional limitations that they experienced on any given day. Tremendous mental and physical effort was employed to develop strategies and plans that aided the individual in meeting their daily needs in a safe and efficient manner. Furthermore, as a result of the combined challenges it was reported that the world of the ESHF sufferer became restricted and the individual became increasingly confined to his or her home environment. There were five sub-themes involved in the work of managing a failing and unreliable body : i) managing / relieving symptom distress; ii) managing coexisting challenges; iii) living good days and bad days; iv) managing one's emotions; and v) living in a small world.

*Managing / relieving symptom distress.*

Every day life for individuals living with ESHF was laden with challenges. Tasks that would require minimal effort in the healthy individual, such as preparing a meal, walking to the bathroom, or getting out of bed, became daunting tasks for the ESHF sufferer. Every participant reported a number of symptoms that they experienced and attempted to manage on a daily basis. The symptoms included: dyspnea, orthopnea, fatigue, drowsiness, weakness, edema, reduced mental acuity, and dizziness. For some participants, the ability to care for themselves was further complicated by their inability to predict what a given day would entail for them in terms of severity of symptoms and the extent to which their activities of daily living would be impacted. Consequently, life involved learning to live day by day and listening carefully to and interpreting what one's body was telling them, particularly regarding the meaning and urgency of specific symptoms they experienced.

Some approaches to relieve symptom distress included maintaining strict sodium and fluid restrictions, adhering to medication regimens, and seeking out assistance from professional resources, such as a dietician. Other strategies that were employed by participants included increasing a dose of, or taking extra diuretics; and limiting participation in physical activities that would lead to worsening symptoms of ESHF or exhaustion. By using these strategies, participants hoped to minimize their current symptoms and prevent further undesired symptom distress. The impact of symptom distress on the participants' lives, and the steps taken to manage them are illustrated in the following exemplars.

One participant spoke about symptoms of fatigue, orthopnea, and adjusting his diuretic medication based on the way he was feeling in his physical body:

*I just get very very tired... I don't choose to sleep... You just fall asleep... Thinking is clouded... Physically you just get exhausted... Umm, just ahh, making it through the day sometimes... Your body can't handle the liquids and you're going to the congestive part... It's hard to breathe and ahh so you take some more Furosemide ... And so you, you have to read like, like you'll sit there and think. Ahh, I feel odd or something like that... ordinarily I would take, take two pills in the, in the morning and the evening, but sometimes my feet swell up and I feel really crappy; I'll take three. (Participant 2010-05)*

The unpredictability of the onset of symptom distress, as well as some of the challenges and frustrations associated with sodium and fluid restrictions were articulated by another participant:

*Often I just sit and think, I, I can't do anything... I don't have breath when I try to do something. I lose my breath frequently... Dizziness... I'm very careful... I'm still on an awful lot of diuretics... Cutting down on salt and not drinking fluids... It was tough. The salt deal... You can't buy one thing in the grocery store without salt... So I called in a dietician... It's a lot of learning to do... You adjust your life as you go a long... It's hard because just like that all of a sudden you're panting for air. Your maybe in the middle of the hallway somewhere and you just sit on your walker ha ha. Wait for a while. (Participant 2010-04)*

The following exemplars speak to the importance of attending to messages of the body in regards to managing symptom distress:

*I do feel ill and this, just a vague feeling that I learned to be very cautious of... There's a certain kind of off day I might have and I have an instinct that there is something more serious going on... I get breathless quite easily... I have to sit down. But it only takes less than a minute and I'm back to normal so far... I have an arrhythmia... I suspect that's really what's happened... just suddenly dropped... You need to listen to what your body tells you... It's all very a matter of listening to the body. (Participant 2010-06)*

*I could feel it coming on... Everything it seems like it gets blurry... But as a long as I was hanging on to a cupboard... I don't know. I, I couldn't tell you what, but I my, my thought says that, that, this, this is coming and I go, is coming pretty close with the, where it shouldn't be... I stay, I stay right there particularly when it, when this happens I don't move from there... Because I might, I will probably fall... You live day by day. (Participant 2010-07)*

*Managing coexisting challenges.*

Other factors apart from symptoms associated with ESHF contributed to the work of managing a failing and unreliable body. Participants reported suffering from: age related changes and challenges associated with aging, such as joint degeneration, erectile dysfunction, constipation, and the death of a spouse. Symptoms of other health conditions were also problematic, consisting of diabetic neuropathies, muscle cramping related to tetany, and expected side effects of medications, such as frequent urination, nocturia, and dizziness that impaired one's ability to function on a daily basis. As captured by the following exemplars, the increased burden of managing other challenges, while living with ESHF further taxed the participants' coping abilities. This diabetic participant struggled with stabilizing his blood glucose levels, and managing hypothyroidism, and neuropathy in addition to managing the side effects from his diuretic medications:

*The hard thing is, is also complicated by the diabetes... If umm, my sugars go crazy and they do... I can get sick... I have ahh neuropathy in the stomach, from, from the diabetes... I feel odd or something like that... Forced to go check your*

*sugars... With diabetes you'll get umm, ahh, spikes in sugar... I just got a new prescription for thyroid pills. So I am hoping that will, that will help for energy... And, so you, you have to read like, like you'll sit there and think. Ahh, I feel odd or something like that. Maybe I'd better check my sugar or you're, in your mind you can, I feel odd and like that, but I'm not going to do anything about it sort of thing. So then you just start feeling worse and worse and worse. And you figure you're forced to go check your sugar or whatever the, and umm, but there's; see the only, the only real things that I, I have to for controlling with the heart – the congestion is the Furosemide, ahh ordinarily I would take, take two pills in the, in the morning and the evening, but sometimes my feet swell up and I feel really crappy; I'll take three. And I, I try to avoid the three, because the, it's hard on your kidneys and, and because you're diabetic its, that's ahh big problem – kidneys too. Also leads to low blood pressure... Dizziness... Light headed... Just stop in your tracks and find a place to sit down and just stop right there... So you ahh, just cross your fingers and hope... Using a cane because of the balance thing. Ahh the neuropathy in my ankles make them kind of weak and my balance is not that great. So I've got a cane... Indigestion from the neuropathy in the stomach... If I have ahh, ahh indigestion, I'll sit in the, the lazy boy chair... and probably sleep in that. (Participant 2010-05)*

Another participant discussed difficulties with ambulation and frequent urination along with balancing electrolytes in her blood to prevent muscle cramps associated with electrolyte loss from diuretic therapy and tetany:

*I'm taking eight diuretics a day. Plus one strong one... So that worries me, because I have a disease... tetany... in the electrolytes in the blood... It causes horrible cramps and that worries me... Because if they wash all those electrolytes out, then I have to replace them. And how do I know how much? That I have to guess, my symptoms that I have learned through the years... You're busy making pee... Sometimes every half hour or so. And that sure disturbs your sleep... As long as I can touch a wall or piece of furniture or something, then I can stabilize... Then I get into the bathroom no problem. (Participant 2010-04)*

Orthopedic challenges required that this participant be extremely careful with his ambulation and rely on a walker to support his mobility:

*I do have a bum knee... This knee, I had knee surgery in 1957... Then my knee buckles. I've got to be damn careful about that... I have troubles standing because of my knee... That's why the doctor got me the walker. (Participant 2010-03)*

This same participant also discussed challenges associated with aging and the side effects of diuretic therapy:

*As you get older, but ahh ha ha there's a few things that are going to happen to you too. Like erectile dysfunction... I lost my wife in 2002... It's so lonely if you are alone all the time... I have to go to the bathroom quite often... I use a urinal at night you know. Then I don't have to walk to the bathroom, because I've fallen at night... My gut was sore I tell you. But I hadn't had a proper bowel movement you know. I tried to have – nothing. I gave myself an enema and I thought I was going to break the toilet bowl. I had to have a bath when I finished... What does tick me off if I can't have a proper bowel movement. (Participant 2010-03)*

The residual effects from a previous stroke in conjunction with joint pain was challenging and worrisome for this participant:

*How I feel? Well not too good. I'm ahh always worrying about one thing or another you know. I keep it to myself, but I really don't know... Well, I can't walk. My knee is giving me a lot of trouble. My hip and I can't go very far... Stroke... I want to do things, but my mind says no... I use a walker. (Participant 2010-02)*

*Living good days and bad days.*

The degree of symptom distress and functional limitations experienced by each individual varied within and between each day; as a result, participants reported having “good days and bad days”. When the interventions aimed at managing one’s symptoms were relatively successful, participants experienced fewer symptoms and increased mental and physical functional capacity. Such days were characterized as “good days”. In contrast, “bad days” consisted of severe symptom distress that drastically reduced the degree of physical functioning and mental clarity, and at times resulted in the individual being severely restricted in what they were capable of doing for themselves.

Unfortunately, for some participants in this study, in any given week, the bad days outnumbered the good. One participant explained:

*I have good days and bad days. The good days I have ability to do things and I don't feel umm, sick. And umm, bad days, umm, I can get , I can get sick... What usually happens is that I just sleep... I just get very, very tired... Physically you just get exhausted... Thinking is clouded... Don't put things together properly and ahh, you can put milk in the cupboard... Your mind just isn't functioning 100%... Sometimes it will be a stretch of three bad days and two good... A good day is*

*ahh, ahh the ability to do things and ... You are able to do things with your mind and ahh, for a longer period of time and, and ahh, concentrate and formulate ideas and stuff like that. (Participant 2010-05)*

Another participant said:

*Not every day is a better day, but you take, anyway, in a week, I have about three days good... When I don't feel well, I can't walk very far... I get kind of, get kind of dizzy... It feels like, like somebody was squeezing you for some reason... There's better days that I can do things what I want to do. Practically think I can do it... I do my own cooking and stuff like this... As long as everything seems to be okay I, I can, I can maneuver in here pretty good... There are days you know that I ahh, I wished that I would have died you know... You feel that you can't do nothing, you can't move around at all, hardly at all and you figure well what the hell am I doing here... No power, no strength. (Participant 2010-07)*

*Managing one's emotions.*

Despite the work of managing a failing and unreliable body, with its associated symptom distress and functional decline, most participants in this study were able to manage their emotions and maintain a positive outlook on life. One participant stated:

*You live day by day... As long as I can do things, what I, what I'm doing I'm happy with the way I am. You got to take what you, what you got a coming. (Participant 2010-07)*

For three participants, spirituality appeared to play an important role in fighting feelings of depression and discouragement, and helped them to mentally accept and cope with the challenges of their illness. One participant explained:

*You have to get your head straight or else you're in trouble... My faith is what takes me through this, I have faith in God and he does it for me... Be prepared I guess. That this can happen to anybody. Some people won't accept it. Some get angry. That doesn't help one bit. Ha ha ha. Others will sit and cry and feel sorry for themselves. That doesn't help either... I have a better future than when I got out [of the hospital]. Christ came to open the way to heaven for me and that's where I'm going... You have to be prepared to accept that it won't change. I mean, like I said to the doctor; I'm not coming to get fixed; I'm coming for comfort. (Participant 2010-04)*

Another participant described the role that prayer played in helping to manage feelings of depression and physical pain:

*The spiritual part of my life... Is a really big deal, big thing and ahh, if I have any problems, I can just pray and meditate... And because there, there are times that you want to be depressed, that you have a natural tendency to be depressed. And I pray and meditate on that. And ask, ask that it go away, and it goes away. And sometimes umm, umm, because of the diabetes, I'll have super pains in my legs and I've, I pray and meditate on that, and the pain seems to, it seems to work for me. And the pain goes away. And, and problems I have, I pray about it and they seem to be taken care of... It's a psychological crutch... It's doing its job for me... A big giant part of my ahh ability to cope with my life. (Participant 2010-05)*

For another participant, spirituality helped to focus on living in the 'here and now' with a sense of gratitude and thankfulness:

*I just accept it... My attitude hasn't changed... That's just the way it is and that's what the Lord has planned for me. We just have to accept it... Just have to accept things in life as they are... I use that, that prayer – God gave me the serenity to accept the things that I can not change and to change the things I can and the wisdom to know the difference. And that's my quote for life. For that's the way I live... And I say the Lord's Prayer every night... Well it's just a wonder that I am still here. You know it's, everyday to me is a bonus. And that's the way I treat it. To make the best out of whatever you can you know. At least that's my attitude towards life... Make every day the best you can and don't worry that you are going to die tomorrow, because you might die tonight. (Participant 2010-03)*

*Living in a small world.*

Some participants reported that their symptom distress, declining physical capabilities, and decreased mobility resulted in their world becoming very small, and the content of their daily activities very limited. These participants stated:

*Not near as much as I used to do... If I feel okay I, I'll go in [to the office] for two hours, three hours – that's about it... Come home early, lie down for a couple of hours, I'll have dinner, watch TV, read a book... Have no you know great desires to do a lot of things. (Participant 2010-01)*

*I can't go very far because I go out of breath... Say 50 feet... I got some good friends next door, across the street they are nice people, but I can't go too far to see them. (Participant 2010-02)*

*You mean go out of the building... Some weeks, this week it's going to be three times... Well it's an appointment. For medical appointments... Otherwise I, that's not just for fun times ha ha... I haven't done any of that since, since I got sick. To just go out for fun... I miss going out... That's about; my world is very small now. There isn't a lot happening in my life. I can't, can't do what I want to do... I'm not expecting to do anything exciting now. (Verification Interview Participant 2010-04)*

A sense of being trapped within one's home environment was identified by one individual:

*No power, no strength... Well, if I have to leave the, leave well the rest of the house, I can as long as there are walls around me that ahh, that I'm, I feel fairly safe you know... Well, you take what I, ahh, the only thing that I do is go outside and sweep a little bit of snow with a broom. And that is got to be very, the snow has got to be very light... As far as living for me now, it doesn't mean much... You're just alive, that's about all, all there is to it... You take now, now you, you're actually tied to the house. To the home. (Participant 2010-07)*

#### *The Work of Choreographing Daily Living*

Participants in this study consistently reported that the physical and psychological challenges associated with living with ESHF made accomplishing the tasks of daily living extremely burdensome. In order to address these challenges, participants identified that they had to adopt a positive mindset and develop strategies and processes in the service of getting through each day. There were four sub-themes involved in the work of choreographing daily living: i) not giving in to it: doing what you can each day; ii) gauging and pacing of activities and routines: conserving self; iii) living with paradox: accepting help in order to remain independent; and iv) taking time to enjoy small pleasures: finding happiness amongst the challenges.

*Not giving in to it: doing what you can each day.*

Although living with ESHF was associated with symptom distress and a reduced functional capacity, participants explained that a diagnosis of ESHF did not mean that

one should give up and allow others to do everything for them. Rather, they stressed the importance of each person living with ESHF continuing to do as much for themselves on a daily basis as they were capable of. Some exemplars highlighting the importance of not giving in to it include:

*Do the best you can every day. Even if it's just a little bit of improvement, makes you feel good to be able to walk rather than crawl... Get as much rest as you can. Your body needs that. Don't do only that, don't give in to it... So don't quit. As long as we live, we need to use it... Sure I want some help, but ahh let me ask... It just makes me feel more worth while ha ha... My daughter will come and pick it [laundry] up. The heavy stuff like the bedding she does. The other stuff I figure I can. It's just across the hallway. (Participant 2010-04)*

*You never want to give up unless you absolutely can't do it... There's lots of things that you can still do... But if you can do it yourself, it's only, you're only helping yourself... You're only helping yourself to, to, to survive in there because you, you if your body stops, totally stops, the movement and everything, well you, you are finished... You don't give everything up just because you're, you're; you take like ok, if I really didn't want to do, do my cooking and everything, they [homecare] told me; they, they would give me a girl that will come and do my cooking. And I, and I said no. I have, I would do it as long as I can. (Participant 2010-07)*

*Gauging and pacing of activities and routines: conserving self.*

All participants in this study reported that the symptoms of ESHF resulted in a decline in their level of physical functioning compared to what they had been able to do before their illness. This limited functional capacity resulted in some participants not being able to continue with previous work/employment, and/or engage in previous hobbies and leisure activities, such as going to the cottage or painting. The work of choreographing daily living required that study participants find ways of carrying out such tasks as cooking, bathing, and ambulation in a safe manner that did not excessively deplete their minimal physical reserves. Participants engaged in a deliberate gauging and pacing of their activities, developing routines and devising strategies in an effort to

conserve energy. Accordingly, strategies used by participants to manage functional decline included reducing one's work hours and giving up hobbies and leisure activities in an effort to prevent exhaustion and preserving the energy necessary to complete activities of daily living.

For one participant, a reduction in his own work hours and the hiring of someone who could complete full days of work was necessary to maintain the operation of his business. This participant said:

*Now, umm not, not near as much as I used to do. I, I will go to the office for an hour or two depending on how I feel... If I feel ok I, I'll go in for two hours, three hours – that's about it... I have the business left that I look into. I've got management and all, basically a system, something I've thrown together. I continue to go there... I don't try to run around too much... I had much more energy and a lot more desire... I'm not running races... Not ahh out running around, I'm ahh living a fairly passive life... I can sit and talk. (Participant 2010-01)*

This participant also discussed the fact that he had given up some activities that he had once enjoyed, owing to the physical limitations imposed by his disease:

*We have a cottage at the lake, well this year we're not going. I just can't go up and down the steps and so on – it's whatever makes it helpful... My wife loves the cottage... I just don't feel like I can, can do it anymore. (Participant 2010-01)*

Another participant discussed that he was no longer able to complete yard maintenance and had to seek out alternate sources of assistance to ensure that the yard work was completed:

*I get a cleaning lady... I hire everybody to do my lawn... Come and cut the grass and stuff like that... I can't really push myself to do anything... I've got to be honest with it... I don't do anything physical anymore really... You can't do what you would like to do sometimes... Like I would never shovel snow or anything like that... I try to keep my house in fairly decent order... It's not all that easy... I got a lot of friends... I just have to phone my, my friend. (Participant 2010-03)*

The lone female participant in the study described that she had given up her hobby of painting. She was hopeful that she would be able to paint again in the future, but for the present, she focused on other activities that she enjoyed that required less energy and effort. She stated:

*Often I just sit and think, I, I can't do anything. So there's a lot TV, if there's sports I'll watch that... I don't have breath when I try to do something... Just getting out of bed does... I've had to cut back my activities for one thing... Like painting and stuff like that. I can't do anything like that no more. I would love to sit here and paint. Not yet but hoping to ha ha... Can't use your body like you used to. (Participant 2010-04)*

Other participants talked about the importance of taking time to rest when they engaged in daily activities and routines:

*You certainly have to be careful... Don't over do anything. Just take your time, you've got lots of it... First thing I do is wash up and do my teeth and shave... I usually go to my lady friend for coffee every Monday, Wednesday and sometimes Friday. Oh sometimes I miss one day... And then I come home, then I'll read the paper... Have a coffee, another coffee and then I'll go to the post office on my scooter, pick up any groceries that I need from before, come home, make my lunch. Usually it's just soup and a sandwich and ahh, then I have to have my nap... I'm not a TV addict. I haven't got a computer. But ahh, I read a lot. Any, a lot of, I've got a lot of reading material so. And then I usually go to bed about nine thirty... I can't really push myself to do anything... Say I'm making my bed in the morning. Then I, but I just sit down and I've got time... So, I just pace myself you know so I can do what I want to do and have to do... I usually sit on my stool. Do my dishes, put them away. (Participant 2010-03)*

*I know in reality I don't have ahh, the heart pumping strong enough that I can go walk to Sobey's all in one shot. Ahh, I know that if I walk some place, I'm going to have to, ahh go a certain distance and stop and rest... And then go a certain distance and stop and rest. (Participant 2010-05)*

Having deliberate strategies and routines helped this participant to conserve energy:

*When I get up the first thing I do, I straighten my bed out... Instead of taking the, the bed totally apart, I only take half of it apart to where, where I'm going lay, sleep. And then I just pull it all back as much as I can... I come and I try to make my breakfast. I make my coffee. I take up my time about it. You think there's*

*nothing; I'm never in a hurry to do anything because I can't do it anyway. Can't, can't move around, not, not like I used to. (Participant 2010-07)*

Gauging and pacing also required that participants devise strategies to ensure that they were safe in engaging in activities of daily living, particularly in regards to the prevention of falls. These participants explained:

*I'll get up and I'll sit on the edge [bed] for maybe five minutes; catch my breath before I stand. And then I'll walk over and do the same thing at that end. So my breathing is a big deal... I have to walk on this tubing [oxygen tubing] so I'm very careful about falling... As long as I touch a wall or piece of furniture or something... Then I get into the bathroom no problem. (Participant 2010-04)*

*In that house there was no, no main floor washroom. I would take one step with both feet, hold onto the banister and take three deep breaths, count them before I would take the other one. (Participant Verification Interview 2010-06)*

*Living with paradox: accepting help in order to remain independent.*

As much as the participants in the study would have preferred to be independent, they all acknowledged the importance of accepting outside assistance on a daily basis in order to safely complete activities of daily living. Participants indicated that they had to become dependent at times in order to achieve some measure of independence. They were able to retain some independence through the use of physical aides, the practical assistance provided by family and friends, care provided by medical professionals, and services provided by private care and homecare support workers. Pets were also identified as sources of help and support. The amount of support required by each individual varied by day and by task.

Physical Aides – A number of physical aides, including canes, walkers, hospital beds, medications, oxygen, specialized devices, motorized scooters, and electric lift chairs were used by participants on a daily basis. The following exemplars illustrate the importance of these aides in activities of daily living:

*Bath, which is not the easiest chore to get out of the tub... But I got supports that I can get out of the tub with not too much trouble... I'll go to the post office on my scooter, pick up any groceries I need from before... I usually sit on my stool. Do my dishes... I walk with a cane now... Defibrillator... All those pills that I have to take... I use a urinal at night. (Participant 2010-03)*

*This bed [hospital bed] for one thing... It is a wonderful thing because you can grab things and pull yourself around. You can turn and get the, without that I couldn't turn... It's not a fancy bed, I don't care about that. It just feels good. I have all these pillows that fill in with it... I can shift around and like I say if I want to turn, I grab these [side rails] and they hold me. And with none of that help, I couldn't turn in bed. I would have to have somebody come and turn me. That would be difficult... Take a few good oxygen breaths ha ha ha. I have a little gizmo now that you have oxygen on demand. You get it only when you inhale... So my tanks aren't always empty. They were always empty before... I use my walker... When I go out in the hallway I always take it... I can go and get the mail now. And then I can put it on my cart and go... When I get tired I can sit on it. (Participant 2010-04)*

*The only real thing that I, I have to for controlling the heart, the congestion is the Furosemide... I've got a cane... Congestion ahh, two pillows is, is, is fine... I'll sit in the, the Lazy Boy chair that you're sitting in and sit up and probably sleep in that because you can't sleep flat sometimes. (Participant 2010-05)*

*I couldn't go anywhere without a cane... I got a, a nice big chair that opens up for me. It picks me up if I can't get off of the chair, I can just push a button and it lifts me right out... I know one thing for sure if you don't take your medication, you, you aint going to be here ha ha ha. (Participant 2010-07)*

Family & Friends – Individuals living with ESHF reported that they relied upon their family and friends to assist them in meeting their daily needs. The following exemplars highlight that participants in this study required a significant amount of support to ensure that they remained safe in their home environments:

*She [participant's wife] realizes that I'm sick and she's doing everything she can to help... She's ahh, been very ahh, umm intimately involved with my medications and care... She calls it ahh proactive... I have a family, a good family, good kids, my wife looks after me. I get ahh probably as good a care as I can get. (Participant 2010-01)*

*I got a lot of friends. It makes it a lot easier... I just have to phone my, my friend... If there's anything wrong he, will, he'll come and fix it... He does all kinds of things for me you know. My son he's here every week... My special*

*friend... I got all the support that I, that I really need. If I ask for it, I get it you know. (Participant 2010-03)*

*I got my daughter to help... She gives me a lot of help... Do errands, shopping, hospital visits and anything else... Well, I don't ask her to, to do very much because she, number one, she has to work just to make a living just like I used to when I was ahh, in her time. So if, if she has a few hours or something like this and she comes, come and just even if she comes to stay with me for, for a few hours or so... Well if it wasn't for her I'd, I'd, there would be a lot of things that I couldn't do... A lot of the times I couldn't go to the doctor. (Participant 2010-07)*

Individuals living with ESHF relied on their family members for support and assistance in order to meet their basic needs; however, they were also cognizant of and appreciated the fact that their family members were very busy themselves balancing their own family and work lives. As a result, two participants reported that they tried to minimize the burden that they placed on their family members.

*As I say I have one daughter and she's got her hands very full. So, I'm trying to save her as much and I hired a cleaner to come and clean the house instead of having her do it. She wanted to, but I said no. That type of thing where I can help, I do. (Participant 2010-04)*

*I got my daughter to help... She gives me a lot of help... Well I don't ask her to, to do very much because she, number one, she has to work just to make a living just like I used to when I was ahh, in her time. So if, if she has a few hours or something like this and she comes, come and just even if she comes to stay with me for, for a few hours. (Participant 2010-07)*

Guilt was expressed by one participant regarding the amount of help that he required from his wife. The challenges associated with living with ESHF meant that he was not able to meet his basic needs independently and relied upon his spouse for a great deal of support. This individual believed that he had become a burden to his wife and felt guilty because of his reliance on her to do almost everything for him. Furthermore, for many years this individual reported that he had not incorporated illness prevention and

health promotion strategies into his daily life, and now he believed that he had caused his development of ESHF.

*I can't do much. She's got to be with me all the time; and I think that's wrong. Because it's too much on her you know. She has to do it, ahh nearly everything... I gave up driving... I can't ahh mow the lawn... I can't haul out the garbage... I can't do nothing... She's got to do everything. That's not fair, but there's nothing I can do about it... She does it all for me... I wait till the last minute before I see a doctor. That's wrong. But I know, I don't like going to see them... I never took care of myself... I was never one to run to the doctor, but then it's too late... I just don't like what is happening to me. It's my own fault. I can't blame nobody but myself. (Participant 2010-02)*

Unfortunately, one participant in this study did not have a support network of family or friends available to assist him in meeting his daily needs. As a result, he needed to be moved from his home setting to an intermediate care facility to ensure that his basic needs were met.

*I just been living alone in this huge house; I had three sons all of whom disappeared. My wife has disappeared and I couldn't bring myself to leave my house and all the things interesting to; of my interest to me. And so I've gradually deteriorated, vaguely aware; into living really in a bit of a pig sty. But then the second heart attack was in the beginning of October this year, last year 2010. I came to the attention of Social Services... They leaned on me a little bit ha ha and here I am. I had to be rescued and put in this place [intermediate care facility] where I am properly looked after... My family isn't interested in me... We're not a close knit family. Sad to say. But that, that is so. Aah, as aah, while I'm here, I must say I've been a lot happier than I had been for a long long time. (Participant 2010-06)*

The certainty of care and support was something realized as a result of his relocation. He explained:

*Well I get attention... There's an RN and a lot of health care providers of other types... I get the certainty of meals... My beds made for me... Got more help than I want in keeping myself clean... A hospital bed... Daily they clean out the garbage and make sure I've got enough tissues and umm... They do all kinds of personal things. (Participant Verification Interview 2010-06)*

Healthcare Professionals – Living with ESHF was discussed as complicated and challenging, which resulted in individuals requiring a great deal of support from numerous healthcare professionals. Five participants believed that they had received optimal medical care in the management of their ESHF. The remaining two did not identify their degree of satisfaction with their medical care. Optimal care from the perspective of study participants meant having confidence in their physician and care team that symptoms were managed in an efficient and timely manner, and feeling secure in the knowledge that one's medical status was being constantly monitored and evaluated. Participants said:

*I think I have had good medical care, ahh my doctors have been very good and ahh they told me anything that ahh you know is unusual or other than to my particular situation... And it's really the confidence that I've had in my doctor... I've got a cardiologist in Coastal USA, I've got a doctor at the Mayo Clinic... I've got a cardiologist here. They all communicate on my behalf... Their information, goes in between, goes in between them all... Like I say, I've, I thought I had the best medical care. (Participant 2010-01)*

*Just did a world of a difference because you take from, from where, where I was to, to where I, to, to when I went the first time I seen, seen this lady, the doctor. I couldn't walk there. She, she took me down there with, in, in a wheelchair... I just couldn't walk. I had no power... On the third time I went there, I, I walked from, from there all the way to her office and I walked all the back already from... If it wasn't for, for her [Dr at Specialty HF Clinic] I'd have been gone already... I have a lot of faith in her. (Participant 2010-07)*

*She [the doctor] keeps tabs on my lab work; and I have to go to the lab twice a week. And she keeps tabs on that and arranges the pills accordingly... The way she supplies my medication and even the other doctors remarked at that because I guess they kind of figured I was on my out, and she kept me here [alive] ha ha ha... I don't know if that's the way it really worked, but she didn't give up. And she kept phoning which was, I think out of her way. But she did it anyway. And I was very pleased. I like her. She's wonderful. They've [Specialty HF Clinic] been very good to me... I don't sit there for hours and hours and wait when I'm like this and I can't, can't breathe ha ha... They take me in right away and do all the tests. ...Even when I was in the hospital. They treated me very well. I just felt I got the best care I could possibly wish for. They were right there when I needed something. Even when I didn't, they kept checking. (Participant 2010-04)*

The vigilant monitoring and adjustment of medications that were part of optimal care was also experienced by participants as the healthcare team, ‘not giving up’ on them. This in turn seemed to help affirm the personhood and value of the patient, despite the ravages of their disease. Participants reported:

*I would say the biggest thing and it would be ahh, for example Nurse, she ahh, doesn't give up on you... She always went above and beyond ... Optimistic and I think the biggest thing is that they just don't give up on you... They, they don't just write you off and say ahh, you go in there, they're, they could just do their ahh ahh monitor your , your ahh, your statistics. You know your blood pressure and whatever. And then ahh write it down and say ok, thank you, we'll see you in such a period of time. Ahh, they talk to you and they find out what ahh, how, how you're doing and ahh, and like I said they just, they don't give up on you... The good doctors can identify with you... Yeah if they treat you as a person and, and as an equal; they're good... Treat you as a human being. Ahh, and not as a, ahh, not as a case file... I think it is very, very important and ahh because it's ahh, it's, it's stressful to have to deal with these people; like doctors and stuff. And umm, because it's ahh, because the outcome of, of what they, what they tell you; umm, is critical to your life. (Participant 2010-05)*

Another participant expressed:

*Well just the way they were, so compassionate and cared whether I'd lived or died ha ha. (Participant 2010-04)*

Optimal care also meant that participants felt included as an important collaborator with the healthcare team in making decisions and devising plans of care in the management of their ESHF. One participant stated:

*There was a pharmacist... The cardiologists and the, the exercise specialists and dietitians... they've taken me seriously, which is a good thing. We've agreed that I'm; what's going on and they, they have a better look than I do. The MRI was basically gave them my ejection fraction which otherwise has never been measured in me before... The first participant in that patient care, you're going to get good results; it has to be the patient himself. It has to be a team job. (Participant 2010-06)*

Homecare – Three participants reported relying on homecare services to assist them in meeting their needs. The services provided from homecare varied according to

the individual's needs, but all assistance was greatly appreciated by study participants.

This participant spoke of the assistance he received for bathing:

*I got some great guys coming here... Homecare... Oh they are beautiful guys. They, they ahh keep me going you know... Very nice guys... Give me a bath, oils me down... Dries me up and everything... Yeah there's one guy coming here and he go like that [making gesture of arm wrestling], ha ha one two three... But we don't. Ahh we just pretend... I feel good to talking with the guys. (Participant 2010-02)*

Housekeeping duties and assistance with bathing were valued by these participants:

*I, I don't do my dishes, I save that for the girls [homecare worker] ha ha. Anything that's difficult where I have to lift or push or anything like that, that they have to do... Homecare comes and makes my breakfast... When they leave they have everything cleaned up... They take me away for a bath...In a wheelchair, so I have nothing to worry there... That happens once a week... This is the one they gave me. And not a fancy bed, I don't care about that. It just feels good... Homecare when they come and clean up my kitchen. That is, I think that is the biggest help... Somebody comes in and my kitchen's a mess, that bugs me... Lots of help. Couldn't do it on my own... The homecare girls, they are pretty well trained... I made up a list of jobs that I can't do. And they can choose from those... Some of them do one thing, some do another... They do the garbage, the mail, they do everything. (Participant 2010-04)*

*I have a lady that comes here specially one, there's one coming today. She's going to; what she does is she, she does my laundry, she does my, washes the floors, she vacuums the, the in the house. She does everything that you need to do in a house...From homecare... I have a man comes and to give me a bath every, every Thursday... He helps me get in the tub and out of the tub... The, the homecare, I, I, I like that you know. They come. What I tell you that this homecare is a good thing. (Participant 2010-07)*

Private Support – In order to maintain their independence and remain in their home safely two individuals living with ESHF sought out alternative sources of support, which they funded privately to ensure that their needs were met. Specifically, these participants spoke of hiring help for managing the yard and home cleaning:

*I get a cleaning lady... I pay for it... I hire everybody to do you know my lawn. (Participant 2010-03)*

*I hired a cleaner to come and clean the house instead of having her [participant's daughter] do it. She wanted to, but I said no. That type of thing where I can help, I do... I have a driver once and a while when my daughter has her own appointments or something like that... They volunteer but you still have to pay for it. (Participant 2010-04)*

*Taking time to enjoy small pleasures: finding happiness amongst the challenges.*

Although living with ESHF involved facing many challenges and a great deal of effort to mitigate them, an important part of the work of choreographing activities of daily living also involved taking time to enjoy simple pleasures. Several participants in this study reported a need to discover and partake in activities that brought them pleasure and happiness. These activities provided a buffer to counteract the negative aspects associated with living with ESHF that they faced on a daily basis. For some individuals, sources of pleasure and happiness were found within their home environment.

Participants explained:

*I can enjoy my life. I can enjoy company, I can, I do phone, I don't have conversations like I used to because I can't breathe... I love to talk, but ha ha kind of have to cut short a little bit sometimes. (Participant 2010-04)*

*I like my birds. I like to feed them. I feed them every day no matter what. I like to watch them... Well, it depends to how you treat them. If you feed them, they'll come and sit on your shoulder, and if you, if you don't give them nothing to eat and you could be around there and if you haven't, you, you should; I look at it in a way that, they, in the winter months they can't find food. So you should, if you can help it, you should feed them. In the summertime; like most of my neighbors that they, they don't want to feed them in, in the winter, they feed them in the summertime where, where, there's always plenty of food all over that they can pick up. Worms and stuff like this; they, they still give them food. I don't give them food in the summer time. Unless, the only bird that I like to see that when the canaries come. When they come, then you, you put their kind of food in, in the feeders, you can't, they, they'll come right there, you could be sitting right beside it and they'll come and, and eat out of there. And I like that you see. I, I like to watch them. And the way; I got a few chickadees that I go out there and they come and sit on my head. (Participant 2010-07)*

One participant reported having a pet cat, and for this individual their pet became a source of comfort, unconditional love, and a distraction from the challenges of every day living with ESHF.

*Another big thing is this pet cat. Is a pet. I, I would, I would highly recommend a cat. Dogs are, are umm, you have to be pretty active to keep up to a dog... Just company... A lot of people don't like to talk to themselves. But you can talk to a cat... When I have a real bad day, yes. He, he knows... He'll come and he'll climb up on me and he'll be about twice as affectionate as, as in a, as in a good day... Getting sympathy from, from somebody ahh without the, without having to give it back... You can just accept it... Just accepts you as you are and they give you sympathy. (Participant 2010-05)*

Other individuals found pleasure in escaping their normal surroundings, where they found themselves trapped as a result of the symptoms and limited physical functioning that they suffered due to ESHF. For these individuals, venturing away from the limited and confined surroundings of their home environment to spend time with people that they loved and enjoyed spending time with was very satisfying.

*I go to a day program... Exercises, coffee, discussion... Good. I like it... Because I got a lot of friends there now and they keep you going... And we [participant and wife] go to South Beach... Oh yeah. Ding. Ding... I use my walker there... I can sit on it when I get tired. (Participant 2010-02)*

*We [participant and female friend] go on the casino trip you know. We used to stay there for ahh two nights. Well we would have to sleep together but what, there's no, no sex. We love each other and kiss goodnight and kiss good morning and that's life. (Participant 2010-06)*

In one case, happiness and pleasure were 'rediscovered' by a participant who decided to forgo adherence to a strict diet, despite possibly risking worsening HF.

*I've made up my mind I want to enjoy what's left rather than fuss about what I can't eat, what I figure oh, what's the difference. I can eat anything now haa haa... So things that I have not eaten before I enjoy now... And enjoy what I can and forget about the rest. Enjoy people coming in. Phone calls and stuff like that. That's nice. (Participant Verification Interview 2010-04)*

### *The Work of Charting the Final Chapter of One's Life*

Participants in this study had all lived with HF for many years. As a result, their daily lives had been interrupted and they had to learn to function on a daily basis with the illness and its consequences. However, once their HF had progressed to end-stage disease, study participants indicated that it became important to recognize that a cure was no longer possible. Though they did not know exactly when death would occur, individuals in this study all understood that they would eventually succumb to their disease and that they were living on “borrowed time”. This reality served to prompt study participants to think about how they wanted to live out the remainder of their lives, and what their end of life care needs and preferences were. Through engagement in these activities, participants were charting the final chapter of their lives.

Three sub-themes became apparent within the interview data that spoke to the process of charting the final chapter of one's life: i) acknowledging the inevitable: living on borrowed time; ii) embracing life: living in the moment; and iii) planning for the future: thinking ahead.

#### *Acknowledging the inevitable: living on borrowed time.*

Individuals living with ESHF who participated in this study recognized that they were living with a terminal illness that would claim their lives. Furthermore, a number of participants also recognized that they were elderly and that their increased age also increased their risk of death. Acknowledging the inevitability of death was an essential step that allowed participants to engage in the other tasks associated with charting the final chapter of their lives.

*Well, I guess it's never going to change. Because I was told by, by not by one doctor but quite a few already. You're on borrowed, borrowed time. (Participant 2010-07)*

*You know, at my age, at 82 I think I'm ahead of the game... I'm just thankful that I'm still here... Surprised that I am you know. But I'm not scared to go... If I go, I go, I just accept it... I'm comfortable with that, that, that I, that can happen. (Participant 2010-03)*

*I think I have been very fortunate... I don't see myself living umm you know not many more years or many more days or you know, I'm not kidding myself as to what's potentially there for me... You know. Going to be, I'm going to be ahh 84 in February... I expected this would come at some point in time and now is that time it seems. (Participant 2010-01)*

Although most participants were grateful for whatever remaining time they had left, one participant expressed that he did not welcome the extension of life that living on borrowed time afforded him. Rather, the inevitable could not come soon enough, as death was viewed as a release from many years of suffering through what was described as a difficult and disappointing life. Prominent in this participant's story were feelings of uselessness and isolation from family members.

*I've been on a whole lot of drugs; a tremendous number of drugs to, to prolong my life. A huge expense. Some of them dangerous and requiring recent frequent blood assays to make sure they're ok. And I refused to do, to; I filled the prescription, but never took any of them and let everyone know it, and I said I really don't want my life prolonged any more... I'm useless to myself and I'm useless to the world... My family isn't interested in me... I just haven't found that life was worth living and I don't want to be contaminating the earth surface. (Participant 2010-06)*

An important factor that helped participants acknowledge the inevitable was the information they received about their ESHF from healthcare professionals. Participants recognized and endorsed the importance of receiving honest information from their healthcare team concerning the severity of their illness, and that they would die from it. Such information was highly valued, even if exact prognostication was not possible:

*Dr. A. says I could drop right here or I could live another ten years. You don't know... Recognize that it [death] is just a part of your life... That your end could be at any time sort of thing. He [Dr. A] says... we don't know. No body knows... So that helped me. (Participant 2010-05)*

*And death itself we just have no idea when that will be. The doctor said it could be just like that and I'd be gone. They are very honest about it, which I think I prefer. I want to know what's what. They don't know, but I mean they tell me what could happen. And of course I might linger, who knows. (Participant 2010-04)*

*Like she (Dr.) told me right from the beginning. If you do what I, what I ask you to do, I'll try to keep you alive for, for as long as I can, can be possible. But she says I can't do miracles. I can't do miracles you know... Well I have, I had other doctors seeing me and I got very much the same kind of approach from, from the other doctors too... Very straight forward... Straight out. (Participant 2010-07)*

A notable gap in what healthcare providers discussed with participants involved if, or when, the patient's ICD should be disabled to prevent the delivery of unwanted shocks as death approached. Two of the three participants in this study with an ICD could not recall having had a discussion with their medical team about this decision. The third participant did not wish to discuss the issue with the researcher.

*I, I can't shut it [implantable cardiac defibrillator] down... I have no, no there's no control from my part... Why should I shut it off? (Participant 2010-03)*

*Still live... No discussion. (Participant 2010-01)*

*Embracing life: living in the moment.*

Despite the fact that participants knew their life expectancy was limited, they stressed the importance of fully embracing and living out the time they had left. As evidenced by the following two participant exemplars, this required a mental outlook that focused on living in the moment versus ruminating about the inevitability of death:

*Like we're all going to die, but is there, and there's some people that just sit there and, and dwell on it and dwell on it, it's too, so to the point that ahh, that they have mental breakdowns... You have to; you have to live with it you know... Don't worry about the mortality bit... Enjoy your life that you have, that you got. Do what you can... Try to keep yourself busy. (Participant 2010-05)*

*Make every day the best you can and don't worry that you are going to die tomorrow, because you might die tonight. (Participant 2010-03)*

'Embracing life' also required that the individual be as active as possible, within the limitations imposed by his/her cardiac disease.

*I won't be racing down the street, but, or down the hallway, but I'm trying to walk. Do what I can, that's all I can do... If I'm just going to lie here and be a thing, then I might as well not be here... I want to keep on living. I don't want to lie here and just die. (Participant 2010-04)*

*I'm in ESHF because I was told that I am, while I say this clinical assistant... he stood in the doorway and said you have, your heart's in terrible shape... I count myself a lucky guy... It hasn't turned me into a cardiac neurotic... I also am well aware that there's all sorts of dangers held over my head... In fact if you got some one around the household that is fragile, he still has residual life, they should be living to the full so far as he can or she can... A guy shouldn't be kept in bed if he's capable of getting up and doing things for himself. (Participant 2010-06)*

While there was some level of acknowledgement that extra help might be needed as ESHF progressed, accepting such help before it was actually needed was identified as something that might undermine one's ability to remain active. These participants explained:

*I'm guessing I'll probably have to have help cleaning the place and ahh, because my mom gets ahh, gets Homecare. She gets; somebody comes in every day and ahh makes sure she takes her medication and ahh, yeah. Makes her breakfast and ahh, but actually I'm going to put that, like you know, anything like that I'm going to put it off as long as possible because it also makes me do something. (Verification Interview Participant 2010-05)*

*If I really did not want to do my cooking and everything, they [homecare] told me they would give me a girl that will come and do my cooking. And I said no... I figured that as long as when I'll do everything I can for myself as long as I can... And when I can't do it any more, then I'm going to ask for help (Participant 2010-07)*

"Embracing life" also appeared to be important to participants' QOL in this study. For two participants, thoughts of being unable to do anything for themselves and

reliance on others made the thought of continued living untenable. Death was preferable to being totally dependent on others:

*But as long as I can do things, what I, what I'm doing, I'm happy with the way I am... If it comes down to that I can't do nothing for myself, I just as soon, close, let's close the door if we can... But if you take it that you can't do nothing; you can't do nothing, you're better off to, to stop the medications. (Participant 2010-07)*

*Sure I want some help, but ahh let me ask... If I'm just going to lie here and be a thing, then I might as well not be here... I have a better place to go... Christ came to open the way to Heaven and that's where I'm going. (Participant 2010-04)*

*Planning for the future: thinking ahead.*

An important part of charting the final chapter of participants' lives in this study concerned planning for the future or one's remaining life left to live. Two sub-themes were associated with planning for the future. They include: a) reflecting on care needs and preferences at the end of life; and b) tying up loose ends

Reflecting On Care Needs And Preferences At The End Of Life – In reflecting on care needs and preferences at the end of life, it was clear from the data that participants had given some careful thought as to what an ideal death would look like for them. Being assured of comfort in the final days was a prevalent notion in this regard. A quick and painless death was identified as desirable by these participants:

*What, what I expect; I expect if I'm lucky is I will suddenly die. My father went; he was diabetic with heart disease, long, long ago where there was not too much known of much and he just went to bed one night and didn't wake up. And that's ideal... That's the way, yes. I do not want to deteriorate, I want this to come to an end. (Verification Interview Participant 2010-06)*

*I'm comfortable with anything that, that I, that can happen. It's simple... Go to bed and don't wake up. (Participant 2010-05)*

*I wait till the last minute before I see doctor. That is wrong. But I know, I don't like going to see them... I don't like being poked and probed... To go to the hospital I got to be pretty bad... Just let me go. (Participant 2010-02)*

*I said to the doctor; I'm not coming to get fixed; I'm coming for comfort. Try to make comfortable and that's why I'm taking a big handful of pills everyday. (Verification Interview Participant 2010-04)*

One participant identified the option of assisted suicide as the solution for a comfortable death that would occur on his own terms.

*I have made a few inquires about assisted suicide... It strikes me as being a necessary function and I'm a candidate... I do see far ahead, I'm not always going to be as cheerful as I have been the last few weeks here. So yes, I would because it's not a thing I fear in any way at all. (Participant 2010-06)*

This participant's description speaks to the importance of attentive physical and emotional care, and management of pain at end of life:

*I expect to be made comfortable... Where, where the pains involved has to be dealt with. And clean up in the bed and that sort of thing, those services, that, that's sort of what they don't do here. Somewhere else would... So just tender, tender loving care as I disappear from the face of the earth. That's all... Oh, well some, someone to attend to you when you have a little complaint. Pain. Moving around in bed when you're not able to shift you over to another position... And those kinds of things, propping up the pillows, having those, all kinds of things like that. (Participant 2010-06)*

All participants in this study identified that death would occur because of their ESHF, and the data indicated that six participants had clear preferences about not being resuscitated should they experience a cardiac arrest. Such an activity was inconsistent with the attainment of the peaceful death that these participants desired. Six of the participants reported that they had communicated their wishes to their family physician, cardiologist, or an emergency room doctor who had attended them. However, in three cases it was not clear that any formal care plans or directives had been developed to ensure that their end of life healthcare wishes would be respected into the future.

*I'm not scared to go, so there's, there's no problem... If I go I go, I just accept it... I made arrangements with my doctor. (Participant 2010-03)*

*Told the Drs in emergency... I just say let me go... You know I'm not afraid of it... I don't want to be on life support. Just let me go, let me die in peace... I don't want none, none of that stuff. (Participant 2010-02)*

Moreover, in one of these cases being hooked up to machines to sustain life post-resuscitation appeared to be inconsistent with desirable end of life care. This participant said:

*Told the Dr.... No resuscitation... I don't want life support. If you can help me, fine, but I don't want to be hooked up to all those machines if that's what's making me live. (Participant 2010-07)*

In contrast, three participants identified that they had developed and discussed plans regarding the role of resuscitation in their future care with the healthcare team and family members to ensure that their wishes were respected.

*No, I asked my doctor for no resuscitation. I mean what's normal yes, but not like they said they would press on your chest till your bones break and that kind of thing. I don't want that, why should I?... But ahh, no we've talked about that, yeah. My daughter has been wanting to. She said I just want to know what you think. Ha ha. Well that's the way I feel. If I'm going, I'm going. (Participant 2010-04)*

*A living will... No resuscitation. You know let me go. (Verification Interview Participant 2010-05)*

*The Dr. came along and said pretty much the same thing and wanted to know if I wanted to be resuscitated in the event of an arrest. So we agreed that on record that I did NOT want to be resuscitated and it's true here too... It's my son who's got power of attorney. (Participant 2010-06)*

Tying Up Loose Ends – An important part of charting the final chapter of one's life concerned participants' tying up loose ends in anticipation of their death. One aspect of tying up loose ends in this study included making provisions for those who would be left behind after the patient's death. In this exemplar, steps were being taken by one study participant to ensure care arrangements for a beloved pet:

*I used to have ahh, my pet cat, but I figured something is going to happen to me one of these days... And I had that cat for a long time... So, I, I phoned the vet hospital and told her why I was doing this... I says could you find a home for my cat?... Two days latter she phoned and said, your cat found a home ha ha. (Participant 2010-03)*

Another participant ensured that he had implemented a plan for his business to continue to function into the future:

*I have the one business left that I ahh look into. I've got a management and all, basically a system, something I had thrown in for many years... I don't see myself living umm you know not many more years or many more days... I've been like this for a long time... I have a will. (Participant 2010-01)*

Within the following exemplars, tying up loose ends consisted of culling through and disposing of a lifetime of accumulated documents, selling one's home and providing loved ones with financial relief:

*The table is full of papers. And I'm going through my drawers to get rid of a lot of stuff that I've saved over the years, so. Yeah, cleaning up for the end ha... Not the end, the beginning I guess of something else. (Verification Interview Participant 2010-04)*

*It, it's [personal home] going to be sold when it's sellable... My son's got power of attorney and we just signed a caveat... knocked off two hundred thousand dollars off the sale price of the house. (Participant 2010-06)*

*My daughter... They were fixing their home and, and ahh inside and everything and I said to her – how are you fixed for money? You got ahh, money to pay for all this. She says no. So I says to her how much do you think you need? And she says I don't know. Ten thousand maybe twenty thousand. So I said lets go to the bank. So I went and I gave her twenty thousand dollars... I figured it's worth it you know. You take, so she's my daughter anyway and at the end she'll get the rest. (Verification Interview Participant 2010-07)*

Furthermore, one participant traveled to visit with family in order to say his goodbyes:

*I decided to go to Alberta because I figured it, I haven't got much time to, to see all the family... I went to see them all and I figures if something did happen that ahh I've seen all my family before I passed away. (Participant 2010-07)*

### *Themes Discovered from the Photovoice Interviews*

In addition to participating in the interpretive interviews, all participants were provided with the option of taking part in the photography, or Photovoice portion of the study. Three participants agreed to use the disposable cameras provided to them by the researcher to take photographs that they felt depicted what their daily lives were like living with ESHF. A time frame by which the picture taking was to be completed was negotiated with each participant and ranged from two weeks up to four weeks. In two cases the participants requested an extension of time to take more pictures. The number of photos taken by participants varied from five to 55.

Five photos were selected by each participant, and these photos were discussed with the researcher during individual interviews. The interview provided each participant with an opportunity to reflect upon the meaning and significance of the photographs that they had selected. Participation in the Photovoice portion of the study was particularly helpful for one participant who had suffered a previous cerebral vascular accident and experienced some challenges with verbal expression during the initial interpretive interview. In this case, the photographs served to support memory recall and aided him in identifying what daily life with ESHF entailed. Content analysis of the Photovoice interviews reinforced and supplemented the three themes and their associated sub-themes that were discovered during the phenomenological analysis of the participants' interpretive interview data. The participants did not discuss in great detail the specific strategies or the work involved in managing their failing and unreliable bodies. The researcher did not further investigate the work involved in managing their failing and unreliable bodies as all participants had provided lengthy descriptions of their every day

lives living with ESHF in the first interviews of the interpretive portion of the research study. As a result, the first theme was renamed “living with a failing and unreliable body” to capture the daily challenges that were faced by the individuals living with ESHF. The themes: (1) living with a failing and unreliable body, (2) the work of choreographing daily living, and (3) the work of charting the final chapter of one’s life were identified during the analysis of the Photovoice data.

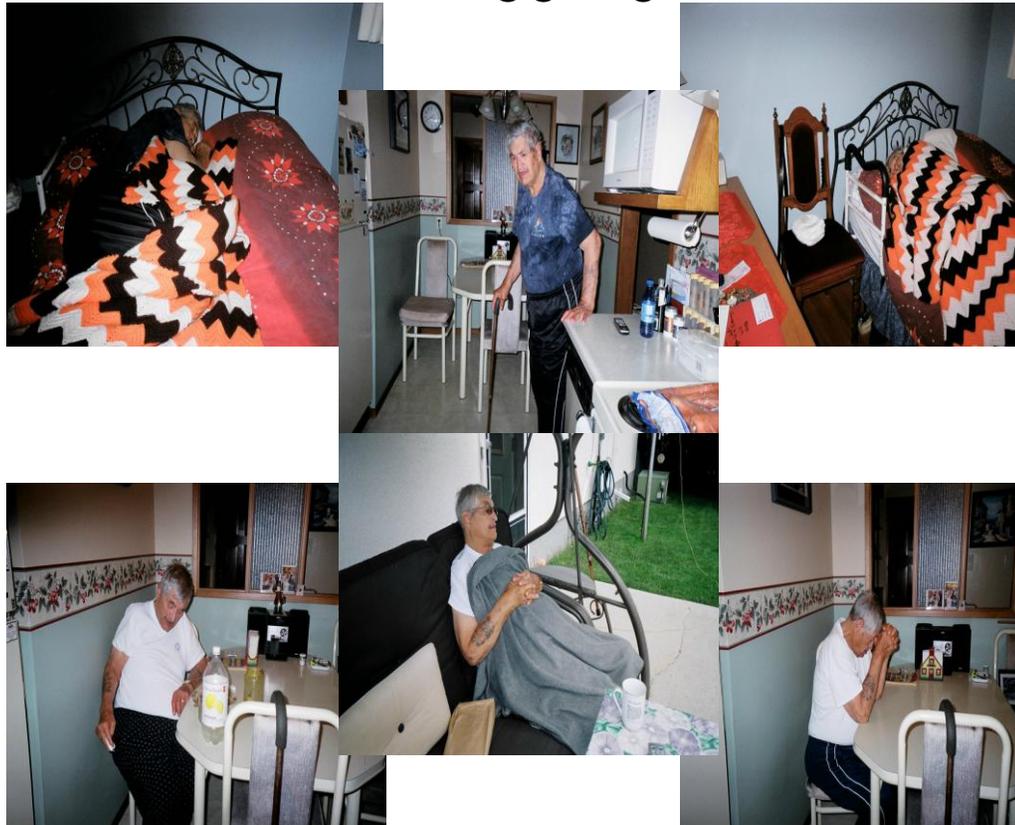
### *Living with a Failing and Unreliable Body*

The theme living with a failing and unreliable body identified that each individual suffered from symptoms of ESHF and that their symptoms impacted their physical and mental capabilities. The discussions pertaining to the photographs reinforced the degree of suffering and the associated limitations imposed on the individual participant as a result of living with ESHF. However, in contrast to the interpretive interviews, the participants did not discuss in detail the work that was associated with coping with ESHF on a daily basis. Life for these participants encompassed varying degrees of symptom distress and limited functional capacity, along with many other challenges associated with life in general. These challenges included, but were not limited to age related changes (e.g. death of a spouse) and issues associated with coexisting illnesses (e.g. neuropathies from diabetes mellitus), all of which caused uncertainty related to how each participant felt and what level of functional ability and independence they would be able to attain each day. While participants described that some days were better than others, no day was identified as free of ESHF symptoms. For some participants, experiencing particularly severe symptoms meant that entire days were spent in bed. All participants

expressed a sense of feeling trapped by their failing bodies because of their ever present physical symptom burden.

Participants also reported a sense of feeling trapped within their physical environment as a result of their ESHF. Overall, the participants identified that the world they lived in was a small one consisting mostly of remaining in, or closely proximal to their home for the majority of their days. All three participants identified that their symptoms of ESHF restricted what they were capable of performing; thereby, negatively impacting how they viewed themselves as a whole.

## “ A Normal Day Living With ESHF – Struggling to Survive”



*Sleeping... I do a lot of sleeping... That's my, my bedroom... It's hard to say. Sometimes just about all day... I get very tired all the time... I've got a cane... I can take, take my time... I got aching legs, I have trouble walking, you know. My hip is going on me. My knee is going, so. And I'm not going to operate... I can't walk ahh even down to the end of the driveway... My voice don't work... That's since the stroke... I can't hold my water sometimes. It just comes without, without notice... I don't feel like walking.... Now I can't do nothing. That really gets me... I can't even, even wiping my nose; sometimes I have trouble... Very very tired... I don't go very far... It is no picnic let me tell you. (Photovoice Interview 2010-02)*

## “A Normal Day Living With ESHF – Struggling To Survive”



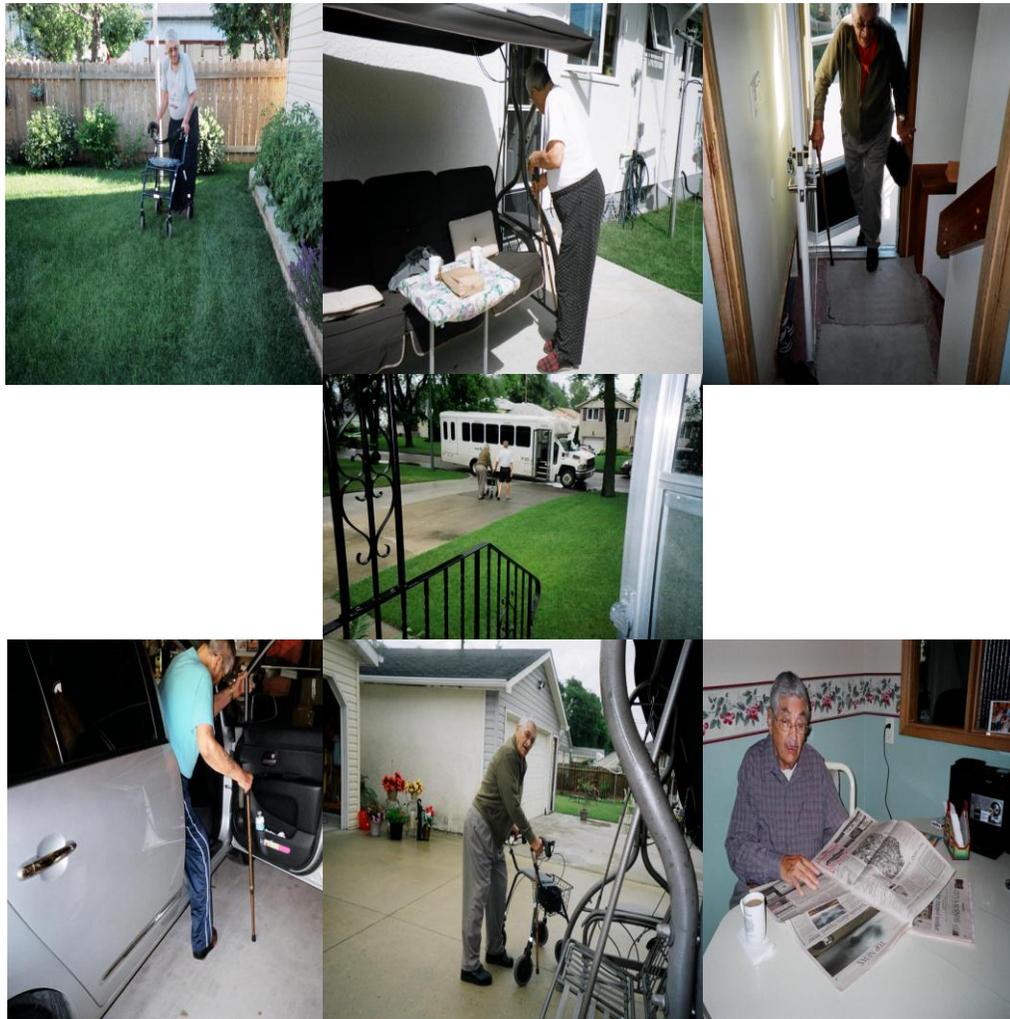
*Monitor my blood all the time and the sugar ahh, sugars can go up and down and some days and ahh, they're some time hard to control... Drugs are for the heart and ahh, sometimes it's ahh little bit annoying because there's side effects from those. Especially ahh, dizziness... Sometimes you get frustrated with them... You kind of accept it you know. You have no choice... Well, one time I, I, when I passed out I think it has, it had to do with low, low sugars. But ahh, I have a historically ahh low blood pressure. So it could be that. And ahh, and it says, says on the, I think the Furosemide and the other one. I forget which is the other one, that they're, it's umm, one of the side effects is dizziness... You don't move around much; if there's umm, also some signs that you, you can tell that ahh, ahh if you get light headed and ahh you sort of like umm; it's like a yellowish light almost. That's a real danger sign, because about three, three times out that I've, or two times that I've noticed that ahh, I've passed out... Insulin and a big bunch of pills... Sometimes three if my feet swell up then I'll take three... There's some in the morning; ahh Furosemide and ahh Rantidine in the morning; and ahh, and then the rest I take early evening so that if there's any side effects they'll happen while I'm sleeping... I have not been too sharp last; in the last little bit... Like ahh, slow... I had plenty of sleep. I, I get you know sometimes I feel like I sleep too much, but ahh. You still get tired... Neuropathy of the stomach... The stairs have been umm, what bugs me is... Now, I have to go; this is a half flight like for a half, a half storey and ahh; it's ahh, it takes quite a bit of effort to go just that half a flight... My legs are not as strong as they used to be... Get short of breath... I don't go far enough, ahh or fast enough to get short of breath ha ha... The big outing for me is ahh, is Sunday going to church... Sometimes I miss. Like ahh, the last Sunday I, I just was feeling pretty crappy, so I cancelled it... No other outings between except to the doctors. (Photovoice Interview 2010-05)*

## “What Used To Be”



*Nothing is working too good... There's days I feel not too bad. But there's days that are terrible you know. Take like there's lots of days that you don't feel like getting out of bed... But that's the way life is... Some have it good and some have it bad... Having trouble getting out of the chair... Well I got a bad leg too... There's lots of things you can't do you... I can't shovel... Last time I used the snow blower is about four days ago... It was a battle... Hard work... Feels like you, just not enough air... Lately I haven't, I haven't done anything... Just no, no strength... I can't go no where... You take the other, the other day I went to the store with my daughter. Went to get some groceries and then, I used to always go and I'd take ahh the cart and I'd push the cart around and she'd pick up the groceries. But this time I said to her, I'll, you take the cart and you, you get I'll give you the list and you pick all this up. I'll walk around with you. Well I went down there and I, we went through the store and got everything we wanted and we come back out of the store and I, I put the groceries away. She brought the groceries in for me; I put them away. I never had no supper, I was too tired to, to, to sit down and have supper. I went straight to bed. And I thought to myself; well, you're sure not fit to do anything ha ha ha... Ahh, lately I haven't, I haven't done anything... I can't go nowhere. (Photovoice Interview 2010-07)*

# “ A Good Day”

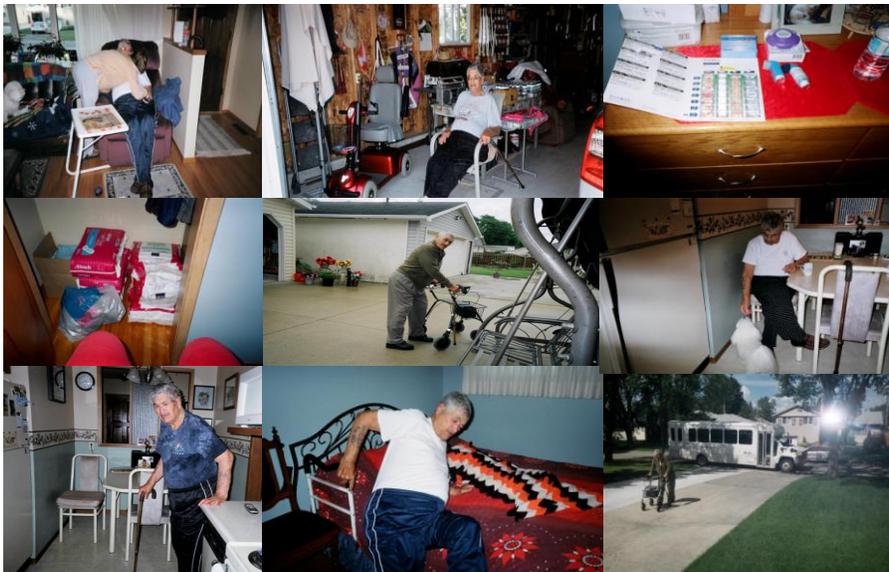


*That would be a good day... Because I'm going to day program... Most time I don't feel good... It's hard to say. You know, you don't really know till the morning... I can't do it everyday. (Photovoice Participant 2010-02)*

*The Work of Choreographing Daily Living*

The second theme, the work of choreographing daily living identified that individuals living with ESHF work at developing and implementing strategies to enable them to carry on with life and activities of daily living. For participants in this study, giving up was not an option; rather, they stressed the importance of continuing to do as much as possible for oneself on a daily basis as symptoms allowed. The challenge in this regard was gauging one's energy and pacing oneself in order to conserve one's strength; while at the same time balancing one's dependence on medications, physical aides, family, friends, support workers and healthcare professionals and struggling for and maintaining a degree of independence. All participants depended upon a number of forms of assistance to meet their needs; however, the assistance that they accepted also served to enhance and ensure the likelihood of their being able to maintain some degree of independence. All three Photovoice participants reported that they believed that they were well taken care of and supported on a daily basis. And, despite living in a world filled with great challenges they were able to find sources of happiness and some degree of pleasure.

## “Keeping Me Going – Balancing Independence With Dependence”



*All my medications... My pull ups... A nice bed... They [homecare worker] take me down the basement, have a shower, they help me up back to, back up the stairs. Then on ahh, at night time, Pauly comes; he gives me ahh, a spongy. I'm well taken care of... On the bed I've got the help in and out of... Adapted rails on the side of the bed... I pull myself up with that... Pull up pants... I change a couple of times a day... Hearing aides... Use my cane. Yeah I can do it [get self out of house]. I can take my time... You know you got to do this, you got to that, so... She [participant's wife] takes care, good care of me... Valise I carry with me when it, oh, this is going on the bus [handitransit] ... Oh yeah I carry that [valise], that's extra pad incase I need it, my wallet, my puffer ahh, Nitro ahh puff... My walker and that's my cane I carry with me all the time... I can take, take my time... Then I got my scooter, but it's too big to take to ahh in the bus... My puffer. That's my Nitro patch. That's my medication, those are my puffers... Well if I didn't have that, I'd, I'd be down... I got to take so much medications... She [participant's wife] does when I, I get mixed up. Because I was taking too many [pills], too much at one time and she fixed it up with the doctors that to take less... She knows I don't know. (Photovoice Interview 2010-02)*

## “Keeping Me Going – Balancing Independence With Dependence”



*It's the drugs that are keeping me alive. If I don't have those drugs then I wouldn't be alive and ahh, see the Insulin... Other drugs are, are for the heart... Sometime it's ahh little bit annoying because there's ahh side effects from those... You kind of accept it... You have no choice... Two of these or, usually this is the Furosemide... Sometime three if my feet swell up then I'll take three... Glucose meter... If I go out someplace it's, ahh, the HandiTransit ahh, comes to the front... I get them [groceries] delivered to me... It's a little bit more expensive, but you're not bugging anybody and they bring it right in here and they put it on the chair... I don't go far enough or fast enough to get short of breathe ha ha... I have to use like go on a hundred yards or whatever and then stop and just stand there and let everything catch up with everything. (Photovoice Interview 2010-05)*

## “Keeping Me Going – Balancing Independence With Dependence”



*My next door neighbour... come around here to see what, what, where I am and what, what I'm doing and, and ahh, and he says if you need any help at any time, we'll help you... Whenever he [neighbour] didn't see me outside, he'd come and knock on the door and ask if I was okay... I got a guy [homecare] comes and gives me a bath every, once a week... I got a girl [homecare] that comes every two weeks. She comes and does, does all my house work... There's my chair. I spend a lot of time in that chair... All I have to do is push a button and the chair will lift you up... It made, made things a lot better for me, then, then it was in; then I had... I have no problem asking my daughter. You don't, I don't have to ask her, she'll come and she will do anything I want her to do... I have a young fellow that will come... He'll come and he'll clean my drive, my walk, my sidewalk and clean the front yard up and, and ahh, wherever I have to go, he'll take the garbage out... I do things like in the house, it takes me long time to do it, but I still can do whatever I can do. I don't, I never quit working... Whatever I can do, I'll do... As long as I can do it on my own, I don't want anybody to... The one doctor told me... I'll keep you alive as long as I can with medications... She [doctor] did help me a lot... Oh, I got lots of meds. (Photovoice Interview 2010-07)*

One of the individuals who did not discuss spirituality during his interpretive interview identified spirituality as an important aide in dealing with ESHF on a daily basis.

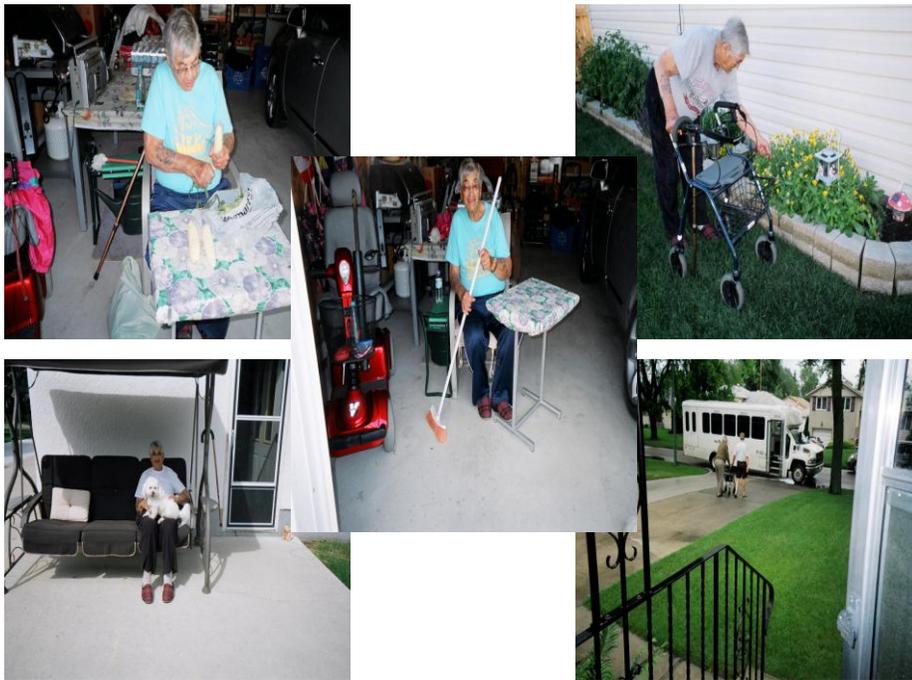
## “Spirituality - Seeking Guidance”



*I do believe in God everyday... Ask the Lord for, for help. Not for just for yourself for help; ask the Lord to help the, the people, even the, the people that's running the world... I read the bible a lot... I read the bible every day. Some you know, and you take like if I have nothing to do, or anything like, I'll sit down and pick up the bible and read the bible. I believe in that. In the, I believe that God is; if it wasn't for Him, I wouldn't be here. (Photovoice Interview 2010-07)*

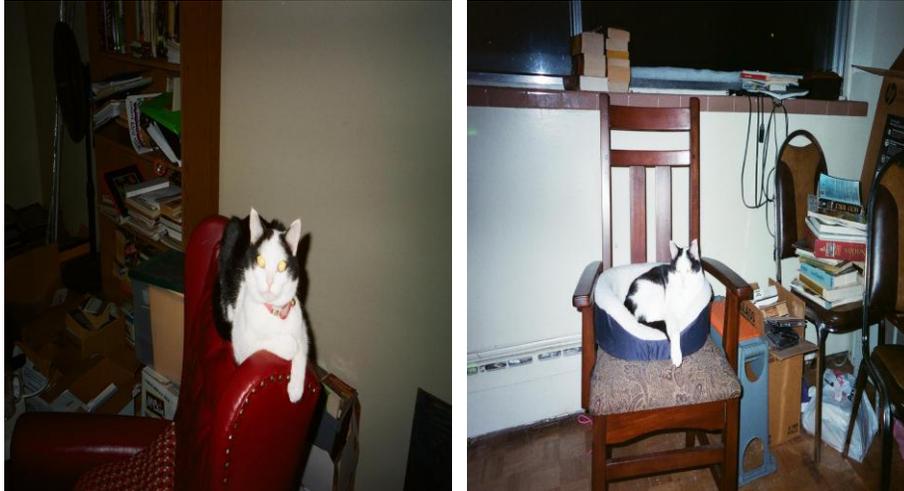
Furthermore, all three participants identified the importance of discovering sources of happiness and pleasure that distracted them from the challenges of daily life living with ESHF.

## “Finding Happiness Despite One’s Challenges”



*My daughter bought me that swing, so I could sit in the sun or in the shade. She's [pet dog] always on my lap... She sits on my lap for hours on end. As long as I scratch her, she'll put her head down where, wants her head scratched, or put it down wanting her neck scratched. And she'll lay there so I can scratch her chest... If it's nice I'll spend a couple hours at a time... Every Wednesday I go to day program... That would be a good day... Because I am going to day program... Because we do exercises and everything... They're a great bunch over at day program. They take good care of you... You feel happier... You are mixing with people. (Photovoice Interview 2010-02)*

## “Finding Happiness Despite One’s Challenges”



*That’s my cat and ahh he’s ahh; I think he’s become an important part of my life because he’s ahh, like a stress relief valve and ahh company and ahh, just all, all around like ahh, he ahh contributes to my well being... Distracts you from yourself... He demands attention... He’s affectionate and he demands, he wants, wants affection and attention and he wants ahh, he gets playful sometimes and he wants you to participate in that and... Well, well days like today he distracts you from and you’re not so miserable that or, or you, like I don’t get, I don’t get depressed or, or, but it’s ahh, it’s a pleasant distraction... One other thing is occupying my time lately is I’ve been playing ahh a game on the computer... It’s a multiplayer. People from all over the world... It’s kind of like an escape... Plus it’s a social thing. I made friends in there... You type to other people... The big outing for me is ahh, is Sunday going to church. (Photovoice Interview 2010-05)*

## “Finding Happiness Despite One’s Challenges”



*Them birds mean a lot me. I've been feeding them for years... Hah, they come right up, right up to me and they would just chirping away like, like you wouldn't believe... So, I've been feeding them for, for many years. I, like I got ahh, there's blue jays come, sparrows, sparrows that, ahh, sparrow; and everybody says he's only a bird. But you got to remember that sparrow is a little bird that he's with us all year round. And in the winter time, there, there is no, there is nothing for them to eat. Somebody has to feed them. And I figure well, if nobody wants to feed them I'll feed them... I figure that there, that's a chore that I have to do regardless whether is good or not. Even if I am having trouble to get there, I still feed them... So, so they're, they're entertainment... But ahh, I, I make sure that I, that I, I can be very sick, very sick and, but I'll still feed my birds. I figure they're, because that, what, what else have I got. You take, I can watch them for hours. Ahh, you take, especially in the summer time. I can sit out there for hours with them chirping around and flying around. I love the birds... The birds are important to me because; what else is there for me. I got; if I can't, can't feed them, then they, then they're not there. You take and if I, I figure if I can feed them, and they, they'll come to, to kind of make, make me feel good you see. That they're here. Ha ha. (Photovoice Interview 2010-07)*

One participant reinforced during his Photovoice interview that he had feelings of guilt related to the fact that he had to rely on his spouse for a large portion of his care needs. This individual did not believe that this was fair and would have preferred if he could have been able to do more for himself. He stated:

*She [participant's wife] takes care, good care of me... She's got to do all the work, I don't feel so good... It's not fair you know... I don't think it's right that she's got to do everything, but I can't do nothing...She takes good care of me... She makes sure I've got everything I need. (Photovoice Interview 2010-02)*

### *The Work of Charting the Final Chapter of One's Life*

The final theme, the work of charting the final chapter of one's life, and its sub-themes of acknowledging the inevitable, embracing living, and planning for the future were also captured within the pictures that participants took. Although, no specific pictures taken depicted the individuals' experiences of the work of charting the final chapter of one's life, the participants did discuss the associated sub-themes while describing the meaning of the five pictures they selected. As a result, no pictures are included within the following discussion of the theme the work of charting the final chapter of one's life. The degree to which the participants discussed each theme varied; thus, not all themes were discussed in depth by each participant. All three participants were aware that they were living with ESHF and would ultimately die from the illness. One participant highlighted and discussed the reality and acceptance of his mortality in depth and included a discussion about the fact that he was living on borrowed time as he was elderly and had already surpassed the average age for most individuals:

*When I worked; was working I used to do a lot more than I did. I never used to; you take I used to grow a garden in the backyard was all garden. And before I went to work I'd go out there and I'd weed the weed the garden and everything else; then I'd go to work and I'd work all day and come back and do the same thing around the house again... Lucky I'm still here... I don't intend to live too*

*much longer because one of these days, I'll just go to sleep and forget to wake up ha ha ha... And I'm not afraid of that because I figure that this is; I'm getting too old; fairly old already. You take like eighty; eighty seven years old... That's old. You take an average; average man's life is only about seventy... It doesn't matter for me, if today or tomorrow, what's the heck's the difference? Really, there is no difference if you're going to; you, you know that you're not going to be around. And ahh, you; the age tells you that you, you, you're way, way over the limit already. Ha ha ha ha. (Photovoice Interview 2010-07)*

The participants also discussed their need to embrace living and continue to do things for themselves within the limits of their ESHF in order to have purpose in life. However, they also recognized that their future may entail them requiring and thus planning for increased assistance or a change in living arrangements to ensure that their needs were met. The participants did not discuss resuscitation preferences within the Photovoice interviews.

*Wendy bought me that swing, so I could sit in the sun or in the shade...She [pet dog] sits on my lap for hours on end. I scratch her, she'll put her head down where she wants her head scratched, or put it down wanting her neck scratched. And she'll lay there so I can scratch her chest... I use my cane... Yeah I can do it [get self to swing]... I can take, take my time... I can't do it every day... You know you got to do this, you got to do that, so. (Photovoice Interview 2010-02)*

*There's days I feel not to bad. But there's days that are terrible you know. There's lots of days that you don't feel like getting out of bed. But ahh, that's one thing that I never did. I always get out of bed. I'll get out, I'll wash, get cleaned up and, and I always make my own meals... I don't, I don't believe in letting somebody work and that ahh, if they don't have to so. If I can help I don't see why I shouldn't... I do things like in the house, it takes me a long time to do it, but I, I still do whatever I can do. Well, my birds are, they, they are my birds and I, I make sure that they get fed...The birds are important to me because; what else is there for me? They make me feel good you see... I don't, I never quit working... What ever I can do, I will do... I have no problem asking my daughter. She will do anything I want her to do... She [homecare] said if you ever need help again, more help, you just call me... I know that if I need something that she will come and help because she told me. She said if you ever need somebody to cook for you or something, she says just let me know. (Photovoice Interview 2010-07)*

*If you dwell on, on things that are not ahh, like, like it would be easy to get into it, into depression...One thing is occupying my time lately is I've been playing ahh a on the computer... A multi player game... It's kind of an escape... It's a social*

*thing. I made friends on there... The stairs have been umm... quite a bit of an effort to go just that half a flight... Probably the best thing if it gets to be an issue would be to move to a place that ahh, that has elevators. (Photovoice Interview 2010-05)*

This participant recognized the importance that is placed on being as self-reliant and active as possible, and that their inability to do so was distressing for them:

*I lived a full life you know. I did everything I wanted when I was young. Now I can't do nothing. That really gets me... Makes me feel terrible... Because I was ahh, I was a sniper in the war. I boxed. I did some wrestling. You name it, I did it. Now I can't do nothing... I can't even, even wiping my nose; sometimes I have trouble... See if I could, if I can't do something, she's [participant's wife] got to do it for me. (Photovoice Interview 2010-02)*

The photos also prompted discussion about potential strategies that could further improve one's mobility and conserve their energy. One participant highlighted that he contemplated how he could improve his mobility into the future, although he had not yet acted:

*But I've been thinking that I should buy myself a, some kind of a scooter that I can get around in... Yeah, well I figure that way I can go and get my own groceries and go to a store and look around... Well I, I'd buy one so. And then, and then I'd have it and then I'd have transportation. (Photovoice Interview 2010-07)*

Another participant discussed how he had devised a plan to improve his mobility in the future with the hope that the outcome would be facilitating and enhancing his ability to leave his home environment and promote increased socialization:

*I am looking forward to this spring because I bought, it's classified as a power assisted bicycle... And it looks like ahh, a regular scooter. And ahh, so my friend found one on Kijiji for two hundred and, two hundred and twenty bucks and he's got it, in his, in his garage. So in the spring... I'm looking forward to that... Well, just to go to short distance to the store or something like that. And apparently it can go quite a long distance. (Photovoice Interview 2010-05)*

In one situation, the photographs did encourage the participant to discuss that he was “tying up loose ends” prior to his death. This participant stated that he travelled to

say goodbye to family members and indicated that one of his most prized possessions was to be given to his daughter:

*I got little bit better and ahh... I told my daughter, I says you know, I'm going to go to Albeta, see the family there. I says I don't feel so good. I says I'll go and see everybody before something happens. I says when I go, then I see, at least I've seen everybody... I told her [daughter], I says when I'm gone, you remember that's your chair. (Photovoice Interview 2010-07)*

### Chapter Summary

Chapter five presented the research findings. A demographic profile of the study participants was provided followed by a discussion of the essence of the lived experience of ESHF and its attendant themes and sub-themes. The three themes were: (1) the work of managing a failing and unreliable body; (2) the work of choreographing daily living; and (3) the work of charting the final chapter of one's life. The first theme spoke to the many challenges that individuals living with ESHF face on a daily basis and the impact that these challenges had on one's life. The second theme concerned the strategies that individuals living with ESHF employed on a daily basis in order to live out each day of their lives. The final theme captured the ESHF patients' responses to the very real life-limiting nature of their illness, and the planning that they engaged in in preparing for the end of their lives. The themes discovered from the Photovoice portion of this study were also discussed in relation to how they supported the three overarching themes identified in the interpretive portion of the research project.

In the next chapter, the findings from the study will be discussed with regard to existing literature.

## CHAPTER 6: DISCUSSION OF FINDINGS

### Introduction

This chapter situates the research findings to those of previous studies. First, the essence “working to preserve a sense of self” will be discussed in the context of chronic illness literature. This will be followed by a discussion of the major themes and sub-themes supporting the essence. Next, limitations of the current study will be presented. The chapter concludes with recommendations for nursing practice, education and research suggested by the study findings.

#### *The Essence of Living with ESHF: Working to Preserve a Sense of Self*

The essence of living with ESHF identified in this study was that of “working to preserve a sense of self.” One’s sense of self is the organization of the attributes that become consistent over time and identify to an individual who and what they are. It is clear from the literature that chronic illness disrupts both one’s sense of self and previous experiences of a “normal life” (Bury, 1982; Charmaz, 1995; Charmaz, 1983; Corbin & Strauss, 1991; Corbin & Strauss, 1988). Up until the time illness occurs, one’s sense of self does not include experiencing the illness and its associated symptoms (Charmaz, 1983). For example, one may have viewed him/herself as strong, energetic, beautiful and able to accomplish anything he/she attempted. In the face of illness, however the attributes that a person used to define their sense of self are challenged by the unexpected change(s) that have occurred within one’s body and life as a whole. These disruptions are dislocating to an individual’s sense of self in terms of who they were in the past, who they have become, and what life will entail in the future.

Preserving a sense of self has been defined in the chronic illness literature as, “maintaining a way of being in the world and a way of relating to and knowing self, others, and social worlds.” (Charmaz, 1994, p. 278). Preserving one’s sense of self is also the mechanism by which ill individuals maintain continuity with the past, present, and future. This is no easy task. The course of chronic illness frequently changes. Each and every time such changes occur, the individual must work to make identity adjustments and strive to come to terms with living with the new chronic illness state. As a result of the physical and psychosocial losses suffered, individuals with chronic illness must reassess who they are and who they can become by redeveloping identity goals in an attempt to obtain and maintain as normal of a life as possible (Charmaz, 1995). As individuals strive to meet their new identity goals, both they and their physical bodies are tested and their identity goals may need to be lowered, or trade-offs made to achieve alignment with reduced physical capacity. Conversely, at times, identity goals may be achieved resulting in one further increasing his/her future identity goals. As a result, chronically ill individuals raise and lower identity goals as they adjust to bodily loss and change.

Morse and O’Brien (1995) performed a phenomenological study that investigated the lived experience of surviving a life threatening accident, from impact to recovery. This study included 19 participants who experienced severe burns (n=6), an airplane crash (n=1), gunshot wounds (n=2), and motor vehicle accidents (n=10). It was discovered that survivors of serious traumatic injury who have residual permanent disability are required to come to terms with their disability and regain a sense of self by merging their old and new reality. These individuals redefined themselves by making

sense of their illness experience, learning to know and trust their altered bodies, viewing life beyond self, and accepting the consequences of the experience. Morse and O'Brien concluded that ultimately, participants had to accept their disability as reality and develop a new life course for themselves based upon the limitations and restrictions that their disability forced upon them.

There are clear similarities between preserving a sense of self as it is described in the chronic illness literature, and the experiences of the participants in this study. Preserving a sense of self for ESHF participants involved being engaged in the work of adapting to the physical, psychological, and social changes arising from their illness and the changes in its trajectory. Specifically, the work of managing a failing and unreliable body; choreographing daily living, and charting the final chapters of one's life are similar to types of work described by Corbin and Strauss (1988) in their theoretical papers aimed at helping healthcare professionals, patients, and loved ones to understand the unending work involved in living with and caring for an individual with a chronic illness who is living at home. These authors suggested that living with chronic illness involves four types of work: (1) the work needed to manage one's illness, such as the organizing of medications and care, complying with management regimens and obtaining the care that one requires; (2) the everyday work involved in keeping life going, which consists of organizing daily life, including pacing of one's activity and resting; (3) biographical work, where the individual deals with the threat of potential and actual losses that impact one's identity and challenges their attempts to maintain a recognizable and realistic biography; and (4) arrangement work, entailing the organizing of the appropriate mobility

aides and infrastructure changes made to one's home to ensure that they are able to safely navigate within that environment.

In working to preserve a sense of self, the ESHF patients in this study were trying to harmonize the physical changes and losses resulting from their illness to align with their sense of self as they currently experienced it. This is consistent with Charmaz's theorizing about the process of adapting as one possible method of living with impairment or loss of bodily function. Adapting is defined as "altering life and self to accommodate to physical losses and to reunify body and self accordingly" (Charmaz, 1995, p.657). In order to successfully adapt one must: recognize and acknowledge impairment; resolve the tension that has resulted between one's body and self; and define integration and wholeness of being, while simultaneously experiencing loss and suffering in a socially and personally acceptable manner. While all of the previously mentioned tasks are occurring, it is also the expectation within North American society that the individual remain as independent and autonomous as possible. Overall, adaptation occurs when ill individuals accommodate and transition with the experience of illness versus struggling against it. As a result, one regains a sense of wholeness and unity of body and self in the face of loss.

Adapting to impairment and loss consists of three major stages: (1) experiencing an altered body, (2) changing one's identity goals and (3) surrendering to the sick body (Charmaz, 1995). Experiencing an altered body requires individuals living with chronic illness to acknowledge that they are experiencing physical changes and reduced bodily functions; and to define these changes and/or the illness itself as reality and recognize how the changes and symptoms are impacting their daily life. As a result, comparisons

are made between one's previously healthier body and that of the presently ill body, while simultaneously measuring the costs and risks of ordinary activity. As one recognizes that they are experiencing an altered body, they begin to question and ponder their previously held notions of body and self. Prior to becoming ill, people take their bodies for granted. As a result, one's previously healthy body becomes the baseline by which they measure their currently altered bodies.

How individuals respond to the changes in their body varies and may include; feeling their bodies are alien to them, feeling a sense of betrayal by their body leading to feelings of anger and regret related to their losses, and experiencing guilt or shame because their altered appearance or physical limitations no longer meet social and cultural standards (Charmaz, 1995). As a result, individuals living with chronic illness may choose to struggle against their illness, viewing it as the enemy. They must battle against "the enemy", with the hope that their past identity may be regained and their missing sense of self restored. During this time the individual is unable to accept that a more restricted life and lesser identity is their new reality. Alternatively, when one struggles with illness they do not give up or into their illness, but rather they strive to maintain a functioning body and live a life that is as normal as possible. As a result of struggling with illness, new bodily facts are eventually integrated into one's life and self concept and one begins to objectify their body less. However, until the individual defines the changes they experience as chronic ones that will impact them on a daily basis, they continue to seek out recovery and strive to keep the illness and their bodies distanced from their self concept. These actions result in the continued objectification of their bodies. Once one learns to struggle with illness and begins to objectify his/her body less

he/she becomes increasingly aware of, and responsive to, the cues that one's body is providing them. As a result of listening to one's body and responding appropriately these individuals obtain a degree of control over one's life related to the fact that they have learned how to protect their bodies. Some individuals are able to learn to live with their current body and become familiar and possibly comfortable with it by abandoning attempts to measure their ill body to that of past perfection or previous hopes of obtaining the perfect body.

The literature surrounding living with chronic illness has identified that for individuals to successfully adapt to life with their illness, they must accept that they have an illness and that their previously healthy bodies have been altered and overall life in general has and will continue to be impacted. Successful adaptation occurs when one is capable of integrating the illness into one's identity and discovering strategies to continue to live life as independently and normal as possible. Within this study the participants identified that they have recognized that they are living with a chronic illness that has altered who they are in comparison to who they were in the past, and that their new identity consists of a diagnosis of ESHF. The participants have also reported that they have chosen not to give into their illness and give up, but rather, to struggle with their illness and discover strategies to continue to live with ESHF on a daily basis.

The theme, "the work of choreographing daily living" that emerged from this study identifies the varying strategies that those living with ESHF used to maintain their present state of health and their associated self concept and identity. Participants hoped that they could remain as independent and functional as they presently were and, if possible, experience a slight improvement in their condition. These participants

unequivocally highlighted that living with ESHF meant not giving up and continuing to do as much for oneself as possible, within reason. To do for oneself equated to discovering and employing routines, gauging and pacing one's activities, accepting assistance, and becoming dependent on others to some degree in order to remain independent. Participants gave up striving for total independence and their ability to do everything for themselves. Rather, they began to focus on what they were capable of doing for themselves without causing exhaustion. The participants all realized that they had no choice but to accept assistance and become dependent upon external sources for help in order to retain some degree of independence. Furthermore, the importance of ensuring that one discovers a source of happiness or pleasure was expressed as important to counter balance the negative impact that living with ESHF can have on the individual.

The theme, "the work of charting the final chapter of one's life" that emerged from this study captures the fact that living with ESHF equates to acknowledging one's mortality and that death will occur as a result of the disease. Because predicting when death would occur was not possible, participants chose to trudge ahead and embrace life as much as they possibly could, while at the same time planning for the future, including death and beyond. Overall, for the participants in this study living with ESHF entailed a tremendous amount of work to manage their illness, keep life going, incorporate the illness into self, and look towards and plan for the future.

The participants in this study all identified that they suffered from symptoms of ESHF, including dyspnea, pain, fatigue, dizziness, and reduced mental capacity on a daily basis. It was also highlighted by the participants that ESHF, its symptoms, and effects of management strategies aimed at managing their ESHF impacted their daily

functioning. The participants reported that activities of daily living, such as toileting, bathing, dressing, cooking, cleaning, and shopping became extremely challenging and difficult. They also voiced comparisons of their current body, and the body they had prior to becoming ill. Many spoke of the tasks that they were able to perform with ease before being diagnosed with ESHF, such as gardening, snow-blowing, cutting the grass, and taking out the garbage. They also spoke of previous occupations they had engaged in when they were healthy. However, the participants in this study were able to recognize that their ESHF and its symptoms were not going to be cured. As a result, they appreciated and recognized that living with an altered and failing body was their new reality. The participants were able to give up hope of returning to a body as it was prior to ESHF and chose to struggle with their ill bodies to live a life as normal as they could possibly manage. Participants learned to listen to the cues that their bodies were providing them, and respond accordingly. For example when one became dizzy, it was important to stop physical activity and sit down or to hold onto a wall to prevent a fall. When fatigue was experienced, sitting and resting was important. Individuals recognized their activity limits and learned to prevent fatigue by pacing their activities and balancing activity with rest. All of the participants in this study were successful at learning to struggle with their illness.

The second stage of adapting to impairment consists of appropriately changing one's future identity goals. This occurs by assessing one's altered body and considering how one appears to self and the role that life's context plays (Charmaz, 1995). Although one may have formulated an identity goal, this goal may not be achievable and identity trade-offs may occur based upon assessment of their situation, including losses or gains

that had occurred or may occur. Lowering of identity goals will occur during times of acute exacerbations in illness, or when one discovers that he/she is struggling to manage the sustained losses associated with their chronic illness and that one must adapt in order to survive. However, the challenge in lowering identity goals is that one's identity is associated with commitments and responsibilities to oneself and others. As a result, one's changing identity goals are always influenced by one's own definitions, the views and wishes of one's family and loved ones, and the negotiations and interactions between the two. For example an ill individual may be a spouse, parent, income earner, and friend; therefore, the challenge will become balancing all the roles and associated responsibilities associated with each role by considering both the interpretations and expectations of the ill individual and that of all others involved. Ill individuals will be required to sacrifice some identities that are no longer obtainable or are consuming their coping resources in order to focus their energies on retaining other identities that are considered important at the present time or for their future. Successful adaptation occurs when, despite making identity trade-offs, one is capable of discovering positive aspects and value within a restricted life. Such discoveries in many cases can be aided and assisted by supportive family and loved ones. The ultimate goal is developing an identity based upon who one is and what one remains capable of, while recognizing, but not focusing on the losses and changes that have occurred.

The participants within this study frequently discussed identity trade-offs that they had made, and were continuing to make. For example, the inability to be able to change his own oil required that the participant in this study who was a former mechanic now allowed others to do the oil change for him. He has now chosen to focus his energies on

preparing his own meals independently and other tasks, such as keeping his home tidy. These were tasks, that he was capable of completing without exhausting himself and worsening the symptoms of his ESHF. Another participant identified that he continued to go into the office for a few hours a day. This was a trade-off from spending entire days at the office, but this individual continued to feel valued and productive by going to the office for short times and resting prior to going to the office and after returning home. These participants were able to discover the positive aspects of their identity trade-offs. They were able to focus on their ability to continue to do for themselves as opposed to fixating on what their bodies had become and the losses that they had sustained. They strove to retain who they were and their ability to continue to do as much for themselves as possible; thereby, reducing their sense of uselessness and worthlessness.

The final stage in adapting to loss and limitations in chronic illness is surrendering to the sick body, which is an active intentional process that entails recognizing one is chronically ill, giving up fighting to control the illness, and learning to flow with the illness (Charmaz, 1995). During this stage, individuals must cease seeking control over their body, accept that they will not overcome their illness, and appreciate that one's sick body is a part of them. A chronically ill individual may continue to hope for improvement into the future, but they do not focus on and strive to attain false hopes. Successful adaptation occurs when one recognizes that illness is a subjective experience and is integrated within oneself. The chronically ill individual is required to develop a new body identity and self, based upon their recognition that their ill body is a part of them and their ability to learn to experience their ill body. Most importantly the ill individual becomes able to let go of their past identities and focus on their present and

future identities, which may include the reality of death versus being overwhelmed with illness and despair.

The participants within this study surrendered to their sick bodies as evidenced by the fact that they recognized that they were chronically ill, that they would not overcome their ESHF, and that cure was no longer possible. Living on borrowed time was recognized as the reality for these individuals. Furthermore, by acknowledging that one could not control their body and that as a result of living with HF for many years, study participants were able to appreciate their sick body as a part of them, and work with it, versus fighting it on a daily basis. The participants were able to recall their past identities, but focused on their present and future identities, which included maintaining some values that they deemed important from their past life and anticipating and planning for one's death. Individuals strove to maintain values such as independence and being a hard worker through caring for oneself. Furthermore, they began "cleaning things up" before their deaths. For example participants engaged in such activities as giving away a pet to a more suitable home, selling their home, purging unneeded documents, and ensuring that one's business had the necessary management framework in place to continue to operate upon the individual's passing.

Charmaz (1994) suggests that men may respond to attacks on their identity caused by chronic illness as being attacks on their masculinity and the roles and responsibilities associated with their perceived masculinity. As a result, men may strive to preserve their previous self identified masculine identity that is focused on their past healthy identity, which included their ability to perform paid work. These individuals may attempt to prevent the illness from entering their current life by intensifying the control they have

over their lives when possible, and seeking out methods to disguise or hide the impact that their illness has on them, especially in their work environment. Men may plan and maintain an appearance that disguises their illness and they may organize their work life so that others do not know about their illness through such strategies as, indicating that they are attending work meetings out of the office versus informing coworkers that they are attending a dialysis appointment (Charmaz, 1994). However, when in the confines of their home environment and the presence of those they love the individual may or may not continue to hide the ill individual that they have become. In the case of men, the ability to work provides a sense of control and therefore impacts their identities. Within this study, one participant continued to remain employed on a part-time basis managing a long standing business he had formed. The ability to continue to work provided this individual with a link to his past identity and a sense of value, worthiness, and control. He was able to control his business despite not being able to control his body or its illness. Furthermore, when this participant went to his place of work, he did not take his cane with him, despite always using it when he was at home. This action signifies that he did not want to be viewed by his employees as sick, weak, and not in control. This participant placed great self value in the fact that he was able to continue to work despite knowing that his life was limited and he expected death would occur very soon.

Of the remaining participants, all but one had been retired for many years and had thus given up their past link to their employment. For these individuals, the value of hard work remained within their masculine identities and they strived on a daily basis to work as hard as they possibly could to maintain a functioning body that would support them in meeting their daily needs as independently as possible. These participants filled their

days working towards maintaining their independence and accomplishing the tasks that they could within the constraints of their illness. These tasks ultimately replaced their ability to perform paid work. As a result, these participants were able to preserve a sense of their masculine self by working to ensure that they remained as healthy and independent as they possibly could within the context of their illness.

The sole participant who was forced to quit work and go on employment insurance as result of his HF maintained relationships with friends from his previous work environments. These friends came and took him out of his home for meals and assisted him with his shopping. This participant was able to maintain this link with his past identity as a paid worker through regular contact with former work colleagues.

The lone female in this study a retired school teacher, also discussed values of her past identity. She identified that she valued communication and conversation with other people. Despite no longer being physically capable of being able to go out to visit others as she had in the past, she appreciated when others came to her. As a result, a portion of her daily work also focused on conserving energy so that she could have a phone conversation or converse with friends and family when they came to visit her. This participant retained the portion of her identity that she valued from her past life.

### *Major Themes*

The three major themes underpinning the essence, “working to preserve a sense of self” included: (1) the work of managing a failing and unreliable body, (2) the work of choreographing daily living, and (3) the work of charting the final chapter of one’s life. These themes and their sub-themes are discussed with respect to relevant literature in this section.

*The Work of Managing a Failing and Unreliable Body*

It was clear from this study that individuals living with ESHF suffer from numerous symptoms related to both their disease, and other co-morbid conditions as well. Unpredictable fluctuations in symptom severity, physical stamina, and mental clarity from day to day resulted in study participants experiencing their bodies as failing and unreliable. As a result, they needed to engage in the work of managing their failing and unreliable bodies on a daily basis. The work of managing a failing and unreliable body involved participants facing challenges of varying proportions on a daily basis. While some days were less challenging than others, no day was entirely free of challenges. This description is consistent with Charmaz's (1983) portrayal of the impact of chronic illness on an individual. She notes that living with chronic illness results in a substantially more challenging life than that experienced by healthy individuals. For those with chronic conditions, illness becomes the focus of a person's life and one struggles on a daily basis to learn to live with the illness and its associated symptoms and management strategies (Charmaz, 1983). All aspects of one's life begin to revolve around one's illness and the strategies associated with maintaining some degree of control over it. As a result one's life is taken over and consumed by the illness that has attacked one's body and self as a whole.

The work of managing a failing and unreliable body consisted of five sub-themes: i) managing / relieving symptom distress; ii) managing coexisting challenges; iii) living good days and bad days; iv) managing one's emotions; and v) living in a small world. These sub-themes will be discussed in relation to existing literature in this section.

*Managing / relieving symptom distress.*

The participants in this study reported that they suffered daily from an array of symptoms associated with ESHF. The most common symptoms they reported included dyspnea, pain, and fatigue, all of which limited their ability to perform the simplest of activities, including safely caring for themselves. Accordingly, performing activities of daily living, such as bathing, toileting, preparing meals for oneself, and house keeping all became extremely difficult.

The most frequently reported symptoms associated with HF, advanced HF, and ESHF documented in the literature include; pain, dyspnea, fatigue, and edema, all of which make caring for oneself taxing (Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000; Bosworth et al., 2004; Boyd, et al., 2004; Brannstrom et al., 2006; Europe & Tyni-Lenne, 2004; Levenson et al., 2000; Mahoney, 2001; Nordgren & Sorensen, 2003; Riegel & Carlson, 2002; Ryan & Farrelly, 2009; Waterworth & Jorgensen, 2010; Willems et al., 2006). Of these, fatigue in particular is reported as an extremely persistent and vexing symptom. Ryan and Farrelly (2009), in their interpretive phenomenological study consisting of nine participants, documented that individuals living with advanced HF (NYHA III & IV) reported that they suffered from an extreme sense of “running on empty” due to a sustained feeling that they were mentally and physically exhausted. As a result, completing any type of minimal activity was extremely difficult and required great effort and tremendous amounts of preplanning.

Most notably in relation to managing the symptoms of ESHF, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (n = 9105) demonstrated that in the last six months of life, individuals who

died in hospital from ESHF (n = 539) suffered from severe pain (20%) and dyspnea (35%) (Levenson et al., 2000). Furthermore, as death drew near for these patients, the degree of symptom distress worsened, and in the last three days of life, severe pain (41%) and extreme dyspnea (63%) were reported. In comparison elderly seriously ill individuals within the SUPPORT study reported severe pain (40%) and severe dyspnea (50%+) in their final 3 days of life (Freeborne, Lynn, & Desbiens, 2000).

Nordgren and Sorensen (2003) performed a retrospective chart review of 80 patients who died from HF and discovered that individuals who died from ESHF suffered on average seven symptoms in their final six months of life, with dyspnea (88%), pain (75%), and fatigue (69%) being the most commonly reported. Tragically, these researchers also highlighted that rarely was there any documentation on patients' charts identifying the implementation of interventions aimed at mitigating these symptoms.

Recently, atypical symptoms of HF, advanced HF, and ESHF have been reported in the literature, including; loss of concentration, poor attention, and memory loss, all of which can also be classified as mental fatigue that further impairs one's ability to perform the simplest of tasks (Bennett et al., 2000; Bosworth et al., 2004; Europe & Tyni-Lenne, 2004; Riegel & Carlson, 2002). All of these atypical symptoms of HF were reported by the participants involved in this research study. Riegel and Carlson (2002) further identified that individuals living with HF suffered from other atypical symptoms, including; the loss of consciousness, fainting, and dizziness. In many cases, these symptoms were recognized by the individual as warning signs that something was 'not right' with their health; however, they did not always associate these symptoms as being linked to their HF.

Falling and the loss of balance have also been reported as symptoms of living with HF, though infrequently. The literature suggests that these symptoms are associated with the side effects of medications, such as antihypertensives and diuretics; physical deconditioning; impaired oxygenation of skeletal muscle; and overall impaired cardiac function (Bennett et al., 2000; Riegel & Carlson, 2002). A number of participants within this study also identified that they suffered from episodes of falling, “blacking out”, fainting, or feeling dizzy, all of which further challenged their ability to function on a daily basis. Similar to the findings of Riegel and Carlson (2002) and Bennet and associates (2000) the participants in this study identified holding onto the wall, sitting down, resting and just generally “taking it easy” when these symptoms occurred.

Thirst and dry mouth have been documented as other atypical symptom of ESHF among individuals receiving palliative homecare (Brannstrom et al., 2006). These symptoms are believed to result from fluid restrictions and diuretic therapy. The participants in this study did not discuss suffering from dry mouths or a sense of being thirsty. Possible explanations for these participants not discussing dry mouth or thirst symptoms is that they may not have been maintaining their fluid restriction as tightly as advised by their healthcare professionals, or they may have been suffering from other more severe symptoms, and as a result did not mention thirst and dry mouth as bothersome symptoms. The participants also may not have associated their thirst and dry mouth to their ESHF.

Three participants within this study also discussed their challenges with constipation, although they did not necessarily link their constipation to their fluid restriction or diuretic therapy. Willems and colleagues (2006) also reported constipation

as an atypical symptom of HF. These authors discovered that patients experiencing constipation frequently received contradictory and confusing advice from healthcare professionals about how to manage their array of symptoms. For example, in the case of an individual who had previously had cancer and had an ostomy, the challenge became balancing HF symptoms with constipation and injury to the stoma.

Research has identified that individuals living with HF, advanced HF, and ESHF implement varying strategies on a daily basis to help them manage their illness, and its associated symptoms. Strategies include: maintaining strict dietary restrictions (sodium and fluid); following the advice of physicians and other healthcare providers; resting and restricting one's activity, but also remaining as active as possible (Bennett et al., 2000; Brannstrom et al., 2006; Mahoney, 2001; Riegel & Carlson, 2002; Willems et al., 2006; Zambrowski, 2003); striving to maintain a normal body weight, and weighing oneself frequently (Bennett et al., 2000; Riegel & Carlson, 2002); and learning to listen and respond to what one's body was telling them (Willems et al., 2006; Zambrowski, 2003). Complying with medication regimes has also been identified in the literature as an important strategy to manage the symptoms of the disease. Zambrowski (2003) in a phenomenological study of 11 participants reported that individuals living with HF on average take almost eight medications daily to manage their HF and other illnesses.

The participants involved in this research project reinforced that living with ESHF required great efforts on a daily basis to manage their symptoms and prevent the worsening of their HF. All of the management strategies identified in the literature cited previously were discussed by participants in this study as interventions that they too employed. In contrast to the literature; however, no individuals involved in this research

project identified weighing themselves daily as a strategy to monitor their condition, and only three participants identified that sodium and fluid restrictions were a common practice in their daily efforts to manage their ESHF. It is possible that the participants were so accustomed to following these restrictions that they became second nature to them, and were thus not considered to be strategies aimed at minimizing their symptoms of ESHF. Alternatively, participants might not have been adhering to sodium and fluid restrictions because they chose not to, or because they may have been unaware of the importance of the restrictions. The participants did broadly discuss “following medical regimens”, which may have included abiding by dietary restrictions (fluid and sodium). In many cases the participants did not define what medical regimens entailed, but rather suggested that one did as their healthcare professionals advised them to do.

Noncompliance with treatment regimens in HF has been demonstrated to lead to worsening HF symptoms, hospitalization, and even death. In Canada, research has demonstrated that 15% of HF exacerbations are the result of noncompliance with sodium restrictions, 4% are the result of excessive fluid intake, and that noncompliance with medications are not common causes for admission to hospital (Tsuyuki et al., 2001). German researchers identified that among 179 patients hospitalized for HF, almost 42% of the admissions were preventable and were related to noncompliance with treatment regimens (Michalsen, Konig, & Thimme, 1998). Most notably 23% of admissions were due to noncompliance with one’s cardiac medications and participants reported either not taking their medications at all, or taking them intermittently. These researchers also reported that 34% of participants consumed greater than 2.5 litres of fluid per day and that only 26% of the participants were knowledgeable about the reasons a fluid restriction

was necessary. Furthermore, although most of the participants (86%) had weigh scales at home, fewer than 40% weighed themselves regularly.

In relation to noncompliance with sodium restrictions, research in the United States demonstrated that individuals suffered from more frequent and increased severity of HF symptoms, including dyspnea, orthopnea, edema, fatigue, and loss of appetite when sodium restrictions were not followed (Son, Lee, & Song, 2011). These individuals were also almost twice as likely to present to emergency rooms, be hospitalized, and even die from cardiac associated difficulties. Opasich and colleagues (2001) also identified that worsening HF was the result of noncompliance (21%) with fluid and sodium restrictions and medication regimens, and infection (12%) among 215 individuals who were hospitalized with decompensated HF. In 21% of cases no precipitating factor was identified.

*Managing coexisting challenges.*

The participants in this study reported that they not only faced daily challenges from ESHF, but also various other challenges related to aging, coexisting illness such as arthritis, diabetes mellitus, and residual effects from previous cerebral vascular accidents. The extra burden of balancing and managing other co-morbidities in addition to their ESHF further taxed each individual's ability to cope on a daily basis and added increased stress to their lives.

That individuals living with HF, advanced HF, and ESHF also live with a number of other illness that in combination make daily life extremely challenging has been reported in the literature. The majority of patients living with ESHF are elderly and have more than one other illness (Boyd et al., 2004; Kaasalainen et al., 2011; Mahoney, 2001;

Riegel & Carlson, 2002, Willems, 2006). Boyd and colleagues (2004) reported that in their study of 20 individuals living with ESHF (NYHA IV) 11 participants also suffered from considerable co-morbidity as a result of diabetes mellitus, lung disease, arthritis, visual impairment, deafness, and liver and renal problems. Willems and associates (2006) reported that of their 31 participants living with ESHF (NYHA III-IV), the majority suffered from important co-morbidities ranging from diabetes mellitus and chronic lung conditions to bladder polyposis. Participants in that study were attempting to manage their daily weights and symptoms of ESHF, whilst at the same time struggling with blood sugar control and the administration of numerous medications for varying illnesses. Willems and colleagues (2006) also highlighted that the addition of extra challenges and burdens further resulted in the participants having to develop, alter, and revise plans and strategies in order to deal with the multiplicity of challenges they faced in the hopes of achieving the best possible outcome.

Consistent with the findings in this study, the literature documents that, in addition to the challenge of managing their ESHF, individuals face every day challenges, such as coping with the death of a spouse or serving as a caregiver for an ill, dependent spouse (Riegel & Carlson, 2002). The participants in this study reported experiencing the similar everyday challenge of grieving the loss of a spouse or a friend; however, none of the participants were caring for an ill dependent spouse. One participant had a close special friend who was battling depression whom he was struggling to support while managing his own ESHF.

The fact that medications utilized for HF management may have side effects, such as frequent urination, urgency, and incontinence related to diuretic therapy, which can

interrupt one's sleep cycle or one's ability to perform social activities during the day, has been documented in previous research (Bennett et al, 2000; Boyd et al., 2004; Riegel & Carlson, 2002; Willems et al., 2006; Zambrowski, 2003). Individuals living with HF have reported that as a result of diuretic therapy, they can spend up to a total of four hours per day in the bathroom eliminating fluid from their bodies (Zambrowski, 2003). Balancing social interaction with fluid elimination is a difficult task and research suggests that in order to facilitate leaving their homes, some HF patients have resorted to wearing adult briefs or diapers (Riegel & Carlson, 2002), preplanning activities based upon locations of restrooms (Riegel & Carlson, 2002) and altering the timing of their diuretic medications or skipping a dose (Bennet et al., 2000; Boyd et al., 2004; Riegel & Carlson; 2002; Zambroski, 2003). Similar strategies were embraced by the participants in this study as they worked to manage the co-existing challenge of medication side effects. These strategies included altering the timing of diuretic medications, wearing adult diapers, and use of a urinal at night to avoid the risk of a fall associated with having to get up to the bathroom.

*Living good days and bad days.*

Chronic illness is unpredictable and individuals live with daily uncertainty regarding when they might experience an exacerbation of their symptoms, how long a period of symptom exacerbation might last, and when their symptoms might stabilize (Charmaz, 1983). For individuals living with chronic illness "good days" and "bad days" and even "bad spells" becomes their reality. The degree of symptom distress and functional impairment experienced governs how one defines his/her day. Within this study, participants identified that their symptoms and functional limitations varied over

each day, and day by day. As a result, they lived some days that were better than others and these days were described as “good days.” Specifically, good days occurred when strategies aimed at managing symptoms of ESHF were relatively successful; participants suffered minimal symptom distress, and were able to perform increased physical activity. In contrast, “bad days” entailed severe symptom distress and severely reduced physical functioning.

Ryan and Farrelly (2009) in their interpretive phenomenological study of nine individuals living in the community with advanced HF (NYHA III & IV) identified that the participant’s symptoms of HF varied over the day and from day to day influencing participants’ abilities to plan activities over the day. Some days were reported as better than others. Better days occurred when the symptoms of HF were less and the individual was capable of performing more physical activity. When their symptoms of advanced HF were less prominent, participants reported a “precarious calm” where they feared and lived with the uncertainty of when the symptoms would return. Participants all definitely expected that their symptoms would worsen and possibly be severe and unbearable. Interpretive phenomenological research examining the experiences of four non-hospitalized individuals living with ESHF and receiving specialized community palliative care (PC) described life as a “roller coaster” where the participants oscillated between ups and downs due to the variability and unpredictability of symptoms involved with their ESHF (Brannstrom et al., 2006). This oscillating of symptoms led to confusion for the individual and a lack of understanding of what to expect during the course of the day, and day to day. Consistent with previous findings, the individuals in Brannstrom et al’s study too reported that some days were better than others and other days were worse.

*Managing one's emotions.*

Not surprisingly, research documents that patients living with chronic illness experience a variety of distressing emotions. These include: frustration and anger related to not being able to do as one had in the past or no longer being able to fulfill one's home or work responsibilities; guilt as a result of relying on others to meet one's daily needs; fear of the unknown; having a body that is out of control; and of dying (Rush Michael, 1996). Individuals with chronic illness may also experience sadness or discouragement because they feel physically incapable and ponder about what could have been if their illness had not occurred.

The literature documents that living with HF, advanced HF, and ESHF is psychologically and emotionally difficult for patients due to the number of physical and social losses they endure as a result of their disease and its symptoms. The literature documents that individuals with ESHF often experience multiple and ongoing losses within their relationships and social networks. Most notably these include the loss of; one's spouse through divorce (Europe & Tyni-Lenne, 2004), friends, hobbies, and roles or responsibilities (Bosworth et al., 2004; Boyd et al., 2004; Evangelista, Kagawa-Singer, & Dracup, 2001; Martensson, Karlsson, & Fridlund, 1997; Rhodes & Bowles, 2002; Riegel & Carlson, 2002; Ryan & Farrelly, 2009; Waterworth & Jorgensen, 2010; Willems et al., 2006; Zambroski, 2003). Consistent with emotions reported in patients living with chronic illness, the literature documents that those living with HF, advanced HF, and ESHF experience feelings of frustration, anger, worry, and depression (Bosworth et al., 2004; Boyd et al., 2004; Europe & Tyni-Lenne, 2004; Evangelista, Kagawa-Singer & Dracup, 2001; Riegel & Carlson, 2002). Ryan and Farrelly (2009)

identified that many individuals living with advanced HF (NYHA III-IV) developed a sense of hopelessness, powerlessness, and despair related to the symptoms of advanced HF and its associated negative impact on their lives.

Participants in this study also expressed feelings of frustration and powerlessness due to the fact that they were not able to complete tasks as readily as they had in the past, if at all. Individuals uniformly expressed their desire to be able to do more for themselves by way of performing physical tasks and activities. None of the participants in this study expressed anger or appeared to be depressed; however, they identified that maintaining a positive outlook on life was important to them and aided them in having the mental strength to make the most of each day. As a result, despite recognizing that they lived with a debilitating illness, the participants focused on what they could continue to accomplish and remained dedicated to meeting these goals.

Other research, although minimal, has also reported that individuals living with HF, advanced HF, and ESHF strive to maintain a positive attitude in an attempt to cope with living with their illness and to provide them with the strength to carry on each day (Dougherty, Pyper, Au, Levy, & Sullivan, 2007; Europe & Tyni-Lenne, 2004; Rhodes & Bowles, 2002; Waterworth & Jorgensen, 2010).

Four participants in this study reported that their spirituality provided them with a buffer against the tremendous losses and daily challenges that they faced living with ESHF; thereby, counteracting negative and discouraging feelings. Spirituality provided these individuals with a source of strength and assisted them in maintaining a positive outlook in life, and a focus on the here and now. Participants indicated that prayer provided them with an opportunity to ask God for assistance and guidance through their

difficult times. Prayer also reinforced their belief in a higher power who had an overall plan for their life. Furthermore, participants in this study identified that their spirituality offered them a source of hope for a better future, most notably an afterlife free of suffering. As a result, spirituality was viewed by these participants as a coping mechanism that helped them to mentally accept the reality of living with and dying from ESHF.

Spirituality is considered an important aspect of quality end of life care, and patients living with chronic illness have demonstrated their desire to have spirituality included within their care (Alcorn et al., 2010; Bosworth et al., 2004; Delgado-Guay et al., 2011; Evangelista et al., 2001; Mahoney, 2001; McNulty et al., 2004; Patel et al., 2002; Rhodes & Bowles, 2002; Riegel & Carlson, 2002; Waterworth & Jorgensen, 2010, Zambroski, 2003). Spirituality has been defined by Puchalski and colleagues (2009) as:

The aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. (p.887)

This definition does not differentiate religion as a separate entity, but rather considers religion as an important aspect of spirituality. Thus one's spirituality may or may not contain components of organized religion. Individuals who participate in spiritual/religious practices, such as prayer or the worshipping of a higher being may experience comfort and hope during their illness (Cohen, Headley, & Sherwood, 2000; Lazenby, 2010; Narayanasamy, 2002; Riley et al., 1998). In many cases, spirituality assists chronically ill individuals in their search for meaning and purpose in life during illness, through a connectedness to God or other higher being(s). In particular spirituality

has been identified as helping improve patients' quality of life (QOL) and aiding them to cope with such diseases as advanced cancer (Alcorn et al., 2010; Delgado-Guay et al., 2011), end-stage renal disease (Patel, Shah, Peterson, & Kimmel, 2002), multiple sclerosis (McNulty, Livneh, & Wilson, 2004), and HF, advanced HF, and ESHF (Bosworth et al., 2004; Evangelista et al., 2001; Mahoney, 2001; Rhodes & Bowles, 2002; Riegel & Carlson, 2002; Waterworth & Jorgensen, 2010; Zambroski, 2003).

Bosworth and colleagues (2004) identified that individuals living with advanced HF and most commonly those with NYHA stage III and IV disease more frequently discussed spirituality as an important coping mechanism than those individuals living with NYHA stage I or II HF. For these individuals attending church, praying and believing that a higher power had control over one's course of illness provided individuals with a coping mechanism and strategies that helped them manage their illness in the present, and prepare for a better future.

*Living in a small world.*

The findings of this study identified that living with ESHF limits an individual's functional ability and ultimately the ability to venture very far from their home environment. The restrictions imposed by the illness resulted in the limiting of one's social life, and in some cases, feelings of isolation. For example, participants in this study reported that they had given up going to church, had to rely on friends to come and visit them if social interaction was to occur, and had to have groceries delivered versus going out to do shopping. For most participants, leaving home was a rare event, except for going to doctor appointments. These findings support those of other researchers who have also identified living with advanced HF and ESHF results in a restricted life (Boyd

et al., 2004; Brannstrom et al., 2006; Murray et al., 2002; Ryan & Farrely, 2009). Ryan and Farrely (2009) reported that for individuals living with advanced HF everyday tasks that were once easily accomplished such as walking down the street or going to church had become daunting challenges. As a result, their participants reported becoming increasingly confined to their home environment and developing feelings of being imprisoned and defeated. Murray and colleagues (2002) also found that as one's HF worsened and progressed towards end-stage disease, individuals became increasingly confined to their home environment and later their bed. Boyd and associates (2004) identified that ESHF resulted in severe physical limitations and reduced confidence in one's abilities to venture about safely, which led to considerable social isolation. Willems and colleagues (2006) reported that individuals living with ESHF had to deal with progressively deteriorating physical functioning. This deterioration resulted in them becoming increasingly restricted to their homes, and eventually to the ground floor of their home. This reality resulted in an inability to leave their home on an impulse and ultimately to a limited social life. Willems and associates (2006) also reported that the reduced ability of their participants to satisfy roles and relationships because of their disease and the impact of this on their self-esteem further increased the social isolation individuals with ESHF experienced. However, participants in their study who had a strong support network were reported to more readily cope with ESHF and felt they were less socially isolated.

Individuals living with ESHF and receiving palliative homecare have also reported that they struggled with a sense of loneliness, isolation, and feelings of being trapped at home (Brannstrom et al., 2006). These researchers reported that as an

individual's HF progressed to end-stage disease they became less physically capable of leaving their homes, or going out into their yards. They had fewer and fewer visits from friends and family, which caused them to feel abandoned and let down. Furthermore, the transition from acute medical care in hospital to PC in the community initially caused participants to feel abandoned by the healthcare team until the PC services were initiated. Feeling alone, abandoned, and isolated was especially acute during the winter months, and for those individuals who lived alone. However, receiving visits from palliative homecare workers reduced feelings of isolation, abandonment, and loneliness among the sample, and provided them with a sense of security that they had someone they could call for round the clock assistance if needed.

Six of the participants in the present study reported no sense of feeling abandoned by their friends, loved ones, or healthcare professionals. Rather, they all reported that they were extremely satisfied with the care and support that they received from their healthcare team, and all but one participant indicated feeling well supported and loved by their family and friends. However, this individual had not received support from his family for many years prior to his development of ESHF. It was frequently reported by participants that if they required help, they just had to place a telephone call and a family member or friend would come to assist them. Despite receiving tremendous support from family and friends and being desirous of interaction with them, study participants indicated that on most days they did not have the physical strength to participate in social activities. As a result they developed a sense of feeling trapped within their physical bodies and the confines of their homes.

This finding is consistent with Charmaz' (1983) work examining the impact of chronic illness on one's environment. She notes that living with chronic illness consumes one's life and challenges the values and meaning that one had previously associated with their self concept in healthier times. Physical limitations, symptom distress, and the daily struggle to manage one's illness along with its emotional and psychological consequences becomes the reality for the individual. Thus living with chronic illness ultimately can lead to difficulties in leaving one's home environment resulting in one living a restricted life (Charmaz, 1983). As managing one's illness becomes the priority, all energy is refocused on meeting the goals of the individual. Trade-offs must occur, including curtailing the amount of time and energy that can be invested in work, and social relationships. As physical limitations impact the ability to meet one's employment responsibilities or responsibilities of social relationships, one's world becomes increasingly smaller. An individual with ESHF who was previously readily able to go to work or to visit with friends, must now rely on others to come to them; thereby, placing extra burden on others and ultimately reducing social contact further. Individuals with ESHF who live alone have even further reduced social contact and are at even greater risk of social isolation and living in a small restricted world. As was evidenced in the present study, chronic illness results in living a restricted life encompassing social isolation.

Other research has also highlighted the isolating impact that chronic illness has on individuals. Rush Michael (1996) completed a phenomenological study of 17 people with varying chronic illnesses and identified that a sense of isolation occurred as a result of: the physical and emotional symptoms, physical limitations caused by the illness, and

feeling different from others due to illness related symptoms or physical deformities. As a result, individuals living with chronic illness may perceive that they are not being seen as a “person” by family, friends, and healthcare professionals, but rather as an illness or disease.

### *The Work of Choreographing Daily Living*

Life consists of change on a daily basis and living with chronic illness is no exception; however, chronic illness leads to many unexpected and undesired changes. Individuals living with chronic illness must make many accommodations in their daily lives, to respond to the demands and counterbalance the consequences of their disease (Rush Michael, 1996). The participants within this study identified that living with ESHF was extremely burdensome because the physical and psychological impact of the disease. To counteract the negative impact that ESHF had on their lives, participants reported that they adopted a positive mindset (as previously described) and devised strategies and processes to aide them in getting through each day, and meeting their needs safely. The work of choreographing each and every day was described by participants as extremely difficult work.

### *Not giving in to it: doing what you can each day.*

The participants within this study identified that continuing to do for themselves within their functional abilities was an important aspect of living with ESHF. Not giving into the illness and discovering one’s capacity to care for oneself to the degree possible within the limitations imposed by ESHF provided participants with a sense of control and purpose in life, despite facing a great number of losses and challenges. This finding reinforces those of Zambroski (2003), who identified that living with HF equated to living at sea

where the individual developed strategies to navigate and overcome the physical, emotional and social turbulence associated with HF. The phrase coined by Zambroski to capture this experience was “too much water and not enough wind.” Consistent with the findings of the current study, Zambroski’s sample of HF patients reported that giving up was not an option. Rather the participants opted to forge ahead and learn how to live life with a diagnosis of HF. Navigating within the context of HF as reported by Zambroski (2003) encompassed patients asking three questions, which included “Where am I?” In answering this question, participants were determining position, which entailed them figuring out how their HF was currently being managed or controlled, and the successfulness of the strategies employed to achieve that goal. “Where am I going?” was the second question asked and in answering this question, patients were charting the course of their lives. This entailed analyzing their prevailing circumstances, forecasting the effectiveness of anticipated actions, and incorporating the information that they had been provided surrounding the management of their HF. As a result of determining their position and charting their course, participants in Zambroski’s study engaged in the process of operating, that included a series of self care strategies that individuals engaged in to manage the turbulence caused by their HF. Operating answered the question “How do I get there?”

Other research has also highlighted that individuals living with HF choose to continue to do for themselves despite their diagnosis (Bennett et al., 2000; Martensson, Karlsson, & Fridlund, 1998; Martensson et al., 1997; Rhodes & Bowles, 2002; Stull et al., 1999). The HF participants within these studies reported that they had not given up,

and they forced themselves to continue to do things for themselves no matter how bad they felt.

Bosworth and colleagues (2004) identified that living with advanced HF involved making concessions where individuals gave up specific tasks that they could no longer do for themselves, but at the same time found other less physically demanding things that they could do. These individuals reported that they did not dwell on what they were unable to do but rather, focused their energies on what they were capable of doing.

Waterworth and Jorgensen (2010) also reported that individuals living with advanced HF endorsed “not giving up”, forging ahead, taking an active role in meeting one’s needs, and working to minimize physical deterioration. Engagement in these tasks was reported as providing the individual with a sense of purpose, control, self worth, and most importantly reduced the belief that they were being a burden to others. Willems and colleagues (2006) reported that individuals living with ESHF made the decision to continue to perform activities for themselves, such as meal preparation, bathing and getting to the toilet, all of which represented serious, energy consuming work for the individual. All of these aforementioned studies reinforce the findings of this research project highlighting that individuals living with ESHF tend not to give into their illness, but rather work to find ways to live as normal a life as possible within the confines of their illness.

*Gauging and pacing of activities and routines: conserving self.*

Individuals living with ESHF in this study identified that continuing to be an active member in their self care was important; however, to continue to do for oneself required that each individual discovered methods and strategies that would allow them to

meet their needs in an energy efficient manner. Such strategies helped in conserving energy for future activities and preventing exhaustion and worsening symptoms of ESHF. Strategies employed included; listening to and interpreting what one's body was telling them, gauging and pacing of activities, and developing routines and resting when required. Some of the participants also reported that they altered their work habits and postponed or gave up activities that were too physically taxing for them to complete, replacing them with other less taxing activities that they enjoyed. These findings reinforce those of Bennett and colleagues (2000) who identified that individuals living with HF implemented a number of strategies in order to manage the symptoms and fatigue associated with HF. Some of the strategies employed included: gauging the required energy to perform the specific activity; changing one's level of physical activity, by completing activities at a slower pace, resting between activities, waiting a few minutes prior to performing an activity; and avoiding certain activities, such as climbing stairs.

By weighing the energy required to perform a task and then balancing one's available energy during activity and resting as needed, individuals attempted to prevent exhaustion and worsening of HF symptoms. Research suggests that some individuals living with HF and advanced HF give up certain activities that consume more energy than they could provide and spare (Bosworth et al., 2004; Martensson et al., 1997; Waterworth & Jorgensen, 2010; Willems et al., 2006; Zambroski, 2003). Activities that had been given up were replaced with other activities that they enjoyed and required less energy, such as reading or watching television (Bosworth et al., 2004; Waterworth & Jorgensen, 2010; Zambroski, 2003). For others individuals, changes in employment in the form of

change in job, reduction of work hours or retirement was required (Bosworth et al., 2004; Europe & Tyni-Lenne, 2004; Evangelista et al., 2001; Martensson et al., 1997; Riegel & Carlson, 2002; Willems et al., 2006; Zambroski, 2003).

Waterworth and Jorgensen (2010) also identified that living with advanced HF required that individuals learn to read and listen to their bodies and develop an ability to pace activities and incorporate rest periods between and during activities. For these individuals, structure and working towards minimizing deterioration aided them in developing a sense of control, while at the same time assisted in making them feel better physically and mentally. The desired outcome associated with listening to one's body and pacing activities was the ability to perform tasks for oneself without causing exhaustion and worsening of HF symptoms.

Research conducted with those living with ESHF receiving palliative homecare services indicates that these individuals too devised strategies to live with their illness on a daily basis. These strategies involved resting and sleeping a great deal during the day, resting between activities, and developing everyday routines, which facilitated sleeping and resting. For example, going to bed and getting up at the same time each day and taking one's time to perform their activities of daily living and allowing for rest periods during and in between activities (Brannstrom et al., 2006).

One other strategy for managing HF identified in the literature is that of calling for help or sending out a "mayday call" during times of emergencies. Such calls were necessary when the individual was no longer able to effectively control their symptoms of HF (Zambroski, 2003), advanced HF (Ryan & Farrelly, 2009) or ESHF (Brannstrom et al., 2006). Although the participants within this research study indicated that they believed

they received excellent care from their family physician and members of the HF clinic, they all too reported that at some point in time they had needed to call for help from their family, friends or healthcare professionals because of worsening symptoms of ESHF, including severe dyspnea, lethargy, orthopnea, edema, and pain.

*Living with paradox: accepting help in order to remain independent.*

Despite the fact that participants in this study valued being independent and able to do as much for themselves as possible, the findings from this study identified that they also recognized the need to accept help from external resources to meet their daily needs safely. Participants in this study accepted this help willingly. “Help” took different forms, such as: physical aides, including canes, walkers, hospital beds, medications, oxygen, specialized devices, motorized scooters, electric lift chairs; family and friends; medical professionals; homecare; and private support workers. These findings reinforce those of Bennett and colleagues (2000) who identified that individuals living with HF rely on: medications, such as diuretics, sedatives and antidepressants; dietary restrictions, including fluid and sodium restrictions; physical aides, such as canes to prevent falling and aide with ambulation, weigh scales to check daily weights, computers to improve one’s memory and concentration; and family and friends to provide emotional support and practical assistance with such things as household chores. Unlike the findings of the present study, Bennett et al did not report that their participants identified healthcare professionals, homecare support, or privately hired support services as beneficial strategies in managing their HF on a daily basis.

Riegel and Carlson (2002) also identified strategies employed by individuals living with HF to maintain their independence. Strategies employed by participants in

their study included: following treatment regimens, such as complying with dietary practices (sodium and fluid restrictions), exercise routines, daily weights, and prescribed medications; finding ways to adapt, including modifying one's environment, such as using a step stool in the kitchen, a night light in the hallway at night to reduce the risk of falling, utilizing canes and walkers, and wearing diapers to manage incontinence.

Depending on others, such as family, friends, healthcare professionals, and paid caregivers for emotional support and tangible support for transportation, house cleaning, cooking, and bathing and medical professionals for information, guidance, support, and medical care was also reported by these researchers. Riegel and Carlson (2002) also reported that some of the individuals in their sample developed a sense of comfort and trust with the nurses and doctors who provided them with care.

The findings from this research study and those of Riegel and Carlson (2002) have demonstrated that individuals living with HF and ESHF desire a good relationship with their healthcare team, and wish their care to be holistic in its focus. Individuals living with chronic illness have expressed concerns related to the way that they are viewed by others, including healthcare professionals, who focus only on the illness characteristics of the individual, such as deformed hands or oxygen needs and fail to acknowledge the whole person (Rush Michael, 1996). Though they desire to be seen and treated as a person requiring an individualized plan of care (Charmaz, 1983), the literature indicates that some individuals with chronic illness experience a loss of connectedness, perceive that as persons they go "unnoticed" and ultimately develop the feeling that they are not cared about as a person. Charmaz's (1983) work in the area of chronic illness has identified that the relationship between healthcare professionals and

the chronically ill can take on significant meaning for the ill individual, and a healthcare professional who dedicates time to the chronically ill and listens to their concerns is important and desired by patients. Furthermore, Boyd and associates (2004) have identified that patients appreciate healthcare professionals who are not rushed, have good communication skills, convey a genuine interest in their wellbeing, and include them as a partner and active participant in the discussions when developing their plan of care.

The literature suggests that health care professionals may not always listen to, or engage patients in the manner that patients desire. Boyd and colleagues (2004) reported that the care received by individuals living with advanced HF (NYHA IV) tended to be professionally led, meaning that the healthcare professional devised the plan based upon what they believed was in the best interest of the patient and the patient was to follow it, versus through a partnership approach preferred by patients. Within the present study, all participants identified that they felt they were well taken care of by their healthcare professionals, were treated with respect and as an individual, and that all aspects of their care and needs were considered. Overall, the participants within this study felt that their healthcare professionals understood what they were going through and developed care plans that were specific to their individualized needs.

Individuals living with ESHF in the community also reported that they accepted help to manage their HF on a daily basis. Willems and associates (2006) identified that their participants utilized sodium and fluid restrictions, medications, and walking aides along with relying on healthcare professionals and family and friends to assist them to meet their needs and manage their HF symptoms. Brannstrom and colleagues (2006) have also reported that individuals living with ESHF and receiving palliative homecare

manage their HF by following sodium and fluid restrictions, using medications, using continuous positive airway pressure ventilation as a source of oxygen delivery, using urinary catheters to aide in urine elimination, weighing oneself, sleeping in an arm chair, and relying on loved ones and friends for assistance with bathing, cooking, cleaning and meal preparations. These individuals were also receiving specialized palliative homecare and viewed the overall experience as a positive one. Factors contributing to the positive nature of patient experience included the healthcare professional treating the individual as a person and demonstrating a genuine interest in their wellbeing and considering the patient as a partner within their care team. Overall, the individuals reported that the competent professional care they received provided them with a sense of being well cared for and feelings of trust and security were formed related to the fact that they had access to specialized healthcare professionals 24 hours a day seven days a week.

As participants in this study commented about feeling a burden to others on occasion, the issue of dependence as described in the chronic illness literature is relevant to this study. Chronically ill individuals struggle on a daily basis to control themselves, their illness, and their lives as a whole. When this control is no longer possible, one's image and self concept are negatively impacted (Charmaz, 1983). When a person discovers that they are no longer able to fulfill a valued attribute or function that they had linked to their past positive self image, they begin to discredit themselves. Over time, as one fails to meet their expectations or goals, they begin to believe that they are a permanent failure and burden to others. Most commonly, being a burden is linked to increased dependence, immobilization, and reliance on others to meet one's needs (Charmaz, 1983). Some individuals living with chronic illness may also view themselves

as a psychological or financial burden on others. The dependent individual does not desire to be dependent, and as a result further suffers a loss of self concept related to the fact they are no longer able to claim identities based upon previous external activities, interests, pursuits and obligations of past relationships. The end result of believing that one has become a burden is developing feelings of uselessness to self and others. Therefore, dependence on others has the potential to lead to a sense of uselessness for those living with chronic illness.

Individuals living with HF have also reported that they were or feared becoming dependent upon and a burden to others (Evangelista et al., 2001; Gott et al., 2008; Waterwoth & Jorgensen, 2010). This finding is similar to those of Ryan and Farrelly (2009) and Bosworth and associates (2004) who also reported that becoming dependent upon others to meet the needs of individuals living with ESHF can lead one to feel that they are a burden on their loved ones and ultimately feelings of frustration, sadness, anger, and guilt within the individual related to their loss of independence and their dependence upon others. Unfortunately, Boyd and colleagues (2004) identified that few patients living with ESHF were offered social services, benefits advice, or volunteer services and that some individuals who had to accept help from others for tasks, such as bathing or were required to use a wheelchair or other mobility aid struggled with a sense of loss of dignity. The finding in this study that all participants were extremely appreciative of the assistance that they received stands in contrast to findings reported in the literature.

The findings of this research study reinforce the previously discussed research findings which identify that individuals living with ESHF do believe that they have

become a burden to their loved ones and the overall healthcare system as a whole and as a result feel that they are useless to themselves, and others. One participant expressed concern and feelings of guilt about how dependent he had become on his wife to meet his daily needs. Another participant discussed how he had distanced himself from his family and now had to rely on paid workers and social services to ensure his needs were met. This participant considered himself a burden to the tax payer and healthcare system as a whole. Other participants highlighted the fact that they relied on their children who also had busy families of their own and associated family responsibilities to assist them in meeting their needs. Because these individuals perceived themselves as a burden to their families, they made efforts to minimize the number of times that they would have to disturb their children to help them. All participants involved in this research study expressed to some degree that they felt that they were useless based upon the fact that they had to rely on others to assist them in meeting their daily needs. Overall, the findings from this research study reinforce that individuals living with ESHF have complex needs and face many challenges on a daily basis, one of which is balancing dependence on available supports with independence.

In regards to the issue of financial burden, the SUPPORT study has also demonstrated that living with ESHF causes dire financial consequences for the individual and their families. By the time the individuals with ESHF were three days from death surrogates (n=539) reported that 13% had a family member who quit work to care for the ill individual, 16% of families had lost their major source of income, and 23% of families had exhausted most or all of their family savings due to the individual's illness (Levenson et al., 2000).

A great deal of care and support is especially required during one's end of life. In 1996 more than 262,917 Canadians had cared for family members or friends who died within the past year, providing 2.2 million hours of care per week, or the equivalent of 59,569 full-time employees (Fast, Neihaus, Eales, & Keating, 2002). Those who provided care were most commonly young, married/cohabitating, relatively well educated, and employed, causing tensions between providing care to a loved one/friend and other roles associated with work and home life, resulting in economic, physical, social, and psychological consequences for those providing care. Services frequently provided by carers included personal care, meal preparation, transportation, and domestic care, such as shopping and housekeeping.

Charmaz (1983) highlighted the importance of social contact with family, friends or even just a friendly neighbor to reduce the sense of isolation and loss of self that people living with chronic illness feel. However, in order for a family member or friend to be supportive it is necessary for them to be capable of placing the ill person's behaviors into perspective related to their illness and management strategy, without themselves feeling diminished by it. It is also imperative that family and loved ones emphasize the positive aspects of the ill person's current life and are comforting surrounding the lost attributes, functions, and actions that the ill person has sustained. Most notably, wives have been demonstrated to support their husband's identity development and reduce the impact that dependency has on the individual's illness identity (Charmaz, 1983). Overall, supportive family members and loved ones enhance and support the ill person's self and maintain a link to one's past pre-illness self.

Waterworth and Jorgensen (2010) reported that some individuals living with advanced HF may need to move from home to facilities where staff are readily available to meet one's care needs. One participant in this study who did not have a supportive family identified that he had to move out of his house and to an alternate care setting where his needs could be met. This move was viewed as a positive experience for this individual. That this individual reported his experience as positive stands in contrast to reports in the literature indicating that individuals living with HF, advanced HF, and ESHF typically report that they fear becoming dependent on others to provide their physical care needs and prefer death over total dependence and moving to a personal care home (Boyd et al., 2004; Dougherty et al., 2007; Willems et al., 2004).

Research has also documented that individuals living with advanced HF frequently had to seek assistance to manage acute episodes of HF by being admitted to the hospital. Although it accomplished the desired goal of reducing the symptoms of HF, in many cases the hospital experience was characterized as not being a positive one (Martensson et al., 1998; Ryan & Farrelly, 2009). Some individuals who were frequently admitted to hospital began to develop a sense that they were a nuisance to the staff and were wasting the time of the healthcare professionals. Although few of the individuals within this research project discussed hospitalization, none of them indicated that they were made to feel that they were a nuisance to their healthcare professionals. Rather, in all cases participants reported that they felt that they received excellent compassionate care from their healthcare professionals.

*Taking time to enjoy small pleasures: finding happiness amongst the challenges.*

Living with ESHF encompasses many losses and daily challenges, and the participants within this study identified that it was important to recognize and grieve these losses. However, they also stressed the importance of discovering new sources of happiness and pleasure. The sources of happiness and pleasure acted as a buffer to counteract the daily negative aspects of living with ESHF. Study participants identified that they found happiness within their home environment through: telephone conversations with and visits from loved ones; feeding birds in one's yard; and interacting with beloved pets. Other research has also highlighted the importance of moving beyond the losses associated with living with HF, advanced HF, and ESHF and rediscovering activities and interests that one is capable of performing (Bosworth et al., 2004; Waterworth & Jorgensen, 2010; Zambroski, 2003).

Individuals in this research study also discussed finding sources of happiness outside of their home, such as at day programs where socialization occurred with individuals with similar health concerns, or outings with family members or loved ones. Bosworth and colleagues (2004) also have reported that individuals living with advanced HF who attended a support group for individuals living with HF found comfort in not only discussing living with HF with others, but most importantly, in having the opportunity for social contact. Within this research study two participants discussed that their pet cat or dog, respectively, were a source of happiness, and offered comfort and distraction from the challenges of living with ESHF. This finding reinforces those of Rhodes and Bowles (2002) and Riegel and Carlson (2002) whose study participants

discussed the important role that pets play in providing emotional support, helping them cope with living with HF, and providing them with a sense of purpose in life.

One participant in this study identified food as a source of pleasure for her. She reported that she had opted to eat foods that she enjoyed prior to her diagnosis of HF. This individual acknowledged that she was dying as result of ESHF and decided to enjoy the remainder of her life, versus living a life governed by dietary restrictions. As a result, she did not abide by a sodium restriction and chose to eat what she enjoyed. Riegel and Carlson (2002) also reported that one individual in their study coped with the strict dietary restrictions that were part of managing his HF by opting to treat Sundays as his “cheating day” where he went to a restaurant and ate what ever he wanted. This weekly compromise was experienced as a source of pleasure for that individual. The subtheme, “taking time to enjoy small pleasures: finding happiness amongst the challenges” revealed that it was important for individuals living with ESHF to discover sources of happiness and pleasure in an effort to counteract the negative aspects of living with their disease. Many individuals were able to find sources of happiness and pleasure within and outside the confines of their home environment.

#### *The Work of Charting the Final Chapter of One’s Life*

All of the participants within this study acknowledged that they would die from ESHF at some point in time, and recognized that they were living on borrowed time. Interviews with participants demonstrated that they all had contemplated and planned for the end of their lives; each in their own unique way. This contemplation and planning was involved in the work of charting the final chapter of one’s life.

*Acknowledging the inevitable: living on borrowed time.*

Though all participants in this study knew that they would die from ESHF, they did not know when death would occur. Participants had developed an illness identity such that regaining a healthy state as prior to ESHF was not possible. Considering oneself to be healthy includes: a sense of feeling good again or feeling like one's old self again; the absence of strange sensations, where the unfamiliar body becomes familiar again; an overall sensation that one has regained control over one's life and one's body; and also an ability to trust one's body once again (Corbin, 2003). These factors were clearly not part of the participants' experience. Rather, they reported that they suffered severe symptom distress and a limited functional capacity on a daily basis. Accordingly, they were unable to trust their progressively failing bodies and recognized the fact that they would not become healthy again. Furthermore, all of the participants in the study communicated that they had accepted that the body that they currently inhabited was their new reality. Consistent with the chronic illness literature they had formed a new identity, which included acknowledging one's disabilities and mortality.

The fact that living with moderate HF (NYHA class II – III) requires one to form a new identity based upon one's illness was described by Europe and Tyni-Lenne (2004). These researchers identified that living with moderate HF required men to form a new illness identity that was based upon a number of consequences of their illness. The consequences that were identified included: i) physical consequences, which were described as physical signs and symptoms (fatigue, dyspnea and dizziness); ii) reduced functional capacity and sexual dysfunction; emotional consequences that varied from a sense of anxiety and frustration through to feelings of depression; iii) cognitive

consequences related to decreased memory function; iv) social consequences, including the potential for divorce, due to symptoms and the inability to meet the demands of one's former social life; and v) vocational consequences that ranged from retiring, reducing one's work hours, or changing jobs. This new illness identity was formed on the basis of an unhealthy and failing heart and included acknowledgment that death would occur because of it. Overall, the new illness identity that was formed resulted from the pathophysiological changes of moderate HF and its effects on the individual's daily life.

Mahoney (2001) identified surrendering as a method that individuals employed to reconcile living with HF. Surrendering was defined as the "act of accepting, letting go, having peace that one can handle the illness, or abdicating responsibility for the management of the illness to another." (p. 434) Furthermore, peaceful surrender was considered as a spiritual peace that provided the individual comfort. It did not mean giving up; rather, the individual developed a realistic view that what ever happened to them things would turn out okay. Within the present study, a number of participants identified that they knew that they were going to die from their illness and that they were accepting of that reality and how it would play out.

All of the participants in this study also highlighted the fact that they had received honest information from their healthcare professionals indicating that no further invasive treatment options existed to improve their cardiac function, that their HF had progressed to end-stage disease and would only continue to progress, and that death would occur. Included within the information participants received from their cardiologist and HF clinic staff was a clear acknowledgement that prognosticating when exactly death would occur was impossible, but that death could occur today, tomorrow, or even months to

years into the future. The participants reported that receiving open, honest information surrounding the fact that death for them had become a reality aided them in realizing their own mortality and highlighted their need to plan ahead for their future.

The fact that individuals living with ESHF desire honest discussions about their illness trajectory early in their diagnosis has been reported by other researchers (Caldwell, Arthur, & Demers, 2007; Dougherty et al., 2007; Gott, Small, Barnes, Payne, & Seamark, 2008; Strachan, Ross, Rucker, Dodek, & Heyland, 2009). Caldwell and colleagues (2007) identified that Canadian individuals living with advanced HF desired to have open, honest discussions surrounding prognosis and what to expect while living with HF and ESHF early in their illness. Early timing of such discussions was important to ensure that participants were physically and mentally well enough to participate in the associated discussions and their own future planning. It was also reported that patients preferred that their physician initiate the discussion surrounding prognosis.

Research has documented that not all individuals living with ESHF receive information from their healthcare provider pertaining to their prognosis. A Canadian study conducted by Strachan and colleagues (2009) reported that patients hospitalized with advanced HF (NYHA IV) expressed a desire for information to be shared with them honestly from their healthcare professionals, and that life support be avoided in situations where no hope for a meaningful recovery existed. However, only 11% of the 106 participants reported having had a discussion with a physician pertaining to their prognosis, 43% had not discussed their wishes surrounding resuscitation preferences with anyone, and 57% of participants appreciated that they were currently or had recently faced end of life issues. Furthermore, these researchers also identified that fewer than 2%

of the participants could identify all four components involved in cardiopulmonary resuscitation (artificial breathing, chest compressions, defibrillation and drugs) and 30% of the sample could not identify any of the components. These findings reinforce the need for explanation and discussion with ESHF patients regarding what is involved in a resuscitation attempt and what the individual patient would desire.

Quite apart from meeting patients' needs in providing honest information about the progressive and terminal nature of HF, the mandate to provide such information has been stipulated within the Canadian Cardiovascular Society (CCS) HF management guidelines beginning in 2006 (Arnold et al., 2006).

Gott and colleagues (2008) interviewed 44 individuals living with ESHF about their views surrounding a good death and discovered that while very few of the participants' health professionals had discussed prognosis with them, many participants had self acknowledged the reality that they had a limited prognosis. These findings reinforce that many ESHF patients desire honest discussions with their healthcare professionals surrounding their prognosis and that individuals living with ESHF often self identify the reality that they have a terminal illness. Caldwell and colleagues (2007) also discovered that although individuals living with advanced HF (NYHA III-IV) were not informed of their prognosis by their physician, the failure of treatment options and their continued physical deterioration led patients to deduce the likelihood of their own death. Patients desired that physicians confirm this, and initiate discussion pertaining to end of life care.

As a result of receiving open, honest information from their healthcare professionals, participants within this study acknowledged that they would die as a result

of their ESHF. This awareness of their impending mortality helped them to develop the understanding that they were living on borrowed time, and that every day was a bonus day. This finding of living on borrowed time, or having one's life placed in the control of a higher being, who controlled the time that they had left to live has also been reported by other researchers. Bosworth and associates (2004) identified that individuals living with ESHF as well as their physicians were often amazed that the patient continued to be alive for subsequent appointments. The expectation was that at some point in time death would occur, but surprisingly despite poor overall health and physical functioning death had yet to occur. In the case of some men who have been diagnosed with HF and have recognized that it carried a poor prognosis it has been reported that they lost their belief for a future and became grateful for each and every day that they remained alive (Europe & Tyni-Lenne, 2004). In these studies the individuals all became aware of their mortality and the fact that each and every day was a bonus day and that they were living on borrowed time.

Contrary to the findings of the present study, Willems and associates (2004) reported that only 14 out of 31 participants living with advanced HF (NYHA III-IV) spoke about dying, while the remaining individuals did not acknowledge to the researchers that they potentially might die earlier as a result of their HF. This lack of acknowledgment may indicate that participants were missing essential information pertaining to a diagnosis of HF. It may also mean that patients were engaged in some level of denial regarding the seriousness of their condition.

Within the community PC setting, living on borrowed time was akin to what ESHF patients described as becoming aware that "one's life hangs by a fine thread." This

awareness developed from the individual: sensing one's "bad" heart through unrelenting symptoms of ESHF; visiting death's door as a result of a near death experience or the death of a loved one; and being reminded about one's failing health by physiological measures, such as undesired "bad" blood pressure and weight measures (Brannstrom et al., 2006). The very fact that they were receiving specialized community based PC was also viewed by some participants in Brannstrom and colleague's study as anxiety provoking and as an indicator that one's life was limited, and death was near.

Other research has highlighted the fact that individuals living with ESHF acknowledge their mortality and in some cases even identified that they were ready for, and looked forward to, death (Boyd et al., 2004; Dougherty, et al., 2007; Gott et al., 2008; Waterworth & Jorgensen, 2010). Within these studies death was not feared, but rather was viewed by participants as a natural part of life, and an end to their suffering from ESHF. Although individuals recognized that death would occur, they reported varying beliefs about how long they had left to live, ranging from days to months, or years. Conversely, one study reported that some patients living with ESHF fear death. Bennett and team (2000) reported that some individuals living with HF feared going to sleep at night as they may not wake up and their life would end earlier than expected. For these individuals, living with the symptoms of ESHF was preferred over death. For other individuals living with ESHF, not thinking about death was used as a coping mechanism that facilitated enjoying the present and focusing on managing the day to day realities of living with a chronic illness (Gott, et al., 2008).

Six participants within this study reported that they had lived a full life, realized many personal and professional accomplishments, and were prepared to die. These

participants stated that they preferred a peaceful death, and characterized an ideal death as going to bed and dying in their sleep. This finding reinforces that of Dougherty and colleagues (2007) and Gott and associates (2008) who reported that for individuals living with ESHF the best death was considered one that was peaceful and dignified, consisted of minimal panic and suffering, and occurred quickly in one's sleep.

The fact that the participants within this study who had an implantable cardiac defibrillator (ICD) inserted could not recall ever having had a discussion about when they would prefer to deactivate their ICD to allow for a natural death to occur due to sudden cardiac arrest is concerning. These findings are similar to that of Dougherty and colleagues (2007) who identified that despite participant preferences for a quick, and peaceful death, which excluded resuscitation measures and having their life sustained by machines or artificial feeding options, few mentioned deactivating their ICD as an action that would help realize this scenario. The participants in Dougherty and associates (2007) study indicated that they were unaware that their ICDs were designed to prevent sudden death from a cardiac arrhythmia. Research has demonstrated that of 100 individuals who had an ICD inserted and were dying from ESHF, 27% of the total and 45% of individuals with do not resuscitate orders reported having had a discussion with their health care provider about deactivating their ICD (Goldstein, Lampert, Bradley, Lynn, & Krumholz, 2004). These researchers also reported that 75% of the discussions occurred within the last few days of one's life and in some cases minutes before the patient died, resulting in the individual receiving painful shocks immediately prior to their death.

Conversely, preplanning of comfort care strategies, including discussions pertaining to the withdrawal of ICD therapy in individuals who develop a terminal illness

or whose chronic illness has progressed to end-stage disease, have been shown to prevent painful and undesired shocks at end of life (Lewis et al., 2006). As a result, in 2006 the CCS (Arnold et al., 2006) followed by the American College of Cardiology and the American Heart Association in 2009 (Jessup et al., 2009) recommended that early and reoccurring discussions pertaining to the option of deactivating one's ICD should occur prior to ICD insertion, with each hospital admission, and when changes in one's HF status occur. Overall, early discussions surrounding the implications of ICD therapy in patients entering end-stage disease become paramount in order to determine patient preferences and options available to them in order to prevent undesired shocks as death approaches. Unfortunately, within the present study it appeared that participants had not had any discussions with their healthcare providers about deactivating their ICD to allow for the potential of a natural death free of painful shocks. Though participants within this study reported that they believed they received open honest information, the absence of discussion about ICD deactivation suggests that they are missing an important piece of the information required for them to engage in the work of charting the final chapter of one's life.

*Embracing life: living in the moment.*

The participants in this study reported that although they recognized that they had a terminal illness, they also decided that it was important to live out the remainder of their lives as best as they could. For these participants that entailed not giving up, continuing to do as much for themselves as they possibly could, and ultimately embracing the remainder of time they had left to live.

The participants within this study identified the importance of maintaining a positive outlook on life despite living with ESHF and knowing that they will die as a result of it. They stressed the importance of living in the moment versus worrying about their mortality. This finding reinforces those of Dougherty and colleagues (2007) who identified that some individuals living with ESHF chose not to focus on the reality of their death, but rather to seek out the positive aspects of their life, live day by day, and maximize the time they have left to live. Men living with moderate HF have also reported the need to think positively and not focus on death as a reality for them in order to carry on living (Europe & Tyni-Lenne, 2004). Although death is a reality for individuals living with HF one's ability to maintain a positive outlook on life assists one in continuing to live and carrying on with daily life.

Conversely, Ryan and Farrelly (2009) reported that for some individuals living with advanced HF continuing to do for oneself may become extremely difficult. In response, some individuals may develop great despair and loss of hope, which may lead one to seek a hastened death. Willems and associates (2004) identified that one out of their 14 participants living with advanced HF who had survived a previous cardiac arrest indicated that he would consider euthanasia if he became bedridden or had to be institutionalized. The authors did not discuss if symptom distress played a role in his consideration of euthanasia.

*Planning for the future: thinking ahead.*

Chronic illness literature posits that the meaning of life is derived from one's body and one's inherent ability of being able to do, to look and to experience as one desires and expects (Corbin 2003). As a result, when one's body is unable to meet one's

expectations or desires, one may change their meaning of life and begin to prefer death versus living a life encompassing severe disability. One must decide for themselves what they consider acceptable body limitations.

Participants in this study reported the need to remain as active as possible and to continue to do as much as they possibly could for themselves within the limitations and restrictions of their ESHF. For five of these participants, becoming totally dependent on others to meet their physical needs was untenable. These participants expressed the sentiment that if they lost their independence death was preferred. Becoming a physical burden on one's loved ones was also deemed as not acceptable by some of the participants within this study. Similar findings are reported elsewhere indicating that in the case of ESHF death was preferred over becoming an invalid, being confined to one's bed, relying on others to meet one's physical needs (Dougherty et al., 2007; Gott et al., 2008; Vig, Davenport, & Pearlman, 2002; Waterworth & Jorgensen, 2010; Willems et al., 2004), and burdening one's loved ones to perform one's physical care (Gott et al., 2008; Vig et al., 2002). Individuals living with terminal cancer have also identified that death was preferred over total dependence upon others and burdening loved ones (Chochinov et al., 2005)

One participant within the present study briefly introduced the issue of assisted suicide during his interview as something that he would be desirous of when his ESHF progressed to a point where he lost his independence and was suffering from unmanaged physical distress. This individual stated that he inquired about assisted suicide but denied having a plan in place related to this action.

Individuals who participated in this study clearly identified that they did not fear death, and expected that it would occur in the near future. In thinking about their future death, participants identified that they preferred a comfortable symptom free death. They described their ideal death as occurring suddenly during sleep versus a protracted one characterized by progressive symptoms.

Research has identified the attributes that characterize a “good death”. De Jong and Clarke (2009) identified that from the perspective of patients, care providers and PC physicians a good death consisted of symptom management that minimized pain and suffering, and receiving honest information surrounding prognosis. Such information was critically important so that patients could engage in discussions about their preferences and wishes for death with their loved ones, and to say their good-byes. Patients in this study also described a good death as one that occurred peacefully and in one’s sleep, resulting in minimal burden on loved ones. Conversely, a bad death was characterized by uncontrolled pain and other symptoms, emotional anguish, spiritual distress, physical dependency, and feeling that one was a burden to others. A bad death was also described as one in which the wishes of the individual were not respected and followed. It is also important to note that these researchers also identified that the stories told about what constitutes a good or bad death were as individual as the person who told the story.

Steinhauser and colleagues (2000) identified six major attributes of a good death gleaned from the perspectives of patients with human immunodeficiency virus and cancer, family members, and healthcare providers. Those attributes included: (1) effective pain and symptom management; (2) clear decision making, based upon open honest communication between the physician, patient, and family members; (3)

preparation for death, including an understanding of what to expect during the course of the illness and how to plan for the immediate time after one's death (will, funeral, or obituary); (4) completion, which may encompass faith issues, life reviews, resolution of conflicts, saying good-byes and spending time with family and friends; (5) contributing to others, such as giving gifts or imparting knowledge to others through self-reflection of one's successes and failures; and (6) affirmation of the whole person, which included empathic healthcare providers who identified and treated the individual as a unique person, who was not only considered as living with an illness, but also as someone who had values, preferences and a past life.

Tong and colleagues (2003) interviewed individuals of varying ages, health status, faiths and ethnicities living in the community to elicit their views on death, dying, and wishes for end of life care. These researchers discovered that a good death was defined by 10 common domains, which included: (1) physical comfort, which included being clean and symptom free; (2) minimizing burden on one's family, such as caregiving responsibilities, financial hardship and responsibilities to make difficult treatment decisions; (3) location and environment of one's death, where dying in one's home environment was desired; (4) presence of others, which highlighted that individuals do not want to die alone; (5) undesired prolongation of life, such as being kept alive by machines and feeding tubes that would inflict suffering and cause poor QOL; (6) communication, which included that healthcare professionals discuss honestly their medical condition, prognosis and treatment options and then listen to their wishes at end of life; (7) completion and emotional health, which included completing unresolved or uncompleted business and avoiding negative emotions; (8) spiritual care and in many

cases faith or religious based issues; (9) consideration of cultural traditions and concerns; and (10) individualization, where each person is considered unique and each dying experience will be different requiring that care be provided in a non-judgmental manner.

Research identifying what constitutes a good death has also been informed by the perspectives of HF patients. Vig and associates (2002) studied 16 participants who had a diagnosis of cancer, HF, or a combination of both who were expected to live for six months or longer. A good death was most frequently described as a death that occurred quickly with minimal pain and suffering. Ideally, participants wished death to occur while sleeping as it was associated with being pain and symptom free and a lack of awareness of one's impending demise. A quick death was desired related to the fact that pain and suffering along with dependence and being a burden to others was minimized.

In contrast, a bad death was described by Vig and colleagues (2002) as a death that entailed uncontrolled pain and suffering, a prolonged course of dying, dependency on others, and unpreparedness. These researchers also discovered that what constituted a good or bad death was unique to each individual, thereby reinforcing the need to discover each individual's perspective on this issue. Suggestions about how to introduce the topic of one's end of life preferences were offered by Vigg and colleagues (2002), and have been reported elsewhere.

Australian researchers have described what constitutes a good and bad death from the perspective of acute care nurses and PC nurses in the community setting who provided end of life care to individuals dying from ESHF (Borbasi, Wotton, Redden, & Chapman, 2005). These researchers identified that a good death occurred when symptoms were controlled effectively; patients and family members were informed

through open communication and were included in decision making; and the patient and family accepted death and planned ahead, such as completing advance directives and making funeral arrangements. Furthermore, a good death was described as occurring when the individual patient's desires and needs were catered to and the specialized PC team was consulted. The fact that achieving a good death within hospital required time and resources, such as a private room and adequate staffing to attend to symptom management was also identified by Borbasi and colleagues.

Borbasi et al (2005) also identified characteristics of a bad death in the context of ESHF from the perspective of acute care nurses. Interestingly, these nurses indicated that what they described as hallmarks of a good death were actually gleaned from experiencing many more bad deaths than good deaths when providing end of life care to individuals dying from ESHF in the hospital setting. Characteristics of a bad death included the following dimensions. First, nurses described situations in which the patient and family members were in denial that death would occur was problematic because it resulted in the continued implementation of undesired interventions and lack of planning or preparation for death. A lack of open, honest communication between healthcare professionals, patients and family members was also identified as contributing to a bad death because it too negatively impacted the patient's ability to plan for their death appropriately. Third, a bad death was characterized as one where health professionals failed to manage symptoms effectively leading to an undesired degree of suffering. Related to this was either no consultation to a specialized PC team for assistance in symptom management, or one that was not made in a timely fashion.

Singer and colleagues (1999) have investigated the dimensions of quality end of life care from the perspective of individuals living with; renal disease undergoing hemodialysis, human immunodeficiency virus, and residents of long term care facilities. Quality end of life care consists of: i) adequate pain and symptom management; ii) avoidance of life prolonging measures, such as being kept alive by machines and lingering when one could no longer enjoy their lives; iii) achieving a sense of control over one's end of life care decisions, including identifying a proxy decision maker; iv) relieving burden on loved ones; and v) strengthening relationships with loved ones through open communication about end of life preferences and desires.

PC was developed to meet the end of life care needs of dying individuals with the focus of obtaining a “good death” through the provision of interdisciplinary biopsychosocial care that targets relieving physical, mental and spiritual suffering, supporting patient dignity, and ultimately improving QOL (Cohen et al., 2001; Ferris et al., 2002; Gottlieb, 2003; Zerwekh, 2006). Over the past decades in Canada it has been recognized that not all Canadians have had access to quality end of life care. As a result, in 2000, a Canadian sub-committee report declared that a “quality death” was the right of every Canadian (Carstairs & Beaudoin, 2000). Following this declaration, increased funding for PC research and education occurred; however, it has been recently been estimated that only 15% of dying Canadians receive specialized PC services (Carstairs, 2005) of which 92% are cancer patients (Gaudette et al., 2002). Access to and receiving quality end of life care in Canada continues to be a challenge.

Many of the characteristics and processes related to a good death identified in the literature have begun to appear in professional practice guidelines. For the first time in

2006, the CCS addressed the fact that HF is a terminal progressive condition by including a section on ethical and end of life issues in their recommendations for HF diagnosis and management in Canada (Arnold et al., 2006). This set of recommendations, although brief and not fully operationalized, highlighted the need for healthcare professionals to discuss the disease process of HF and ESHF, including its poor prognosis, realistic goals of care and available management options. This set of guidelines also encouraged discussion between clinicians and patients about advanced medical directives, wishes for resuscitation and life prolonging interventions early after the diagnosis of HF is made. Goals of therapy should be reviewed regularly and with changes in a patient's condition, and especially when symptoms of end-stage disease are becoming evident. The need to discuss the completion of a living will and to identify a substitute decision maker were also highlighted as necessary to clarify patients' wishes for end of life care. Finally, the recommendation was made for initiation of a PC consultation when patients demonstrated evidence of progression to end-stage disease. This document did not include any specific guidelines for the management of the ESHF patient.

In 2008 the CCS addressed the transition of care in HF between cardiologists and specialized HF clinics and the individual patient's primary care physician based in the community (Arnold et al., 2008). This set of guidelines included a recommendation for continued collaboration between specialized HF clinics and the individual's primary care physician to ensure that the needs of the patient are met in a consistent manner. The recommendation further reinforced the need for patients and their families to be provided with the opportunity to engage in discussions in and counseling about their; physical, emotional, social, and spiritual concerns, along with their goals of care, and end of life

care directives. It was further recommended that the information gleaned from discussions surrounding the individual's goals and preferences for end of life care be shared between all healthcare professionals to ensure that patient needs and preferences are met. An important change in the 2008 guidelines concerns the early, versus late involvement of specialized PC teams to aide in identifying and addressing physical, psychosocial and spiritual concerns and shifting the overall goal of care to symptom relief and improved QOL.

Despite the recommendations from the CCS pertaining to the early involvement of specialized PC services in ESHF to ensure that the end of life care needs of patients living with ESHF were met, it appears that this practice is not occurring in Canada. The findings from this research project continue to demonstrate that specialized PC services are not incorporated into the care of the ESHF patient. Within this study none of the participants had a consult generated to the specialized PC service and none were receiving specialized PC services. Other research has demonstrated that if consult and involvement of specialized PC does occur it was late into the illness trajectory and in many cases occurring just prior to the individual's death, resulting in one having suffered unnecessary symptom burden and psychosocial distress (Borbasi et al., 2005; Boyd et al., 2004; Kaasalainen et al., 2011).

This researcher remains hopeful that individuals living with ESHF will receive improved and ultimately optimal end of life care. In 2011, for the first time the CCS included a substantial section within their HF management guidelines addressing the terminal stages of HF and the necessary and important role that PC plays in meeting the end of life needs of ESHF patients (McKelvie et al., 2011). Not only are

recommendations made, but specific suggestions are provided to describe how optimal end of life care can be provided to ESHF patients, including specific strategies aimed at managing the symptoms of ESHF. Once again the recommendation is made for the early involvement of specialized PC teams as a collaborative multidisciplinary intervention, where all specialty services work together to meet the needs of the ESHF patient. The provision of PC is to be based upon the individual patient's needs and symptoms rather than a projected life expectancy. As a result, the CCS panel of HF specialists adapted the World Health Organization's (WHO) definition of PC to include the realities of HF management in end-stage disease and defined PC in the context of ESHF as:

A patient-centered and family-centered approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It is applicable early, as well as later, in the course of illness, in conjunction with other therapies that are intended to prolong life, including but not limited to in the setting of heart failure, oral pharmacotherapy, surgery, implantable device therapy, hemofiltration or dialysis, the use of intravenous inotropic agents, and ventricular assist devices. (p.327)

In Canada one published research study was located that investigated the use of PC in ESHF (Kaasalainen et al., 2011). These researchers investigated the care processes involved in providing PC to ESHF patients in the community setting from the patient's, family caregiver, and varying healthcare professional's perspectives. What was discovered was that the provision of PC to ESHF patients was hindered by a number of

contextual factors, including the reality that resources are limited and PC services are provided based upon a cancer model (requiring six months or less prognosis), which prevented individuals living with ESHF from accessing subsidized equipment and community services (transportation) that were only available to cancer patients. Furthermore, Kaasalainen and colleagues highlighted the fact that prognostication in ESHF is challenging and in many cases patients who were on their death beds recovered and in other cases patients declined and died without PC consultation because it was believed they may recover. Furthermore, healthcare professionals expressed concern surrounding the fact that they lack the necessary skill and experience to provide PC to ESHF patients at end of life. Concerns were also raised about the safety issues surrounding the disjointed transition of care from HF care to PC and managing the large number of medications that patients with HF are prescribed and the effect that adding opioids may potentially have with all the other cardiac medications. Overall, these researchers discovered that: the patients who participated in the study desired effective symptom control and a peaceful death; PC must be introduced early in ESHF care; and there is a need for optimal interprofessional collaboration when providing PC to individuals living with ESHF in order to meet their needs in a holistic manner.

The 2011 CCS HF management guidelines also included recommendations about how to assess an individual's readiness to participate in end of life discussions and provided examples of "opening lines" that can be used to initiate conversations about end of life care preferences, and how to continue subsequent discussions pertaining to end of life care in ESHF (McKelvie et al., 2011). The recommendations also include the need for early and reoccurring discussions with patients and their loved ones surrounding

advance care planning and identifying a surrogate decision maker who will make end of life care decisions on one's behalf when one is no longer capable of doing so for oneself.

Advance care planning is defined within the document as:

A process whereby a patient, in conversation and reflection with family members, important others, and health care providers, makes decisions about future health care. Advance care planning is a process of reflection on and communication of a person's goals, values, and preferences for future health care, to be used should they become incapable of giving informed consent. Advance care planning can encompass rich conversations, which go beyond "to resuscitate or not to resuscitate" and may include meanings and fears around illness and dying, preferences for after death rituals, and spirituality. (p.327)

Individuals living with ESHF have expressed a desire for honest information about their illness progression and prognosis along with assistance in planning for their end of life. As a result of open, honest communication between healthcare providers, patients and their loved ones advance care planning can and should become a reality. Advance care planning has been described as a tool for patients to: maintain their autonomy at end of life; avoid the indignity of prolonged dying and undesired medical interventions; and finally to assist and reduce the burden of family members in making healthcare decisions when one becomes incapacitated (Gott et al., 2008; Seymour, Gott, Bellamy, Ahmedzai, & Clark, 2004). Within Canada, Caldwell and colleagues (2007) have identified that individuals living with advanced HF (NYHA III-IV) desired to partake in advance care planning discussions early in their diagnosis of HF to allow for time to contemplate one's options and at a time when one was believed to be mentally

alert and physically well enough to have meaningful discussion. Furthermore, the participants also reported that they desired honest information and discussion to occur in a two way conversation that balanced truth with hope, most notably in the case of ESHF that hope existed to effectively manage one's symptoms and ensure that a dignified death occurred.

In the case of the general public, Emanuel and colleagues (1991) demonstrated that 93% of individuals receiving outpatient care and 89% of the general public desired one or more of three types of advance directive, which included a conversation with their physician, a living will, or a durable power of attorney. However, despite desiring and recognizing one's need for some form of advanced care planning, few participants had actually made explicit arrangements prior to the study. In the case of outpatients 7% had written an advance directive, 8% had designated a proxy decision maker and 5% reported having had a discussion with their physician surrounding advance directives. Conversely, 74% of the general public and 57% of the outpatients reported that they had developed a will outlining the disposal of their estates. Reasons provided for not having completed one of the three types of advance planning included patient's expectation that their physician should instigate advance care planning discussions and that such planning was relevant to people older than themselves and in worse health. To assist physicians in discussing advance care planning as a component of routine care, Emanuel and associates (1995) have provided a five step process and an associated conversation guide that may be utilized to initiate and continue subsequent discussions surrounding advance care planning with patients and their loved one designated as one's proxy. This process consists of: (1) raising the topic and giving information; (2) facilitating a structured

discussion; (3) completing a statement and recording it; (4) periodically reviewing and updating the directives; and (5) bringing prior wishes to bear on actual decisions.

Advance care planning must include the development of directives, such as living wills or written advance directives, which outline one's preferences for treatment and designating a proxy decision maker. Discussing advance care planning with patients in order to obtain an understanding of one's wishes for end of life care is desired by patients and therefore healthcare professionals must initiate such discussions in order to prevent undesired harm to the patient.

In an attempt to maintain one's wishes surrounding their healthcare and resuscitation preferences advance directives, including living wills, power of attorney and advance care plans have been completed by some individuals living with ESHF.

Dougherty and associates (2007) reported that 67% of individuals living with ESHF had completed an advance directive to outline their end of life wishes, which increased their feelings of taking charge of their life, and provided them with a chance to discuss their end of life desires with their family and healthcare team. During these discussions participants identified that they did not want to be kept alive on artificial life support, did not want to become bedridden and unable to care for themselves, and refused cardiopulmonary resuscitation. These individuals feared that others would make decisions for them to sustain their life by artificial means. Therefore, outlining their desires for their end of life care was important to them to ensure that their wishes for end of life care would be honored in the future.

Conversely, Boyd and colleagues (2004) identified that most individuals living with ESHF thought about dying and many had made plans with relatives for funerals and

arrangements for property and money; however, few patients had discussed their end of life care wishes or preferred place of death with their healthcare professional. This finding is consistent with that of Gott and associates (2008) who identified that out of their 44 participants living with ESHF, only one participant discussed advance care planning, but many more had identified that they had “gotten their affairs in order” and had arranged for their funerals. Formiga and associates (2004) also discovered that although 64% of their sample of 80 participants living with moderate to severe HF (NYHA II-IV) were aware that their illness was chronic and progressive, only two individuals reported that they had engaged in discussion pertaining to their wishes surrounding life sustaining treatment with their physicians. These investigators also identified that 40% of the participants preferred not to be resuscitated and that 66% advocated for PC when their recovery from HF was unlikely. These findings are similar to those discovered in this research study. Despite acknowledging that death was approaching, discussing resuscitation preferences with family members, and preparing for after one’s death by giving away belongings or pets few study participants had documented resuscitation preferences or end of life wishes with the specialized HF clinic. Furthermore, none of the participants in this study indicated that they were knowledgeable about how or where their death may occur. Even the participant with a substantial medical background and living in an intermediate care facility was unaware of the end of life services that could be available to him, or where his death would occur.

Research identifies that individuals dying from HF desire to die at home in their bed or in an environment that they are familiar with and comfortable in versus a hospital (Formiga, Chivite, Ortega, Casas, Ramon, & Pujol, 2004; Gott et al., 2008; Strachan et

al., 2009). Strachan and colleagues (2009) discovered that 44% (n=106) of individuals hospitalized in Canada with advanced HF (NYHA IV) preferred to be discharged home to die, though they anticipated barriers; including, burden on their family caregivers (58%), lack of healthcare services (48%) and living alone would prevent them from dying within in their homes.

Tragically, Gott and colleagues (2008) also identified that individuals living with advanced HF (NYHA III-IV) expected that their death would be uncomfortable and that they would suffer from pain and breathlessness. Although research has indicated that individuals dying from ESHF fear that they will experience pain, dyspnea and other symptoms as they progress towards death they also reported that they hoped that their symptoms would be treated effectively and a comfortable death would ensue (Caldwell et al., 2007; Kaasalainen et al., 2011; Waterworth & Jorgensen, 2010). One participant in this study discussed his expectations to be made comfortable during his death.

### Recommendations

Recommendations for practice, education, and research are presented within the following section along with limitations of the study.

#### *Implications for Nursing Practice*

The findings from this research study highlight a number of important implications not only for nursing practice, but for all healthcare professionals. These recommendations include the following:

- 1) The participants within this study clearly identified that living with ESHF is very laborious, with many hours being spent each day in managing one's disease in order to remain independent and live as normal a life as possible. The focus of

healthcare professionals must be on assessing each individual holistically and developing individualized care plans that meet one's desires and needs.

Healthcare professionals must ensure that the physical, psychosocial, and spiritual needs of each individual living with ESHF are considered and that they perform thorough physical examinations and conduct assessments focusing on the social, spiritual and emotional care needs of the individual. Consideration must also be given to the fact that individuals living with ESHF may have developed negative feelings related to the every day challenges they face. Feelings of frustration, sadness, anger, and guilt along with a sense of being a burden to others may be present, and the individual may require reassurance that these feelings are normal and assistance and support may be provided to aide the individual in overcoming their negative feelings. Furthermore, the individual may require support and treatment for clinical depression. Holistic care plans must be developed in consultation with patients to assist them in maintaining their independence, and supporting them in their daily work of living with ESHF as they struggle to meet their care needs safely.

- 2) Individuals living with ESHF experience a great many symptoms in varying degrees. Although most individuals will suffer from the three most recognized symptoms of ESHF, namely dyspnea, pain, and fatigue, many will also suffer from less commonly recognized symptoms, such as confusion, reduced mental acuity, and unsteadiness and associated falls. Healthcare professionals must be astute and recognize the typical and atypical symptoms of ESHF, and implement interventions aimed at alleviating the distressing symptoms of ESHF. For those

individuals suffering from confusion or reduced mental acuity, it becomes increasingly important that plans of care are devised to ensure that the safety and needs of the individual are met. This may involve having a loved one or friend attend clinical appointments to aide in the integration of information, having medications bubble packed, and consulting homecare to assist in medication reminders or to administer the medications.

- 3) The findings of this research study reinforce that individuals living with ESHF desire to be independent; however, in order to be independent they also acknowledged that they were dependent upon their family and friends to assist them in meeting their daily needs. As a result, it is of utmost importance that healthcare professionals recognize the supporting role that family and friends play in the life of individuals living with ESHF. Furthermore, it is necessary for healthcare professionals to assess if patients living with ESHF have a support network. Healthcare professionals are also required to consider the availability of community support services/programs such as; homecare, HF/ESHF support groups, and adult day programs. For individuals who lack a strong support network, healthcare providers may need to emotionally support the individual during transition to an alternate care setting where their needs can be safely met.
- 4) The physical and psychosocial care needs of the ESHF population are complex. Healthcare professionals must appreciate that they can not know everything about how to meet all of the needs of the individual living with ESHF. Accordingly, in order to ensure holistic care, consultation with other professionals; such as, physiotherapy, occupational therapy, dietician, pharmacist, homecare, social

work, spiritual care, and PC physicians or clinical nurse specialists may be warranted to ensure optimal care is provided. The CCS recommends early consultation of PC services in the care of the ESHF patient. Consultation does not mean transfer of care, but most importantly the sharing of knowledge and expertise between the disciplines of PC and cardiology. Only through collaborative practice and interprofessional healthcare teams will all the needs of the individual living with ESHF be attended to. Cardiac clinical nurse specialists possess the specialized knowledge and skills to holistically assess and provide the necessary care, lead the healthcare team, and to act as liaison between all services for individuals living with ESHF. Individuals living with ESHF must receive collaborative interprofessional care across all environments whether in the community or in hospital setting to ensure that smooth transitions occur between all situations and environments and disjointed/fragmented care does not occur.

5) The participants within this study identified that receiving open and honest information from healthcare professionals about ESHF being progressive and terminal was important and necessary in order to aide them in planning for their future and devising plans of care that would meet their needs and expectations. This study underscores the importance of all healthcare providers engaging in discussions with ESHF patients about end of life care, and their wishes surrounding resuscitation in the event of a cardiac arrest, most importantly a clear description of what a resuscitation attempt would entail. These discussions should occur at the time of diagnosis of HF and with all changes in healthcare status, including hospitalizations. In the case of ICDs these discussions must also include

information pertaining to the reasons why an ICD would be inserted, the advantages and disadvantages of an ICD, along with when one would desire to have their ICD therapy terminated.

- 6) All participants involved in this study highlighted the fact that they appreciated being treated as a valued member and participant of their healthcare team. This required that healthcare providers as much as possible engage those individuals who desire to be involved in all discussions surrounding their care, and elicit their wishes and concerns. Healthcare professionals must be willing to openly and honestly provide individuals living with ESHF and their loved ones the necessary information to ensure that a realistic plan that respects their wishes can be developed for the future, whatever its duration. Individuals living with ESHF desire to be treated as valuable members of their care team; and as such, they must be provided an opportunity to be involved in the development of their care plans and their care plans must be developed focusing on their needs.
- 7) The participants within this study indicated their preference for a comfortable death that was as free of distressing symptoms as possible; however, they did not have knowledge and had not received information from healthcare providers as to how this could be achieved. This finding alone reinforces that individuals living with ESHF want and need information surrounding how and where death may occur, and what options exist to meet their goals of care and ensure that they have a comfortable death.

### *Implications for Nursing Education*

The following recommendations for education are suggested by this study.

- 1) Education programs for healthcare professionals, which include undergraduate nursing programs, continuing education and general hospital orientations, must place a strong emphasis on the impact that living with chronic illness has on the individual and their loved ones. Healthcare professionals must come to understand how chronic illness shatters the individual to their core and leaves an ever lasting impact that in most cases is relived every day by the symptoms they suffer. Individuals living with chronic illness will have suffered, and will continue to suffer, many losses and face many challenges on a daily basis. Information must be provided highlighting that individuals living with chronic illness are required to make many identity trade-offs throughout the course of their illness and ultimately one's identity changes and adapts to align with daily life living with the chronic illness. Healthcare professionals must understand and appreciate that the impact of illness on the individual is everlasting and that it will change overtime, most commonly not for the better.
- 2) In this study individuals living with ESHF desired to remain as active and independent as possible in their home environment. The focus within educational programs must be on healthcare professionals identifying the strengths patients have that allow them to remain independent and active versus focusing on patient deficits. Educators must stress the importance of viewing an individual with ESHF as a whole person with spiritual, psychosocial and physical dimensions, as opposed to only seeing the manifestations of illness and; thereby, ensure that

students know how to conduct physical, spiritual, emotional and social assessments. As a result, nurses will obtain the required skills to explore with the individual living with ESHF what their care needs are and develop individualized care plans based upon their physical, spiritual, emotional and social assessments. The identification of patient strengths will help healthcare providers develop interventions that support self care of the individual with the goal of them remaining independent and active.

- 3) Education programs must ensure that healthcare professionals are aware of the co-morbid conditions common in ESHF patients, and how management of these conditions increases the complexity of managing ESHF for patients on a daily basis. Healthcare professionals must be educated about the importance of interprofessional collaboration and what supports can be offered to the individual living with ESHF to help them manage their multiple health challenges, such as homecare services, day programs, private homecare services, and meals on wheels.
- 4) Healthcare providers must learn that ESHF is a chronic condition that will eventually result in death. This reality requires that all nurses and healthcare professionals possess the necessary skills to be able to communicate with patients about the nature and duration of their expected illness trajectory, and learn how to initiate discussions about end of life care planning, so that patients' wishes about their care in this regard can be explored.
- 5) Educational programs must also continue to promote collaborative multidisciplinary evidence based practice where healthcare professionals are

encouraged to consider the knowledge and expertise of members of the healthcare team, and integrate each discipline's expertise into the care of individuals living with ESHF. All professions contribute expert knowledge in the care of the ESHF patient and a team approach will ensure that all the needs of the individual are addressed and that care plans are developed that will meet these needs. The role that PC can play throughout the patient's illness trajectory in supporting other members of the healthcare team who have direct responsibility in caring for ESHF patients should be included in healthcare curricula.

#### *Implications for Nursing Research*

A number of recommendations for research were gleaned from this research study.

- 1) Minimal research has occurred into the lived experience of ESHF resulting in limited descriptive and interpretive data that can assist healthcare professionals and others in understanding what it is like to live with ESHF. Further qualitative research must occur to reduce this knowledge gap.
- 2) Within this study, five of the participants were older than 80 years of age, only one participant was younger than 60 years of age, and only one participant was female. The sample was also devoid of ethnic diversity. Research examining the lived experience of ESHF must be conducted that captures the perspectives of those younger than 60, female, and from diverse ethnic backgrounds. Such work will help to determine the differences and similarities in patients with different demographic characteristics that might inform the provision of care.

- 3) The findings from this study suggest that a collaborative approach between PC, HF specialists and a patient's general practitioner is required early in the diagnosis of HF to ensure that the holistic care needs of the ESHF patient are met. To date, scientific evidence is lacking to support this hypothesis. Research studies must be undertaken to evaluate the effect that a collaborative approach might have on such outcomes as reduction of the symptoms of ESHF, improved QOL, promotion of psychological well being, sense of dignity, feelings of burden, and family satisfaction with end of life care.
- 4) Research has demonstrated that specific PC strategies are successful in managing symptoms in cancer patients, such as the utilization of opioids versus benzodiazepines for the management of dyspnea. However, empirical data is lacking supporting the use of PC symptom management strategies in ESHF patients. Future research must occur in this area, and might be informed by the symptom management strategies that have been developed in caring for advanced cancer patients. Furthermore, PC was developed to alleviate suffering in patients with cancer by focusing on relieving physical, mental, and spiritual suffering and ultimately improving ones QOL. PC has been demonstrated to successfully relieve physical, spiritual, and emotional suffering in patients with cancer; however, studies verifying its efficacy in ESHF are lacking. Future research must occur within Canada and throughout the entire world evaluating the effectiveness of specialized interprofessional PC programs, in reducing suffering that individuals living with ESHF endure.

- 5) Further research must also occur in the development and evaluation of prognostic markers and models in HF so that individuals and their loved ones can be provided with information about what their life expectancy might realistically be. Individuals living with HF who are provided with a life expectancy that is supported by empirical data will have the opportunity to plan and prepare for their future.
- 6) Research must also be undertaken to evaluate the QOL of individuals living with ESHF and most importantly to assess the impact that interventions aimed at managing symptoms and improving one's physical function have on their QOL.

#### Limitations of the Study

Limitations of this study are that it included only English speaking participants who lived within Winnipeg and the surrounding area. The experiences of patients in more remote locales and those whose first language is not English may differ somewhat from those who participated in this study. The experience of those who agreed to participate within this study may vary from those who declined participation. For example, the experience of those individuals who did not have a positive outlook on life while living with ESHF, or those individuals who were less satisfied with the medical care that they were receiving may have had a very different story to share than the participants involved in this research study. Those participants who declined to participate often stated that they were just too unwell to participate and take on the extra burden of a research study. It is possible these individuals, experiencing what may have been acute exacerbations of their illness, could have reported experiences that were different from study participants. Finally, the sample lacked diversity in terms of ethnicity, gender, and age. Five of the

seven participants were of Caucasian European decent. Only one female and one individual younger than 60 years of age participated in this study. The experiences of females, non-Caucasians, and younger adults living with ESHF may or may not be consistent with the findings generated in this study.

#### Chapter Summary

This chapter situated the findings of this research project in light of existing literature. The essence of the lived experience of ESHF and its three associated themes were discussed and compared with both chronic illness literature and relevant research about ESHF. Recommendations for nursing practice, education, and research were identified, and the limitations of this study were presented.

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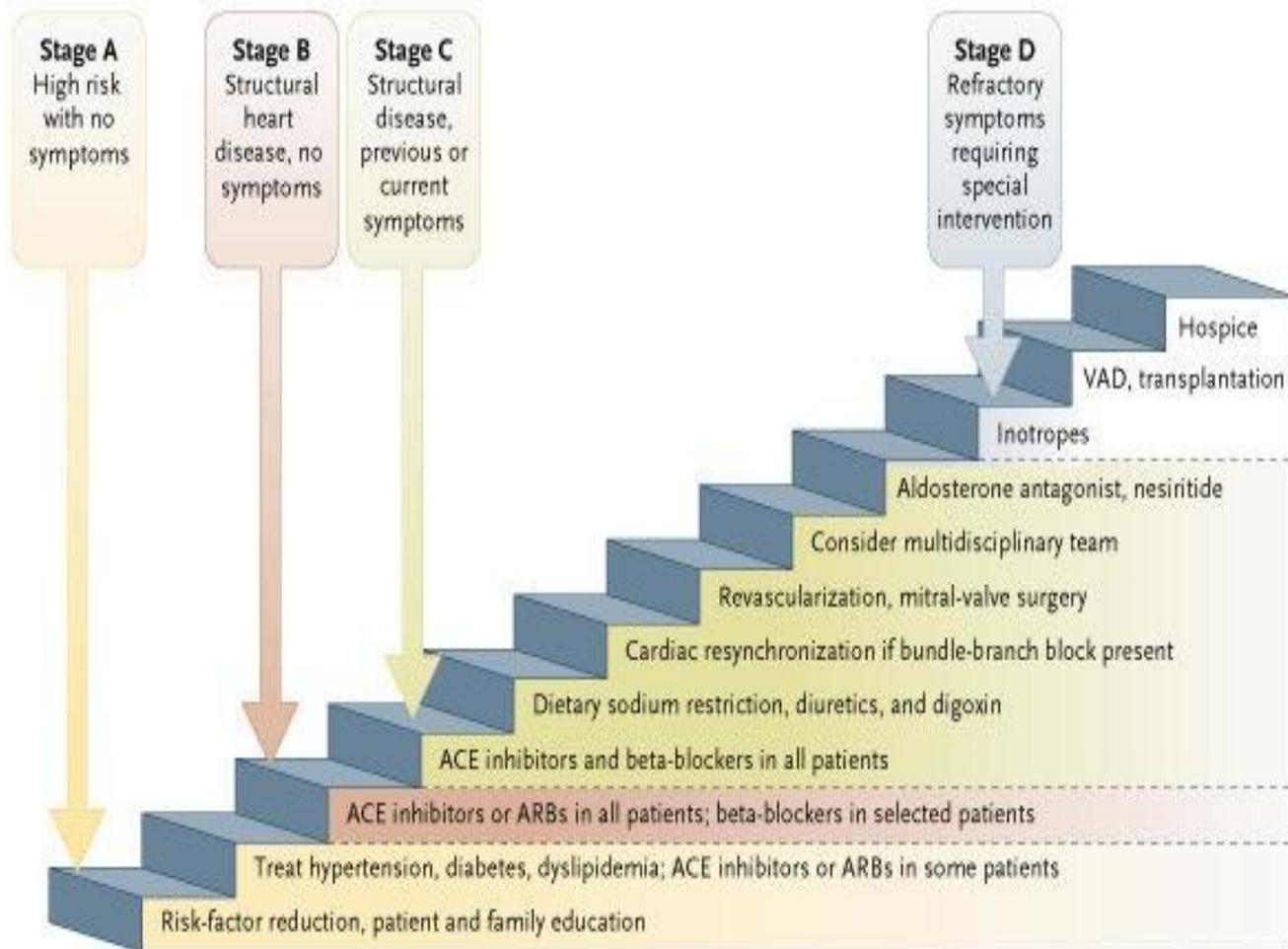
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## APPENDIX A

## Staging of Heart Failure and its Associated Step-Up Management Strategy



Note. From “Heart Failure,” by M. Jessup and S. Brozena, 2003, *The New England Journal of Medicine*, 348(20), p. 2013. Copyright 2003 by Massachusetts Medical Society. Reprinted with permission.

## APPENDIX B

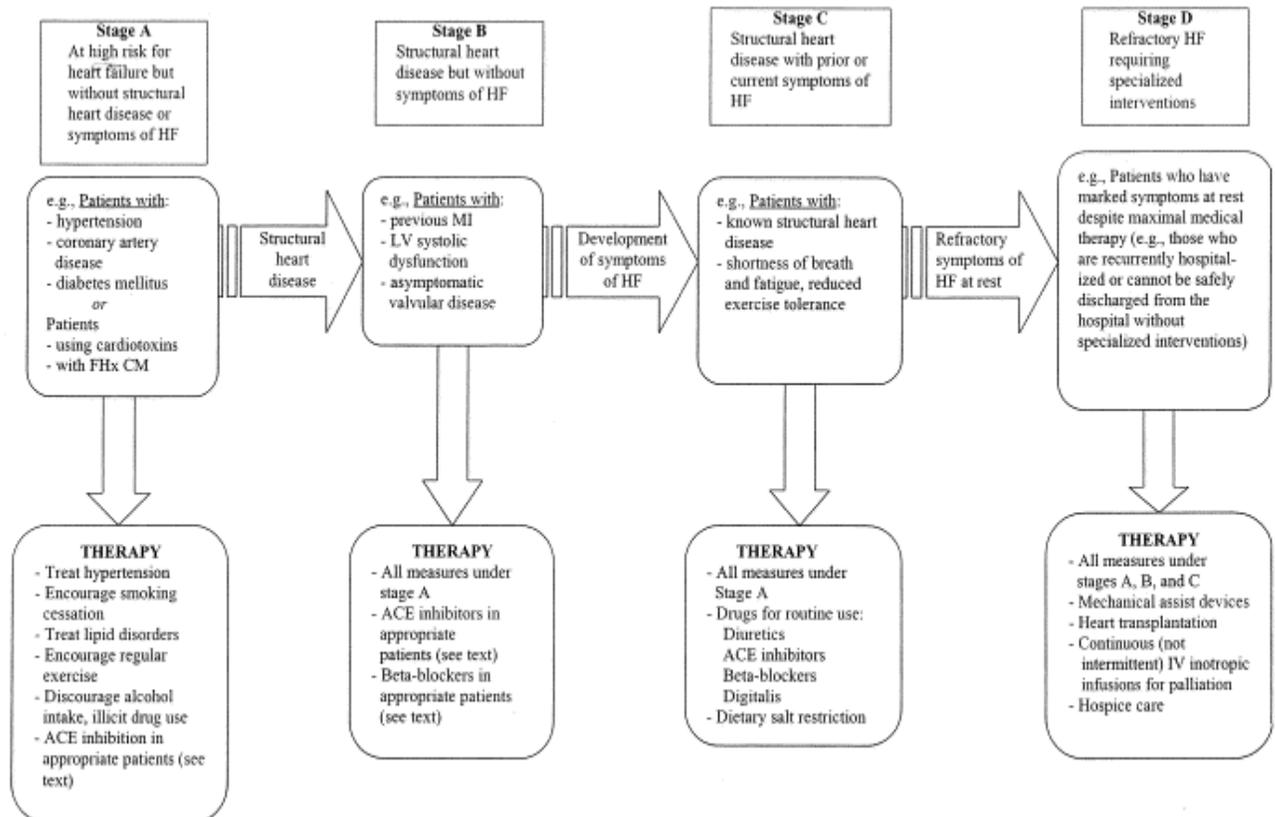
## New York Heart Association Classification of Heart Failure

<b>New York Heart Association functional classification</b>	
<b>Class</b>	<b>Definition</b>
I	No symptoms
II	Symptoms with ordinary activity
III	Symptoms with less than ordinary activity
IV	Symptoms at rest or with any minimal activity

Note. From “Canadian Cardiovascular Society Consensus Conference Recommendations on Heart Failure 2006: Diagnosis and Management,” by J.M.O. Arnold, P. Liu, C. Demers, P. Dorian, N. Giannetti, H. Haddad, et al., 2006, *Canadian Journal of Cardiology*, 22(1), p. 25. Copyright 2006 by Pulsus Group Inc. Reprinted with permission.

## APPENDIX C

## Staging of Heart Failure



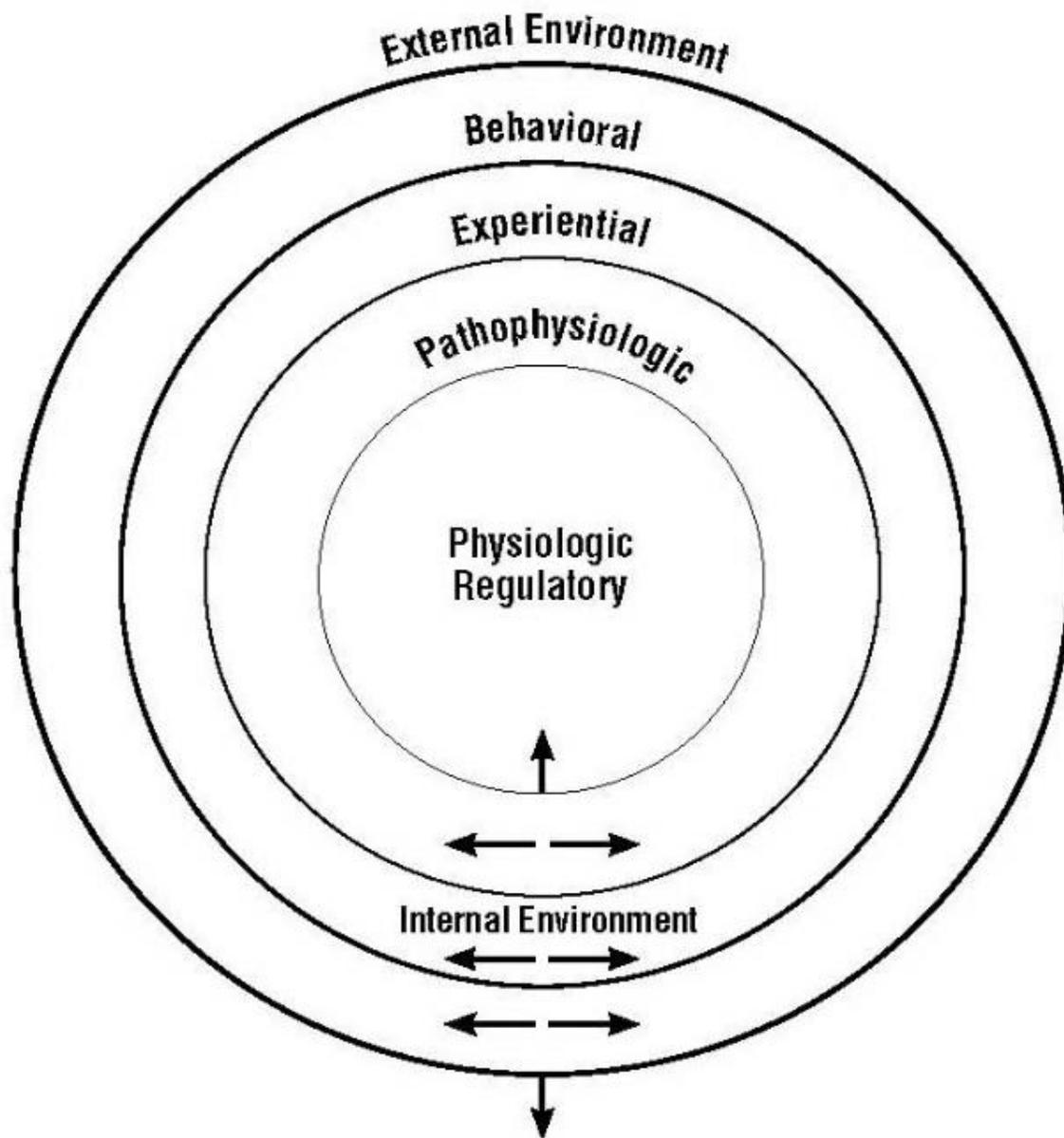
Stages in the development of heart failure and the recommended therapy by stage. FHx CM indicates family history of cardiomyopathy; ACEI, angiotensin converting enzyme inhibitor; and ARB, angiotensin receptor blocker.

Note. From “ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: Summary Article: a Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure),” by S.A. Hunt, W.T. Abraham, M.H. Chin, A.M. Feldman, G.S. Francis, T.G. Ganiats, et al., 2005, *Journal of the American College of Cardiology*, 46(6), 1121.

Copyright 2005 by the American College of Cardiology Foundation and the American Heart Association Inc. Reprinted with permission.

## APPENDIX D

## Human Response to Illness Model



Note. From "Perspective on Human Response to Health and Illness," by P. H. Mitchell, B. Gallucci, and S. G. Fought, 1991, *Nursing Outlook*, 39(4), p. 155. Copyright 1991 by Elsevier, Inc. Reprinted with permission.

## APPENDIX E

## Ethical Approval from Education/Nursing Research Ethics Board



UNIVERSITY  
OF MANITOBA

OFFICE OF RESEARCH  
SERVICES  
Office of the Vice-President (Research)

CTC Building  
208 - 194 Dafoe Road  
Winnipeg, MB R3T 2N2  
Fax (204) 269-7173  
www.umanitoba.ca/research

## APPROVAL CERTIFICATE

April 13, 2010

**TO:** Reid Love  
Principal Investigator  
[Redacted] Advisor - Susan McClement

**FROM:** Lorna Guse, Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2010:039  
"Living with End-Stage Heart Failure: An Interpretive  
Phenomenological Study "

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to [Redacted] in the Office of Research Services, (e-mail [Redacted], or fax [Redacted] including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**

## APPENDIX F

## Access Approval from St. Boniface General Hospital Research Review Committee



Hôpital général **St-Boniface** General Hospital  
 Research Review Committee  
**Approval Form**

**Principal Investigator:** Mr. R. Love  
**RRC Reference Number:** RRC/2010/1060  
**Date:** June 10, 2010  
**Protocol Title:** Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

**The following is/are approved for use:**

- Protocol (with Appendices), reviewed at the April 7, 2010 Research Review Committee Meeting
- Protocol changes, reviewed at the June 2, 2010 Research Review Committee Meeting
- Information and Consent Form dated May 4, 2010
- Study Poster, reviewed at the June 2, 2010 Research Review Committee Meeting

The above was approved by Dr. B. Light, Chairperson, Research Review Committee, St. Boniface General Hospital, on behalf of the Committee. As the recommendations by the Research Review Committee have been met, final approval is now granted.

Any significant changes to the study Protocol and Informed Consent Form must be reported to the Research Review Committee along with any other documents required as per Standard Operating Procedures for Clinical Investigators.

Sincerely yours,

  
 Dr. B. Light  
 Chairperson, Research Review Committee  
 St. Boniface General Hospital

**Please quote the above reference number on all correspondence.**

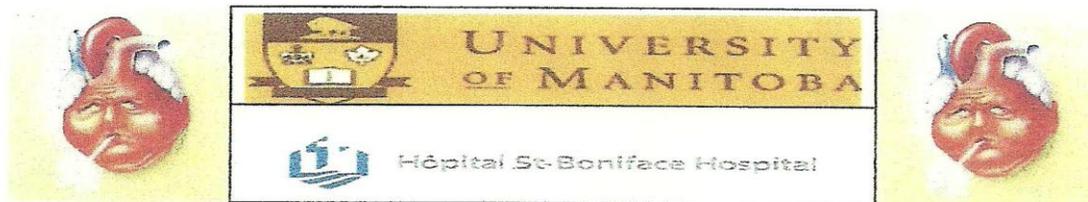
Inquiries should be directed to the RRC Secretary  
**Telephone:** (204) 235-3623 **Fax:** (204) 237-9860  
 N1004 – 409 Taché, Winnipeg, MB, Canada R2H 2A6

409 Taché, Winnipeg, Manitoba, Canada R2H 2A6  
 Tel (204) 233-8563 Website: [www.sbg.h.mb.ca](http://www.sbg.h.mb.ca)

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 Affiliated with the University of Manitoba/Affilié à l'Université du Manitoba

## APPENDIX G

## Recruitment Poster



## Are You Living With End-Stage Heart Failure???

### Would you like to participate in a research study to describe what it is like to live with End-Stage Heart Failure???

**Purpose:** To provide patients with ESHF the opportunity to: i) describe in their own words what it is like to live with their illness; and ii) take pictures that capture their illness experience.

**Research Question:** What is it like to live with ESHF?

**Sample:** A sample of 10-20 patients meeting the inclusion criteria listed below are required for the study.

**Recruitment Site:** St. Boniface Heart Failure Clinic

#### Inclusion Criteria

- > 18 years of age
- Ability to read & speak English
- Primary diagnosis HF
- Optimized medical therapy
- Continue to suffer from HF symptoms
- NYHA functional class III & IV

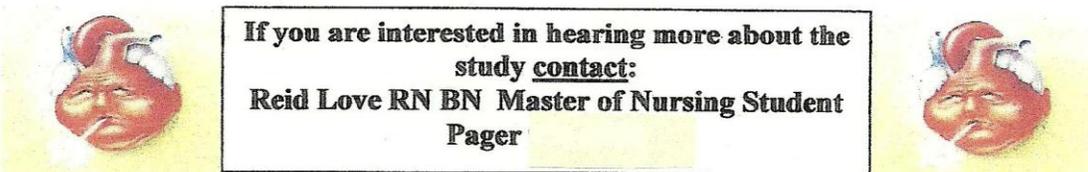
#### Exclusion Criteria

- Organ transplant candidate
- Unable to speak or read English
- No telephone access
- Cognitively impaired
- Secondary end-stage illness
  - stage IV cancer, renal disease on dialysis

**Recruitment:** If you meet the inclusion criteria a staff member associated with the heart failure clinic will introduce the study to you and provide you with an information sheet that briefly describes the research study.

This study is the Thesis I am doing as part of my Master of Nursing Degree at the University of Manitoba. This project has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. If you have any concerns about this project you may contact the Human Ethics Secretariat at 474-7122, or e-mail

Site access has been approved by the St. Boniface Research Review Committee.



**If you are interested in hearing more about the study contact:**  
**Reid Love RN BN Master of Nursing Student**  
**Pager**

## APPENDIX H

## Information Sheet



UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing  
Winnipeg, Manitoba R3T 2N6  
Canada  
Telephone (204) 474-7452  
Fax (204) 474-7682

## Information Sheet

**Research Project Title:** Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

**Researcher:** Reid Love RN BN Master of Nursing Student University of Manitoba

**Thesis Committee Members:** Dr. Susan McClement (Thesis Supervisor)  
Dr. Jo-Ann Sawatzky  
Dr. Mike Harlos

This document is intended to provide you with basic information about the purpose of this research project and the nature of your involvement in it, should you decide to take part. If you have questions or require further explanation about anything discussed in this Information Sheet please contact me at, pager [redacted] or telephone [redacted]

The purpose of this study is to hear first hand from individuals with end-stage heart failure what it is like to live with this illness. I am conducting this thesis research as part of my Masters in Nursing degree at the University of Manitoba. I hope that the findings from this study will provide a glimpse into what it is like to live with end-stage heart failure and assist nurses and other health care providers to improve care provided to those living with this disease.

If you agree to take part in this study, I will make an appointment with you to interview you about your experience in living with end-stage heart failure. I can come to your home to interview you, or the interview can be held in an alternative location that is mutually convenient to both of us. In this case you will be reimbursed for transportation or parking costs. Prior to beginning the interview, I will ask you to read and sign a consent form that describes the study. The interview will be audio-recorded so that I can listen carefully to what you are saying. It is estimated that the interview will last about one hour, but will be dependent on how much you have to say. If you are in agreement, I would also like to schedule a follow-up interview with you so that you can offer me some feedback about the accuracy with which I have interpreted and captured your description of living with end-stage heart failure. At that follow-up interview, you will also have the opportunity to add any additional information about what it is like to live with this disease that wasn't mentioned at our first interview.

In addition to interviewing you about your experiences, I will be asking you some general questions about yourself to collect socio-demographic information. I will also require access to your medical chart that is kept at the heart failure clinic at St. Boniface Hospital in order to collect information about other illnesses you may have, the date that you were diagnosed with end-stage heart failure, the diagnostic tests that were used to determine your end-stage heart failure, your use of community support services, such as home care and whether or not documentation exists in your clinic chart pertaining to the occurrence of a discussion about your resuscitation preferences.

As part of this study, I would also like to give you the opportunity to express, reflect and communicate your everyday life living with end-stage heart failure by capturing the lived experience through photography. I will provide you with three disposable cameras and ask you to take pictures of anything in your life that describes or identifies what it is like to live with end-stage heart failure. If you choose, you may also have others photograph you in an attempt to capture your lived experience of end-stage heart failure. You will not be permitted to photograph people other than yourself.

If you agree to participate in the photography part of the study, I will take a couple of minutes to explain how to use the cameras to take pictures. I will also arrange to pick up the cameras one week after you receive them and to schedule a second interview for two weeks thereafter. During this interview you will be asked to select and discuss five photographs that you feel are the most significant in identifying with the lived experience of end-stage heart failure. The interview will be audio-recorded. The interview is expected to last about one hour, but will be dependent on how much you wish to say. If you would rather not participate in the photography part of the study that is fine. You are still welcome to participate in the interview portion of the project.

Participation in this study is entirely voluntary. The care and services that you are currently receiving will not be affected whether you choose to participate or not participate within this study. It is your right at any time to choose to no longer participate in this study. If you remove yourself from the study after the initiation of the study any information you provided will be destroyed and treated as confidential waste and the care and services that you are receiving will not be affected. Furthermore, if you feel uncomfortable answering any questions you may choose not to answer them.

This research project has been approved by the: University of Manitoba Education Nursing Research Ethics Board, St. Boniface General Hospital Research Review Committee and Winnipeg Regional Health Authority Research Review Committee. If you have any concerns about this project you may contact the Human Ethics Secretariat at 474-7122, or e-mail [redacted]

Should you wish to contact me for further information my phone number is listed below:  
Thank you for your consideration to participate in this study.

Reid Love  
Telephone: [redacted]

Pager: [redacted]

## APPENDIX I

## Information and Consent Form

Living with End-Stage Heart Failure: An Interpretive Phenomenological Study



UNIVERSITY  
OF MANITOBA

Faculty of Nursing

Helen Glass Centre for Nursing  
Winnipeg, Manitoba R3T 2N2  
Canada  
Telephone (204) 474-7452  
Fax (204) 474-7682

## Information and Consent Form

**Research Project Title:** Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

**Researcher:** Reid Love RN BN

**Financial Support:** Provided by the Fort Garry Legion Poppy Trust Fund

This consent form is only a part of the informed consent process. It should provide you with a basic understanding of what this research project entails and your involvement as a research participant. If you require further information or explanation about something discussed within this form or not included in detail feel free to ask. Please take the time to read this information thoroughly. A copy of this consent form will be left with you for your records and future reference.

The purpose of this study is to hear first hand from individuals with end-stage heart failure what it is like to live with this illness. I am conducting this thesis research as part of my Masters of Nursing degree at the University of Manitoba. I hope that the findings from this research will provide a glimpse into what it is like to live with end-stage heart failure and assist nurses and other health care providers to improve the care they provide to people living with end-stage heart failure. The members of my thesis committee are Dr. Susan McClement, Dr. Jo-Ann Sawatzky and Dr. Mike Harlos.

If you agree to take part in this study, I will make an appointment with you to interview you about your experience of living with end-stage heart failure. I can come to your home to interview you, or the interview can be held in an alternative location that is mutually convenient to both of us. In this case you will be reimbursed for transportation or parking costs. The interview will be audio-recorded so that I can listen carefully to what you are saying. It is estimated that the interview will last about one hour, but will be dependent on how much you have to say. In addition to asking you about your experiences, I will be asking you some general questions about yourself to collect socio-demographic information. I will require access to your heart failure clinic medical chart in order to collect information about you; co-existing medical illnesses, diagnosis of end-stage heart failure (date and diagnostic tests), use of community support services, such as home care and whether or not documentation exists in your clinic chart

### Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

pertaining to the occurrence of a discussion about your resuscitation preferences. Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

A follow-up interview may also be scheduled where you will have the opportunity to verify that I have interpreted your description of living with end-stage heart failure correctly, and to add any additional information you would like to share.

In addition to taking part in an interview, I would like to offer you the opportunity to convey what it is like to live day to day with end-stage heart failure through photography. I will provide you with three disposable aim and shoot type cameras and ask you to take pictures of anything in your life that describes or captures what it is like to live with end-stage heart failure. If you choose, you may also have others photograph you. However, photographs can not be taken of anyone other than yourself. Photographs that include people other than you will be destroyed and treated as confidential waste. All photographs will be considered the property of the researcher and you will not be permitted to keep any of the photographs.

If you agree to participate in the photography part of the study, I will take a couple of minutes to explain how to use the cameras to take pictures. I will also arrange to pick up the cameras one week after you receive them and to schedule a follow- up interview for two weeks thereafter. During this interview I will ask you to select and discuss five photographs that you feel are the best in capturing what the experience of living with end-stage heart failure is like. The interview will be audio-recorded. The interview is expected to last about one hour, but will be dependent on how much you wish to say. If you would rather not participate in the photography part of the study, that is fine. You are still welcome to participate in the interview portion of the project.

No risk or harm is anticipated as a result of your participation in this study. If during the interviews you suffer psychological distress or anxiety or have any immediate physical concerns that arise, the interview will be stopped to focus on your immediate needs. You and I will decide if further follow-up care is required. If follow-up care is required I will seek your permission to contact the St. Boniface Heart Failure Clinic on your behalf.

All data collected for the study will be kept confidential, and every effort will be made to ensure your anonymity. Each person participating in the study will be assigned a unique code number. The specifically assigned code number and not your name will be placed on all data. A master list linking participant's names to assigned code numbers will be kept in a locked drawer in my home office and apart from consent forms.

The audio-recorded interviews will be typed out in full by a transcriptionist, who will sign a pledge of confidentiality, to preserve the authenticity of what you have said. Any names or other identifying information will be replaced with pseudonyms when the interviews are transcribed. All information shared by participants, except that which is reportable by law, will be held in confidence by the researcher.

The findings of the study may be published in scientific journals or presented at research meetings. Data that is presented will not contain any names or identifying information about participants. Direct quotations from the interviews will be incorporated into the reporting of the data in a manner that ensures the participant remains anonymous.

Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

With your consent, photographs that you have taken may also be included as part of these publications and presentations. If any of the photographs is a picture of you, your name would not be used, but replaced with a pseudonym. However, it is possible that your image may be recognizable to others, thus absolute anonymity in this instance cannot be assured.

All data (including photographs) and research materials will be stored in a locked filing cabinet in my home office. Only Dr. McClement, who is my thesis advisor, and I will have access to the collected data. Interview data will be stored in my personal computer, which is password protected thereby allowing only myself access. All study data will be securely stored for the duration of the research project and for five years thereafter, at which time it will then be destroyed and treated as confidential waste.

If you would like to receive a summary of the study results once the project is completed, please provide your mailing address and indicate so at the end of this consent.

You will not receive any remuneration for taking part in this study, however should arrangements be made to interview you outside of your home I will reimburse you for travel or parking costs.

Participation in this study is entirely voluntary, and you can choose not to answer any questions that are asked of you. The care and services that you are currently receiving will not be affected whether you choose to participate in this study, or not. Your signature on this form indicates that you have opted to participate in this study. However, you may withdraw from the study at any time once you have started, simply by telling me that you no longer wish to take part. If you remove yourself from the study after the initiation of the study, any information (interviews and photographs) you provided or I collected will be destroyed and treated as confidential waste and the care and services that you are receiving will not be affected.

Your signature on this form indicates that you have read and understood the information within this form and any accompanying information to your satisfaction and agree to participate in this research project as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or the involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and / or refrain from answering any questions you prefer to omit, without prejudice or consequences. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Should you wish to contact me or my research committee chair our phone numbers are listed below:

Reid Love  
Nurse researcher  
Pager

Dr. Susan McClement  
Thesis committee chair

Living with End-Stage Heart Failure: An Interpretive Phenomenological Study

This research project has been approved by the: University of Manitoba, Education/Nursing Research Ethics Board, St. Boniface General Hospital Research Review Committee and Winnipeg Regional Health Authority Research Review Committee. The University of Manitoba Research Ethics Board and St. Boniface General Hospital may review research-related records for quality assurance purposes. If you have any concerns or complaints about this project you may contact either of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail \_\_\_\_\_ . A copy of this consent form has been given to you to keep for your records and reference.

Thank you for your time and participation.

I, \_\_\_\_\_, agree to participate in this study about the lived experience of end-stage heart failure and grant permission for Reid Love to access my heart failure clinic medical chart for the collection of information about my diagnosis of end-stage heart failure (date & diagnostic tests or markers), co-existing medical conditions, utilization of community support services, such as home care and documented discussion of resuscitation preference / advanced care plan.

I, \_\_\_\_\_, agree to participate in the photography part of the study and grant Reid Love permission to utilize my pictures and stories for research and educational purposes at conferences or in publications. This means that photographs of me may be publicly displayed and possibly recognized by others.

I have read the above information explaining the study. I am aware that participation is voluntary and I may choose not to answer certain questions or withdraw from the study at any time without penalty. I give Reid Love permission to anonymously use any information from my interviews in any educational presentations or publications that result from this study.

\_\_\_\_\_  
Participant's Name Printed

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date

A summary of the findings of this study will be made available once the study has been completed. Would you like a summary of the results mailed to you?

Yes

No

If 'yes' please include your name and mailing address:

---

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Mailing Address (if different): \_\_\_\_\_

Postal Code: \_\_\_\_\_

---

## APPENDIX J

## Demographic Data Collection Form

**Participant ID #:** \_\_\_\_\_

Age: \_\_\_\_\_ Gender: \_\_\_\_\_ Marital Status: \_\_\_\_\_

Ethnicity: \_\_\_\_\_ Level of Education Completed: \_\_\_\_\_

Occupation: \_\_\_\_\_ Employment status: \_\_\_\_\_

Date diagnosed with End-Stage Heart Failure: \_\_\_\_\_ Unknown \_\_\_\_\_

Ejection Fraction: \_\_\_\_\_ Unknown \_\_\_\_\_

Note in chart about discussion of resuscitation preference: Yes \_\_\_\_ No \_\_\_\_

Utilization of Homecare Services: \_\_\_\_\_

Utilization of Community Services: \_\_\_\_\_

Other illness or co morbidities: \_\_\_\_\_  
\_\_\_\_\_

Name: \_\_\_\_\_

Assigned Participant ID Number: \_\_\_\_\_

Address: \_\_\_\_\_

Mailing Address (if different): \_\_\_\_\_

Postal Code: \_\_\_\_\_ Phone Number: \_\_\_\_\_

## APPENDIX K

## Semi-Structured Interpretive Interview Guide

1. I am interested in learning about your experience of living with end-stage heart failure. Can you please describe for me in as much detail as possible what it is like for you to live with end-stage heart failure?

Probes: Please describe what a normal day of living with end-stage heart failure entails for you?

Can you describe what it feels like to live with end-stage heart failure?

Do you feel your life has changed since being diagnosed with ESHF?

How? (e.g. positive things and negative things)

2. Can you please tell me what it means to you to live with end-stage heart failure?

Probes: Do you feel differently about yourself since you have been living with this disease?

In what way?

3. If I were to be diagnosed with end-stage heart failure today, and I was coming to you for advice as to what to expect living with this illness would be like, what would you tell me?

4. What suggestions would you offer to healthcare professionals about how they can best help individuals live with end-stage heart failure?

Probes: What do they do that is helpful to you? Not helpful?

Are there parts of your illness experience that health care providers do not really fully appreciate or understand?

5. What suggestions would you offer to family members about how they can best help individuals live with end-stage heart failure?

Probes: What do they do that is helpful to you? Not helpful?

Are there parts of your illness experience that your loved ones do not really fully appreciate or understand?

6. If there was 1 thing in your life that you could change right now what would it be?

7. Is there anything that you feel I have missed and would like to add?

Probe: Are there any other questions that you feel I should be asking about the experience of living with end-stage heart failure?

8. The disposable cameras will be shown to the participant, with a brief explanation of how to use them and that the participant can photograph anything that they feel describes the experience of living with end-stage heart failure or that they can have someone else photograph them to capture the experience of living with end-stage heart failure. It will also be stated that an appointment will be made for 1 week thereafter to pickup the cameras to develop the pictures and an interview setup for 2 weeks after that time to discuss five of the pictures that they believe best portrays the experience of living with end-stage heart failure and the associated meaning to them. I will then ask the participant... Would you be willing to be involved in the Photovoice portion of this study in an attempt to visually capture the meaning of living with end-stage heart failure? If so, I will provide you with further information on how to use the camera and leave an instruction sheet with you.

Thank you for your time. Is it alright with you if I contact you in the future for a follow-up interview in order to verify my interpretations of your description of what it is like to live with end-stage heart failure and to provide you with an opportunity to present any information that you feel you may have omitted?

## APPENDIX L

## Photovoice Interview Guide

1. You have been provided with cameras to photograph what living with end-stage heart failure means to you. I am now going to ask you to select a total of five pictures that you feel are the most significant to you in describing what it is like to live with end-stage heart failure. Please take your time now to select the five photos.
2. Now that you have selected the photos that you believe are the most significant in portraying what the experience of living with end-stage heart failure is like I am going to ask you some questions about each photo.

\*\*\* Each photograph will be numbered randomly one to five and the following questions will be asked about each photograph individually:

3. What do you see in photograph (1) (2) (3) (4) (5)?
4. What is happening in photograph (1) (2) (3) (4) (5)?
5. Is there anything else you wish to say about photograph (1) (2) (3) (4) (5)?
6. What can healthcare workers do to address these issues you discussed in photograph (1) (2) (3) (4) (5)?
7. Is there anything else that you feel I should ask others about the pictures they select?

Thank You for participating in the Photovoice portion of this study!