

DETERMINANTS OF SELF-CARE FOR HEART FAILURE PATIENTS IN AN
AMBULATORY CARE SETTING

BY

Karen Noreen Schnell

A Thesis
Submitted to the Faculty of Graduate Studies
In Partial Fulfillment of the Requirements for the Degree of

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ABSTRACT

Chronic heart failure is an illness associated with debilitating symptoms, diminished quality of life and frequent hospitalizations. It is suggested that effective everyday self-care decision-making has the potential to improve outcomes in heart failure patients.

The purpose of this study was to examine self-care practices and determinants of self-care decision-making in heart failure patients living in urban and rural settings. Using a descriptive, correlational, cross sectional design, a convenience sample of 65 patients in an ambulatory care setting was enrolled in the study. Guided by Connelly's Model of Self-Care in Chronic Illness, the data collection methodology included chart reviews, questionnaires and open-ended interviews.

The study findings indicated taking medication as prescribed, seeking physician guidance and following sodium dietary restrictions are self-care activities commonly engaged in. Self-care was influenced by a number of factors including self-concept, psychological status, co-morbidity, ethnicity, satisfaction with care, health beliefs and perceptions and self-efficacy. Although individuals without dyspnea had higher self-efficacy compared to those with this symptom, both groups in this study engaged in similar self-care practices. Individuals with higher efficacy scores also had fewer hospital admissions.

Four conceptual themes emerged from the open-ended interviews. The themes provide insight about: clinic features that contribute to patient satisfaction with care; factors that influence patient behavior as it relates to contacting the clinic for guidance; the nature of strategies used to manage symptoms; and, the role of social support in self-care.

Application of the findings of this study will facilitate developing care plans for heart failure patients that target factors likely to facilitate self-care.

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CHAPTER ONE

Statement of the Problem

Introduction

Progressive heart failure is associated with debilitating symptoms that severely limit an individual's daily functioning on a physical, personal and social level. Self-care is a critical component in the management of heart failure, particularly in an ambulatory setting.

An estimated 15 million people are affected worldwide by heart failure (Mosterd et al., 1999; Eriksson, 1995; Packer, 1987). Within North America, heart failure is being seen with increasing frequency, as the number of individuals diagnosed with this condition has almost doubled over the last two decades (American Heart Association, 2002; Massie & Shah, 1997; Smith & Kelly, 1991). Presently, there are approximately 350,000 Canadians and 4.8 million Americans afflicted with heart failure (Massie & Shah, 1997; Institute for Clinical Evaluative Sciences, 1999; Hunt et al., 2001).

Background

The prevalence of heart failure significantly increases with age. An estimated 10 percent of the population over the age of 80 has heart failure (Ho, Pinsky, Kannel & Levy, 1993; Kannel & Belanger, 1991). This age trend initially noted in 1948 with the Framingham Study and subsequent Framingham Offspring Study 30 years later is well documented within the literature (Hunt et al., 2001; Ghali, Cooper & Ford, 1990; Rich, 1997; Kupari, Lindroos, Iivainen, Heikkila & Tilvis, 1997; Ho et al., 1993). Currently, heart failure is the most common diagnosis for hospitalized adults 65 years

and older (Haldeman, Croft, Giles & Rashidee, 1999). The number of people diagnosed with heart failure is expected to double over the next 40 years due to Canada's aging population trend (Haldeman et al., 1999; Massie & Shah, 1997).

The progressive nature of heart failure impairs myocardial contractility, leading to inadequate oxygen delivery to meet the body's metabolic needs. The underlying pathophysiology and associated symptoms diminishes an individual's quality of life and functional level, leading to premature death (Bennett, Cordes, Westmoreland, Castro & Donnelly, 2000; Moser, 2000). Although the mortality rate from coronary artery disease has slowly declined over the last 30 years in part due to medical advances, the residual weakness of the surviving heart muscle has led to a steady rise in the prevalence of heart failure (Deedwania, 1994; Jarrsma, Ab-Saad, Dracup & Halfen, 2000; Kannel & Belanger, 1991). With 550,000 new heart failure cases occurring each year in the United States alone, experts anticipate heart failure will reach epidemic proportions in all industrialized countries over the next century due to the aging population and improved survival of other cardiac illnesses (Massie & Shah, 1997; Hunt et al., 2001). Individuals with heart failure tend to experience debilitating symptoms such as fatigue, shortness of breath, difficulty sleeping, along with peripheral swelling and abdominal third spacing (Grady, Jalowiec, Grusk, William & Robinson, 1995; Konstram et al., 1994). As compensatory mechanisms fail, the severity of these clinical symptoms intensifies, leading to hospitalization and ultimately death. Data from the initial Framingham Study as well as the Framingham Offspring Study clearly correlates heart failure and mortality rate, as three quarters of

the men and two thirds of the women with this condition died within five years of their diagnosis (Ho et al., 1993).

Self-care activities describe behaviors undertaken by individuals in an effort to prevent complications, maintain health, improve functional status or manage disease processes (Riegel, Carlson & Glaser, 2000). Over the past ten years, national and international cardiology consensus statements concerning self-care have been published, forming a base for clinical guidelines related to self-care that appears repeatedly within the literature (Liu et al., 2000; Konstam et al., 1994; Remme & Swedberg, 2001; Grady et al., 2000).

The inclusion of self care in the management of heart failure is supported by research findings indicating a positive relationship between self-care activities, symptom management and quality of life for people suffering from chronic illnesses (Baker & Stern, 1993). Over the last decade, there has been some preliminary research focused on the impact and determinants of self-care in heart failure patients. Although a significant number of heart failure patients are being treated in an ambulatory care setting, there is limited research on the determinants of self-care for these patients. Engaging in self-care activities by heart failure patients may facilitate the detection of a relapse as well as diminish debilitating symptoms (Bushnell, 1992; Rich, Grey, Beckham, Wittenberg & Luther, 1996). Incorporating self-care into patient management has led to significant clinical and economic benefits, as early treatment is sought, symptom distress prevented and hospitalization avoided (Bennett, Cordes et al., 2000; Rich et al., 1995; West et al., 1997). Unfortunately, individuals with chronic illnesses, such as heart failure who are aware of the health benefits of

self-care activities tend to engage in only a few of such activities (Ni, Nauman, Burgess, Wise & Crispbell, 1999; Bushnell, 1992). Once thought to be the sole stimulus for self-care, it is now recognized that patient awareness and education about their condition is not an accurate predictor of self-care behaviors (Riegel & Carlson, 2002). The choice of self-care activities performed by individuals with chronic illnesses appears to be primarily dependent on a person's health beliefs and motivation within the context of a given situation (Connelly, 1987, 1993; Becker, 1974). Identifying the specific reasons why individuals with heart failure perform certain self care measures while others do not will assist health care providers develop more effective care plans for this patient population.

Statement of the Problem

The focus on management of chronic illnesses in the community has translated into more heart failure patients being treated in a cardiac ambulatory care setting. The management of these patients in such a setting is dependent on the successful adaptation of appropriate self-care behaviors and activities into their lifestyle. However, as Bushnell (1992) indicates, even simple self-care activities, such as weighing oneself daily tended to be disregarded by individuals with heart failure. The reason why some heart failure patients follow self-care and others do not continues to elude researchers and practitioners (Riegel & Carlson, 2002). Understanding the determinants of self-care for this patient population will enable health care providers to develop a management plan targeted at promoting factors likely to facilitate the performance of self-care.

At present, there has been limited research on the determinants of self-care for patients diagnosed with heart failure, with only three published studies to date conducted on self-care behaviors with this patient population specifically in an ambulatory care setting. The first of these studies was a pilot study of heart failure clinic patients (Sulzbach-Hoke, Kagan & Craig 1997). A descriptive design was used to examine the specific self-care activity of weighing oneself, in relation to symptom distress. Although the primary research instrument within this study had established reliability and validity, use of a small convenience sample creates a design limitation. A second study was conducted by Ni and colleagues (1999) using a needs-assessment approach to examine self-care practices and associated factors in patients attending a heart failure clinic. Although a large sample was used, all the study participants were selected from one clinic known to accept patients with advanced heart failure for possible heart transplant. The third study conducted on ambulatory care heart failure patients used a qualitative approach to explore the self-care practices and strategies (Bennett, Cordes et al., 2000). This research provided rich data from the perspective of the individual on troublesome symptoms and self-care practices. A limitation identified by the researchers, was the large number of patients who declined to participate in this study.

A related concept of self-care is treatment compliance. There are four additional studies that examine this concept in relation to heart failure patients in an ambulatory care setting. Three of these studies used a quantitative approach to examine adherence to specific treatment components, such as physical activity and medication and dietary restrictions (Bennett, Milgrom, Campion & Huster, 1997;

Oka, Gortner, Stotts & Haskell, 1996; Neily et al., 2002). The other study examined compliance with general medical treatment for heart failure using a qualitative approach (Stromberg, Brostrom, Dahlstrom, Fridlund & Linkopang, 1999). Although these research studies add to the body of knowledge on treatment practices in heart failure patients, compliance research tends to focus on comparisons between medical advice and one or two specific behaviors often concerning medication and diet. In contrast, self-care activities focus on lifestyle behaviors and overall modifications that individuals incorporate based on everyday decision-making.

Purpose of the Study

This study will examine the determinants of self-care activities in ambulatory care patients in a heart failure clinic at a tertiary care teaching hospital. The findings of this study will add to the body of knowledge needed to support strategic recommendations aimed at fostering self-care on a daily basis. There are four research questions and corresponding hypotheses that will guide this study on self-care activities in heart failure patients:

1. In an ambulatory care setting, what are the self-care activities most commonly used by individuals diagnosed with heart failure?

Hypothesis: In an ambulatory care setting, taking medications as prescribed will be one of the most commonly practiced self-care activities for individuals diagnosed with heart failure.

2. What are the determinants of self-care for individuals diagnosed with heart failure seen in an ambulatory care setting?

Hypothesis: The determinants of self-care for individuals diagnosed with heart failure seen in an ambulatory care setting include social support, self-efficacy and psychological status. These factors will be positively correlated with self-care in this patient population.

3. When ambulatory care patients suffering from heart failure experience shortness of breath, are they more or less inclined to perform self-care activities?

Hypothesis: Ambulatory care patients suffering from heart failure who experience shortness of breath will be more inclined to perform self-care activities.

4. What is the relationship between self-care and hospital admissions for ambulatory care patients experiencing heart failure?

Hypothesis: Heart failure patients with a high level of self-care will have a lower hospital admission rate related to heart failure, as these two factors will be negatively correlated.

The research will be guided by Connelly's Model of Self-Care in Chronic Illness (MSCCI), in which an individual's health beliefs and motives are thought to be the primary reasons for consistently performing self-care activities (Connelly, 1987, 1993). The determinants of self-care will be identified primarily through a quantitative approach using the Self-Care of Heart Failure Index (SCHFI), designed specifically for this patient population. A small qualitative component will be incorporated to facilitate a comprehensive understanding of self-care determinants through the interviews.

Significance of the Study

As heart failure progresses there is a decline in the quality of life due to the sequelae associated with fluid overload symptoms, such as shortness of breath and edema, along with symptoms of poor perfusion, including fatigue and physical inactivity (Konstam et al., 1994). Self-care activities are incorporated into the management of this condition as a means of ameliorating the functional disability associated with heart failure and stabilizing the detrimental compensatory mechanisms that develop. As the prevalence of heart failure and the number of people treated in an ambulatory care setting increases, more emphasis is placed on a person's ability to consistently perform self-care activities. Preliminary research indicates that this is not occurring with the majority of heart failure patients living in the community (Ni et al., 1999; Bushnell, 1992).

The proposed research will elucidate demographic characteristics as well as health beliefs and motives, which it is suggested, could be important determinants of self-care. The findings will make a significant contribution to the health care providers assigned the responsibility for efficiently strategizing the care of heart failure patients living in the community. The findings will also contribute to the body of limited research and lead to development of clinical practice guidelines that will more accurately predict which factors result in successful use of self-care behaviors in this vulnerable population.

Chapter Summary

The increasing incidence of cardiac diseases has led to a steady rise in the number of individuals experiencing heart failure. Self-care activities are an integral

part of management for this chronic condition, which requires further understanding and development. Identifying the determinants of self-care for patients with heart failure in an ambulatory care setting will facilitate the development of strategies to promote health in this patient population. This research study will document the specific self-care activities and determinants of self-care in a convenience sample of individuals being treated for heart failure in an ambulatory care setting.

Definition of Terms:

Heart Failure

- A chronic clinical syndrome where cardiac remodeling (structural changes in the shape and dimension of the heart) results in a severely impaired ability of the heart muscle to contract and supply the body with adequate tissue perfusion (Riegel, Carlson & Glaser, 2000; Dahl, 2001).

Self-Care Activities

- The behaviors a person undertakes based upon a cognitive decision making process (Riegel et al., 2000).

Self-concept

- A person's own view of one's self.

Health Motivations

- A patient's perception of the importance of health in general and their willingness to perform health care behaviors (Connelly, 1987).

Self-efficacy

- The belief that a person can perform a behavior necessary to achieve a certain outcome or effect (Rice, 1998)

CHAPTER TWO

Conceptual Framework

Introduction

A theoretical framework is “a set of relatively abstract and general concepts that address the phenomena of central interest to a discipline” (Fawcett, 2000, p. 15). It provides a conceptual base for a comprehensive understanding that can be applied to practice. In this study, a theoretical framework focused on the phenomena of self-care in the chronically ill will serve as a guide to direct the research.

Self-care refers to an active process in which a person engages to maintain health and manage illness. It is a learned behavior based on beliefs and motives that require a person to change longstanding patterns of conduct (Connelly, 1987). The concept along with its corresponding theories has evolved over time to become a futuristic strategy embraced by the health care community. Today, self-care in chronic illness has been adopted as a primary approach in health promotion and disease management.

Background

There are numerous conceptual models and theories that postulate about self-care and its impact on health and wellbeing. In 1856, Florence Nightingale acknowledged the use of self-care in her work entitled, *Notes on Nursing* that was republished in 1969 (Nightingale, 1969). It was not until nearly a century later that the women’s movement re-ignited the notion of self-care (Kemper, Lorig & Mettler, 1993). The concept and its use was re-introduced into the nursing domain in 1955 through the work of Henderson, who defined nursing in terms of assisting people to

care for themselves. Another influential nursing scholar during this era, Lydia Hall reviewed the role of nurses and formalized self-care to be one of nursing functions in the late 1950s (George, 1980). Dorothea Orem expanded on this preliminary work in 1959, as she believed self-care deliberately performed by people to maintain health and wellbeing was the primary focus of nursing. She continued on to develop a theoretical framework, known as the Self-Care Deficit Theory of Nursing, based on the related concepts of self-care, self-care requisites and self-care agency (Orem, 1985). Different approaches to self-care have been formulated over the last few decades. An influential approach to self-care that evolved from the work of Levin (1978) was the medical model, which conceptualizes self-care as a behavioral process where lay people act as the principal source for their own health.

The framework used in this study, the Model of Self-Care in Chronic Illness (MSCCI), is based on the Health Belief Model, a 1974 systems model conceptualized by Becker. The Health Belief Model is a motivational theory focused on a person's beliefs and expectations (Becker, 1974). Four basic factors influence a person's decision to perform health related actions: their belief of disease susceptibility, their understanding of disease severity and potential benefits and costs of doing that action (Becker, 1974). This benchmark model has been used extensively in multidisciplinary health research, as a person's perceptions and health motives drive health related behaviors one practices (Becker, 1974). In 1987, a nursing theorist, Catherine Connelly refined this general model to reflect the unique characteristics of chronic illness and the specific issues of self-care. This revised framework, the Model of Self-Care in Chronic Illness (MSCCI), is based on the premise that "human

beings can be expected to respond in a manner that they believe will lead to the most subjectively valuable outcome for that particular situation” (Rockwell & Riegel, 2001, p. 19).

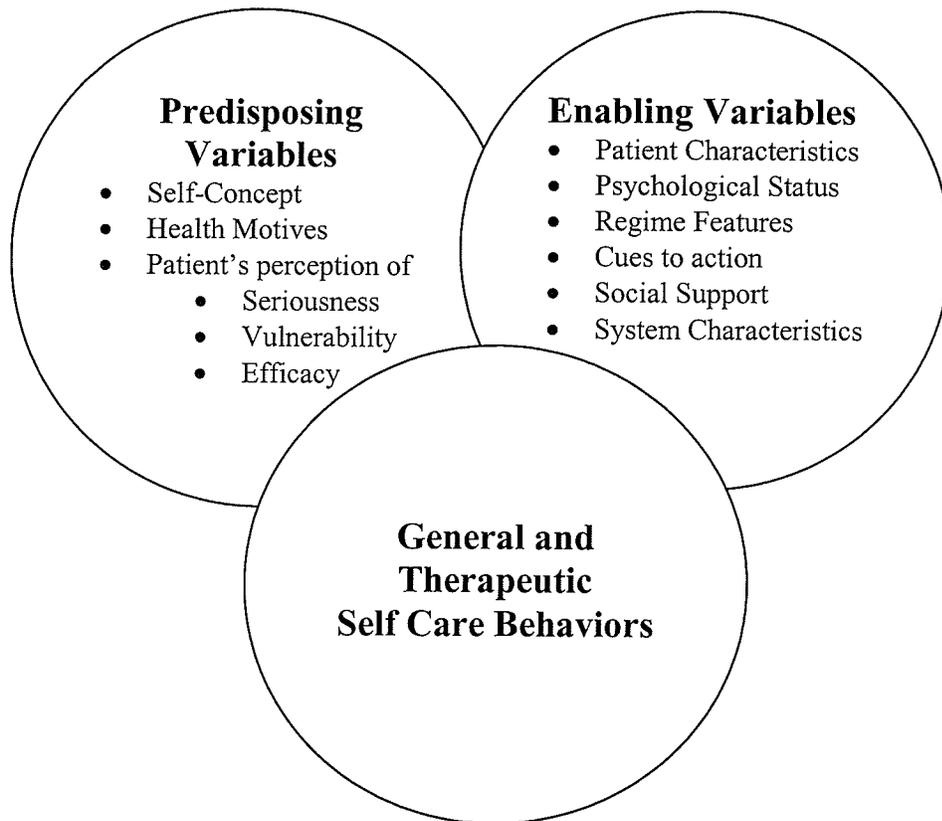
Model of Self-Care in Chronic Illness

Connelly’s Model of Self-Care in Chronic Illness (MSCCI) has been selected as the framework to guide this study, as it is consistent with a holistic view of self-care engaged in by individuals living with a chronic illness such as heart failure. Once believed to be a simple management strategy, self-care is now thought to be the result of complex factors and motives that places the chronically ill in the center of care. Connelly (1987) developed this framework to “describe, explain and relate the variables that influence self-care behaviors in chronic illness” (p. 247). The long-term nature of chronic illness, the multidimensional treatments required and the fact that much of the care occurs in an ambulatory setting all contribute to how self-care is perceived by an individual (Connelly, 1987). A critical research review on chronic illnesses such as diabetes and epilepsy conducted by Janz and Becker (1984) supports the use of concepts from the Health Belief Model in the chronically ill. With the focus on the outcome of ‘self-care’ rather than ‘compliance’, the MSCCI framework has been effectively tested in two studies conducted on individuals with chronic illnesses (Bennett, Hays, Embree, & Arnould, 2000; Connelly, 1993). It is hypothesized that this framework will assist health care providers in developing a decision making process to promote and support self-care in the chronically ill (Connelly, 1987, 1993).

The MSCCI incorporates features of the Health Belief Model but differs in that the latter model is predicated on ‘compliance’ as the outcome variable whereas in the MSCCI it is ‘self care’. In addition, Connelly’s (1993) MSCCI is described as “a general systems framework in which self care outcome is not a consequence of a causal relationship. Rather the predisposing and enabling factors and self-care behaviors (are seen as) interacting with and modifying each other in a circular relationship” (p. 248), as depicted in Figure 1 below (Connelly, 1987). Thus, for example, self-care behaviors may affect the predisposing variables self-concept, motivation and perceptions about seriousness, vulnerability and efficacy which, in turn may affect enabling variables such as patient psychological status, regime features, cues to action and the need for social support.

Figure 1

The Model of Self-Care of Chronic Illnesses (MSCCI)



Predisposing Variables

The predisposing variables are founded on the past experiences, health beliefs and motives that a person living with a chronic illness holds to be true (Connelly, 1987). There are three components that make up the category of predisposing variables: self-concept, health motives and perceptions of seriousness, vulnerability and efficacy related to a specific chronic condition (Connelly, 1987, 1993).

Self-concept is simply seen as an individual's own view of one's self. It impacts the perception a person has of past, present and future events (Connelly, 1993). Living with heart failure, where quality of life is detrimentally affected, can significantly influence how people see themselves. Self-worth and self-respect govern a person's view of the world and shapes the decisions they make with regard to participating in care (Connelly & Dilonardo, 1993).

The general health motivations of an individual address the importance that is attached to one's own wellbeing and the role a person is willing to perform as part of his or her health. Traditionally, patient education has assumed people view health as their sole priority where they seek out an active role in their health. People with a chronic illness tend to feel that they have limited control over health, which may result in prioritizing other facets of life over health. Understanding a person's general health motives and their willingness to be an active participant in care impacts how a self-care activity is perceived and ultimately preformed.

A patient's health perceptions related to a specific illness are instrumental in determining the probability of a person performing a specific health behavior related to self-care (Becker, 1974; Connelly, 1987). Perceptions of illness severity and

vulnerability of a relapse adopted by a person is dependent on past experiences and current knowledge of one's illness. Denial of a chronic illness tends to eliminate any willingness a person has to engage in self-care behaviors (Connelly & Dilonardo, 1993). The perceived benefits of self-care are weighed against the costs and inconveniences of performing a particular health action at a given point in time. Connelly identified self-efficacy – a person's perception or confidence about his or her own ability to exert control over situations (Bandura, 1977) – as a significant predisposing factor to self-care. With chronic illness, an exacerbation or deterioration in a person's condition can occur despite diligent self-care efforts. The chronically ill need to rely on their self-efficacy to consistently practice these behaviors irrespective of the limited or partial effect it has on alleviating symptoms or functional disability (Connelly & Dilonardo, 1993).

Enabling Variables

Enabling variables are based on the current circumstances a person faces as part of the management of his or her condition (Connelly, 1987). The components that comprise this category include patient characteristics, social support, psychological status and system characteristics. Connelly also categorizes regime feature and cue to action as enabling variables, which are not included in this study. This model modification was considered necessary since the study participants are in a structured ambulatory care setting where the regime features have been mutually planned with the same resources. The variable 'cue to action' that refers to the direct and indirect reminder or suggestions given by health care providers to patients was excluded due to a revision of the Self-Care of Heart Failure Index, the primary

instrument used in this study. Adapting a small aspect of the model to the study does not alter how the enabling factors reflect on a patient's current situation or the interaction it has with the predisposing factors.

Patient characteristics and social support are key factors that can influence a person's perception and the self-care behaviors that are incorporated into one's lifestyle. Patient characteristics describe the demographic features (such as age, gender, education, socioeconomic status and co-morbidity) that differentiate one heart failure patient from another. These characteristics interact with other enabling factors and perceptions leading to different belief patterns related to self-care. The social support network for the chronically ill is a fundamental aspect that is recognized by health care providers. It is hypothesized that social and emotional support received by a significant other motivates a person to perform self-care activities on a consistent basis. A related component that Connelly has incorporated into this model is the psychological status of a person, as preliminary testing found a person's general mood and feelings reflect affective and cognitive processes that govern self-care practice (Connelly, 1993). Level of anxiety, stress and outlook on life are part of psychological status that requires consideration in order for health behaviors to be effective.

The system characteristic discussed in the model refers to patient satisfaction with their health care providers and the care they have received (Connelly, 1987). The quality of the interactions between patient and health care provider influences the meaning and perception the patient attaches to information received from their care providers. When individuals believe their health care providers are not only

competent but also genuinely care how they are feeling, they are more open to self-care strategies and lifestyle changes (Connelly, 1987, 1993). This system characteristic is particularly evident if a patient perceives one specific person to be the primary source of care for a specific problem, rather than a group of individuals.

Chapter Summary

The underlying principle of Connelly's MSCCI framework that drives this study is an individual's health motives and perception, along with a person's current enabling variables, will determine whether a particular self-care activity is performed (Becker, 1974; Connelly, 1987, 1993). The interactive structure in this model is consistent with self-care in the chronically ill. Using the MSCCI as the conceptual framework provides a comprehensive approach to self-care based on a person's motives and belief system.

CHAPTER THREE

Literature Review

Introduction

The literature review examines the current body of knowledge related to self-care for heart failure patients being treated in an ambulatory care setting. Computer searches were conducted using the MEDLINE and CINAHL databases, along with the Internet and a manual literature search from key articles. Primary subject terms included heart disease, coronary artery disease, cardiac, congestive heart failure, heart failure and chronic illness that were cross referenced with self-care, health behaviors, determinants, health beliefs, self-regulation, self-directed and self-management. To ensure a comprehensive understanding of heart failure in a national context, numerous Canadian websites were also searched including: the Heart and Stroke Foundation of Canada, the Canadian Cardiovascular Society, the Canadian CHF Clinic Network, the Canadian Institute for Health Information and Health Canada. International websites including North American and European sources were also searched: the American Heart Association, the American College of Cardiology, the Heart Failure Society of America, the European Society of Cardiology and the World Heart Federation. As part of the detailed literature review related to heart failure, an overview of the pathophysiology underlying this condition as well as a review and synthesis of the research related to self-care in chronic illnesses in general and heart failure in particular was undertaken.

Pathophysiology of Heart Failure

Heart failure refers to a “pathophysiological state in which the heart is unable to pump blood throughout the circulatory system to meet the peripheral demands of the metabolizing tissues” (Liu et al., 2000, p. 3). This disordered physiological state results from either structural or functional cardiac dysfunction where the filling or ejection of blood from the ventricle is impeded (Hunt et al., 2001). The cardinal manifestations of heart failure, dyspnea, fatigue and fluid retention relate to this underlying pathophysiology such that an individual’s quality of life including physical and functional capabilities are impaired.

Systolic and Diastolic Dysfunction

Heart failure may be classified as either systolic or diastolic dysfunction, depending on the nature of the predominant ventricular abnormality. In systolic dysfunction, the heart is unable to contract effectively, as the ventricular chambers become significantly dilated causing a marked reduction in ventricular wall motion during a contraction (Albert, 1999). This results in a reduced cardiac output and depressed left ventricular ejection fraction, as the amount of blood ejected by the heart in a single beat becomes less than 40 percent (Hunt et al., 2001). The etiology of left ventricular systolic dysfunction in the majority of the patients is coronary artery disease (Carelock & Clark, 2001; Gheorghiade & Bonow, 1998). The remaining patients with this type of heart failure have non-ischemic impairments such as long standing hypertension, valvular dysfunction, idiopathic disease or dilated cardiomyopathy (Carelock & Clark, 2001; Gheorghiade & Bonow, 1998).

In contrast, patients with predominant diastolic dysfunction have abnormalities in ventricular filling, where the ventricle cannot fill with an adequate amount of blood under normal cardiac pressures during the diastole phase (Albert, 1999; Hunt et al., 2001). Although cardiac contractility is normal, there is reduced ventricular relaxation, increased ventricular stiffness or a combination of the two leading to slow, delayed or incomplete filling (Zile & Brutsaert, 2001). The etiology underlying diastolic heart failure tends to be vague, although it is associated with cardiomyopathy, valvular heart disease, coronary artery disease and hypertension (Hunt et al., 2001; Albert, 1999). Patients with chronic heart failure frequently have ventricular abnormalities with a component of both systolic and diastolic dysfunction (Albert, 1999).

Cardiac Functional Classification Systems

There are various classification systems created to describe and categorize the progression of chronic heart diseases, such as heart failure. The New York Heart Association (NYHA) Functional Classification has been accepted internationally as a standard for describing the degree of cardiac impairment ranging from Class I to IV (see Appendix A). In 1994, this classification system was refined based on objective assessment categories frequently used in cardiac research. In 2001, the American College of Cardiology and the American Heart Association introduced a new approach for describing heart failure that reflects its progressive nature (Hunt et al., 2001). This classification system is used in conjunction with the NYHA Functional Scale and categorizes heart failure as stage A through to D based on established cardiac risk factors, symptom severity and structural impairments present with heart

failure (Hunt et al., 2001; Carelock & Clark, 2001). Stages A and B describe patients with existing cardiac structural impairment or significant risk factors for heart failure. It does not describe patients that presently exhibit cardiac symptoms. In comparison, Stages C and D describe patients with varying levels of symptoms and underlying cardiac pathophysiology requiring heart failure treatment (see Appendix B).

Compensatory Mechanisms

A myocardial insult or injury that impairs the functional ability of the left ventricle initiates heart failure. This ventricular dysfunction manifests as tissue hypoperfusion and arterial underfilling, irrespective of subsequent injury or removal of the initial insult (Piano, Bondmass & Schwertz, 1998). This poor perfusion state associated with the failing cardiac function triggers compensatory mechanisms as the body attempts to stabilize its impaired circulatory system to meet metabolic demands.

The activation of these compensatory mechanisms involves four key physiological responses: the stimulation of the sympathetic nervous system, the activation of the renin-angiotensin-aldosterone (RAA) system, the release of natriuretic peptides and the initiation of ventricular remodeling (Albert, 1999). Initially, this compensatory process preserves cardiac output, blood pressure and contractility of the weakened heart. However, continual use of these mechanisms over time further deteriorates myocardial function. As excessive neurohormones are released into the circulation, cardiac structural changes are initiated (Piano et al., 1998). This re-development creates an imbalance between oxygen supply and demand, altering the four determinants of cardiac performance: preload, afterload, contractility and heart rate (Albert, 1999; Piano et al., 1998).

Sympathetic Nervous System Stimulation

Chronic heart failure creates a sustained state of poor perfusion throughout the body. This depressed perfusion reduces the cardiac output and the systemic blood pressure, activating baroreceptors within the left ventricle, aortic arch and carotid sinus. When this occurs, the vasomotor regulatory center in the medulla is stimulated and the sympathetic nervous system is activated. Specific neurohormones, known as catecholamines (norepinephrine and epinephrine) are released into the circulation.

This activation of the sympathetic nervous system increases cardiac performance in response to a rise in catecholamines, as the preload, afterload, heart rate and contractility are elevated (Albert, 1999). The release of epinephrine and norepinephrine in the body leads to a significant increase in heart rate, as well as venous and arterial vasoconstriction (Piano et al., 1998). Vasoconstriction increases blood pressure, raising afterload, the pressure that the left ventricle must contract against. This peripheral vasoconstriction also pushes blood forward towards the heart, increasing the blood volume (preload) and stretch of the muscle fibers in the left ventricle prior to contraction. The elevated blood volume in the heart also intensifies the influx of calcium into the cardiac muscle cells leading to increased cardiac contractility based on Frank-Starling Law of the Heart (Albert, 1998, 1999; Dracup, 1996; Pratt, 1995; Sherwood, 2001).

Continual stimulation of the sympathetic nervous system gives rise to detrimental hemodynamic and ventricular remodeling effects. Chronic sympathetic activation diminishes and impairs the responsiveness (down-regulation) of the adrenergic receptors resulting in functional cardiac impairment (Albert, 1999). The

blood flow becomes regionally redistributed and the heart muscle cells (cardiac myocytes) alter as structural remodeling in the ventricle occurs. Continual sympathetic stimulation is associated with decompensated heart failure, as the myocardial oxygen consumption increases and necrosis of the cardiac myocytes leads to rhythm disturbances and ultimately cardiac cellular death (Piano et al., 1998; Carelock & Clark, 2001).

Renin-Angiotensin-Aldosterone Activation

The impaired filling or contractility associated with heart failure leads to reduced blood flow to the essential organs of the body such as the kidneys. When renal perfusion is diminished, the body activates the renin-angiotensin-aldosterone (RAA) system to regulate sodium and water balance. This neuroendocrine response begins in the juxtaglomerular apparatus of the kidneys, where the release of renin into the blood stream intensifies in response to the reduced renal blood flow and arteriole pressure. Renin interacts with another substance in the blood, angiotensinogen to produce angiotensin I, which converts into a potent vasoconstrictor, angiotensin II. The subsequent narrowing of the peripheral blood vessels increases both the blood pressure and afterload (Albert, 1999; Sherwood, 2001).

Another function of angiotensin II, the by-product of this physiological response, is the stimulation of the adrenal cortex to produce more aldosterone. This hormone promotes arterial vasoconstriction even further, while enhancing retention of sodium and water (Albert, 1999). This effect is intensified by the stimulation of the antidiuretic hormone. The resultant re-absorption of sodium and water elevates the

plasma volume, leading to a higher preload and increased contractility (Albert, 1998, 1999; Dracup, 1996; Pratt, 1995; Sherwood, 2001).

In addition to these systemic effects, the chronic activation of angiotensin II triggers structural changes, such as fibroblast proliferation along with over-stretching and hypertrophy (increase in cell size) of the cardiac myocytes (Capriotti, 2002). This reduces the effectiveness of the RAA system to respond as a compensatory mechanism. Other neurohormones such as vasopressin, endothelin and cytokines that are activated in heart failure lead to further cardiac hypertrophy and fibrotic changes (Capriotti, 2002). Cardiac research supports this understanding of the RAA system, as high levels of angiotensin II and aldosterone correlate with adverse cardiac structural changes (Piano et al., 1998).

Natriuretic Peptides Activation

The profound vasoconstriction that occurs in heart failure activates the secretion of low molecular weight protein molecules, known as natriuretic peptides. The compensatory mechanisms of RAA system to retain sodium and water causes atrial stretch signaling the release of these counter regulatory substances. Natriuretic peptides induce vasodilation, vascular smooth muscle relaxation and diuresis within the body (Capriotti, 2002). Atrial natriuretic peptide (ANP) and brain natriuretic peptide (BNP) are the specific protein molecules produced respectively in the atria and ventricles (Carelock & Clark, 2001). The co-activation of these two peptides promotes vasodilation, reducing the cardiac preload and afterload, while minimizing the sodium and water retention within the body (Albert, 1999). ANP and BNP balance the vasoconstrictive effects of the compensatory mechanisms by inhibiting

sympathetic tone and blocking the RAA activation. Individuals afflicted with heart failure have elevated plasma levels and ventricular gene expression for these two natriuretic peptides. In particular, a positive correlation between BNP levels and severity of heart failure is evident within recent research (Carelock & Clark, 2001; Albert, 1999).

Initiation of Ventricular Remodeling

The underlying pathophysiology of heart failure involves changes that occur at the molecular level. Ventricular remodeling describes the alterations in the shape, dimension and gene expression of the myocardial cells in the left ventricle that are initiated even before the appearance of clinical symptoms (Carelock & Clark, 2001). It is hypothesized that these changes are an attempt by the heart to increase contractility and preserve cardiac function. Paradoxically, cardiac remodeling has the opposite effect, as myocytic hypertrophy, altered myocyte organization and fibrous tissue accumulation lead to poor cardiac contractility (Albert, 1999). The enlarged myocardium places an increased oxygen demand on the body, while reducing the cardiac compliance and contractility force. These events heighten the imbalance between the myocardium oxygen supply and demand (Albert, 1999; Baig et al., 1999; Piano, Kim & Javis, 2000; Pratt, 1995).

Ventricular remodeling begins with hypertrophy of the cardiac myocytes through the regression of protein synthesis, which yields large, genetically abnormal cells incapable of effective contraction. Over time, this cellular change leads to cardiac hypertrophy, where the ventricles enlarge, becoming stiff and elliptical in shape (Albert, 1999; Pratt, 1995). Despite its large size, these structural changes

diminish the ability of the ventricles to pump and increased the stress on the chamber wall, which results in further myocardial oxygen consumption (Hunt et al., 2001). The extent of cardiac remodeling that occurs is proportionate to the disease progression, which is why some classification systems have incorporated structural changes into the stages of heart failure (see Appendix B). These cardiac changes contribute to both the impaired relaxation and contraction of the heart.

Another component of the ventricular remodeling process is the reduction of the number and strength of the myocytes that furthers impaired myocardial function. This phenomenon is known as apoptosis and refers to the preprogrammed cellular death of cardiac cells that occurs even in the absence of an inflammatory process (Albert, 1999). The expression of angiotensin II, norepinephrine and epinephrine that are present in excess with heart failure potentates the process of ventricular apoptosis and ultimately myocardial cellular death. This myocytic change contributes to the dilation of the left ventricular chamber as it hypertrophies. As the mechanical performance of the heart deteriorates, the remodeling process is exacerbated (Hunt et al., 2001).

Self-Care Behaviors in Chronic Illness

Various research studies related to self-care for individuals with chronic illnesses have been carried out over the last 20 years. Much of this research has focused on individuals with diabetes or hypertension (Dodd, 1984). The unique characteristics of individuals afflicted with a chronic illness influence not only their perceptions, but also the performance of self-care behaviors.

Self-Care Practices

Overall, individuals with chronic illnesses tend to perform self-care activities infrequently, even when they are aware of the associated health benefits. A review of the compliance research indicates that only half of the patients diagnosed with a chronic illness follow their prescribed medication regime and corresponding self-care activities (Sackett & Snow, 1979; Oldridge, 1988). In one study conducted by Makinen, Suominen and Lauri (2000) on 150 adults with asthma, the use of self-care behaviors varied depending on the type of activity involved. For example, less than half of the participants suffering from asthma stopped smoking and took measures to eliminate exposure to smoke in their home environment, while more than 80 percent of these individuals ensured their living space was free of dust and perfumed detergents.

Several studies conducted on the diabetic population have found that self-care practices related to medications were followed more consistently than practices related to lifestyle modification such as physical activity and diet (Connell, 1991; Ary, Toobert, Wilson & Glasgow, 1986; Wilson, Ary, Biglan, Glasgow, Toobert & Campbell, 1986). For example, a descriptive study of 76 amputees with non-insulin dependent diabetes conducted by Pharm, Fortin and Thibaudeau (1996) found more than 80 percent of the participants followed the prescribed regime of medication and glucose testing, while 59 percent followed their prescribed diet.

Another descriptive correlational study conducted by Connelly (1993) examined self-care practices for 181 ambulatory care patients with various chronic illnesses. In contrast to previous studies, a disproportionately high number of

participants performed self-care consistently. Over 80 percent of the participants followed therapeutic self-care behaviors related to prescribed medications and diet all or most of the time. The use of self-reports as the sole indicator of self-care within this study may have contributed to this unusual finding.

Determinants of Self-Care

Self-care research in chronic illness has explored associations between several variables and the level of self-care achieved within specific patient populations. This research has attempted to identify specific factors or beliefs that characterize individuals who practice self-care regularly.

Perceived Benefit

An individual's perception of health in relation to oneself and their chronic illness have been examined within the self-care literature. Perceived benefits and barriers to self-care along with the person's underlying health belief impact the self-care practices that are adopted. People tend to practice a self-care behavior when they have a motivating factor or believe it will benefit them to perform that particular behavior. The behavior is dismissed when a person believes no benefit will result (Connelly, 1987).

There have been several studies that have examined the perceived benefits and barriers of performing self-care behaviors. A qualitative study conducted by Paterson, Thorne and Russell (2002) on a sample of 21 individuals with chronic illnesses such as non-insulin dependent diabetes, HIV and multiple sclerosis examined the underlying decision making process for self-care. A primary theme emanating from this study was the significance and benefit attached to a self-care

behavior, impacts on the consistency in which that behavior is practiced. For instance, when fatigue was perceived as being detrimental to a person's life, then self-care measures believed to alleviate fatigue were readily practiced. These researchers examined self-care decision-making further through secondary analysis of 43 qualitative interviews with chronically ill individuals (Thorne, Paterson & Russell, 2003). One of the primary themes within this secondary study was the need of the chronically ill to assume control over their disease by weighing the benefits and burdens of a self-care activity prior to implementing it.

This association was supported by a Dutch study conducted by Mollem, Snoek and Heine (1996) on 240 ambulatory care diabetic patients. These researchers found that self-care behaviors participants practiced were negatively correlated to perceived barriers associated with that behavior. Another correlational study was conducted on 309 adult patients with type 2 diabetes to determine the impact of perceived barriers on self-care. Aljaseem, Peyrot, Wissow and Rubin (2001) found individuals who believed there were fewer barriers to self-care performed self-care related to physical activity for a longer period of time and more readily adopted dietary self-care practices. Although perceived barriers of self-care was predictive in this study, it accounted for only a small portion of the variance in dietary practices.

Two research studies on the use of specific self-care practices in healthy adolescents also support this premise. Ferguson, Yesalis, Promrehn and Kirkpatrick (1989) found that perceived benefits of exercise significantly predicted exercise behaviors in 603 middle-school students. Riccio-Howe (1991) examined the effect of perceived health benefits of safety-belt use in 300 adolescents and found that use of a

safety-belt was directly associated with the benefits and inversely associated with the barriers perceived by adolescents in relation to performing such an activity.

The beliefs about health and illness a person holds in general, as well as specifically to their illness, impacts self-care practice according to the research. Frank-Stromberg, Pender, Walker and Sechrist (1990) examined the relationship between health beliefs and self-care in 385 ambulatory cancer patients. Participants who defined health in a positive context were more likely to engage self-care activities within this study. This finding is supported by Nicholas (1993) who studied 72 older adults, where a positive association between self-care practices and an optimistic view of a participant's health status was found. In contrast, a study by Nagy and Wolfe (1984) on 149 patients with a chronic illness found that the perceived control a participant believed he or she had over their health did not significantly impact their self-care practices. Researchers attributed this unexpected finding to the notion that health beliefs may be initially important, but other variables become more influential over time with self-care.

Illness Characteristics

An individual's experience with a chronic illness is patient-specific. The severity of the symptoms and patient satisfaction with the care plan can affect the performance of the self-care behaviors.

Nagy and Wolfe (1984) found that individuals with chronic illnesses, such as diabetes, hypertension or respiratory disease who were satisfied with the medical care they received and rated their caregivers as competent, had increased medication compliance. Another finding emanating from this study was individuals with chronic

illness who had limited symptoms, performed self-care strategies specific to their chronic illness more consistently. In contrast to this latter finding, Hampson and colleagues (1993) and Cronan, Kaplan and Kozin (1993) found the opposite to be true for individuals with musculoskeletal diseases. In these two studies, participants experiencing more symptoms or functional impairments used different self-care activities and performed them more frequently than their asymptomatic counterparts.

Patient Characteristics

The characteristics that define a person have been examined in relation to performance of self-care activities. These include age, sex, marital status, socioeconomic status, ethnic background and educational level.

Age

Research on healthy older adults as well as the chronically ill has found no association between age and self-care (Makinen et al., 2000; Nicholas, 1993; Hanucharunkul, 1989; Smits & Kee, 1992; Mollem et al., 1996). For example, one study of 213 diabetic patients found that there was no statistically significant association between adherence to disease-specific self-care practices and age (Toljamo & Hentinen, 2001). This finding is consistent with research conducted by Connelly (1993), who initially hypothesized age would influence self-care behaviors.

Sex

The patient characteristic of sex does not appear to be a determinant of self-care for the chronically ill. Research studies concerning individuals with various chronic illnesses found no correlation between the sex of an individual and self-care performance (Hanucharunkul, 1988; Nicholas, 1993; Smits & Kee, 1992; Mollem et

al., 1996; Toljamo & Hentinen, 2001). An exception to this finding is a correlational study on self-care conducted by Makinen and colleagues (2000) on 150 diabetic patients. These researchers found female participants practiced self-care related to social activities more frequently than their male counterparts.

Marital Status

The patient characteristic of marital status does not appear to correlate with self-care practices for individuals with a chronic illness. Two studies that examined these variables found no association between a participant's marital status and self-care behaviors (Hanucharunkul, 1989; Connelly, 1993). An exception to this finding is a study conducted by Hubbard, Muhlenkamp and Brown (1984). These researchers found that married individuals not only reported a higher degree of social support but also performed self-care more frequently as compared to their single counterparts.

Socioeconomic Status

There are conflicting reports related to socioeconomic status and self-care. In a study of 48 healthy elderly adults, it was found that a participant's income level and employment status did not affect self-care scores (Smits & Kee, 1992). This finding is supported by Connelly (1993) who found that socioeconomic status is not a predictor of self-care for the chronically ill. In contrast, one study conducted by Hanucharunkul (1988) on a convenience sample of 112 head and neck cancer patients used education, income and occupational prestige as a measure of socioeconomic status. In this study, socioeconomic status accounted for 21 percent of the group variance with self-care practices, making it a significant factor for self-care. Hanucharunkul hypothesized that people with a higher socioeconomic status have

access to more resources to assist with the engagement of self-care, enabling them to practice more of these behaviors.

Ethnic Background

There are limited studies that have examined the relationship between ethnic background and self-care. The two studies conducted in this area examine the relationship specific to African American descent. Kart and Engler (1994) and Aljaseem and colleagues (2001) both found individuals of African American descent used few self-care activities and adhered to their medication regimes less frequently than their Caucasian counterparts.

Educational Level

There is conflicting evidence regarding the association between educational level and self-care. Connelly (1993) found no correlation between educational level and self-care for individuals with a variety of chronic illnesses. Mollem and colleagues (1996) supported this finding in a study of 244 diabetic patients. In contrast, research by Smits and Kee (1992) on 48 healthy elderly individuals found that an individual's educational level approached significance for predicting self-care. In this study, participants with a higher educational level practiced more self-care behaviors. Qualified support for the Smits and Kee findings is seen in Katz and colleagues' 1996 study. Katz conducted 471 telephone interviews with individuals afflicted with rheumatoid arthritis. This research showed a non-linear positive relationship between educational level and self care only in individuals with 13 or more years of education.

Positive Thinking

There are three studies that examine the relationship between positive thinking and self-care. This link between positive attitude and self-care behavior was initially identified within the diabetic research. De-Weerd, Visser, Kok and Van der Veen (1990) conducted a correlational study with 558 insulin dependent diabetic patients to examine self-care practices. These researchers found the most significant determinant of self-care practices was a participant's positive attitude and belief system. In another study, Baker and Stern (1993) examined the relationship between a person's belief system and their perception of self-care for 12 chronically ill individuals. A primary theme that emerged was participants who viewed their life and illness in a positive light indicate they would practice self-care more frequently. Nicholas (1993) supported this finding in a study on 72 older adults where psychological status was significantly related to both general self-care and medication compliance.

Self-Concept

Self-concept, the belief in oneself is closely correlated with self-care. Two correlational studies on healthy adults found that a person's self-concept correlates with the ability of a participant to take on a self-care role and perform it regularly (Smits & Kee, 1992; Lantz, 1985). This positive correlation between self-care and self-concept was also demonstrated in Whetstone's 1987 study on 17 healthy German adults. Whetstone found a moderate association between self-concept and self-care. The findings were echoed in the research conducted by Connelly (1993) on

individuals with a chronic illness, where a positive self-image was associated with self-care behaviors.

Self-Efficacy

There have been several studies that examine the relationship between self-efficacy and self-care. Research over the last twenty years has found that there is a positive link between self-efficacy and the performance of self-care in relation to weight control, use of contraceptives, excessive alcohol use and smoking (Colleti, Supnick & Payne, 1985; Nicki, Remington & McDonald, 1985; Strecher, DeVellis, Becker & Rosenstock, 1986). This finding was echoed in a large integrative research review conducted by Gillis (1993), where a person's perceived self-efficacy was a significant predictor of self-care for sedentary female adults.

One study on individuals with disabilities conducted by Stuijbergen, Becker and Sands (1990) used a different approach to the study of self-efficacy, where barriers to self-care were identified. These researchers found a significant inverse correlation between self-efficacy and barriers to self-care. Skelly, Marshall, Haughey, Davies and Dunford (1995) who conducted a prospective non-experimental study on 118 African American women living in the inner city with non-insulin dependent diabetes support this relationship. In this study, self-efficacy had the greatest effect on diet and exercise adherence in relation to the diabetic self-care. Robertson and Keller (1992) conducted another study that supports this premise. Their study used a sample of 51 individuals with coronary artery disease and found a positive correlation between activity and self-efficacy.

A research study with an experimental design conducted by Kaplan, Atkins and Reinsch (1984) examined adherence to a walking program for 60 individuals with COPD. A significant correlation between adherence to this self-care activity and self-efficacy was found. Research by Aljaseem and colleagues (2001) support this finding. They examined this relationship for individuals with diabetes and found perceived self-efficacy was positively correlated to self-care performance.

Social Support

As an important part of a person's life, social support appears to impact on the self-care practices adopted by individuals with a chronic illness. Several studies have found a positive correlation between social support and self-care in the elderly (Hubbard et al., 1984; Hanucharunkul, 1989; Norburn, Bernard & Konrad, 1995). This relationship between social support and self-care is also reflected in the research on individuals with chronic illnesses, such as with diabetes (Tillotson & Smith, 1996) and other conditions with a chronic nature (Connelly, 1993). This finding is consistent with a study by Hanucharunkul (1988), which reports a positive relationship between self-care practices and social support in cancer patients. In addition, this association between social support and self-care has also been seen in healthy adults. A research study conducted by Muhlenkemp and Sayles (1986) found social support directly affects a person's self-esteem, which positively influenced self-care practices.

In a study by Toljamo and Hentinen (2001) on 213 insulin treated diabetic patients in an ambulatory care setting, participants who more readily adhered to self-care activities had received more social support from family than their counterparts.

However, the researchers found that the relationship between social support and self-care only existed when the support came from family, rather than peers. Conversely, Connelly (1993) found that the social support a person received was inversely associated to dietary self-care behaviors for the chronically ill. This unforeseen finding was believed to reflect the elevated level of responsibility for self-care that individuals with limited social support assume.

Self-Care in Heart Failure

Self-care activities within the heart failure population tend to impact on the clinical and economic well-being of these individuals (Konstam et al., 1994). Practice guidelines for heart failure set out by the Agency for Health Care Policy and Research and the Canadian Cardiovascular Nursing Council emphasize the promotion of self-care for managing heart failure (Grady et al., 2000).

Self-Care Practices

Self-care activities have been incorporated into the management of heart failure. However, many of these activities are not being performed on a consistent basis in this patient population. Several studies have assessed the extent to which individuals with heart failure practice specific self-care activities in their daily lives.

Riegel & Carlson (2002) interviewed 26 individuals diagnosed with heart failure to identify adopted self-care strategies. Participants identified diet modification, built-in rest periods, regular exercise, along with medication compliance as their primary strategies. Another qualitative study conducted by Bennett, Cordes and colleagues (2000) found similar results, as heart failure patients indicated physical activity, medication compliance, weighing themselves daily and

seeking family support were strategies used to help themselves. A correlational study conducted by Artinian, Magnan, Sloan and Lange (2002) on 110 heart failure patients examined the consistency of specific self-care practices. These researchers found that self-care activities related to prescribed medications were followed most frequently, whereas activity related to symptoms monitoring was followed the least. In this study, individuals with heart failure could identify several self-care strategies, but these activities were not consistently performed.

The consistent use of a sodium-restricted diet is a self-care behavior accepted as a standard heart failure management strategy. In the needs-assessment survey conducted by Ni and colleagues (1999), over 90 percent of patients were aware that they should limit their salt intake but less than half of the participants did so regularly. This finding is consistent with a correlational study conducted by Bushnell (1992), where only 60 percent of the patients with heart failure followed a low sodium diet more than half of the time. A descriptive, comparative study conducted by Carlson, Riegel and Moser (2001) on 139 heart failure patients echoed similar findings, as only 60 percent of the participants who experienced ankle swelling reduced their dietary sodium intake.

Another self-care activity identified in the management of heart failure is the practice of weighing oneself consistently to monitor fluid retention (Grady et al., 1999). Sulzbach-Hoke and colleagues (1997) conducted a descriptive study on the weighing behaviors of 30 ambulatory care patients with heart failure. They found that only 12 of the 30 participants who were given a weight log and instructed to weigh themselves daily performed this activity. Patients cited no access to a scale

and forgetfulness as the primary reasons for not weighing themselves. A lack of understanding related to daily weight taking existed as a third of the participants indicated that they would do nothing if their weight significantly changed. Ni and colleagues (1999) found less than a quarter of the 113 heart failure patients believed that weighing themselves was important and only practiced this activity twice a month. Bushnell (1992) found similar findings in a convenience sample of 41 CHF patients, as 17 percent of the participants weighed themselves weekly and 12 percent weighed themselves daily.

Adhering to a medication regime is another self-care activity for heart failure patients. Ni and colleagues (1999) conducted a survey on 113 heart failure patients to examine adherence to self-care activities. Most participants reported following their medication regime all the time, with a quarter of the patients reporting they followed the prescription instructions most of the time. Another self-care study using 41 heart failure patients found approximately 80 percent of the participants followed their exact medication regime more than half the time, whereas approximately 10 percent were compliant less than half the time and the remaining 10 percent reported not taking their prescribed medications (Bushnell, 1992). In contrast, a large study conducted on 7,247 elderly individuals with heart failure found only 10 percent of the participants filled enough of their cardiac medication prescriptions to have the prescribed daily dose of their medications until their next follow-up appointment (Monane, Bohn, Gurwitz, Glynn & Avorn, 1994). This finding may explain why nearly 45 percent of the hospitalizations of elderly heart failure patients were related to non-compliance with cardiac medications (Happ, Naylor & Roe-Prior, 1997). This

inconsistency in the research related to medication regimes suggests that the use of a self-report methodology in some studies may artificially inflate compliance rates.

Determinants of Self-care

Lack of self-care behaviors deployed by heart failure patients impacts on their disease management and subsequently their quality of life. Although recent research on heart failure patients has examined some predictors of self-care practices, the inconsistent findings have given rise to more unanswered questions.

Illness Characteristics

Rockwell and Riegel (2001) conducted a correlational study on 209 heart failure patients, where the relationship between symptom severity and self-care was examined. These researchers found that symptomatic patients were more knowledgeable about symptoms that required self-care and attained a higher self-care score than their asymptomatic counterparts.

The correlation between co-morbidity and self-care practices is inconsistent in the research literature. Rockwell and Riegel (2001) found no association between co-morbidity and self-care practices. In contrast, a secondary analysis study of 66 heart failure patients conducted by Riegel, Chriss, Sheposh and Carlson (2003), found participants with fewer co-morbid conditions practiced more self-care maintenance behaviors than their counterparts with more co-morbidity three months after an educational intervention. A qualitative study by Riegel and Carlson (2002) supports this finding as heart failure patients identify co-morbid conditions as well as lack of physician support as significant barriers that negatively impacted on the performance of self-care. As indicated by one participant, "one thing you can't eat for the heart,

another thing you can't eat for the diabetes" (p. 290). Artinian and colleagues (2002) found a person's health status and presence of other health conditions influenced several specific self-care activities. Individuals with poor health sought guidance from their health care provider more frequently, but tended not to undertake regular weighing behavior as compared to their healthier counterparts.

Patient Characteristics

Traits that describe an individual with heart failure have been explored in relation to self-care practices. Characteristics such as age, sex, marital status, ethnic background and educational level have been examined to identify the specific features that individuals with high levels of self-care exhibit.

Age

Rockwell and Riegel (2001) examined the relationship between age and self-care in 209 heart failure patients. They found that there was no significant relationship between the self-care practices and a person's age. This is consistent with research by Artinian and colleagues (2002), where total self-care scores and age were not related. However, age appeared to be significant in relation to specific self-care behaviors within this study. Younger patients were less likely to report worsening symptoms to their physician, whereas older patient tended to follow their medication regime and fill their prescriptions on time more consistently.

Sex

The patient characteristic of sex does not appear to be correlated with self-care practices in heart failure patients. One study conducted by Rockwell and Riegel (2001) on 209 heart failure patients tested this potential predictor of self-care and

found there was no association between the participant's sex and self-care practices. Research by Artinian and colleagues (2002) supported this finding, as no significant relationship existed between total self-care behavior and the participant's sex. However, one correlational study using secondary data for 66 heart failure patients found sex was a significant predictor of self-care, as men scored higher with self-care maintenance behaviors as compared to women (Riegel, Chriss et al., 2003).

Socioeconomic Status

Socioeconomic status in relation to self-care practices has been examined in one recent heart failure study. Rockwell and Riegel (2001) explored the relationship between socioeconomic status and self-care in over 200 patients with heart failure and found no association between the two variables. Artinian and colleagues (2002) examined a similar variable, income level, in relation to self-care for 110 heart failure patients. In this study, there was no association between overall self-care and income level.

Marital Status

The association between marital status of individuals with heart failure and their use of self-care behaviors is inconsistent in the research. A study conducted by Ni and colleagues (1999) found a positive correlation between being single and non-adherence to self-care recommendations. Contrary to this finding, research by Artinian and colleagues (2002) found that marital status does not correlate to self-care practices in heart failure patients. To further understand the relationship between these variables, Artinian and colleagues examined the variable of living situation and self-care. Again, there was no significant relationship between living alone versus

living with someone and total self-care scores. This is contrary to a study conducted by Rich and colleagues (1996) who found that individuals with heart failure who live with someone are more compliant with their medication regimes than those who live alone.

Ethnic Background

The patient characteristic of ethnic background in heart failure patients has been examined in one heart failure study. Artinian and colleagues (2002) explored this variable in relation to total self-care practices and found no significant relationship existed. However, some difference between African Americans and Caucasians were noted for some individual self-care behaviors. African American more consistently sought out medical assistance and monitoring their fluid level as compared to Caucasian participants. In contrast, Caucasians took medications as prescribed and got annual immunizations more consistently than their African American counterparts.

Educational Level

Rockwell and Riegel (2001) used a sample of hospitalized patients diagnosed with heart failure and found that individuals with higher educational levels tend to engage in self-care more frequently than those with low educational levels. Education was identified as a significant predictor of self-care, as approximately 5 percent of the variability was explained by this variable. This is inconsistent with two other research studies. Artinian and colleagues (2002) as well as Riegel, Chriss and colleagues (2003) found no significant relationship between the total self-care behavior and a person's educational level.

Self-Efficacy

An individual's thoughts about his or her ability to perform self-care and manage symptoms referred to as self-efficacy can influence that individual's actions. The unique characteristics of chronic illness tend to reduce an individual's self-efficacy (Connelly, 1987). Consistent with this premise, a study conducted by Carlson and colleagues (2001) on 139 hospitalized heart failure patients found only 45 percent of the participants had high self-efficacy related to their ability to relieve symptoms while a fifth of the participants expressed an absolute lack of self-efficacy.

The relationship between self-care and self-efficacy has been explored over the last 10 years. Ni and colleagues (1999) conducted a study in a sample of 113 individuals with heart failure. These researchers found that a lower perceived self-efficacy was associated with reduced compliance in self-care behaviors. This finding is consistent with research conducted by Oka and colleagues (1996). They examined the performance of physical activity by 43 ambulatory care patients with chronic heart failure. Self-efficacy was found to be the strongest predictor of physical activity, however, this same correlation did not exist between daily general activity and self-efficacy.

Social Support

Rockwell and Riegel (2001) found no relationship between social support and self-care practices in a sample of 209 hospitalized heart failure patients. This finding was supported by a secondary analysis study conducted by Riegel, Chriss and colleagues (2003). However, qualitative research conducted by Riegel and Carlson (2002) as well as Bennett, Cordes and colleagues found the social support,

particularly emotional support through friends and family assisted with adopting lifestyle changes.

Knowledge about Heart Failure

Patients with heart failure often have extensive knowledge deficits that need to be addressed. Carlson and colleagues (2001) studied 139 hospitalized heart failure patients and found participants had difficulty recognizing heart failure symptoms, particularly if newly diagnosed. Once symptoms were recognized, the participants often could not interpret them. This is consistent with research by Ni and colleagues (1999) who found that two thirds of their sample reported being taught about heart failure self-care, but 37 percent indicated they knew “a little or nothing” about self-care.

A factor identified as a potential predictor of self-care is an individual’s knowledge level about self-care and their disease. Although initially part of this proposed study, the revised version of the primary study instrument, the Self-Care of Heart Failure Index did not support the examination of this variable. To facilitate a complete review of potential variables associated with self-care in this patient population, the research on knowledge level will be explored. Research by Lacy (1988) indicates that patients knowledgeable about disease-specific self-care more readily practiced non-pharmacological self-care strategies. This is consistent with research by Jaarsma, Abu-Saad, Dracup and Halfens (2000), where lack of knowledge was identified as the primary reason heart failure patients ignored self-care. A needs-assessment conducted by Ni and colleagues (1999) supports this finding, as limited knowledge about self-care activities was associated with reduced

self-care practices. Riegel and Carlson (2002) who studied 26 heart failure patients found similar results within their study.

The correlation between educational sessions and self-care is of great interest to the health care community. A randomized control study conducted by Rich and colleagues (1996) on 142 elderly heart failure patients found a comprehensive patient education session increased the use of self-care behaviors related to medication regimes after hospital discharge. Jaarsma and colleagues (2000) studied a sample of 128 heart failure patients to assess self-care behavioral changes at various intervals after the introduction of a supportive educational program. The investigators found the program significantly enhanced self-care behavior at one and three months post-hospital discharge but it did not impact behavior after a year.

Self-Care and Hospital Admissions for Heart Failure

The effect of self-care on the clinical outcome of hospital re-admissions is an important practice based question addressed indirectly within the heart failure literature. Research in this area has used educational interventions as the independent variable and self-care along with hospital admissions as the outcome variables.

Several randomized studies have found a correlation between a multidisciplinary heart failure intervention focused on patient education and the use of self-care behaviors and hospital re-admission rate. A pre- and post study conducted by Hershberger and colleagues (2001) on 108 ambulatory care heart failure patients examined self-care practices and hospital admission rates for participants after completing a multi-disciplinary heart failure outpatient program. Participants practiced self-care behaviors related to weighing oneself and dietary salt restriction

more consistently after the program. In addition, hospitalization for cardiovascular causes and emergency room visits dropped by 52 percent and 72 percent respectively for these participants. This finding is supported by an experimental study conducted by Stromberg and colleagues (2003) on 106 heart failure patients. Participants were either assigned to care in a nurse led clinic or usual community care. The researchers found participants in the nurse led clinic had significantly increased their self-care behavior. The hospital admission rate for this group decreased by 42 percent after three months but no significant difference was observed after 12 months.

The relationship between these variables was also seen in an experimental study on 142 heart failure patients conducted by Rich and colleagues (1995), where patients who received an intense educational program, significantly increased their self-care practices and reduced their hospital re-admission rate by 44 percent. Finally, West and colleagues (1997) conducted a study on 51 participants who were part of a multidisciplinary heart failure management program. The researchers found self-care related to dietary sodium restrictions improved and the number of emergency room visits for heart failure and for all other causes declined by 67 percent and 53 percent respectively.

Chapter Summary

The importance of consistent self-care activities is recognized as integral to the management of ambulatory care heart failure patients. However, a review of the literature indicates that many of these activities are not being practiced by the chronically ill, particularly heart failure patients. Although patient characteristics such as age, sex and education do not appear to be associated with self-care

behaviors, findings are inconsistent. Social support and self-efficacy have been associated with self-care performance, while other determinants of self-care continue to elude researchers.

CHAPTER FOUR

Methodology

Introduction

Self-care activities and factors associated with these activities in ambulatory care heart failure patients were explored using a cross-sectional, correlational approach. This descriptive study specifically addressed a) self-care activities most commonly used by individuals diagnosed with heart failure; b) correlations of self-care practices with symptoms, functional status, general well-being and selective demographic variables; and c) the influence of symptom distress on the performance of self-care activities. A small qualitative piece was included to further explore self-care in this patient population. The data was analyzed to evaluate if predisposing and enabling variables outlined in Connelly's Model of Self-Care in Chronic Illness (MSCCI) correlated with the self-care behaviors of heart failure patients.

Research Design

This project used primarily a descriptive, correlational, cross-sectional design to answer the research questions. The data collected through this quantitative approach was enriched by a qualitative piece that incorporated open-ended interview questions into the design.

Polit and Hungler (1999) depict descriptive research as a method "to observe, describe and document aspects of a situation as it naturally occurs" (p. 196). Through this methodology, the essence and characteristics of a group as it relates to a particular phenomenon can be understood. In a descriptive correlational study, the tendency for variability between different variables is used to describe the

relationships for a specific phenomenon (Polit & Hungler, 1999). As a non-experimental approach, this methodology does not use experimental manipulation or random assignment of groups. The study intent was to explain relationships between variables, rather than infer a causative relationship. However, when a study examines a hypothesis based on an established theory, the direction of causation can be deduced using this methodology (Polit & Hungler, 1999).

The cross-sectional design involves a fixed point in time, where “the phenomena under investigation are captured, as they manifest themselves, during one period of data collection” (Polit & Hunger, 1999, p. 162). Collecting data at one point in time through the use of cross-sectional surveys provides a practical strategy for gathering a large amount of data (Polit & Hunger, 1999). This design is consistent with studies focused on describing the relationships among a phenomenon through sample surveys and interviews.

Combining a quantitative approach with qualitative methodology provides complementary data to examine the research questions. This strategy, referred to as triangulation, describes “the use of multiple methods or perspectives to collect and interpret data about some phenomenon, to converge on an accurate representation of reality” (Polit & Hungler, 1999, p. 717). A qualitative approach can provide an in-depth and holistic description of a phenomenon through the use of narratives (Polit & Hungler, 1999). In this study, the qualitative data provided an opportunity to further understand factors associated with self-care not clearly identified in the quantitative component.

The Setting

This study was conducted at the Heart Failure Clinic, an ambulatory care clinic located at the St. Boniface General Hospital in Winnipeg, Manitoba. Funded through the Winnipeg Regional Health Authority, the clinic serves patients following physician referral, from Winnipeg and surrounding communities. As only one of two heart failure ambulatory care centers in Manitoba, it was anticipated that using this setting would provide the opportunity to compare rural and urban populations.

The Sample

Patient criteria for inclusion in this study were as follows:

- Established diagnosis of heart failure for six months or longer.
- Being followed-up for heart failure in an ambulatory care setting.
- Able to speak and read English.
- 18 years of age or older.
- No evidence of mental confusion in interactions with the health care providers or the researcher.

Ethical Considerations

Ethical approval from the Education/Nursing Research Ethics Board at the University of Manitoba and access approval from St. Boniface General Hospital was obtained prior to beginning the study (see Appendix C and D). During the course of this study, all ethical policies and procedures were strictly adhered to and issues regarding access and confidentiality were addressed using the guidelines of the Human Subject Research Ethical Protocol provided by the Education/Nursing Research Ethics Board.

Participants were made aware that participation in the study was voluntary and they could withdraw from the study at any time without compromising their care. Anonymity of the participants was ensured throughout this research project. All information collected was kept strictly confidential. Only the researcher and her advisor had access to non-coded raw data. Subjects were assigned a code number and their names did not appear on any documents or reports about the study or in any future publication. The data will be stored in a locked filing cabinet for seven to ten years and then discarded as confidential waste. A summary of the study findings will be made available to participants who request it.

Risks and Benefits

There were no significant risks for individuals related to participation in this study. Participants may experience feelings of emotional distress related to the questions posed in the interview. If this situation arises, the researcher will recommend that he or she contact the clinical nurse specialist in the Heart Failure Clinic and the interview will be terminated. A potential benefit of participating in this study is it will provide an opportunity for participants to discuss their feelings related to self-care and factors associated with it. The study findings will not directly benefit participants; however, the results will impart health care providers with specific information about self-care that will potentially improve overall patient management.

Participant Recruitment and Study Procedure

Permission from St. Boniface General Hospital to conduct the research project in the Heart Failure Clinic was obtained prior to the commencement of this study.

A convenience sample was recruited to participate in the study based on the number of patients currently seen in the clinic. To date, there are approximately 200 patients managed in the Heart Failure Clinic, with an average of 20 people being seen weekly (E. Estrella-Holder, personal communication, March 27, 2003; E. Azevedo, personal communication, March 2, 2004).

The researcher met with the clinical nurse specialist and cardiologist from the Heart Failure Clinic to discuss an overview of the study and the inclusion criteria. If the patient indicated he or she was interested, the clinical nurse specialist or cardiologist contacted the researcher.

Once the participant had completed his or her clinic appointment, the researcher, in a private room within the clinic, provided further information about the study, using the invitation to participate sheet as a guide (see Appendix E). It was explained that the study was divided into two parts.

In part one, the participant completed a package of questionnaires concerning experiencing heart failure, their health status and questions related to various factors such as age, marital status, social support and general well-being. This package was either filled out with the researcher at clinic after their appointment or taken home and fill it out with the help of the researcher by telephone at a time convenient to the participant. If the questionnaire package was filled out at home, the participant was asked to mail the completed questionnaire back to the researcher in a stamped self-addressed return envelope.

It was then explained that part two of the study involved an optional telephone or in-person interview to discuss other factors associated with living with heart

failure. If the patient agreed to participate, the consent form (see Appendix F) was signed and an appointment to complete part one was made with the participant. The researcher ascertained if the participant was interested in making an appointment for part two of the study. It was emphasized that the interview was entirely optional.

Data Collection

Data collected for this study came from various sources. Preliminary demographic information collected from the clinic chart included age, sex, ejection fraction, NYHA functional classification, co-morbidity, date of diagnosis and initial appointment in the heart failure clinic. Qualitative and quantitative data collection methods were combined to facilitate a comprehensive understanding of the variables under investigation. Data collection began over the summer months of 2003.

Quantitative Data Collection

The primary method of data collection was through the administration of a questionnaire package to participants containing four quantitative measurement instruments (discussed under the instrumentation section). Guided by Connelly's MSCCI framework, this questionnaire package that took participants approximately twenty minutes to complete, was used to assess self-care practices, potential factors related to these practices and their health status. The researcher assisted in filling out the questionnaire for this primarily ill and often elderly population to ensure the participant's questions and concerns are addressed. Precautions were taken to not bias participant responses by reading the exact wording on the questionnaire and providing the same explanation for participants who sought clarification of questions.

Qualitative Data Collection

Structured interviews were conducted with participants who indicated an interest in answering open-ended questions. These telephone or in-person interviews lasting approximately twenty to thirty minutes in length were conducted in an attempt to examine and describe self-care practices in this patient population and the factors that both facilitate and deter self-care.

The development of the qualitative questions for this study was also derived from Connelly's MSCCI. This framework was designed through the creation of an assessment guide that addresses numerous factors thought to influence self-care in the chronically ill. The five questions posed in part two of the study were loosely based on this assessment guide. This section provided the opportunity to assess variables identified as being significant in the MSCCI not directly measured in the quantitative part of the study.

Two variables identified in Connelly's MSCCI as being influential in the self-care for the chronic ill guided the questions to be addressed during the participant's interview. The first variable, system characteristics refers to the attributes of the health care system and the care providers perceived by the individual in relation to their care (Connelly, 1987). Information relating to this enabling variable was accessed by asking participants questions related to satisfaction with and continuity of the care received in the clinic. The following question measured the perceived system characteristics:

1. How satisfied are you with the care you receive for your heart condition?

2. How comfortable do you feel contacting someone from the clinic when you are experiencing a health problem?

The second variable, self-concept refers to the attitudes, beliefs and motivations that a person perceived to be true about oneself (Connelly, 1987). Participants were asked questions related to the perceived beliefs and attitudes about self to access information relating to the predisposing variable of self-concept.

3. Do you feel that you are able to do activities of daily living as well as other people?
4. Do you find yourself dwelling on your flaws?

In addition to questions that address these two specific elements outlined in Connelly's MSCCI, a general question about self-care was asked. This broad question invited the participants to discuss factors that they feel impacts on their self-care. The inclusion of this type of question enabled the researcher to explore other possible factors that impact self-care not specifically addressed in Connelly's MSCCI.

5. What influences your decision when you make a lifestyle change to improve your health?

The responses to the interview questions were recorded using short hand notes in the participants' own words as much as possible. After the interview was completed, the researcher wrote out the responses in more detail.

Measurement Instruments

Four types of measurement tools will be used in this study. The first tool is a measure of self-care practices and associated factors specific for heart failure patients,

referred to as the Self-Care of Heart Failure Index (SCHFI). The second tool that will be used in this research project is the Kansas City Cardiomyopathy Questionnaire (physical and social limitation sub-scales) that measures the functional ability of the participants. The third tool examines the participant's perceived psychological status and well being, referred to as the General Well-Being (GWB) Schedule. The final instrument, the Demographic Questionnaire identifies the demographic characteristics of the participants.

The strength of biometric measurements (notably reliability and validity) for an instrument is an important consideration in assessing the findings of a given study. Polit and Hungler (1999), describe reliability as "the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure" (p. 713). Polit and Hungler (1999) define validity as "the degree to which an instrument measures what is intended to measure" (p. 717). The four selected tools in this study will be described, and the reliability and validity of each scale presented.

Self-Care of Heart Failure Index

The Self-Care of Heart Failure Index (SCHFI) is a relatively new instrument used to measure self-care through self-reports specifically in heart failure patients (see Appendix G). It is a four-point Likert scale, 22-item self-report tool with three sub-scales used to evaluate different aspects of self-care: self-care maintenance, self-confidence and self-care management. The design of this tool evaluates self-care in terms of maintaining health through positive health behaviors as well as managing and making decisions related to heart failure symptoms. The SCFHI was also

initially designed to measure a person's knowledge and ability to identify heart failure symptoms, however, this component was removed from the revised version of the tool based on empirical testing (Riegel, Carlson, Moser, Sebern et al., 2003). A summative index known as the self-care of heart failure index score is derived from the combination of the three sub-scales to ascertain the overall self-care ability related to heart failure. Individuals not short of breath use only self-care maintenance behaviors and are evaluated for this sub-scale. This total index score is calculated only for those heart failure patients who have experienced shortness of breath within the last three months, as it measures both self-care maintenance and the decision-making process of managing symptoms (Riegel, Carlson, Moser, Sebern et al., 2003). The administration time for this tool is approximately 10 minutes (Riegel, Carlson, Moser & Sheposh, 2003).

The SCHFI is grounded on the Self-Management of Heart Failure instrument, a comparable tool developed by the same author for clinical use based on Connelly's Model of Self-Care in Chronic Illness (Riegel & Rockwell, 2001). Like the Self-Management of Heart Failure Instrument, the SCHFI fits with the Connelly Model, as it measures therapeutic self-care behaviors, specific aspects of self-care management and self-efficacy which corresponds to the predisposing variables and self-care behavior categories outlined by Connelly. Unlike the Connelly's Model that is concerned with self-care in all chronic illness, SCHFI is a concise instrument that addresses symptoms and practices unique to heart failure population. As a relatively new instrument with limited empirical testing, this research project provides the

opportunity for further psychometric testing of the SCHFI with an ambulatory care population, through the provision of coded, raw data for further instrument testing.

Self-Care Maintenance Sub-Scale

The first sub-scale of the SCHFI, self-care maintenance measures the ability of an individual with heart failure to adopt seven specific health behaviors to help them remain physiologically stable (Riegel, Carlson, Moser, Sebern et al., 2003). The ability to perform such behaviors as exercising and eating a low salt diet is measured in Section A of the tool, regardless of whether the participant has recently experienced shortness of breath. The self-care activities included in this sub-scale are based on the testing of disease-specific behaviors endorsed within clinical heart failure guidelines (Riegel, Carlson, Moser, Sebern et al., 2003; Adams et al., 2000).

Self-Care Management Sub-Scale

The self-care management sub-scale in the SCHFI examines the ability of an individual to recognize and evaluate symptoms of heart failure that are experienced as well as implement and evaluate appropriate self-treatment (Riegel, Carlson, Moser & Sheposh, 2003). Since this sub-scale is specific to managing symptoms that are currently present, only heart failure patients who have experienced shortness of breath in the last three months are included in the calculation of this part of the tool.

Understanding the ability of heart failure patients to use an appropriate self-care measure is dependent on their interpretation of symptoms with respect to themselves. Although the importance attached to a particular symptom measured in Section B correlated to the perceived disease susceptibility and 'cue to action' within Connelly's Model, this section was not included in the revised version of the tool

based on empirical testing (Riegel, Carlson, Moser, Sebern et al., 2003). The ability to recognize shortness of breath as a symptom of heart failure examined in Section C indirectly measures the predisposing variable of disease susceptibility. As a classic sign of disease progression, shortness of breath tends to be recognized more readily when an individual perceives a vulnerability to such an occurrence. If a disease exacerbation is not seen as likely, the association between symptoms and an exacerbation tends to be overlooked.

Once changes in symptoms are recognized, the individual makes a decision on how to respond in terms of the action or treatment performed. The ability of a patient with heart failure to implement a treatment strategy such as taking an extra water pill and evaluate the effectiveness of that treatment is measured in section C of the SCHFI. If the individual perceives the action was beneficial, the situation becomes a motivating factor to continue to perform that self-care activity. These perceived benefits reflect the predisposing variable of health motivations from Connelly's MSCCI.

Self-Confidence Sub-Scale

The self-confidence sub-scale is a measure of self-efficacy that relates to heart failure management. The individual's perceived ability to exert control over heart failure through the recognition and treatment of their symptoms that is measured in Section D of the SCHFI. Measuring the level of self-confidence provides information on the predisposing factor of self-efficacy derived from Connelly's self-care model.

Reliability of the Self-Care Heart Failure Index

Preliminary testing of the SCHFI measured internal consistency to identify the reliability of this tool. As a psychometric measure, internal consistency refers to “the degree to which the subparts of an instrument are all measuring the same attribute or dimension” (Polit & Hungler, 1999, p. 704).

The first sub-scale of this index, self-care maintenance focused on seven specific health behaviors that has a combined Cronbach’s co-efficient alpha of 0.60 (Riegel, Carlson, Moser & Sheposh, 2003). Further analysis of this coefficient alpha indicates two variables explained approximately half of the variance in self-care maintenance. The first factor, health behaviors contains 29.7% of the score variance with the second factor, medication compliance comprising the other 20.5% of the variance. Additional reliability testing on this sub-scale using a sample of 760 heart failure patients found a co-efficient alpha of 0.56 for this sub-scale (Riegel, Carlson, Moser, Sebern et al., 2003).

The other two sub-scales in the tool, self-care management and self-confidence have the co-efficient alpha of 0.70 and 0.82, respectively (Riegel, Carlson, Moser & Sheposh, 2003). Further psychometric testing has found the overall score referred to as the self-care of heart failure index has a co-efficient alpha of 0.76 (Riegel, Carlson, Moser, Sebern et al., 2003).

Validity of the Self-Care Heart Failure Index

The SCHFI has been tested using divergent (discriminant) validity testing. Within a survey instrument such as this, discriminant validity evaluates the extent to which the measured constructs can be differentiated from other similar constructs

(Polit & Hungler, 1999). The classic symptom of heart failure, shortness of breath is used to measure symptom recognition, treatment and evaluation of treatment within the SCHFI. To determine how participants who recognized symptoms of heart failure differed from those who did not, discriminant analysis was used. According to Riegel, Carlson, Moser and Sheposh (2003), “participants who readily recognized shortness of breath were significantly more likely to implement treatment ($p=0.004$), and higher in self-efficacy ($p=0.008$) than those who failed to recognize the symptom” (p. 2).

Construct validity testing was also performed to measure the sub-scale to sub-scale correlation within the SCHFI. Polit and Hungler (1999) describe construct validity as the extent a research tool measures a construct or concept that is being investigated. Riegel, Carlson, Moser, Sebern and colleagues (2003) found that “the subscales were significantly correlated, but not highly inter-correlated (not >0.42), indicating that they were not measuring the same construct” (p. 16).

Kansas City Cardiomyopathy Questionnaire

The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a measure of health status created specific for individuals with heart failure patients (see Appendix H). This tool developed four years ago has undergone significant psychometric testing and is currently being used in clinic research with heart failure patients (Green, Porter, Bresnahan & Spertus, 2000).

The physical and social limitation sub-scales of this tool provided a concise measure of functional status specific for heart failure patients for this study. The ten items address the activity level using a five-point Likert scale format. To ensure the

individual's activity level identified is related to heart failure or the functional limitation associated with it, the authors of the tool provided a place to indicate activity limitations due to reasons other than heart failure. According to Connelly's MSCCI, functional status is a significant characteristic that influences self-care practices both directly and indirectly through effects on predisposing and enabling variables. The administration time for the physical and social limitation scales of the KCCQ is less than 5 minutes, making it concise measure of functional level.

Reliability of the Kansas City Cardiomyopathy Questionnaire

The reliability of the KCCQ was measured by internal consistency and test-retest reliability. The internal consistency of this tool was measured to ensure each item under a sub-scale examined the corresponding attribute. The Cronbach's coefficient alpha for the physical limitation scale was 0.90. The internal consistency remained high in the social limitation scale with a Cronbach's coefficient alpha of 0.86. Test-retest reliability of the KCCQ was conducted using a three-month interval. The scores were analyzed using paired t-tests, where Green and colleagues (2000) found the "mean changes of 0.8 to 4.0 points on a 100-point scale over three months of observation were small and not statistically significant" (p. 1249).

Validity of the Kansas City Cardiomyopathy Questionnaire

Concurrent validity testing was used to evaluate if the physical and social limitation scale of the KCCQ accurately measures functional status of heart failure patients. The physical limitation domain was compared with the NYHA classification, where the Spearman's correlation coefficient was -0.65 (p-value <

0.001). Additional validity testing also indicated this domain of the KCCQ correlated significantly with the 6-minute walk test (Green et al., 2000).

Concurrent validity testing of the social limitation scale within the KCCQ occurred with other measures of functional status: the Short Form-36 Functional Status Scales and NYHA Classification. As clearly identified by Green and colleagues (2000), “the KCCQ Social Limitation domain was significantly correlated with the Short Form-36 social limitation scale ($r=0.62$, $p<0.001$) and with the NYHA Class ($r=-0.57$, $p<0.001$)” (p. 1251).

The General Well-Being Schedule

The General Well-Being (GWB) Schedule is an 18-item index developed to assess the psychological wellbeing and distress of individuals living in the community (McDowell & Newell, 1996; Monk, 1981). This widely used index was created in 1978, as a component of the initial Health and Nutrition Examination Survey. The GWB Schedule measures six dimensions of wellbeing: anxiety, depression, positive wellbeing, self-control, vitality and general health. Questions one through fourteen of this tool use a six-point Likert scale that represents either strength or regularity related to an item (see Appendix I). The other four items use a 0-10 rating scale that measures the intensity of a feeling (Taylor et al., 2003; McDowell & Newell, 1996). This tool correlates to the predisposing variable of health motivations as it identifies perceived control and concern of health outlined in Connelly’s MSCCI. The GWB Schedule also measures the enabling factor, psychological status within Connelly’s model. This concise tool can be administered in approximately 5 minutes.

Reliability of the General Well Being Schedule

Reliability of the GWB Schedule was assessed through measures of internal consistency and test-retest reliability. The internal consistency was used to measure the degree different items within the scale measured general wellbeing. The Cronbach's co-efficient alpha for each of the specific dimensions in this tool are reported to be over 0.90 (Monk, 1981; Taylor et al., 2003). The test-retest reliability for the GWB Schedule found reliability coefficients ranged from 0.68 to 0.85, indicating moderate to adequate reliability (Monk, 1981; Taylor et al., 2003).

Validity of the General Well Being Schedule

Concurrent validity testing on the GWB Schedule was used to evaluate the ability of this tool to measure psychological well-being. The GWB Schedule was compared to Zung's Self-Rating Depression Scale, the Personal Feelings Inventory-Depression, as well as with psychiatric services, where Spearman's correlation coefficient ranged from 0.66 to 0.70 (Monk, 1981; McDowell & Newell, 1996).

Demographic Questionnaire

Several measures derived from the MSCCI framework, will be collected using a demographic survey: social support, educational level, marital status, age, sex, ethnic background, living situation and socioeconomic status including last occupation, current occupational status and income level (see Appendix J). The administration time for this tool is approximately 10 minutes. Examining these patient characteristics, which have been incorporated into previous studies on the determinants of self-care, will provide a clear understanding of the relationship between these variables and self-care. The demographic tool will provide a

description of the sample and determine if a relationship between certain data items and self-care exists.

Clinical information related to heart failure such as ejection fraction, NYHA functional classification, initial clinic appointment and diagnosis age were collected from the patient's hospital chart once consent was obtained. The chart version of the Charlson Co-Morbidity Index was used to measure co-morbidity in the sample. This chart review co-morbidity instrument identified and scored specific health conditions such as stroke, renal disease and diabetes to describe the co-morbidity status of an individual. The majority of the co-morbid conditions identified are scored with one point, however some conditions such as cirrhosis with active bleeding or renal disease requiring dialysis are assigned more than one point (Charlson, Pompei, Ales & MacKenzie, 1987). The score range is from 0 to 34, although in this study every participant will score a minimum of one based on their heart failure diagnosis (Charlson et al., 1987; Riegel, Carlson, Moser, Sebern et al., 2003). Individuals were placed into one of three categories (low, moderate or high) based on their scoring.

Data Analysis

Quantitative Analysis

Numerical data was entered into a computer for analysis with the SAS program for statistical analysis. Tables were used to summarize the data and correlational matrixes were used to present the relationships between the study variables. A description of the quantitative data analysis techniques is presented for each research question below:

1. In an ambulatory care setting, what are the self-care activities most commonly used by individuals diagnosed with heart failure? (chi-square test)

2. What are the determinants of self-care for individuals diagnosed with heart failure seen in an ambulatory care setting? (Pearson “r” correlation coefficient, chi-square and ANOVA).
3. When ambulatory care patients suffering from heart failure experience shortness of breath, are they more or less inclined to perform self-care activities? (t-tests for independent groups).
4. What is the relationship between self-care and hospital admissions for ambulatory care patients experiencing heart failure? (Pearson “r” correlation coefficient and ANOVA).

Qualitative Analysis

Content analysis as described by Burnard (1991) was conducted to analyze the transcribed notes taken during and following the interviews. Patient responses were categorized through manually writing and highlighting key words and phrases on the interview transcripts. Recurrent categories were identified and clustered to facilitate the development of broad themes that emerged from the transcripts. An initial draft of this analysis was shared with an experienced expert in qualitative research analysis to ensure categories and themes were reflective of the interview transcripts. These categories were then reorganized to present the data within conceptual categories to either answer the research questions or explain the quantitative relationships between the study variables.

Chapter Summary

This research study used triangulation, a technique involving collection of quantitative and qualitative data. The primary methodological components used in

this study were a chart review, the administration of four measurement instruments and a semi-structured interview.

CHAPTER FIVE

Results

Introduction

This chapter presents the findings of this study, which explored determinants of self-care in ambulatory patients experiencing heart failure. Data collection for the project took place over a five-month period from June to November 2003. Subject recruitment was conducted in a heart failure clinic at a tertiary care hospital. Of the seventy-nine patients approached, sixty-five (82%) agreed to participate in the study. Fourteen patients refused to participate due to fatigue, lack of available time, or simply “did not want to answer more questions”. Fifty-four participants (83%) completed the quantitative questionnaire component of the study, while eleven participants (17%) consented to also be interviewed for the qualitative component of the study.

Demographic Characteristics of the Sample

Table 1 provides a summary of the demographic characteristics for the sample. The mean participant age was 59 years (± 13) with ages ranging from 21 to 88 years. The majority of participants were male (77%), with high school education or less (66%), resided in Winnipeg (63%), were married (71%), and had a family income of \$40,000 or less (51%). Fifty-two of the participants (80%) lived with family or friends regardless of marital status. Within the sample, twenty-one of participants (32%) were currently working, twenty-five participants (39%) were retired, fifteen participants (23%) were on medical leave and the other four participants (6%) were unemployed. For the third of the sample that was working,

most participants were currently employed in a full-time position. When asked about whether heart failure had caused a change in their job at some point, half of the sample (48%) indicated this was true for them. The last occupation that the majority of participants held was classified as a laborer (34%), with equal portions of the sample placing themselves in either the retail/clerical category (28%) or the professional /management category (28%).

Table 2 provides a summary of the clinical characteristics of the study participants. The mean age for diagnosis of heart failure was 55 years (± 13) with diagnosis ages ranging from 20 to 87 years. All participants had been diagnosed with heart failure for at least six months. Within in the sample, fifty-eight participants (89%) had a current left ventricular ejection fraction of forty percent or less and fifty-five participants (88%) were categorized as functional classification of II or III according to the New York Heart Association (NYHA) guidelines (see Appendix A for a description of the guidelines). Over half of the participants indicated they were living with mild or no physical and social limitations (57% and 59%, respectively). Using the Charlson Co-Morbidity Index, where 'low' indicates two or less co-morbid conditions including heart failure and 'moderate' indicates 3 to 4 co-morbid conditions, fifty-seven participants (87%) were in the low to moderate co-morbidity categories. Seven participants (11%) had heart failure with no other co-morbid conditions. The three most common co-medical conditions experienced by the participant were myocardial infarction (65%), diabetes mellitus (32%), and hypertension (28%). According to the General Well-Being Schedule for psychological status, thirty-one of the participants (48%) considered themselves to

have a positive sense of well-being, while twenty-three participants (35%) placed themselves in the severe distress category. With regard to family support, the majority (66%) indicated they had two or more family supports currently in their life, while half of the sample (52%) indicated that there was no supportive friend in their life.

Table 1

Demographic Characteristics of the Sample

Characteristics	Mean	Standard Deviation
Age at time of survey (years)	58.9	12.7
	Frequency	Percent
Sex		
Male	50	77
Female	15	23
Marital Status		
Single	8	12
Widowed/Divorced/Separated	11	17
Married/ Common-law	46	71
Residence		
Within Winnipeg	41	63
Within Manitoba, Outside of Winnipeg	21	32
Outside of Manitoba	3	5
Living Situation		
Alone	13	20
With spouse or common-law partner	28	43
With spouse & other family	18	28
With other friends or family	6	9
Education		
< High School	28	43
High School	15	23
> High School	22	34
Occupational Status		
Full Time	13	20
Part Time	8	12
Medical Leave	15	23
Unemployed	4	6
Retired	25	39
Family Income Level *		
< \$20, 000	16	26
\$20,000 - \$39, 999	15	25
\$ 40, 000 - \$ 59, 999	15	25
\$ 60, 000 +	15	25
Last Occupation		
Laborer	22	34
Retail/ Clerical	18	28
Professional/ Management	18	28
Other	7	11
Job Change due to Heart Failure		
Yes	31	48
No	34	52

Due to rounding, items may not add up to 100%.

* the items related to this category was completed by 61 participants (n=61).

Table 2

Clinical Characteristics of the Sample

Characteristics	Mean	Standard Deviation
Age at time of diagnosis (years)	55.0	12.8
Length of Time since initial Clinic Appt. (months)	15.2	11.3
Length of Time since Diagnosis (months)	47.4	57.4
	Frequency	Percent
Left Ventricular Ejection Fraction		
20% or less	22	34
21 – 40%	36	55
41% or greater	7	11
NYHA Functional Status Classification		
Class I	5	8
Class II	26	40
Class III	29	44
Class IV	5	8
Physical Limitations		
Mild Limitations (70-100)	37	57
Moderate Limitations (31-69)	21	32
Severe Limitations (0 –30)	7	11
Social Limitations		
Mild Limitations (70-100)	36	55
Moderate Limitations (31-69)	21	33
Severe Limitations (0 –30)	8	12
Co-Morbidity Categories		
Low (2 or less)	25	38
Moderate (3-4)	32	49
High (5+)	8	12
Psychological Status		
Positive Well-Being (73-110)	31	48
Moderate Distress (61-72)	11	17
Severe Distress (0-60)	23	35
Number of Family Supports		
1 or less	22	34
2-4	26	40
5+	17	26
Number of Friend Supports		
0	34	52
1-2	18	28
3+	13	20

Due to rounding, items may not add up to 100%.

Table 3 provides a summary of the participants' self-care experiences.

Activities specific to heart failure were measured using the Self-Care of Heart Failure Index, which is described in detail within the Methodology section. This tool has three specific sub-scales used to evaluate different aspects of self-care: self-care maintenance, self-confidence and self-care management. There is also a summative index known as the self-care of heart failure index to ascertain the participant's overall self-care related to heart failure.

Two of the sub-scale scores, self-care maintenance and self-confidence were calculated for the sample based on specific questions relating to these areas. Both of these sub-scales have possible scores ranging from 25 to 100, with 25 indicating the lowest ability in this area and 100 indicating the most advanced ability in this aspect of self-care. The mean self-care maintenance score was 72.4 (\pm 14.5). Figure 2 illustrates the distribution of self-care maintenance scores. The majority of the sample (73%) scored between 56 to 85 for this sub-scale. The mean self-confidence score was 63.9 (\pm 16.0). Figure 3 depicts the distribution of self-confidence scores. Within the sample, the majority of the participants (63%) scored between 56 to 85 for this sub-scale.

The other subscale self-care management and overall index referred to as the self-care of heart failure index were calculated for only participants with shortness of breath within the last three months (symptomatic), based on the scoring guidelines for the tool. The self-care management score was calculated based on questions relating to symptom recognition, self-treatment and self-evaluation. The possible scores for this sub-scale ranged from 15 to 100, with 15 indicating the lowest ability to perform

self-care management and 100 indicating the best ability to perform self-care management. The mean self-care management score for symptomatic participants was 43.9 (\pm 24.6). Figure 4 illustrates the distribution of self-care management scores. The majority of these participants (65%) scored between 15 to 45, placing them in the lower one third of this scale. The self-care of heart failure index score is a summation of the three previous scales, reflecting the ability of an individual to overall provide self-care when diagnosed with heart failure. The overall index has a possible score range of 65 to 300, where 65 indicates the lowest ability to care for oneself and 300 indicates the highest ability to care for oneself. The mean score for the self-care of heart failure index is 177.5 (\pm 36.5). Figure 5 illustrates the distribution of the self-care of heart failure index scores for the symptomatic participants. Although there are no specific classifications delineating mild, moderate, or severe for this overall score, the majority of the participants (61%) scored between 151 and 200, placing them in approximate middle one third of this scale.

Table 3

Self-Care Sub-Scale Scores for the Sample

Self-Care Sub Scales	N	Mean	Standard Deviation
Self-Care Maintenance (25-100*)	65	72.4	14.5
Self-Confidence (25-100*)	65	63.9	16.0
Self-Care Management (15-100*)**	31	43.9	24.6
Self-Care of Heart Failure Index (65-300*)**	31	177.5	36.5

* Potential score range developed by tool author.

** Symptomatic patients only.

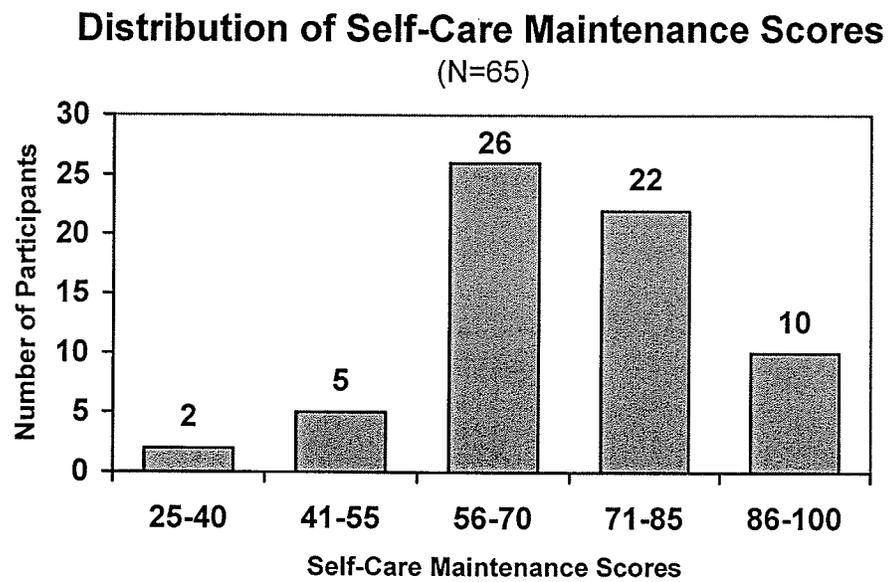
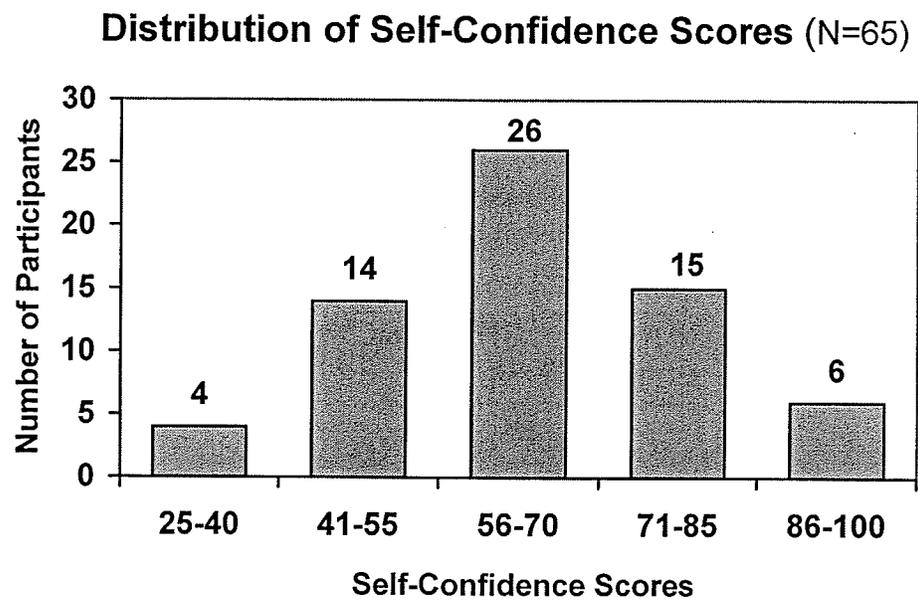
Figure 2Figure 3

Figure 4

Distribution of Self-Care Management Scores for 'Symptomatic' Participants (n=31)

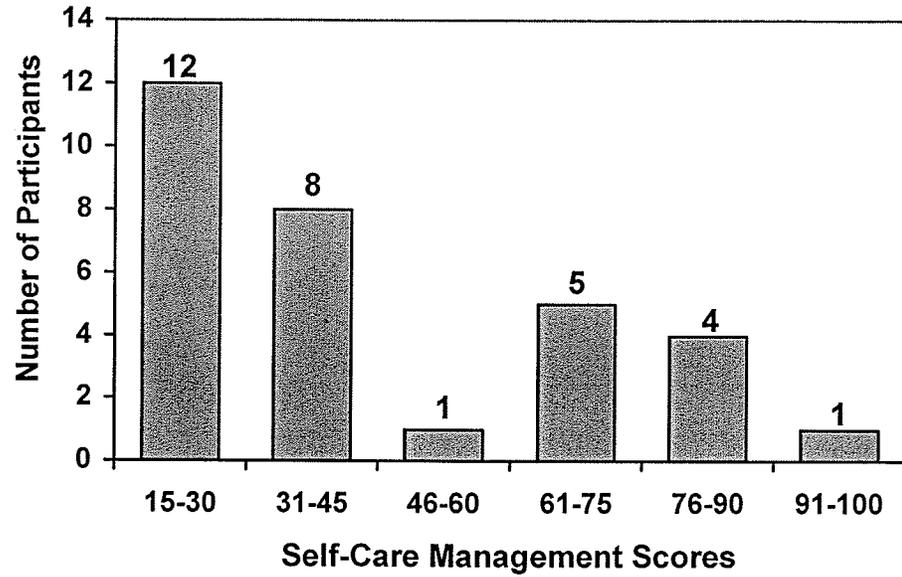
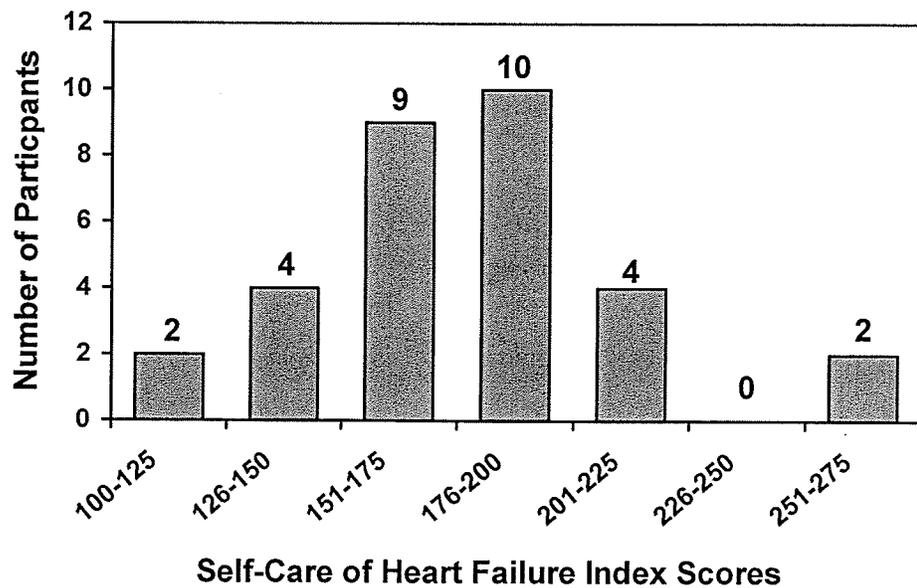


Figure 5

Distribution of SCHFI Scores for 'Symptomatic' Participants (n=31)



Quantitative Data Analysis

The researcher scored the quantitative data from this study and transferred it into a Microsoft EXCEL spreadsheet. The Statistical Analysis System (SAS) was used to analyze the results. Data analysis was conducted using the following statistical tests: descriptive statistics, Pearson r correlation co-efficient and chi-square test to compare proportions, t-tests to compare means of two groups, and analysis of variance (ANOVA) to compare means for more than two groups.

Analysis of Research Questions

Research Question #1: In an ambulatory care setting, what are the self-care activities most commonly used by individuals diagnosed with heart failure?

Seven self-care activities related to heart failure were derived from the Self-Care of Heart Failure Index tool. These included: 1) weighing yourself daily, 2) keeping the salt in your diet lower than 2-3 gm each day, 3) exercising at least three times per week, 4) taking medications as prescribed, 5) keeping your weight within 10% of your ideal weight, 6) talking to your doctor whenever you need guidance, and 7) getting immunizations (like the flu shot) every year. Within this particular self-care tool, these seven self-care activities were posed as individual self-report questions with a Likert scale for responses to identify how regularly participants were performing each activity. Based on the summative percentage of the two categories: 'frequently' and 'always', the four most common self-care activities for the sample were determined. Table 4 ranks the seven self-care activities from most to least commonly reported by the sample, with the corresponding frequencies and percentages. The four self-care activities most frequently engaged in by study

participants were: taking medications as prescribed (95%), talking to your doctor when you need guidance (80%), keeping the salt in your diet lower than 2-3gm each day (70%), and getting immunizations (like the flu shot) every year (66%). The self-care activity least likely to be undertaken by participants was exercising at least three times per week, where 56% of the sample recorded that they performed this activity frequently or always.

Table 4

The Most Commonly Used Self-Care Activities for the Sample
(based on the summation of the 'frequently' and 'always' categories)

Self-Care Activities	Frequency	Percentage
Take medications as prescribed	60	95
Talk to your doctor when you need guidance	52	80
Keep the salt in your diet lower than 2-3gm each day	45	70
Get immunizations (like the flu shoot) every year	43	66
Weigh yourself daily	40	61
Keep your weight within 10% of your ideal weight	38	59
Exercise at least three times per week	37	56

The data was further analyzed to determine if 'asymptomatic' participants (n=34) used similar self-care activities when compared to 'symptomatic' participants (n=31). The sample was divided into 'symptomatic' and 'asymptomatic' based on the presence of shortness of breath within the last three months as identified in the SCHFI tool. Although this terminology is consistent with other research conducted using this tool, participants in the 'asymptomatic' category may exhibit other heart failure symptoms such as edema or fatigue as well as experience some degree of functional limitations. In order to rank the seven self-care activities, the percentage of participants that answered 'frequently' and 'always' were added together. Table 5 describes the seven self-care activities most commonly engaged in by participants categorized as 'asymptomatic' and 'symptomatic' based on the SCHFI guidelines. Three of the four most commonly used self-care activities were similar among participants who were dyspneic and those who were not. These include: taking medications as prescribed, talking to your doctor when you need guidance and keeping the salt in your diet lower than 2-3gm each day.

The activity of 'keeping your weight within 10% of your ideal weight' ranks the fourth most common activity engaged in by the 'asymptomatic' group (65%). However, in the 'symptomatic' group, this activity was performed the least, as eighteen participants (52%) always or frequently kept their weight close to their ideal. A significant difference between the groups was found in relation to getting immunizations, like the flu shot annually ($p=0.018$). In the 'asymptomatic' group this activity was least likely to be performed with only 53% performing it frequently or always. However, getting the flu shot annually was the second most common self-

care activity (81%) for 'symptomatic' participants. Figure 6 illustrate the difference related to this self-care activity.

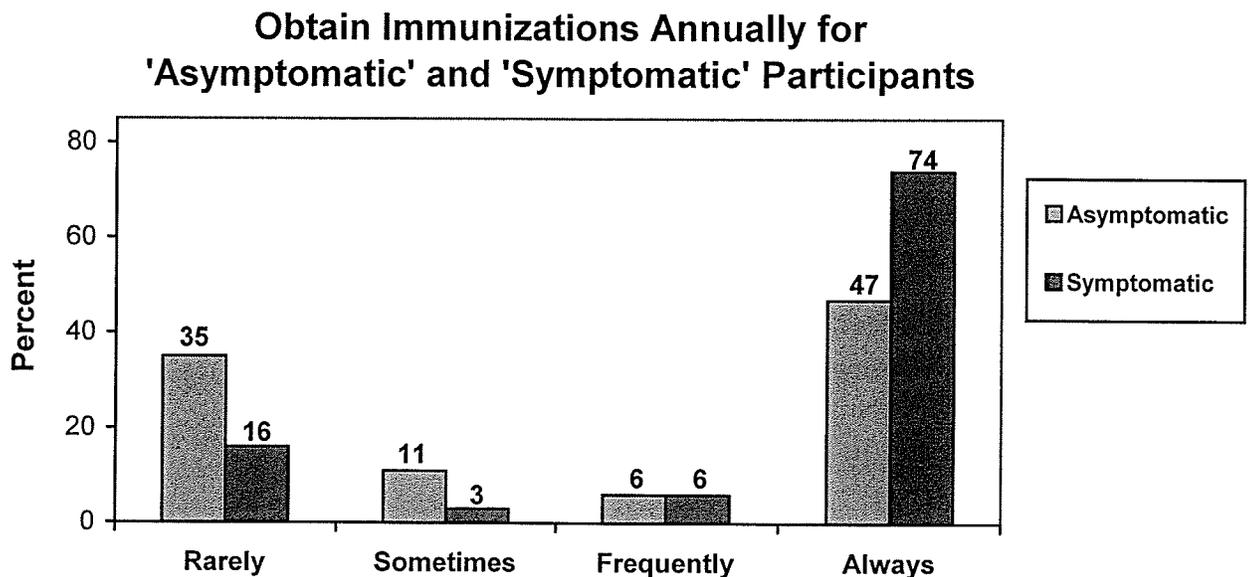
Table 5

**Commonly Used Self-Care Activities for 'Asymptomatic'
and 'Symptomatic' Participants**
(based on the summation of the 'frequently' and 'always' categories)

Self-Care Activities	Asymptomatic (n=34)		Symptomatic (n=31)		P value
	Frequency	Percentage	Frequency	Percentage	
Take medications as prescribed	33	97	27	94*	0.132
Talk to your doctor when you need guidance	29	85	23	74	0.264
Keep the salt in your diet less than 2-3gm each day	24	71	21	68	0.804
Get immunizations (like the flu shot) every year	18	53	25	81	0.018
Weigh yourself daily	19	56	21	68	0.326
Keep your weight within 10% of your ideal weight	22	65	16	52	0.284
Exercise at least three times per week	20	59	17	55	0.746

* the item related to this self-care activity was completed by 29 participants (n=29)

Figure 6



Research Question #2: What are the determinants of self-care for individuals diagnosed with heart failure seen in an ambulatory care setting?

The eight characteristics of the sample considered to be continuous variables were correlated with the four self-care sub-scales. These clinical characteristics included age, age at time of diagnosis, NYHA classification, physical limitations, social limitations, psychological status, ejection fraction, and self-confidence. Table 6 shows the matrix of Pearson “r” correlation co-efficient for these clinical variables in relation to self-care maintenance, self-confidence, self-care management and self-care of heart failure index sub-scales. A significant correlation was found between psychological status and self-care maintenance ($p=0.0303$). The variable, psychological status also approaches a significant relationship with two of the other self-care sub-scales, self-confidence ($p=0.0684$) and self-care of heart failure index ($p=0.0575$). A highly significant correlation was found between self-confidence and self-care maintenance ($p=0.0002$) as well as self-care of heart failure index ($p=0.0004$). The relationship for both physical limitations and social limitations and self-confidence approaches significance, with p values of 0.0867 and 0.0800, respectively. All of the statistically significant correlation co-efficients described are positive, indicating that as the value of one variable increases, so does the value of the other variable. In addition, a chi-square test was performed to examine the relationship between gender and the four self-care sub-scales where no significant relationships were found (not shown).

Table 6

**Pearson “r” Correlation Co-Efficient for Clinical Characteristics
Associated with Self-Care**

Characteristics of the Sample	All Participants (N=65)		Symptomatic Participants (n=31)	
	Self-Care Maintenance	Self Confidence	Self-Care Management	SCHFI
Age	0.10449	-0.01417	0.02622	-0.11818
Diagnosis Age	0.09633	0.01001	-0.02685	-0.15109
NYHA Classification	-0.03824	-0.14640	0.22318	0.01016
Physical Limitations	0.20721	0.21586	-0.09855	0.21224
Social Limitations	0.08184	0.21874	0.01453	0.31915
Psychological Status	0.26887 * (p=0.0303)	0.22746* (p=0.0684)	0.04459	0.34483* (p=0.0575)
Ejection Fraction	-0.07714	-0.05773	-0.13322	-0.16430
Self Confidence	0.44857 * (p=0.0002)	-	0.11231	0.60012 * (p=0.004)

* correlation co-efficient significantly different from zero.

Using analysis of variance (ANOVA) fourteen categorical variables (ethnic background, marital status, residency, living situation, number of family and friend supports, education, occupational status, last occupation, family income, social limitations, physical limitations, psychological status and co-morbidity) were analyzed in relation to four sub-scales of self care, including self-care maintenance, self-confidence, self-care management and self-care of heart failure index. A description of this analysis is represented in Table 7.

There was a statistically significant difference between ethnic background and self-care maintenance ($p=0.0481$). A higher mean self-care maintenance score was found for participants with a European ethnic background as compared to an Aboriginal descent, which was confirmed by a tukey's test. Although not statistically significant, participants in the Aboriginal category have a lower mean self-confidence score as well as a lower mean self-care of heart failure index score as compared to mean scores for other ethnic backgrounds.

In addition, participants who were either in the married category or the widowed/separated/divorced category had higher mean scores in all of the self-care sub-scales than the mean scores of single participants. To clarify if living with others affected self-care, living situation was included as one of the variables. The relationship between living situation and self-care maintenance approached a statistically significant difference with a p value of 0.0566, where participants who lived with a spouse had the highest mean scores in this sub-scale. No other differences were found within this category.

When examining residency (urban/rural/outside Manitoba), there were no statistically significant differences in self-care scores. Although, participants living outside of Manitoba had lowest mean scores on three of the self-care sub-scales, there were only three participants in this category.

There were no significant differences in the two variables that examined social supports in relation to self-care scores. Under the family support variable there were no patterns noted, however, under the friend support variable, participants with no friend supports had a lower mean self-care score in three of the four self-care sub-scales.

Under the variable education, there were no significant differences that existed in relation to self-care scores. However, participants with greater than high school education had higher mean scores in three of the self-care sub-scales.

Variables relating to socioeconomic status, including occupational status, last occupation, and family income showed no statistically significant differences. Although participants in either the unemployed or retired category had a lower mean score for self-care maintenance, self-confidence and self-care of heart failure index scores than the mean scores for participants who were working. The mean scores for three of the self-care sub-scales were higher for individuals who were currently or last employed as either a manager or a professional as compared to the mean scores for the other groups. There were no trends noted in the family income category.

There were no statistically significant differences in the self-care sub-scores in relation to physical or social limitations. However, individuals in the 'severe'

category for either physical or social limitations had lowest mean scores with self-care maintenance, self-confidence and self-care of heart failure index.

The relationship between psychological status and self-care maintenance approached a statistically significant difference with a p value of 0.0505, where participants in the severe distress category had a considerably lower mean score on this sub-scale as compared to participants in either the moderate distress or positive well-being categories. Within the other three sub-scales, no other relationships between the variables approached statistical significance. Participants in the severe distress category for psychological status consistently had lowest mean scores for all of the self-care sub-scales as compared to the other two categories.

Under the co-morbidity variable, there was a statistically significant difference between this variable and self-care maintenance. The highest mean self-care maintenance score was found for participants in the moderate co-morbidity category, followed by participants in the low co-morbidity category. The lowest mean self-care maintenance score was seen in participants in the high co-morbidity category. The relationship between co-morbidity and self-confidence approached a statistically significant difference with a p value of 0.0632, where participants in the high co-morbidity category had the lowest scores in this sub-scale. Although not statistically significant, participants in the high co-morbidity category had the lowest self-care management and self-care of heart failure index scores, as compared to the other two categories.

Table 7

Analysis of Variance for Characteristics Associated with Self-Care

Predictor Variables	Total Sample (N=65)			Symptomatic (n=31)		
	N	Self-Care Maintenance (mean)	Self Confidence (mean)	n	Self-Care Management (mean)	SCHFI (mean)
Ethnic Background						
German	11	75.5	72.7	1	20.0	160.0
Ukrainian	10	78.3	66.6	7	47.9	190.3
English	16	71.3	63.1	9	54.4	184.9
Norwegian	4	76.3	70.3	2	35.0	193.1
Aboriginal	8	56.9	55.9	3	23.3	125.2
Scottish	4	77.5	61.7	2	50.0	178.8
Other	12	73.8	58.6	7	39.3	175.4
P value	-	0.0481 *	0.2610	-	0.5127	0.2361
Marital Status						
Single	8	69.1	62.1	3	40.0	168.8
Married/Common Law	46	73.4	64.4	23	40.9	177.3
Widowed/Divorced/ Separated	11	70.9	63.1	5	60.0	184.0
P value	-	0.6964	0.9186	-	0.2866	0.8560
Residency						
Within in Winnipeg	41	73.5	64.1	20	42.0	173.5
Rural Manitoba	21	72.4	63.5	9	46.7	188.4
Outside Manitoba	3	58.3	63.5	2	50.0	168.4
P value	-	0.2216	0.9911	-	0.8463	0.5755
Living Situation						
Live alone	13	69.2	60.6	6	54.2	189.1
Live with spouse	28	77.8	68.1	17	43.5	185.8
Live with spouse & other Family	18	66.5	58.7	6	33.4	153.0
Live with other family or Friends	6	72.1	67.2	2	47.5	145.9
P value	-	0.0566	0.2016	-	0.5542	0.1242
Number of Family Supports						
1 or less	22	68.8	62.4	11	43.6	173.7
2 - 4	26	72.1	66.1	11	42.3	170.8
5+	17	77.6	62.5	9	46.1	190.4
P value	-	0.1649	0.6680	-	0.9446	0.4608
Number of Friend Supports						
None	34	70.4	60.9	18	44.7	170.5
1 - 2	18	75.3	67.0	8	31.9	173.9
3+	13	73.8	67.3	5	60.0	208.5
P value	-	0.4794	0.3006	-	0.1301	0.1125

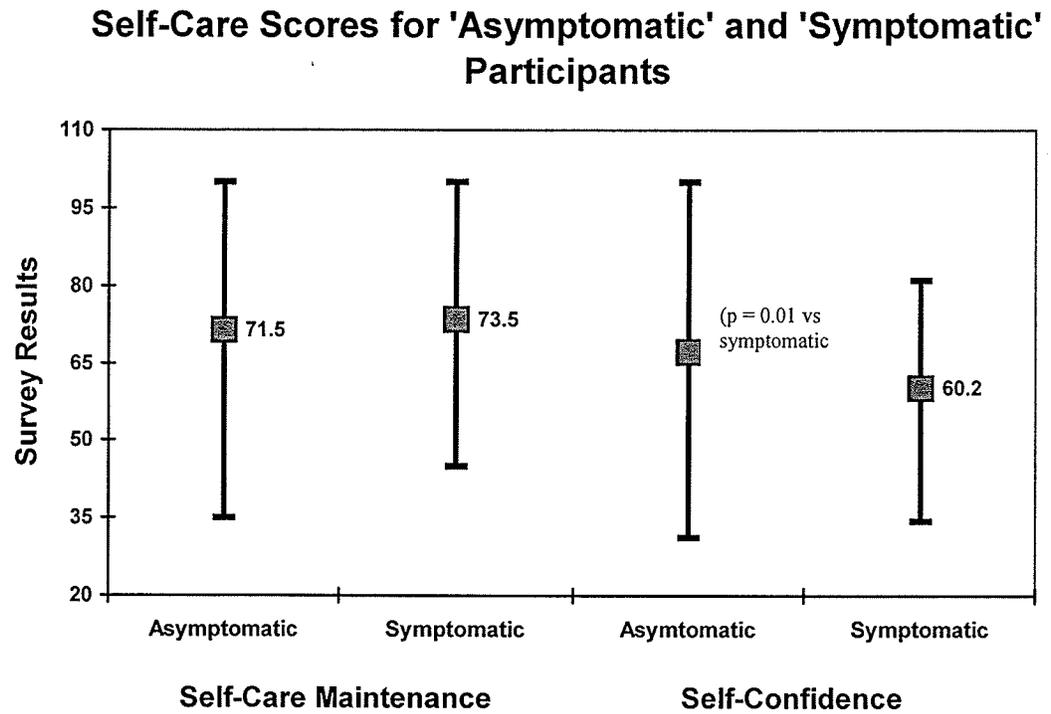
Predictor Variables	Total Sample (N=65)			Symptomatic (n=31)		
	N	Self-Care Maintenance	Self Confidence	n	Self-Care Management	SCHFI
Education						
< High School	28	73.1	61.7	14	41.1	175.9
High School	15	67.0	66.0	7	40.0	164.5
> High School	22	75.2	65.2	10	50.5	188.9
P value	-	0.2287	0.6343	-	0.5988	0.4004
Occupational Status						
Full-Time	13	72.5	63.9	3	66.7	210.8
Part-Time	8	74.1	68.0	4	28.8	178.8
Medical Leave	15	77.5	65.8	7	53.6	191.6
Unemployed	4	56.3	62.5	1	30.0	152.5
Retired	25	71.4	61.6	16	40.0	166.4
P value	-	0.1318	0.8743	-	0.2081	0.2431
Last Occupation						
Laborer	22	69.5	63.6	11	35.9	171.0
Retail/ Clerical	18	69.9	62.8	8	41.9	174.8
Professional/ Management	18	77.9	65.3	8	51.9	185.5
Other	7	73.9	63.8	4	53.8	184.8
P value	-	0.2571	0.9761	-	0.4602	0.8313
Family Income						
<\$20,000	16	73.1	65.0	8	46.9	178.9
\$20,000 - \$39,000	15	70.3	62.1	8	46.3	178.8
\$40,000 - \$59,000	15	71.7	62.9	8	35.6	164.1
\$60,000 +	15	73.3	68.8	5	53.0	202.8
P value	-	0.9424	0.6864	-	0.6692	0.3647
Physical Limitations						
Mild (70-100)	36	72.9	65.8	8	40.0	180.0
Moderate (31-69)	21	74.5	64.0	16	42.9	178.5
Severe (0-30)	7	63.9	54.0	6	51.7	171.6
P value	-	0.2463	0.2120	-	0.6773	0.9074
Social Limitations						
Mild (70-100)	36	73.1	66.7	8	50.0	204.3
Moderate (31-69)	21	72.7	61.5	17	38.1	167.9
Severe (0-30)	8	68.8	57.8	7	50.0	169.1
P value	-	0.7507	0.2602	-	0.4203	0.0524
Psychological Status						
Positive well-being (73-110)	31	75.6	67.2	11	47.7	190.3
Moderate Distress (61-72)	11	75.9	62.5	7	48.6	185.2
Severe Distress (0-60)	23	66.5	60.1	13	38.1	162.6
P value	-	0.0505	0.2552	-	0.5525	0.1485
Co-Morbidity						
Low (2 or less)	25	70.0	65.1	8	48.8	185.2
Moderate (3-4)	32	76.8	66.0	17	45.0	182.8
High (5+)	8	62.5	51.6	6	34.2	152.5
P value	-	0.0231 *	0.0632	-	0.5426	0.1749

* significant p value <0.05

Research Question #3: When ambulatory care patients suffering from heart failure experience shortness of breath, are they more or less inclined to perform self-care?

The participants were categorized as 'asymptomatic' or 'symptomatic' based on the presence of shortness of breath within the last three months in accordance with the SCFHI guidelines, which does not necessarily reflect their clinical presentation (see above discussion). Two self-care sub-scales, self-care maintenance and self-confidence scales were used to measure the participant's ability to perform self-care. The other two self-care sub-scales were not calculated for 'asymptomatic' patients based on the tool guidelines. To compare group mean scores for these two sub-scales, a t-test was conducted. Figure 7 shows the mean self-confidence and self-care maintenance scores for the participants experiencing shortness of breath and those who were not. A statistically significant difference was found for 'asymptomatic' and 'symptomatic' participants in relation to the self-confidence scores ($p=0.0144$). A higher mean score for this sub-scale was found in participants not experiencing shortness of breath (67.3 ± 18.6) as compared to those who had this symptoms (60.2 ± 11.8). Although not statistically significant, 'symptomatic' participants had higher mean self-care maintenance scores (73.5 ± 14.3) than those who were 'asymptomatic' (71.5 ± 14.9).

Figure 7



The squares indicate the mean scores and the error bars indicate the standard deviations.

Research Question #4: What is the relationship between self-care and clinical outcomes (hospital admissions) for ambulatory care patients experiencing heart failure?

The number of hospital admissions for heart failure within the last six months was correlated with the sub-scales of self-care. Table 8 shows the Pearson “r” correlation co-efficient for hospital admissions with the four sub-scales of self-care: self-care maintenance, self-confidence, self-care management and self-care of heart failure index scores. A significant correlation exists between the number of hospital admissions and self-confidence ($p=0.0005$). The number of hospital admissions approaches a significant relationship with self-care heart failure index score ($p=0.0576$). The correlation between this variable and both of these self-care sub-scales was negative, indicating the higher the number of hospital admissions, the lower the self-care scores.

Table 8

Pearson “r” Correlation Co-Efficient for Heart Failure Hospital Admissions Associated with Self-Care Sub-Scales

	All Participants (N=65)		Symptomatic Participants (n=31)	
	Self-Care Maintenance	Self Confidence	Self-Care Management	SCHFI
Hospital Admissions	-0.15320	-0.41970	-0.10770	-0.34463
p value	0.2231	0.0005	0.5642	0.0576

To assist with additional analysis and look for trends in the data, participants were categorized into three groups based on the number of hospital admissions that occurred within the last six months. These hospital admissions groups were compared to the four self-care sub-scales to look for differences between the groups using an analysis of variance (ANOVA). Table 9 describes this data.

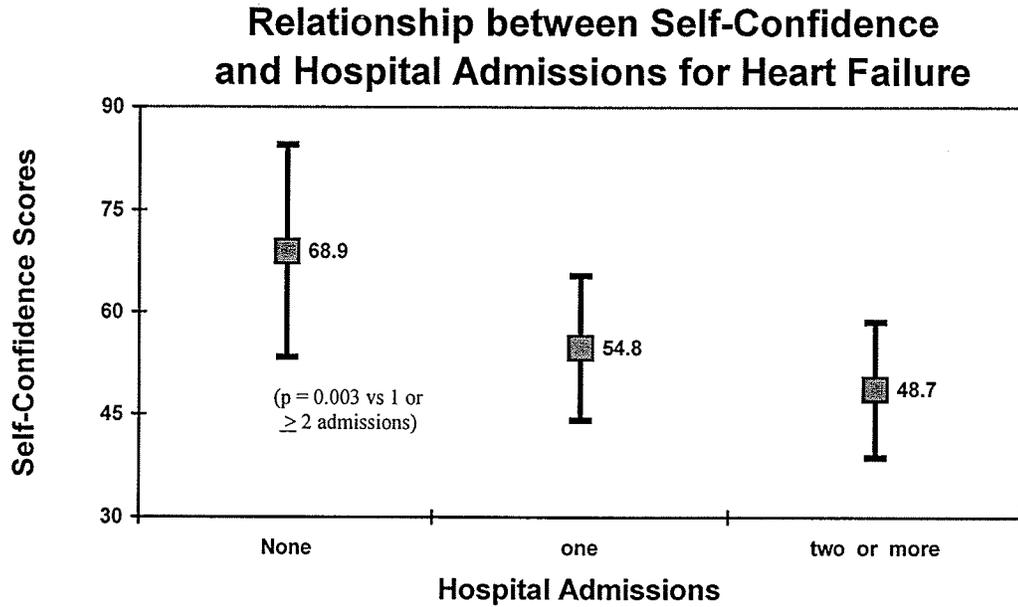
Table 9

Analysis of Variance for Self-Care & Recent Hospital Admissions for Heart Failure

Hospital Admissions	N	Self-Care Maintenance (mean)	Self Confidence (mean)	N	Self-Care Management (mean)	SCHFI (mean)
None	45	74.3	68.9	18	48.9	190.3
1	13	68.8	54.8	8	32.5	163.8
2 or more	7	67.1	48.7	5	40.7	156.5
P value	-	0.2989	0.0003	-	0.3544	0.0635

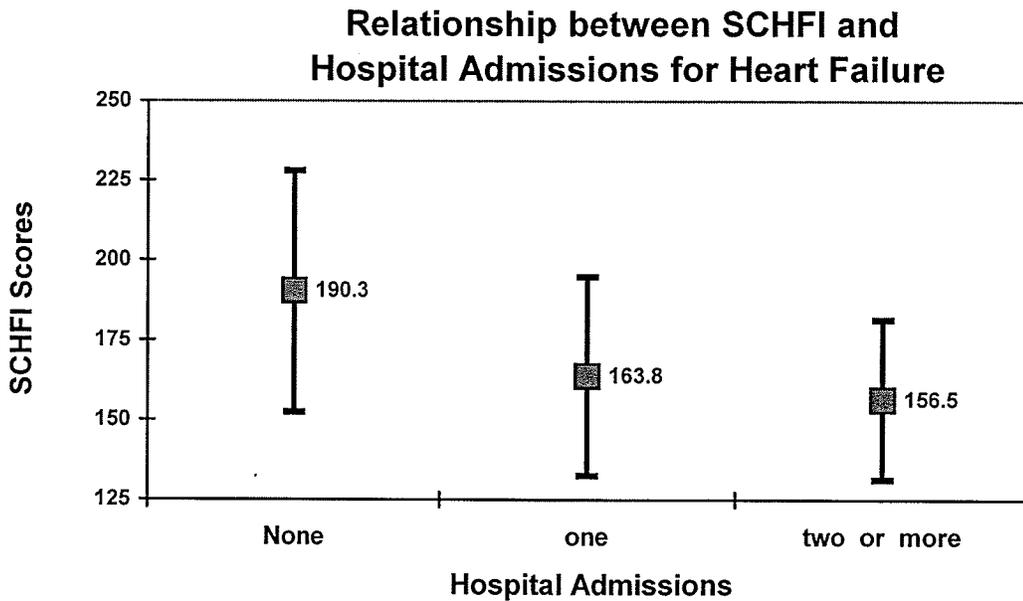
There was a highly statistically significant difference between the number of hospital admissions and self-confidence scores ($p=0.0003$). The differences between hospital admissions and the self-care of heart failure index scores are approaching statistical significant with a p value of 0.0635. Figure 8 and 9 demonstrate the relationship between these variables. The other two self-care sub-scales were not statistically different when compared to number of hospital admissions. However, participants with no hospital admissions for heart failure within the last six months had higher mean scores for self-care maintenance and self-care management than the mean scores for participants with hospital admissions within the last six months.

Figure 8



The squares indicate the mean scores and the error bars indicate the standard deviations.

Figure 9



The squares indicate the mean scores and the error bars indicate the standard deviations.

Qualitative Data Analysis

Self-care for an individual with heart failure involves daily decision-making focused on choosing options related to medications, diet, rest and activity, while monitoring underlying symptoms. The process is complicated as individuals who struggle to obtain a basic understanding of their disease process, are required to make decisions regarding when and how to seek help for debilitating symptoms (Thorne, Paterson & Russell, 2003). To facilitate a realistic understanding of self-care from the perspective of those most intimately involved with it, a qualitative piece was incorporated into this study. Gaining information about self-care for heart failure patients derived from both quantitative and qualitative methodologies helped to better extend the current knowledge base that informs and supports the direction of self-care management.

Of the sixty-five study participants who completed the quantitative portion of the study, twenty were approached to take part in the qualitative portion of the project. Of those twenty, eleven consented and participated in a qualitative interview with the researcher, either via telephone or in person. Of those who declined, seven cited reasons of fatigue or lack of available time to take part, and two who initially agreed to participate did not respond to repeated phone messages regarding an interview appointment.

Telephone interviews were conducted with five of the eleven participants within three weeks of their clinic appointment, where informed consent had been previously obtained. The remaining six interviews were conducted in person at the clinic in a private room after their appointment. Of the eleven participants in the

qualitative portion of the study, seven were males (64%) and four were females (36%). Six of the participants lived within the city limits of Winnipeg (55%). The five other participants (45%) resided outside of Winnipeg, commuting to the clinic for a scheduled appointment. The length of time spent for each interview ranged from 15 to 35 minutes, with a mean interview time of 21.8 minutes.

The questions posed during the interview were based on five research questions identified from the literature as well as the theoretical framework underpinning this study. The following research questions guided the qualitative portion of the study:

1. How satisfied are you with the care you received for your heart condition?
2. How comfortable do you feel contacting someone from the clinic when you are experiencing health problems?
3. Do you feel that you are able to do activities of daily living as well as other people?
4. Do you find yourself dwelling on your flaws?
5. What influences your decision when you make lifestyle changes to improve your health?

The above research questions were re-worded into open-ended interview questions that would enable participants to expand their answers, thereby enhancing the depth and scope of interview data collected:

1. I am interested to know if you have been satisfied or unsatisfied with the care you received at the Heart Failure Clinic. Can you tell me what things are happening at

- the clinic to contribute to your satisfaction or dissatisfaction? Are there things that you think the clinic could be doing to help you meet your needs better?
2. I am interested to know how comfortable you feel contacting someone from the clinic when you are having a problem. Have you had any experiences with this that you would like to share with me? Please tell me what it is about the clinic that makes you feel comfortable or uncomfortable.
 3. Sometimes people with a condition such as yours say that they have trouble doing activities of daily living, such as getting washing in the morning or doing light housework. How about you? Are you satisfied with your ability to do activities of daily living? Do you feel you are able to do these activities as well as the general population?
 4. Sometimes people with an illness such as yours, tell me that they tend to think about themselves in negative ways. That is, they tend to focus on their negative characteristics more than their positive ones. Does that fit you? If so, what kind of things do you focus on? How does this thinking affect how you see yourself?
 5. I am interested to learn about things that influence a person's decision to make changes to their lifestyle to improve their health. What things influence your decision-making about this? Can you give me an example? I am also interested in finding out about things that prevent a person from making changes to their lifestyle. What things prevent you from changing your lifestyle?

During the interviews, brief notes that recorded the participant responses to the interview questions were documented. This method of recording was chosen based on the researcher's preference. It was felt that brief note taking without the presence

of a tape recorder would more readily facilitate the open exchange of feelings and thoughts by participants to questions of a sensitive nature.

Directly after the interview was completed, the brief notes were expanded upon and further detail relating to the participant responses were added. For interviews that were conducted in person, contextual features related to the interview were recorded, such as the participant's facial expressions or hand gestures, as well as the noise level in the clinic at that time. Voice intonation, pauses, and sighs that occurred during interviews via the phone or in person were also recorded when identified.

Content analysis as described by Burnard (1991) was used to analyze the qualitative data collected from the interviews. The data from the interviews were coded manually by writing and highlighting key words and phrases on the interview transcripts. After multiple reviews of each transcript, recurrent categories were identified and coded. These categories were then analyzed and clustered to facilitate the development of broad themes that emerged from the transcripts. Four main thematic areas emerged from the qualitative data: 1) satisfaction with care received, 2) contacting health care providers, 3) strategies for managing symptoms of heart failure, and 4) the role of social support.

Thematic Area #1: Satisfaction with Care Received

The category of 'satisfaction with the care received' refers to how participants perceived the care they received in an ambulatory care clinic for heart failure management and treatment. Four factors influencing the satisfaction with care emerged from the data in this study: i) the extent to which patients' information and

support needs were met; ii) the nature of patient-staff communication; iii) patient ascribed attributes of staff; and iv) the nature of inter-staff relations within the clinic.

Many participants felt the clinic was a source of support where information needs regarding their disease process and management could be met. The staff members at the clinic were considered by participants in this study to be knowledgeable health care providers, who gave clear and prompt explanations. As noted by one participant:

Each time I go to the clinic, I feel a sense of accomplishment. I learn a bit more and get some more answers.

The participants became accustomed to this open style of information sharing at the clinic and looked to the staff to provide them with explanations for how they (the participants) felt physically. When such explanations were not readily provided, participants experienced feelings of frustration. Said one participant:

At the start, things were really good. They explained everything to me. Now, I sometimes find that they just don't explain things. Like I'm feeling sick, but they don't tell me why.

The emphasis on getting timely information that pertained directly to their specific concern was repeatedly identified by participants in this study as being important. The ability to call to clinic and talk directly to their health care provider, especially when symptoms arose, contributed greatly to participants' satisfaction with the clinic. The ability to access health care providers in this way was very reassuring for participants, as they could both seek guidance with relation to symptom management and confirm they were making educated decisions about their health. As one participant described:

Just two weeks ago, I was very tired and short of breath. So, I called the clinic and talked to the nurse right away. I didn't have to wait...It is so good to know that I can call the clinic. It gives me re-assurance to know that.

Conversely, one participant expressed dissatisfaction with clinic care, owing to his perception that clinic staff had not made the expected phone contact to follow-up with him regarding his disease process. This lack of follow-up experienced by the patient in conjunction with his limited knowledge of the disease left the patient with feelings of limited support by the clinic. This particular individual reflected on the importance of having his condition monitored closely by the clinic staff:

Last time I was here, I was started on a new medication. They told me at the clinic that I would be monitored. Whatever that means. Well, someone called me once to check on me and they were supposed to call back the following Friday...no one called me back. Those pills were no good for me. I was barely able to function at all.

The second factor that influenced satisfaction with the clinic concerned the nature of the patient-staff communication that occurred within the clinic. Nearly all of the participants reflected on the importance of the staff, particularly the physician, "taking time to talk with them". According to participant responses, some health care providers were more interactive and communicative than others:

They (the clinic staff) care...some doctors just prescribe, prescribe, but don't talk to you. This doctor is different.

Another participant noted:

If I have anything to say, I can talk to him. He listens to me, doesn't rush me out.

Being able to have the time to talk fostered the flow of information between patient and health care provider and conveyed to patients that their care was being approached in a thorough manner. Staff members within the clinic were seen as

being competent through this interaction, which gave participants a sense of confidence with their care and the clinic. As described by one male participant with a long standing history of cardiac problems:

They are very thorough. The doctor spent a lot of time with me, especially today. Having someone take the time to talk to me and find out about my history means a lot.

The personality traits that participants ascribed to the clinic staff also appeared to influence patient satisfaction with the clinic. Participants consistently used positive personality attributes such as “friendly”, “nice” or “personable” to describe the physician and nurse at the clinic. As identified by one participant, these attributes allowed the physician to give suggestions while remaining respectful of choices that each person has to make:

The doctor is reasonable. He gives suggestions, but he doesn't come down too hard on me.

Finally, the participants' perceptions of inter-staff relations at the clinic appeared to influence the satisfaction they had with their care. Inter-staff relations refer to the nature of the interactions and communication that exist between the staff working at the clinic, particularly the nurse and physician. The inter-staff relations in this study were described solely in a positive manner, as participants witnessed interactions between staff that implied a sense of teamwork and professional respect. Being in such an environment while at the clinic made coming in for an appointment a more pleasurable and satisfying experience. One participant said it simply as “everyone at the clinic seems to be friends.”

Thematic Area #2: Contacting Health Care Providers

The category of 'contacting health care providers' refers to the influences that affect a participant's willingness to seek out help from the clinic when concerns or symptoms associated with heart failure occur. Within an ambulatory care environment, the burden of managing care rests with the individual who is affected (Thorne, Paterson & Russell, 2003). In an attempt to assist individuals with their care, this heart failure clinic has followed the trend to reach out to patients by encouraging individuals to call for guidance when needed. Five factors that influenced whether or not individuals would contact the clinic for help emerged from the data collected for this study. These include: i) recognition of salient heart failure symptoms; ii) recollection of the invitation to contact the clinic in the event that problems arise; iii) patient decision-making regarding symptom severity and the appropriateness of the clinic as a point of first contact; iv) geographic location; v) perceived roles and responsibilities of the health care providers and the patient regarding monitoring and follow-up care.

Patient recognition of salient heart failure symptoms prompted many participants to contact the clinic for guidance. The symptom whether it be weight gain, swelling of either the abdomen or feet, or shortness of breath was perceived as distressing for several participants and prompted them to seek immediate attention from the clinic. Of all these symptoms however, the primary impetus for contacting the clinic that was cited by participants in this study was increased shortness of breath:

I contact the clinic when I need to. Just two weeks ago, I was very tired and short of breath, so I called the clinic.

The decision to contact the clinic regarding symptom management was predicated on the assumption that patients were aware that this course of action was open to them when a symptom exacerbation occurred. Two of the participants in this study however, indicated that they did not do so when an exacerbation occurred. One participant indicated that he was not aware of his responsibility to call the clinic when symptoms increased. The other participant indicated that while he was instructed that this was his responsibility, he failed to remember to do so when a symptom exacerbation occurred. In both situations, the symptom exacerbation was recognized, however the participants “did not think of contacting the clinic” at the time, believing that these symptoms would spontaneously resolve with rest. When left to his own devices, one of these participants chose to contact his own general practitioner for assistance, as the symptoms became unbearable. Although not explicitly stated, this participant suggested the close proximity and the high degree of comfort he felt with his general practitioner influenced his decision of where to seek guidance.

The interview data in this study suggested that patient decision-making as regards contacting the clinic was based on patients’ perceptions regarding the severity of their symptoms and the appropriateness of using the clinic as a point of first contact. For example, some participants deemed their symptoms to be too severe for management from the clinic. This notion of being “too sick” for the clinic was voiced by one female participant:

When I’m short of breath, I need help right away, so I call the ambulance.

When participants had co-morbid conditions, such as arthritis or respiratory disorders the decision with regard to identifying the most appropriate resource to use as the first point of contact had to be made. The vague symptoms of fatigue and shortness of breath are common to various diseases including heart failure, leaving some individuals uncertain of where to go for guidance. One participant recalls contacting the clinic when feeling symptomatic, only to later realize her symptoms were related to another underlying health problem. Co-morbid conditions, especially those with a cardiac origin that mimicked heart failure symptoms led one participant to use a resource other than the clinic as a point of first contact:

Usually I would talk to Health Sciences Centre. I have a pacemaker, so if I felt unwell, I would call them.

Geographic location of the clinic in relation to the participants' residence appeared to influence the pattern of contact that participants had with health care providers in the clinic. There was a lack of consensus among the participants living outside of Winnipeg with regard to which health care resource to contact for guidance when symptoms of heart failure occurred. While some rural heart failure patients reflected on the reassurance they felt knowing the clinic could be easily contacted by phone, only one participant indicated she did so when symptoms occurred. The other participants chose to contact their general practitioner who practiced within their community for guidance due to the close proximity of the practitioner and previous contact with this care provider. In these cases, the participants understood their general practitioner to be not only familiar with their total care but also the management of heart failure symptoms when they occurred.

Differences in expectations between the patient and the clinic staff with regard to patient initiated contact for symptom exacerbation also appeared to influence the willingness of patients to seek guidance from the clinic. The majority of the participants in this study believed the responsibility of contacting the clinic laid with themselves, as they were the ones who physically experienced the symptoms. Concrete reminders such as cards with the clinic phone number served as reinforcement of this expectation:

The nurse gave me the card for the clinic with the phone number and it's on my fridge. I did call once when I felt very short on breath.

However, not all participants understood it was their role to contact the clinic when help was needed. One participant reflected on his perception of clinic, laying the responsibility of phone contact with the clinic staff:

If they (the clinic staff) want to know how I'm doing and that's part of their job, then they should call me

Thematic Area #3: I am still me! (Maintenance of Person-hood)

The category of 'I am still me' that clearly emerged from the data refers to the conviction among participants that a diagnosis of heart failure did not define them as individuals. The vast majority of participants expressed that it was important that they maintain some sense of who they were, irrespective of their disease and stressed the importance of "not letting heart failure take over how they lived their lives." However, living with heart failure did challenge how participants perceived their sense of self-worth, as they became concerned over the perception others had of them and their ability to carry on with activities that were important to them.

The satisfaction and confidence these individuals felt about themselves (self-worth) were affected by the limiting effects of heart failure on physical and social activity they experienced. These beliefs ultimately impacted on a person's view of oneself referred to as self-concept. When activities that once provided pleasure for participants could not be performed, patients reported a sense of depression and dissatisfaction with their life:

Sometimes I feel low because I can't do some of the things that I want to do. I see other people being active, walking around and know I can't do the same thing. So it's hard at times. I try not to think about it.

Several participants in this study echoed the experience of losing their 'former self' and abilities. Activities of daily living took longer to accomplish, leaving participants with feelings of sadness. When the disease impacted on their ability to maintain their means of livelihood, the effect on the patient's self-worth and ultimately self-concept was sometimes detrimental.

Being able to hunt and fish is in my blood. It's who I am. On days where I can't do this, I just survive rather than live...Sometimes I feel like less of a man, especially when I rely on my fishing and hunting to get my livelihood.

The symptom of fatigue experienced by participants was seen as being particularly disheartening. Of all the symptoms encompassed with heart failure, this overwhelming sense of tiredness continually emerged when participants discussed how they saw themselves. One participant put it simply as:

The part that really bothers me is feeling so tired for no reason. I'm down on myself when I'm so tired.

Although fatigue and the limited activity level associated with it appeared to impact negatively at times on a person's self-concept, conversely, some participants described how slight health improvements would enhance or heighten their feelings

of self-worth. These past experiences with symptom exacerbations and remission helped patients to value their worth when they perceived themselves as having control over their disease. One participant who derived her feeling of self-worth from her industrious nature said:

Last summer when I was so sick and could not breathe, I couldn't do anything. I felt really poor about my self. Now I can do so much more...I'm positive because I can do so much more.

The concern over how those around them, including the community at large, would view a person with heart failure was evident in the participant responses. Patients believed that their inability to perform certain activities would be readily noticed by those around them. Ignorant of the debilitating effects caused by heart failure, the public was perceived as labeling these individuals as lazy or viewing some of their self-care strategies as ridiculous. One participant reflected on how others might make such judgements due to the insidious nature of heart failure:

I go slower than everyone else, but I get it done. Some people don't understand that. They just expect you to go, go, and go...It's hard to stay positive when people bring you down. Just because it takes more time doesn't mean that I'm lazy...I don't look sick, like I have a broken leg or am all beaten up. So they (those around him) don't get it.

The extent to which participants would allow heart failure to impact their lives appeared to influence participants' decision-making regarding which interventions and lifestyle changes to adopt and which to ignore. Participants saw heart failure as being a part of them, but were quick to ensure it did not solely define them as a person:

I try to live healthy, sort of speak. But, I can't let it (heart failure) dictate my life.

In order to ensure that the illness did not take over their lives, participants indicated that they adopted a few choice self-care strategies, especially when a perceived link between that strategy and feeling better was present. Other self-care strategies not adopted were seen as a perceived threat to an individual's sense of self. One participant explained the importance that smoking held in his life:

I try to be healthy, but I don't want to give up things that I enjoy. So, I smoke, that's the European way to live. It relaxes me and I have had to give up so many other things.

Holding onto a few 'old behaviors' reassured participants that heart failure had not changed their essential being. As stated by another participant:

It is kind of hard to follow everything, like the low salt part. It gives me a lot of satisfaction to eat and have some salt. I guess it adds to the quality of my life.

Thematic Area #4: Strategies for Managing Symptoms of Heart Failure

The category of 'strategies for symptom management' refers to the changes in lifestyle that a person with heart failure adopts in an attempt to improve their health and reduce symptoms experienced. The strategies for managing symptoms of heart failure that were identified by participants in this study were categorized as either: i) patient generated or ii) clinic generated strategies.

Patient Generated Strategies

Strategies generated by patients with heart failure focused on the balance between lifestyle modification to ease symptoms and maintenance of lifestyle activities to ensure quality of life. Patient generated strategies for symptom management involved modifying specific lifestyle behaviors and strengthening their ability to handle the psychological impact of their symptoms.

Patients with heart failure appeared to be aware of activities that could undermine their health and took steps to avoid situations that required them to perform these activities. Participants were conscious of their physical limitations and accepted that certain activities known to induce symptoms of heart failure could no longer be a part of their life. In particular, behaviors that impacted on the participant's ability to breathe, such as cigarette smoking or performing physical activities thought to be taxing to the respiratory system were simply not done. One female participant recalled being aware of such influences as it pertains to lifestyle changes:

We have a big garden and it bothers me to bend over a lot, I get short of breath. So, I don't pick cucumbers or vacuum because of the bending.

In addition to avoiding these activities, situations believed to contribute to an exacerbation of symptoms were avoided. Outdoor activities in humid weather conditions and restaurants known for salty food were two such circumstances identified by participants.

Nearly all of the heart failure patients interviewed indicated that they gauged the impact of activities on their physical endurance and performed them at their own pace. Continuing to do activities of daily living at a modified speed was a common strategy implemented on a regular basis. One participant applied this same belief to his work life, as he shortened the time spent managing a business he owned to accommodate how symptomatic he felt. Listening to how their bodies felt helped participants to identify a suitable activity level for themselves. No matter how basic or complex the task, participants took the opportunity to take short rest breaks before completing the task when they felt too fatigued:

It takes me longer to do different activities like getting dressed in the morning or washing up. So, I just go at my own pace. If I get short on breath, then I just take a break.

The importance of maintaining a positive outlook and holding onto the belief that heart failure would not control their life was evident throughout the qualitative transcripts in this study. Over half of the participants referred to themselves as “positive people”, choosing to focus on encouraging aspects of their lives. Four of the participants alluded to holding onto feelings of improved productivity and health as compared to times in the past where their symptoms were not as well controlled. Characteristics such as having a sense of humor, perseverance and a lighthearted nature were given as reasons for being able to remain upbeat, despite adversity:

I have always been upbeat, even when times are tough. I just hang it there.

Clinic generated Strategies

Clinic generated strategies for managing symptoms of heart failure refers to the recommendations that health care providers gave to patients seen in the clinic. Participants in this study attempted to adhere to these strategies, as they saw health care providers as a valuable source of knowledge. Complying with these suggestions without understanding the underlying reason appeared to have occurred occasionally as participants “just did what the staff told them to do.” The strategies that were adopted by participants focused on four main lifestyle areas: medication compliance, low sodium diet, weighing themselves, and increased physical activity.

One strategy for symptom management identified by two participants was taking medications as prescribed. While one participant equated compliance with his

medication regime more generally to his survival, the other participant focused more specifically when explaining her reasons for compliance with prescribed medications:

The pills the physician gave to me seem to help a lot, so I take them.

The strategy of following a low sodium diet was a recommendation that several participants indicated they struggled with, before it was incorporated into their lifestyle. Correlating how they felt with the consumption of excessive salt helped them to adopt this strategy:

I remember the doctor saying where salt goes, water goes. I feel a lot better if I don't eat salt.

Two participants acknowledged they were aware of the recommendation to reduce salt intake, but had chosen not to implement this recommendation. These participants appeared to weigh the positive and negative effects of such a strategy, rationalizing that reducing dietary salt would detrimentally impact on their quality of life.

Several of the participants used the strategy of weighing themselves daily to monitor for changes in their condition. This behavior was seen as a simple way that individuals could monitor their health by watching for early signs of fluid build-up.

As noted by one participant:

I weigh myself everyday, just to make sure it does not go up... it's the first sign and I don't want to miss it.

One participant indicated he was aware of this strategy, but chose not to adhere to it, as he perceived that there was little benefit associated with weighing himself daily. The socioeconomic burden of purchasing a required home scale and then performing an activity that could cause ridicule by the community as it was not considered culturally appropriate were cited as primary drawbacks to this activity.

Several participants in this study described the use of physical activity as a self-care strategy to manage heart failure. Two participants adopted the use of a walking program with the aid of a treadmill. Individuals were able to monitor progress in relation to their endurance through this strategy:

The doctor told me to start walking. So I did slowly. Now I walk half an hour in the morning and half an hour in the evening. That's four miles a day. I never used to do that. I have a treadmill if it is too cold outside. That's what I do.

Several other participants discussed the notion of being physically active on a regular basis to manage symptoms. Two of these participants identified that they did such things as walking around the yard to incorporate physical activity into their daily life. One of the participants identified physical activity as an important strategy, but indicated she was not aware of how to incorporate it into her current lifestyle, implying she had not sought help in this regard from the clinic.

Thematic Area #4: Role of Social Support

An underlying theme in the participant responses for this study was 'the role of social support' that patients perceived to be available to them in managing their disease process. Participants reflected on the importance that the social support emanating from either friends or family had on their ability to follow recommended self-care activities and make lifestyle changes. There were two common beliefs within this area that emerged from the data: i) social support entails active involvement based on mutual respect and understanding and ii) the impact of social support on the ability of participants to incorporate and sustain self-care practices.

The expressive and instrumental nature of social support frequently described in the literature was seen through the qualitative interviews as meaningful relationships between participants and their loved ones characterized by mutual respect, open communication, understanding, and active involvement was described. Several participants openly discussed the significance and strength of their social networks, as decisions about lifestyle changes were made together with their families based on respect and understanding of the patient's well-being. In particular, participants felt valued by their spouse when these loved ones took the time to understand who they were as people and how heart failure had affected their daily life. Several references were made with regard to the mutual understanding, caring and empathy that existed in these relationships. Family members and friends boosted the emotional and psychological health of participants by encouraged and motivating them, despite chronic health problems:

My husband motivates me. We have been married for 43 years, so he knows me so well and has been there for me.

Support networks, particular family members also played a significant role in the self-care behaviors that patients incorporated into their lives. Through both words and actions, family members either supported or deterred patient efforts to manage their disease process. Several participants indicated their loved ones were aware of the extent to which they felt physically sick and provided them with continual emotional support to ease the burden of managing their health. Some family members and friends took a more active role in the participant's disease management, especially when the individual was unable to fulfill his/her perceived societal roles:

When I'm tired, worn out you know. Then I don't do much for myself. I can't, I'm too tired. So my family and friends help. They have been a God-send for me.

Conversely, the opposite held true when the actions of family members were seen as being in direct conflict with recommended self-care, particularly those strategies generated from the clinic. Two participants reflected on the difficulty of adhering to behavior changes when the actions of loved ones did not support it. Participants saw reluctance to join in efforts to reduce salt or continue with a walking program by their family as a significant deterrent. One participant even implied it was out of his control to change certain dietary behaviors when his wife does not support it:

My wife adds salt to her cooking. She always has and probably always will. I can't change everything. So I just work on what I can.

Chapter Summary

This chapter presents both the quantitative and qualitative findings of this study based on specific research questions used to explore self-care practices with heart failure patients in an ambulatory care setting. Within this study, three specific self-care activities were identified as commonly practiced by this patient population. These activities include taking medication as prescribed; talking to your doctor when you need guidance, and keeping the salt in your diet lower than 2-3gm each day. There was a significant difference in the use of getting immunizations annually between the asymptomatic and symptomatic participants.

The variables, self-confidence, psychological status, co-morbidity and ethnic background were significantly related to the self-care maintenance, which measures one component of self-care. A highly significant relationship between self-

confidence and the self-care of heart failure index was also found. There were no significant differences in age, age of diagnosis, NYHA functional classification, physical or social limitations, ejection fraction, marital status, residency, living situation, number of family or friend supports, education, occupational status, last occupation, or family income in relation to the measures of self-care.

When comparing symptomatic patients with asymptomatic patients, the data indicated that a statistically significant difference was present with self-confidence, as higher mean self-confidence levels were seen in patients with no symptoms. However, there was no statistically significant difference in relation to self-care maintenance in these patient groups.

The study also indicated there was a statistically significant negative correlation between number of hospital admissions for heart failure and self-confidence suggesting that higher self-confidence level is associated with a lower hospital admission rate for heart failure. There were no statistically significant relations between hospital admissions and the other measures of self-care including, self-care maintenance, self-care management or self-care of heart failure index.

This chapter also has described the qualitative approach used in this study to help elicit information regarding self-care practices in the management of heart failure and factors contributing to patient satisfaction with clinic care. Content analysis of 11 participant interviews resulted in the generation of four main conceptual themes that provides insights about those features of the clinic that contribute to patient satisfaction with care; factors that influence patient behavior as it relates to contacting the clinic for follow-up care and assistance; the nature of

strategies used to manage symptoms of heart failure, and the role that social support plays for individuals in the management of their disease. These findings will be examined in light of existing literature within the Discussion chapter of this thesis.

CHAPTER SIX

Discussion

Introduction

This study was designed to gain an understanding of the determinants of self-care activities in a convenience sample of 65 ambulatory care heart failure patients. The quantitative and qualitative results of this study will be discussed within the context of relevant literature to provide a clearer description of the self-care experience within this patient population. The application of the conceptual framework and the corresponding research questions that guided this study will be discussed. Limitations of the study will be highlighted along with implications for clinical practice and future research recommendations.

Self-Care Activities

Self-care has been the subject of inquiry for various studies conducted on the chronically ill (Connelly, 1993; Paterson et al., 2002; Nagy & Wolfe, 1984; Mollem et al., 1996; Baker & Stern, 1993). This phenomenon has been explored from several perspectives, often with a focus on how to increase self-care behaviors through the use of multidisciplinary initiatives. The exploration of self-care in ambulatory care heart failure patients has been limited to only three research studies (Sulzbach-Hoke et al., 1997; Ni et al., 1999; Bennett, Cordes, et al., 2000). In this study, Connelly's Model of Self-Care in Chronic Illness (MSCCI) was used as the framework to describe the experience of self-care in an ambulatory care heart failure patient population. The purpose of the investigation was to examine the performance and determinants of self-care using primarily quantitative data. The qualitative interviews

further describe self-care and expand on the explanation of the findings derived from questionnaires. The discussion of the finding will be guided by the research questions posed in this study.

Research Question #1: In an ambulatory care setting, what are the self-care activities most commonly used by individuals diagnosed with heart failure?

This research question was developed to explore the specific self-care activities that are practiced by heart failure patients in an ambulatory care clinic located in a Winnipeg tertiary health care facility. Understanding the therapeutic self-care activities within MSCCI for both illness-specific and health promotion behaviors was a fundamental goal of this study. Since the research conducted in this area is limited particularly for heart failure patients being treated in an ambulatory care setting, the study findings add to the current body of knowledge. To discuss this research question, self-care activities derived from quantitative data reported in the Self-Care of Heart Failure Index (SCHFI) and qualitative interview data will be discussed.

Seven specific self-care activities derived from the clinical guidelines for heart failure were measured through the SCHFI, where participants chose one option ranging from 'always' to 'rarely' to describe their self-care practices. For those participants who chose two different answers from the Likert scale to describe their experience with a self-care behavior, the answer closest to the 'rarely' option was used for the data analysis of that activity. For example, if a participant selected both the 'sometimes' and 'always' option to describe the activity of following a low salt diet, then the response 'sometimes' was used for the analysis of this specific activity.

This was done during the analysis to ensure the answer chosen to describe a self-care behavior reflected the participant's current practice, not the level they were striving to practice. The activities described in the SCHFI are a combination of illness-specific activities such as weighing behaviors as well as general health promotion activities such as getting annual flu immunizations.

In this quantitative analysis, the self-care maintenance score, a self-care subscale that represents seven self-care activities in the SCHFI is consistent with the results from a secondary analysis study conducted by Riegel, Chriss and colleagues (2003). These researchers examined the self-care practices of 66 heart failure patients at two separate points in time after hospital discharge. The sample for the secondary analysis study and this study are similar with respect to demographic and clinical features despite the exclusion of ambulatory care patients in the secondary analysis study. Although Riegel, Chriss and colleagues (2003) have not included the scores for each self-care activity, the mean self-care maintenance score were reported upon hospital discharge and three months after hospitalization as 64 ± 18.6 and 73.3 ± 17.1 respectively. This is comparable to the mean self-care maintenance of 72.4 ± 14.5 within this study.

As is the case with most chronic illnesses, individuals diagnosed with heart failure have multiple medication regimens that are prescribed. In this study, the self-care behavior most often practiced by heart failure patients based on self-reports was taking medications as prescribed. Participants viewed this behavior as essential to maintaining their current health status and diminishing deleterious symptoms. This finding was evident in both the quantitative and qualitative components of the study

and is consistent with the study hypothesis, 'in an ambulatory care setting, taking medications as prescribed will be one of the most commonly practiced self-care activities for individuals with heart failure'. This finding is consistent with those of other self-care studies in the chronically ill in general (Pharm et al., 1996; Connelly, 1993) and in the heart failure population specifically (Riegel & Carlson, 2002; Bennett, Cordes et al., 2000; Artinian et al., 2002; Ni et al., 1999). In these studies, taking medication as prescribed was a behavior frequently practiced by the majority of the sample. Although the findings in these investigations and the current study are encouraging, the use of self-report for this activity may have resulted in patients answering questions in a way they perceived to be socially desirable. In a study by Morane and colleagues (1994), medication compliance was objectively measured in heart failure patients. These researchers compared prescription renewals by participants to the written prescriptions and found that very few participants filled their prescription for the accurate amount of time to last till their follow-up appointment. Morane and colleagues concluded that only 10 percent of the sample was taking their medications as prescribed.

Another general health promotion strategy frequently practiced by heart failure patients in this study was seeking guidance from a care provider whenever questions or concerns arose. This finding, seen in the SCHFI scores is supported by the data from the qualitative interviews under the sub-theme 'contacting health care providers'. These ambulatory care participants indicated they were encouraged to contact either the physician or clinical nurse specialist at the clinic for guidance to facilitate further self-care decision-making and to seek reassurance. The behavior of

seeking out support from health care providers is consistent with findings related to self-care decision-making identified by participants in a recent qualitative study concerning chronic illness. Thorne and colleagues (2003) found that individuals with a chronic illness used health care providers as resources when evaluating the effectiveness of a self-care strategy. During the qualitative interviews in this current study, individuals who indicated that they did not seek clinic care providers for guidance identified forgetfulness or lack of perceived role responsibility as reasons for not doing so. Lack of role responsibility, in particular, tends to emerge when an individual perceives the locus of control over illness as being outside of themselves (Baker & Stern, 1993). According to scholars on chronic illness, individuals who do not derive meaning from their illness, do not assimilate it into their identity, leaving them with a feeling of no control over their illness or accountability to actively participate in their care (Baker & Stern, 1993). In a study by Riegel and Carlson (2002) maintaining control over heart failure was identified by patients as a reason for practicing self-care.

In this study, the use of a low sodium diet was reported in the SCHFI as a frequently practiced self-care strategy. This finding is consistent with several self-care studies in the heart failure population (Ni et al., 1999; Bushnell, 1992; Carlson et al., 2001). Interestingly, the percentage of participants who used this strategy was slightly higher in this study as compared to the above-mentioned studies. This difference may be because participants do not consider pre-packaged process foods they consume such as luncheon meat or canned soups as being high in sodium. This premise is supported by research conducted by Neily and colleagues (2002), where

less than half of the heart failure patients could accurately identify foods high in sodium. As reflected through the qualitative sub-theme concerning symptom management of heart failure, it was evident that while some individuals were aware of the strategy of a low sodium diet, they felt it interfered with their quality of life to such an extent they were not willing to implement it. Those individuals who did adopt a sodium-restricted diet described a process of weighing the positive and negative consequences they associated with this activity which influenced their decision to adopt it. The most important benefit patients identified as a result of reducing their sodium intake was a significant reduction in the physical symptoms they experienced. This process of comparing the positive and negative consequences related to an adopted self-care behavior is described in Connelly's MSCCI framework by the predisposing variable of 'health perceptions'. This process of comparing consequences could explain why Ni and colleagues (1999) found over 40% of the individuals who were aware of the importance of reducing salt, chose not to incorporate this behavior into their lifestyle.

A strategy specific to heart failure practiced by participants in this study was daily weight taking. This behavior is consistent with the study's framework and the predisposing variable 'self-concept'. In the qualitative interviews some participants stated they found weighing themselves daily provided them with a sense of control over their disease as is reflected within the sub-theme, 'strategies for managing symptoms of heart failure'. These patients saw daily weight taking as a simple approach for monitoring fluid overload based on the teaching they received from the clinic. In a qualitative study of heart failure patients, Bennett, Cordes and colleagues

(2000) reported similar findings, where participants weighed themselves regularly to monitor symptoms and help them control their disease. It is noteworthy that in the current study, results from the SCHFI showed this self-care strategy was practiced by 60% of the participants. The percentage of individuals who practiced this behavior is high in this study when compared to the three other quantitative self-care studies, which found less than half of the heart failure patients regularly incorporated this strategy (Sulzbach-Hoke et al., 1997; Ni et al., 1999; Bushnell, 1992). This difference may be explained in part by the study setting where a relatively small number of patients were seen in a newly established clinic, which may have facilitate more opportunities for patient education on weight taking behaviors. Interestingly, within the qualitative component of this study, one individual chose not to perform this self-care activity partially due to concerns that it was not deemed a culturally appropriate activity. This notion of self-care activities being encouraged in one setting, while considered unacceptable in another where different traditions are practices is evident within the literature (Leininger, 1995). Another reason identified by a participant in this study for not weighing himself was the socioeconomic burden of purchasing a scale. This finding is consistent with the findings of a study by Sulzbach-Hoke and colleagues (1997) where access to a scale was identified as a deterrent to the self-care strategy of tracking one's weight. The self-care research indicates that the financial expenditure precipitated by a self-care activity can act as a potential barrier towards practice when financial constraints exist (Coates & Boore, 1995).

Self-care concerning physical activity involved regular exercise as well as modifying the pace for activities of daily living based on symptoms experienced. Within the quantitative part of this study, exercising at least three times per week was the health activity that was least likely to be undertaken by heart failure patients. This is consistent with research conducted by Carlson and colleagues (2001), where less than half of the participants participated in regular physical activity. Within the qualitative component of this study, two participants indicated they followed a structured walking program, while most participants generally kept active through performing household activities such as working in the garden or walking in the yard. These findings were echoed in research conducted by Bennett, Cordes and colleagues (2000), where individuals with heart failure were interested in performing exercise to maintain their health, but chose not to participate in formal exercise programs. Findings within the qualitative theme concerning clinic-generated self-care strategies in the current study indicated some individuals limited by heart failure appeared uncertain of how to consistently adopt this self-care behavior to meet their limited physical ability level. However, overall, heart failure patients in this study indicated they remained physically active at some level with household chores and activities, even though they did not tend to participate in activities for the sole purpose of exercising a set number of times each week.

The other aspect of physical activity practiced by heart failure patients in this study was modifying the pace for activities of daily living based on symptoms they were experiencing. This self-care strategy generated by the patient meant short rest periods were incorporated into basic activities such as getting dressed, which were

performed at a slower pace. These individuals were aware of how they felt physically and generally opted not to partake in activities perceived to require high energy reserves. This is consistent with qualitative studies conducted by Riegel and Carlson (2002) and Bennett, Cordes and colleagues (2000), where heart failure patients discussed the use of built-in rest periods and modification of activity level as part of their self-care regime. Chronic illness literature with advanced emphysema patients clearly articulates the importance of individuals planning their daily activities by gauging the oxygen requirement for various activities and strategizing an optimal route to preserve oxygen and energy levels (Fagerhaugh, 1986). Within Connelly's framework, heart failure patients like other chronically ill individuals, recognized their vulnerability to a symptom exacerbation or a relapse of their disease process. Participants in this study appeared to be aware of this vulnerability and incorporated strategies such as rest periods into their self-care activities to cope with this vulnerability.

Another patient generated self-care behavior identified under the qualitative thematic area of 'strategies for managing symptoms of heart failure' in this study was the use of a positive outlook and social support to strengthen an individual's ability to psychologically cope with presence of chronic symptoms. The framework for this study identifies social support and psychological status as enabling variables that continually interact with self-care behaviors. It appears that heart failure patients, like other chronically ill individuals, actively implement the strategies of promoting a positive outlook on their life generally, and their health specifically. Research conducted by Bennett, Cordes and colleagues (2000) also found that patients

identified positive thoughts about their health and positive self-talk as management strategies for heart failure. The findings of this study indicate that patients frequently sought out family and friends in their life to provide emotional support. This finding is consistent with research by Bennett, Cordes and colleagues (2000) on heart failure patients, where seeking family support was identified as an important self-care strategy.

In this study, individuals with heart failure, whether they experienced shortness of breath or not, used similar self-care strategies. The only exception to this, concerns the general health promotion behavior of having annual flu shots. Participants with shortness of breath indicated they received flu immunizations on a regular basis, as compared to those who were not short of breath. However, this activity was less likely to be engaged by participants when they did not experience this symptom in the last three months. This surprising finding appears to be the result of varying degrees of vulnerability experienced by these two groups of individuals. Connelly's MSCCI framework indicated an individual's perception of vulnerability to disease exacerbation influences the performance of related self-care behaviors. Individuals without recent dyspnea may tend to feel less vulnerable to an exacerbation of their disease than their dyspneic counterparts, leading to complacency with preventative behaviors such as immunizations. The notion of perceived vulnerability is discussed within the diabetic research and literature, as a person's perceived threat of complications with their illness acted as a motivator for self-management (Coates & Boore, 1995).

In summary, several self-care strategies were identified as being commonly practiced by the heart failure patients in this study. They included: taking medication as prescribed, seeking guidance from health care providers at the clinic, following a low sodium diet, daily weight taking, keeping physically active, modifying pace for activities of daily living and seeking emotional support from family and friends.

Determinants of Self-Care

Research Question #2: What are the determinants of self-care for individuals diagnosed with heart failure seen in an ambulatory care setting?

This research question explores variables that are potential determinants of self-care for heart failure patients in an ambulatory care clinic. The study framework, MSCCI, will be used to organize this discussion as it describes the interactive relationship that exists between these potential variables and the phenomena of self-care. The framework elements categorized as either predisposing variables or enabling variables will be discussed based on quantitative findings reported in specific SCHFI sub-scales as well as the findings from the qualitative interviews. As part of this discussion, the study hypothesis, stating ‘there will be a positive relationship between self-care and social support, self-efficacy and psychological status in this patient population’ will be critically examined.

Predisposing Variables

In Connelly’s self-care model, predisposing variables refer to past experiences, perceptions and beliefs that a chronically ill individual holds in relation to their self-care practices and their health (Connelly, 1987). The three predisposing

variables in this study that will be discussed as possible determinants of self-care include self-concept, health beliefs and health perceptions.

Self-Concept

A person's view of one's self, referred to as self-concept, was evaluated within this study through the qualitative interviews with ambulatory care heart failure patients, and was captured within the sub-theme, 'maintenance of person-hood'. Participants emphasized the importance of maintaining a strong belief in oneself despite having a chronic illness. Although heart failure did not define or change who they were inside, living with a chronic illness did challenge their self-concept. This was particularly true when physical and social abilities were severely limited as a result of their disease. Heart failure patients in this study attempted not to think about these limitations, however, as doing so led to feelings of despair that negatively influenced their view of themselves. Participants seemed to be aware that low self-concept impacted negatively on their ability to manage their health and chose instead to focus on positive aspects of their lives.

Maintaining a positive self-concept in the presence of illness and health related concerns has also been identified by Chochinov and colleagues (2002) in qualitative work examining the construct of dignity from the perspective of the terminally ill. The patient's belief that the essence of who they are despite their illness referred to as continuity of self, emerged as an important strategy within terminally ill patients' dignity conserving repertoire.

Within this study, heart failure patients indicated that certain self-care strategies were in conflict with who they perceived themselves to be. Self-care

strategies that were perceived as being in conflict with or a threat to self-defining characteristics were not practiced. For example, one participant readily identified himself as a European man, where cigarette smoking was a way of life that defined who he was as a person. Smoking cessation for him posed a threat to his identity that he was not willing to make. Although not directly discussed in the literature, there is some suggestion that personality traits may affect self-care practices. For example qualitative research conducted by Stromberg and colleagues (1999) examining factors affecting self-care, suggests underlying defining characteristics of a person, such as being a perfectionist, affected how and to what extent self-care was practiced.

In addition to defining characteristics, individuals in this study with a positive self-concept, who described themselves as being upbeat, felt they were able to cope psychologically with the symptoms of heart failure and practice self-care in a more proficient way. This finding is consistent with research conducted on healthy older adults (Smits & Kee, 1992; Lantz, 1985; Whetstone, 1987) as well as the chronically ill (Connelly, 1993), where having a positive self-concept correlates with a higher degree of self-care. Unlike the current study, these studies focused on categorizing self-concept as either positive or negative and did not consider defining characteristics of individuals as influencing factors.

Health Beliefs

The variable of health beliefs within Connelly's self-care model refers to the value system individuals hold in relation to their health and their perceived role in their own health care (Connelly, 1987, 1993). Throughout the qualitative transcripts of this study, participants discussed their health beliefs, often choosing to view their

health positively despite experiencing debilitating symptoms. Some individuals maintained this optimistic outlook about their health by celebrating slight improvements in symptom experiences rather than focusing on past exacerbations of their condition. A sense of control over their heart failure was experienced by these participants, which improved their self-concept and appeared to motivate them to continue to practice self-care regularly. This finding is reflected under the 'maintenance of person-hood' sub-theme within the study.

Conversely, participants who viewed their health status as being outside of their control appeared to be reluctant to take on a significant role in self-care or in the management of their disease. As reflected in the sub-theme concerning self-care strategies for symptom management, these individuals attempted to comply with self-care by "just doing what the staff told them to do" without understanding the underlying rationale. In these situations, practicing self-care was dependent on the patient's perception of the health care providers as reliable and trustworthy sources of information.

Self-care research conducted on healthy adults as well as the chronically ill, has produced inconsistent results regarding the relationship between a person's health beliefs and their self-care practices (Frank-Stromberg et al., 1990; Nicholas, 1993; Nagy & Wolfe, 1984). This inconsistency appears to reflect confounding factors that interact with a person's health beliefs and their self-care abilities. For example, in the current study, analysis of the qualitative transcripts indicated self-concept and an individual's underlying health perceptions were often discussed in relation to health beliefs and satisfaction with care, suggesting the interaction of these factors.

Health Perceptions

Health perceptions refer to how individuals perceive their vulnerability to an exacerbation of their disease, the seriousness of their chronic condition and their self-confidence in managing that health condition (Connelly, 1987). In this study, patients made self-care decisions based on health perceptions, where the perceived benefits and burdens of a self-care behavior were considered. These findings are reflected under the qualitative thematic areas concerning either the maintenance of personhood or self-care strategies for symptom management.

Patients in this study who felt vulnerable to a symptom exacerbation tended to perceive self-care as a way to avoid such an occurrence and ultimately avoid further hospitalization. This perceived benefit or motivating factor was strengthened when a significant decrease in symptom intensity was experienced in response to a self-care activity. For other participants, their perceived vulnerability to an exacerbation and the seriousness of heart failure was minimized in comparison to the burden of practicing that self-care activity. In these situations, self-care was not practiced as the burden or threat to a person's self-concept or quality of life outweighed the benefits of practicing that self-care behavior. Two qualitative studies conducted by Thorne and colleagues (2002, 2003) on the chronically ill support this finding. These researchers found that the perceived benefits or significance attached to self-care behavior influences the decision to consistently perform that behavior. Other quantitative studies conducted on adults with diabetes, as well as healthy children, have found similar results (Mollem et al., 1996; Aljaseem et al., 2001; Riccio-Howe, 1991; Ferguson et al., 1989).

The health perceptions of an individual also involved self-efficacy, which refers to that individual's self-confidence to recognize and manage symptoms, and then evaluate the effect of this self-management (Connelly, 1993; Riegel, Chriss et al., 2003). The SCHFI measured this predisposing variable, which was simply referred to as self-confidence by the authors of the tool. In this study, individuals with high self-efficacy scores practiced self-care maintenance behaviors on a more frequent basis, which led overall to a more advanced ability to perform self-care behaviors in comparison to participants with lower self-efficacy scores. For example, individuals who believed in their ability to recognize, monitor and manage symptoms were more likely to engage in health promotion behaviors described as part of self-care maintenance. This supports the study hypothesis that indicated there would be a positive relationship between self-care and self-efficacy. Research conducted on self-care for health promotion activities such as weight control, contraceptive use, excessive alcohol use, smoking and exercise found similar results between self-efficacy and self-care (Colleti et al., 1985; Nicki, Remington & McDonald, 1985; Strecher et al., 1986; Gillis, 1993). In addition, research on the chronically ill with physical disabilities, diabetes, coronary artery disease and respiratory disease have identified a strong positive correlation between an individual's self-efficacy and their self-care practices (Stuifbergen et al., 1990; Skelly et al., 1995; Robertson & Keller, 1992; Kaplan et al., 1984; Aljaseem et al., 2001). Two research studies focused on the heart failure population provides further support for this relationship between self-efficacy and self-care (Ni et al., 1999; Oka et al., 1996).

Enabling Variables

The enabling variables discussed in Connelly's MSCCI focuses on an individual's current circumstances and concerns in relation to their self-care practices (Connelly, 1987). Four enabling variables from this study that will be discussed as possible determinants of self-care: patient and clinical characteristics, psychological status, social support and system characteristics.

Patient Characteristics

Demographic characteristics of individuals with heart failure have been explored in relation to self-care practices through the quantitative component of this study. These characteristics include age, sex, marital status, ethnic background and educational level.

Age

Within this study, an individual's current age or age at the time of the heart failure diagnosis had no significant impact on an individual's self-care behaviors. Connelly's MSCCI framework suggests patient characteristics such as age may influence self-care. However, a study of the chronically ill conducted by Connelly (1993) failed to demonstrate an age and self-care relationship. One possible explanation is younger patients may tend to perform a certain self-care activity more frequently, while older patients tend to perform a different self-care activity more frequently, thus leading to similar overall self-care scores. Artinian and colleagues (2002) work examining self-care in heart failure support this premise. In their study, age had no effect on overall self-care practices. However, it did impact on specific self-care behaviors, such as medication compliance and daily weight taking. The

findings of the current study are consistent with other correlational studies involving healthy older adults and individuals with chronic illnesses. Those investigations also failed to demonstrate an association between age and self-care practices (Makinen et al., 2000; Nicholas, 1993; Hanucharunkul, 1989; Smits & Kee, 1992; Mollem et al., 1996; Toljamo & Hentinen, 2001; Rockwell & Riegel, 2001).

Sex

Within the quantitative component of this study, the sex of the participant did not significantly influence the self-care behaviors. This is consistent with the research conducted on the chronically ill population (Hanucharunkul, 1988; Nicholas, 1993; Smits & Kee, 1992; Mollem et al., 1996; Toljamo & Hentinen, 2001). A correlational study conducted by Makinen and colleagues (2000) on diabetic patients is an exception to previous findings. Female participants in that study practiced self-care related to social activities more frequently than men in the sample. The study conducted by Makinen and colleagues suggests societal roles and perceived social responsibility may play a role in some self-care practices.

The influence of gender on self-care behaviors in other studies examining heart failure patients is inconsistent however. In heart failure patients studied by Rockwell and Riegel (2001) and Artinian and colleagues (2002) sex was not related to self-care. However, in a recent secondary analysis study of 66 heart failure patients, a significant relationship between sex and self-care was demonstrated ($p=0.01$), where men practiced significantly more self-care maintenance behaviors than women (Riegel, Chriss et al., 2003).

Ethnic Background

Within this study, the ethnic background of an individual influenced the self-care maintenance behaviors that were adopted and consistently performed. Overall, participants with a European background practiced self-care maintenance behaviors such as dietary salt restrictions or regular exercise regimes more frequently than those with an Aboriginal background. The qualitative interview transcripts suggest that some of the self-care maintenance activities for heart failure may be inconsistent with Aboriginal cultural norms. Traditional customs such as eating salted meat and seeking out elders in the community for guidance appeared to take priority over eating a low salt diet, seeking out the doctor for guidance or having annual flu shots. As reflected under the qualitative theme, 'strategies for managing symptoms of heart failure', an Aboriginal participant even feared ridicule from his community if he practiced daily weight taking, as he perceived it was not a culturally acceptable behavior.

Since the recommended self-care activities for heart failure tend to be more congruent with American and European beliefs, individuals from other ethnic backgrounds may not find them culturally acceptable or meaningful. Transcultural literature recognizes that self-care in general is a practice within the Anglo-American middle and upper class that may be discordant with the other individual's cultural values or expectations (Leininger, 1995). This may explain why, compared with European participants, Aboriginal participants in this study lacked confidence in their ability to recognize and treat heart failure symptoms.

Although there has been no specific research conducted on Aboriginal ethnicity in relation to self-care, there have been two self-care studies with the chronically ill population, where African American ethnicity has been examined. Research conducted by Kart and Engler (1994) as well as Aljaseem and colleagues (2001) found African American participants practiced fewer self-care activities compared to Caucasian participants. This finding strengthens the notion that self-care activities are generally more congruent with non- African -American belief systems. The only research study to be located examining ethnicity and self-care in heart failure patients, found no significant relationship between total self-care and ethnic background (Artinian et al., 2001). However, these researchers noted that specific self-care practices such as seeking guidance from health care providers did vary between the participants based on their ethnicity.

Marital Status

In this study, marital status had no significant relationship with self-care activities practiced by individuals with heart failure. This dissociation between marital status and self-care is consistent with the findings of research conducted on the chronically ill and heart failure populations (Hanucharurnkul, 1988; Connelly, 1993; Artinian et al., 2002).

A trend noted in this study was the tendency of single heart failure patients to practice fewer self-care strategies and feel less confident in their ability to recognize and treat self-care than individuals who were married, divorced or separated. Two self-care studies with the chronically ill echoed this notion that single people tend not to practice self-care as frequently as their married counterparts (Hubbard et al., 1984;

Ni et al., 1999). To better understand this trend between marital status and self-care, this study explored the potential confounding variable of living situation. The relationship between a participant's living situation and self-care maintenance behaviors practiced approached significance in this study ($p=0.0566$). Heart failure patients living with only their spouse tended to practice more self-care activities than those who lived either alone or with other family members.

There are conflicting findings in the heart failure literature regarding the impact of one's living situation on self-care practices. Research conducted by Rich and colleagues (1996) supports the finding that people who live with someone tend to be more compliant with their medication regime, while Artinian and colleagues (2002) found no significant association between living situation and overall self-care behaviors. However, they did find an association between self-care and living situation for some specific self-care activities such as regular physical activity or eating sodium rich processed foods.

Overall, it appears that marital status in combination with living situation can be somewhat influential in self-care practices adopted by heart failure patients. The findings suggest that the presence of a spouse tends to positively influence self-care, while the strain of additional individuals such as children or elderly parents tends to limit self-care.

Residency Location

In this study, the effect of residency was explored by comparing self-care practices of urban and rural dwelling heart failure patients. Based on the quantitative data it was shown that urban and rural participants practiced similar self-care

behaviors, indicating residency was not a significant determinant of self-care. Specific self-care behaviors that required rural patients to use resources outside their community were discussed within the qualitative interviews and were reflected in the thematic area 'contacting health care providers'. Living in rural areas influenced decision-making for the self-care behavior of seeking guidance from health care providers at a specialty clinic located in the city. Rural participants felt reassured by being able to easily contact the city clinic staff by phone for guidance. Most rural participants, however, chose to contact their general practitioner when concerns arose, because of their close proximity to, and previous contact with, this care provider. Based on the data from this study, it appears that heart failure patients used available health care resources as they encountered challenges with their disease irrespective of their residency. Although research has not explored this aspect of self-care in the chronically ill population, literature on rural nursing indicates consistency of a health care provider, such as a community general practitioner, not only provides rural residents with a sense of quality care but also increased the likelihood of seeking out health care guidance when concerns arise (Stanhope & Lancaster, 2004).

Educational Level

Within this study, the educational level of an individual with heart failure was not significantly associated with self-care behaviors. Research focused on the chronically ill population in general and heart failure patients in particular support this lack of association between education and self-care (Connelly, 1993; Mollem et al., 1996; Artinian et al., 2002; Riegel, Chriss et al., 2003).

A trend noted within this study was the tendency of heart failure patients with post secondary education to practice self-care maintenance strategies and management behaviors more frequently than other participants, leading to higher total self-care score. Two studies conducted on older healthy adults and heart failure patients respectively, support this trend. Individuals with more education tend to practice self-care more consistently than those with less education (Smits & Kee, 1992; Rockwell & Riegel, 2001). As suggested by Rockwell and Riegel (2001), advanced education appears to support the development of critical thinking skills needed to prioritize self-care and comprehend the importance of performing such activities.

Socioeconomic Status

The measures of an individual's socioeconomic status in this study (current occupational status, last occupation and family income) were not significantly associated with self-care activities individuals with heart failure practiced. This dissociation between socioeconomic status and self-care is supported by research within the chronically ill and elderly as well as the heart failure population (Smits & Kee, 1992; Connelly, 1993; Rockwell & Riegel, 2001; Artinian et al., 2002). In a study by Hanucharunkul (1989) with ambulatory care cancer patients, those with a higher socioeconomic status adopted more self-care activities related to cancer management compared to patients with a lower socioeconomic status. This inconsistency in the research may be related to differences in self-care activities required for cancer management versus other chronic illnesses. Most self-care activities for heart failure do not contain a significant financial component that is not

subsidized by the government with the exception of purchasing a scale for daily weight taking. As noted in the qualitative interviews, the purchase of a home scale to perform this self-care activity appeared to be influenced to some extent by socioeconomic status of that individual.

Another trend seen in this study was that compared to individuals who were working, unemployed or retired participants tended to practice less self-care maintenance activities and felt less confidence in their ability to recognize and treat symptoms. This suggests that individuals who are currently working are accustomed to performing tasks, related to work and therefore may be more confident in their ability to manage their health-related needs. The ability to work is often associated with better physical functioning, which also may facilitate the performance of self-care. Heart failure patients in this study who were employed as either managers or professionals tended to practice self-care maintenance activities more consistently and attain a higher level of self-efficacy with the management of heart failure. Overall, it is possible that these individuals possess certain personality traits that predispose them to organize, manage and control their life, holding themselves accountable for their actions at work and in their daily lives. These findings derived from the quantitative component of this study have not been specifically addressed in previous self-care research studies.

Clinical Characteristics

The specific clinical features that differentiate individuals with heart failure from one another can also influence how these individuals approach their health and

self-care. Two specific characteristics that will be explored are limitations to physical or social functioning along with the co-morbidity of individuals.

Physical and Social Limitations

Both physical and social limitations of individuals in this study have been explored in relation to self-care through the quantitative questionnaires and the qualitative interviews. A trend noted in this study was heart failure patients who felt they had *mild* physical and social limitations expressed a higher degree of self-confidence in their ability to recognize and treat heart failure symptoms, as opposed to those with more severe limitations. This trend suggests that individuals who experience less physical and social limitations may feel more in control of their disease process, leading to an increase confidence in their perceived ability to treat themselves. However, in this study, an individual's physical and social limitations as measured through the NYHA functional scale and the Kansas City Cardiomyopathy Scale were not significantly associated with self-care. This suggests that individuals with heart failure tend to become proficient at coping with their physical and social limitations whether they be activities of daily living or self-care. Heart failure research conducted by Rockwell and Riegel (2001) as well as Bennett, Cordes and colleagues (2000) support this premise, as many participants integrated activity modification into all aspects of their lives.

An interesting trend noted within the data was that individuals with severe physical and social limitations tended to practice self-care maintenance behaviors less and had an overall lower ability to perform self-care compared to individuals with mild or moderate limitations. This is consistent with the qualitative theme concerning

managing symptoms of heart failure. Participants indicated they were aware of their physical limitations, took steps to avoid activities that might cause symptom exacerbations. Self-care activities that involved regular exercise could be perceived as being too taxing by these individuals, thus not practiced. This trend suggests that heart failure patients with limited physical and social functioning have less energy to expend on self-care activities particularly those perceived as physically demanding. Within the self-care research, no studies were found that focused on physical and social limitation as predictors of self-care practices.

Co-Morbidity

Overall, heart failure patients in this study with more than four co-morbid conditions (including heart failure) practiced less self-care maintenance activities on a regular basis compared to patients with fewer co-morbid conditions. Interestingly, however individuals with three or four co-morbid conditions practiced self-care behaviors most consistently, participants with more than four co-morbid conditions tended to have the lowest scores for symptom management as well as the lowest overall scores for self-care compared to the rest of the sample. This suggests that co-morbid conditions increase an individual's awareness of self-care that may be necessary to perform self-care and manage concurrent health conditions. When more than four concurrent health conditions exist, the need to practice multiple self-care behaviors simultaneously for different health conditions may become too overwhelming and self-care is not performed. Another explanation is the association of severe co-morbidity with severe physical limitations may further limit the person's ability to perform self-care.

The qualitative component of this study provided insight into this finding for the specific self-care activity of seeking out guidance from health care providers as reflected in the sub-theme 'contacting health care providers'. Participants with several co-morbid conditions such as respiratory diseases or anxiety attacks had difficulty identifying the most appropriate resource to use as the first point of contact when guidance was needed. Generalized symptoms such as fatigue or shortness of breath are common to various diseases including heart failure. Thus, participants with other medical conditions appeared to be uncertain of where to go for guidance.

Within the heart failure research, two studies support these findings, as heart failure patients with fewer co-morbid conditions were found to practice more self-care activities (Riegel, Chriss et al., 2003; Riegel & Carlson, 2002). Using the same measure of co-morbidity, Riegel, Chriss and colleagues (2003) found individuals with several concurrent medical conditions practiced fewer self-care behaviors. However, another earlier self-care study on heart failure patients conducted by Rockwell and Riegel (2001) found no association between co-morbidity and self-care. The Rockwell and Riegel study focused on only hospitalized patients with heart failure which may explain the inconsistency in comparison to current study of ambulatory care patients.

Psychological Status

Psychological status is described in Connelly's MSCCI framework as an enabling variable comprised of mood, anxiety level and stress that either promotes or inhibits self-care behaviors of an individual (Connelly, 1987, 1993). In this study, the emotional state of an individual was explored using quantitative and qualitative data.

Heart failure patients in this study who experienced severe psychological distress used self-care maintenance behaviors related to their disease less frequently than individuals with either moderate psychological distress or those experiencing positive well-being. A trend found in the data suggests that compared to other participants, individuals with severe psychological distress tend to have more difficulty recognizing and managing symptoms of heart failure. This resulted in lower confidence in their ability to practice appropriate self-care. This finding lends support to the hypothesis that there is a positive relationship between psychological status and self-care in this patient population.

As reflected in the theme of 'self-care strategies for symptom management' that emerged from the qualitative component of this study, some heart failure patients maintained their optimism by holding onto current feelings of improved productivity and health rather than dwelling on times when symptoms were not as well controlled. In this study, heart failure patients appeared to be aware of the impact psychological status and mood had on their ability to manage their disease and practice self-care. Research conducted with the chronically ill and healthy older adults supports this premise, as individuals in these studies identified positive attitude and an upbeat mood as significant influences for practicing self-care (De-Weerd et al., 1990; Baker & Stern, 1993; Nicholas, 1993). The findings support the concept of self-care that requires deliberate and consistent decision-making along with the daily performance of behaviors relying on the subjective emotional state and psychological status of individuals (Connelly, 1987).

Social Support

Within the quantitative component of this study, social support was not significantly related to self-care practices. However, a trend within this data found individuals with no supportive friends tended to experience low self-efficacy and practiced less self-care maintenance behaviors than those with friend supports in their life.

In the qualitative interviews of this study, however, social support was identified as an influential factor for self-care under sub-theme of 'self-care strategies for symptom management'. Most individuals felt they were able to more effectively practice self-care activities, with the emotional support and physical care they received when necessary, by family and friends. Overall, the social support of family and friends boosted the emotional health of participants. In some cases, the social support provided by family members was perceived by participants as deterring their efforts to manage their disease. Participants indicated that they tended not to practice self-care behaviors, if these behaviors were in conflict with the actions or wishes of family members and friends. For example, one participant chose not to adhere to a low sodium diet, as his wife preferred to add salt to foods during meal preparation. These findings suggest that social support does influence self-care practices in the heart failure population. However, the effect of this relationship is not linear, as it is dependent on the perceived nature of the social support that an individual receives. While some social supports tend to encourage and promote self-care, other social supports tend to inhibit self-care behaviors. The study hypothesis that predicted a positive correlation between social support and self-care is not supported by the

findings of this study. This lack of positive correlation can partly be explained the failure of the hypothesis to take into consideration the potentially conflicting nature of the social support relationship.

The research studies conducted on the chronically ill (Tillotson & Smith, 1996; Connelly, 1993; Hanucharunkul, 1989) as well as healthy older adults (Hubbard et al., 1984; Norburn et al., 1995; Muhlenkemp & Sayles, 1996) have found a positive correlation between social support and self-care. One study on diabetic patients conducted by Toljamo and Hentinen (2001) found only participants with more family support, not peer support practiced self-care activities more readily than their counterparts. Research by Connelly (1993) found the social support a person received was inversely associated to dietary self-care behaviors in the chronically ill. This researcher explained this unexpected finding in relation to the elevated level of responsibility for self-care that individuals with limited social support assume. Within the heart failure studies there is inconsistency in the findings. Rockwell and Riegel (2001) as well as Riegel, Chriss and colleagues (2003) found no relationship between social support and self-care practices for heart failure patients. However, these findings are contrary to research by Riegel and Carlson (2002), where support from others was seen as a motivating factor towards performing self-care. These inconsistent findings are congruent with the notion that depending on the nature of the relationship, social support can influence self-care in a positive or negative direction.

System Characteristics

System characteristics described in Connelly's model of self-care refer to the satisfaction an individual feels with regard to the care received and the care providers. This variable was explored through the qualitative interviews in this study. Within this study, patients tended to be overall satisfied with the care received in the clinic as identified in the sub-theme 'satisfaction with the care received'. The degree of satisfaction was based on information and support needs being met by staff, patient-staff communication and the inter-staff relations at the clinic.

When the clinic staff met information needs, some participants appeared to be able to gain the knowledge to understand the rationale underlying the self-care behaviors which promoted the performance of these behaviors. The ability to talk directly to their health care provider provided reassurance and reinforced their continued use of self-care practices. The open flow of communication between patient and health care provider and the positive personality traits attributed to clinic staff also contributed to patient satisfaction in this study. The clinic staff was seen as being both knowledgeable and approachable which promoted the self-care activity of seeking guidance from the clinic staff when symptoms arose. When individuals were dissatisfied with the care plan in the clinic, several self-care activities were not consistently practiced. It appears that system characteristics such as an accepting and supportive environment promotes trust and satisfaction within individual patients and thereby positively influence self-care.

Research examining patient satisfaction and self-care supports this finding. A study conducted by Nagy and Wolfe (1984) with chronically ill individuals found that

those patients who indicated they were satisfied with the medical care they received and rated their caregivers as competent, had increased medication compliance. A qualitative heart failure study conducted by Riegel and Carlson (2002) further supported this finding as lack of physician support was seen as a significant deterrent to self-care.

In summary, several determinants of self-care for heart failure patients in an ambulatory care setting were identified within this study. Predisposing variables such as self-concept, health beliefs and health perception positively influenced self-care behaviors. Enabling variables such as psychological status, social support and system characteristics impact self-care in either a positive or negative way depending on the intensity and nature of the variable. Patient and illness characteristics identified as enabling variables did not influence self-care for this patient population with the exception of co-morbidity and ethnic background.

Research Question #3: When ambulatory care patients suffering from heart failure experience shortness of breath, are they more or less inclined to perform self-care?

A classic symptom experienced by individuals diagnosed with heart failure that often causes severe distress is the onset of shortness of breath. This research question explores the performance of self-care in heart failure patients who experienced dyspnea within the past three months (symptomatic) compared to heart failure patients who did not experience dyspnea in this time period (asymptomatic). Guided by Connelly's MSCCI framework the discussion of this research question was undertaken through analysis of patient interviews and responses to questions in the self-confidence and self-care maintenance scales of the SCHFI.

The self-confidence sub-scale is a measure of self-efficacy or confidence to recognize and control symptoms such as dyspnea (Riegel, Carlson, Moser, Sebern et al., 2003). In this study, self-efficacy scores of heart failure patients with no dyspnea were significantly higher compared to scores recorded by those patients who experienced dyspnea in the past three months. Although there have been no direct studies of self-efficacy and symptom severity, research by Carlson and colleagues (2001) examined self-efficacy in heart failure patients primarily during hospitalizations. These researchers found a high level of self-efficacy with symptom recognition, but a lower level of self-efficacy with actual self-treatment and evaluation. Since self-efficacy scores reported in the Carlson study refer to symptomatic patients, it lends support to the findings related to self-efficacy of symptomatic patients in this study. The findings of this study are also consistent with Connelly's (1987) suggestion that reoccurrence of symptoms such as dyspnea in chronically ill individuals may diminish feelings of confidence in symptom control.

The self-care maintenance sub-scale is a measure of ability to engage in health promotion activities and to monitor pathophysiological changes such as dyspnea and weight gain (Riegel, Carlson, Moser, Sebern et al., 2003). Although individuals in this study who experienced shortness of breath over a three month period had higher self-maintenance scores than individuals who did not experience shortness of breath, the scores were not significantly different. Findings of other studies in this area are inconsistent. Riegel, Chriss and colleagues (2003) found no significant relationship between the presence of dyspnea and self-care maintenance behaviors, while other researchers who examined self-care and the related variable of symptom severity

found a positive correlation between symptom severity and self-care (Riegel & Rockwell, 2001; Hampson et al., 1993; Cronan et al., 1993). Interestingly in an early study by Nagy and Wolfe (1984) chronically ill patients with limited symptoms practiced significantly more self-care maintenance behaviors than patients with severe symptoms. One possible explanation for these inconsistent findings is that the intensity and duration of a dyspneic episode may be more predictive of self-care behavior than the mere presence of this symptom.

In this study, findings from open-ended interviews indicated that several heart failure patients had vivid recollections of intense dyspneic episodes that had occurred more than three months ago and often required hospitalization. The informants felt these episodes acted as motivating factors that now influence their current self-care practices. For example, these patients reported that past dyspneic experiences gave them more confidence in their ability to quickly recognize the imminent onset of a serious dyspneic episode and not to postpone contacting a health care provider.

Self-Care and Hospital Admissions for Heart Failure

Research Question #4: What is the relationship between self-care and clinical outcomes (hospital admissions) for ambulatory care patients experiencing heart failure?

This research question is the basis of the study hypothesis, namely that patients with a high level of self-care, as reflected in the practices reported in subscales of the SCHFI instrument, have a lower hospital admission rate related to heart failure than patients with low levels of self-care. The discussion of this research question will focus on the frequency of hospitalization within the prior six month

time period. The present study differs from previous investigations, in that self-care was designated as the independent variable and hospital admissions as the dependent variable.

Patients in this study with a higher degree of self-efficacy had significantly fewer hospital admissions related to heart failure than patients with lower self-efficacy levels. Although the self-care research has not addressed these two variables, in this study, self-efficacy, an element of the predisposing variable of health perceptions, appears to significantly affect whether a symptom exacerbation will lead to hospitalization. It was indicated that heart failure patients more secure or confident in their ability to manage self-care tend overall to practice self-care more frequently than those who are uncertain about their ability to self-treat. These self-care practices appear to enable patients to recognize and treat a deterioration in their heart failure status early and thus avoid hospitalization. Another explanation for the main findings of this study is that patients with confidence in their ability to manage their symptoms tend either not to experience or to tolerate shortness of breath, a common reason for hospitalization in this patient population.

The relationship between an individual's overall self-care ability and the number of prior hospital admissions approached significance ($p=0.0576$); indicating those who engaged in self-care frequently tended to have fewer hospital admissions for an exacerbation in comparison to those who do not engage in self-care frequently. Although the hospital admissions did not differ for participants in relation to the subscales of self-care maintenance and management, there was a trend in the same direction as in the data for self-confidence.

Participants who had no hospital admissions within the last six months tended to practice more self-care maintenance and management behaviors than those with recent hospital admissions. This suggests that preventive self-care and symptom management is effective in avoidance of severe symptom exacerbation and subsequent hospitalization. Overall the findings support the hypothesis of the present study and are consistent with the findings of earlier investigations using both correlational and experimental designs to examine the effect of educational interventions on self-care and hospital admissions. (Hershberger et al., 2001; Stromberg et al., 2003; Rich et al., 1995; West et al., 1997).

Limitations of the Study

Overall, limitations of the study are primarily related to methodological issues such as study design, recruitment and instrument modification.

The use of a cross-sectional design provided a snapshot of self-care practices, but excluded the variable of time, recently suggested to be an important variable in the study of self-care in this patient population, as self-care determinants may change over time (Riegel, Chriss et al., 2003). Lack of randomization in this study increased the potential for the occurrence of systematic biases in the data, where characteristics not controlled in the study affect the dependent variable under inquiry (Polit & Hungler, 1999). Although the use of a convenience sample was appropriate for the exploratory nature of this study, there may have been a 'volunteer bias'. In this case, individuals volunteering for the study may have used a higher degree of self-care than patients not volunteering for the study (Polit & Hungler, 1999).

Other design limitations in this study involved the use of self-reports to measure behaviors, such as regular exercise, dietary sodium restrictions and medication compliance. Although self-reports have been frequently used in self-care research, there is a tendency for patients to answer questions in perceived socially desirable fashion and over-report healthy behaviors practiced. As was the case in this study, this is more likely to occur when the researcher is administering the questionnaire. As noted by Ni and colleagues (1999), "the extent of this over-reporting is difficult to assess but could only result in overestimation of the existing health related behaviors among patients with CHF" (p. 1619).

The design of the qualitative component involved a small sample size, which is typical with qualitative inquires, particularly if it is used in combination with a quantitative methodology. Although participants willing to discuss self-care further in the qualitative component provided valuable insight, the interviews were only conducted on one single occasion. The transcripts reflect the participants' perspectives on self-care at that exact moment, which may not be representative for a different point in time.

Recruitment was limited since the study was undertaken in a relatively new ambulatory care clinic specializing in heart failure and was staffed by only one cardiologist and a clinical nurse specialist. Although this clinic managed the care of approximately 200 patients, many of these individuals had been diagnosed with heart failure within less than six months, excluding them from the study. Frequent return visits by patients experiencing severe symptoms also reduced the number of potential participants. In addition, scheduled clinic days were periodically cancelled to

accommodate the schedule and multiple in-hospital responsibilities of the cardiologist.

Another significant study limitation was related to the SCHFI used to measure self-care within the study. This relatively new instrument had adequate reliability and validity based on psychometric testing. However, the tool did not provide specific categories to rank overall self-care scores as high, moderate or low. The retrospective nature of the question regarding recent shortness of breath in the SCHFI created some challenge for a few of the participants, as they were required to recall if this symptom had occurred within the last three months. Minor revisions to SCHFI by Riegel, Carlson, Moser, Sebern and colleagues (2003) that occurred during the analysis phase of this study, resulted in the subsequent scoring adjustments to accommodate sub-scale modifications in this instrument. As part of these revisions, the sub-scale measuring knowledge of heart failure symptoms was removed from the SCHFI. In this study therefore, knowledge of heart failure symptoms as a possible determinant of self-care could not be evaluated. Although the initial scoring algorithm of the SCHFI produced an overall self-care score for both symptomatic and asymptomatic participants, further tool revisions resulted in a new scoring algorithm in which overall self-care score were available for only symptomatic participants. Continual communication with the principal author of the SCHFI ensured the scoring adjustments and sub-scale modifications made within this study accurately reflected self-care practices as measured by the revised SCHFI.

Implications for Practice

Much attention has been focused on the optimal management of patients with heart failure because of the heavy burden of morbidity and mortality (Ni et al., 1999). This study, conducted in a specialized heart failure clinic, examined self-care and its determinants in a cohort of heart failure patients. It is recognized that patients treated in an ambulatory setting are counseled and educated by nurses to take responsibility for daily self care (Connelly, 1987). The goal is for patients to learn to make decisions concerning general self-care behaviors to promote and maintain health and those concerning specific self-care activities related to therapy (Connelly 1993). Counseling and education by nurses related to self-care practices must take place in the context of other factors that could influence patients' decision making such as ethnic diversity, culture and belief systems. The results of this study provide important insights into the nursing role when caring for heart failure patients in an outpatient setting.

It is particularly disconcerting that heart failure patients without dyspnea appear to be unaware of their vulnerability to a symptom exacerbation or the seriousness of heart failure complications. Through the provision of written and verbal education for patients and their families directed at raising awareness about the seriousness of heart failure and their susceptibility to complications, even in the absence of dyspnea, individuals will gain insight into their vulnerable status. This knowledge or awareness is believed to impact self-care behaviors; however, as noted in previous research, information alone does not guarantee a behavior will be consistently performed in an appropriate manner (Ni et al., 1999; Sulzbach-Hoke et

al., 1997). Although increasing patient awareness is important, nurses need to intervene before a patient is in imminent danger for an exacerbation related to lack of self-care or a decompensation of their physiological status. One possible strategy the nurse can implement is to monitor patients' physical and emotional status through regular telephone contact. This practice change can be incorporated into the management of all clinic heart failure patients, but would necessitate the provision of more than one nurse in this clinic.

Individuals with heart failure need to be knowledgeable about specific self-care activities such as correct use of medication and dietary restrictions to monitor for an exacerbation and manage their illness. Although several specific self-care activities are identified in the clinical guidelines, other self-care activities focused on coping have emerged from the study findings. Nurses need to assess the appropriateness of a person's coping strategies and reinforce positive health behaviors practiced by an individual through encouraging words and praise. As well, patient education and written material should be focused on self-care activities related to maintaining an ideal weight and performing regular exercise, which are practiced infrequently in comparison to medication compliance. This can be accomplished through the development and provision of individualized prescriptions for physical activity or dietary restrictions for the patient that can be used as both an educational tool and a visual reminder of the recommended activity.

Self-care and the decisions that surround it are not preformed in isolation, but rather with various influential factors in a person's life (Connelly, 1987). Assessing the belief system, cultural practices and psychological well-being of an individual is

time-consuming, yet this activity enables education to be provided in a manner consistent with a patient's cultural and health beliefs. It would be necessary to set aside one or two scheduled appointments with each patient to develop an individualized written teaching plan for self-care. In some cases consultation with experts in certain areas, such as Aboriginal services, pastoral care or psychological services may be appropriate. In addition, 15 minutes of each appointment should be devoted to an ongoing assessment of an individual's ability to engage in self-care in relation to his or her health beliefs. Although these practice changes may require additional appointments or lengthening the time of existing appointments, these strategy are supported by work from Baker and Stern (1995) where assessing health beliefs and perceptions solidified the patient's role as self-care provider.

Recommendations for Future Research

Self-care is now accepted as an integral part of patient management in an ambulatory care setting. Despite recent research in this area (Sulzbach-Hoke et al., 1997; Ni et al., 1999; Bennett, Cordes et al., 2000), the multidimensionality of self-care behaviors and their determinants is poorly understood. Therefore, future research needs to be directed towards the development and testing of the MSCCI Framework, self-care practices and determinants, clinical outcomes employing two methodologies.

Connelly's MSCCI described self-care in terms of interactions with variables that focus on the individual's past experiences, perceptions, current circumstances and concerns (Connelly, 1987). Even with only limited testing, this model revealed meaningful associations between the relevant variables, but further research using

large samples is needed to strengthen the case for use of the model (Bennett et al., 2000; Connelly, 1993).

The SCHFI is a relatively new instrument that effectively fits with the constructs of the MSCCI model and was the primary measure of self-care in the present study. It provided valuable data for elucidating the phenomena of self-care in heart failure patients. However, further research and testing of the SCHFI needs to be conducted in the ambulatory care population to assess the validity and reliability of the instrument more fully.

While the self-care practices and determinants identified in this investigation add to the limited body of knowledge about this subject in heart failure patients, deeper understanding of self-care requires further research with large sample sizes to explore other significant relationships for ambulatory care patients. For example, knowledge of heart failure was identified as an influential variable in prior studies (Ni et al., 1999), but was not examined in the present study.

No association between self-care behaviors and urban or rural dwellers was found in the present study although the literature suggests there are differences in the self-care perception between urban and rural dwellers (Stanhope & Lancaster, 2004). This discrepancy needs to be addressed in future research. Longitudinal research designs also need to be used to explore the evolution of self-care and its determinants since it has been suggested that these phenomena change over time (Riegel, Chriss et al., 2003).

Several longitudinal studies have reported hospital admission rates decline and self-care practices increase following an educational program (Hershberger et al.,

2001; Stromberg et al., 2003; Rich et al., 1995; West et al., 1997). In this study self-care practice, the independent variable was measured using the SCHFI and its sub-scales self-efficacy and self-maintenance. Hospital admission was designated as the dependent variable. It was demonstrated there was a significantly lower admission rate in those with high self-efficacy scores. Overall self-care scores were associated with fewer admissions, but did not reach a level of statistical significance. The self-maintenance scores were not associated with the number of hospital admissions. Because education interventions were not systematically studied, future research should consider the effect of an educational program on the SCHFI, its sub-scales and admission rates. In addition future research should include examining the association of self-care in heart failure patients with other clinical outcomes such as quality of life, length of hospitalization and mortality.

Finally, a combined quantitative and qualitative methodology was used in this study to explore the phenomena of self-care and its determinants in the ambulatory care heart failure population. The combination of these methodologies constituted a more effective means of studying the phenomenon of self-care and its determinants than can be achieved using a single methodology. This suggests that future research directed at expanding knowledge about self-care, as an important strategy for heart failure patients requires a multi-faceted approach

Conclusion

This study examined self-care practices and determinants of self-care decision-making in a cohort of community dwelling heart failure patients attending an ambulatory care heart failure clinic. The study combined qualitative and quantitative

methodologies to investigate the phenomenon of self-care. The majority of patients successfully undertook self-care behaviors such as taking medications as prescribed and seeking physician guidance when concerns arose. However, other behaviors including regular exercise and weight control were not always consistently undertaken. Self-care strategies generated by some patients focused on psychologically coping with symptoms as a means of sustaining their self-concept and identity in the face of debilitating symptoms.

In this study, predisposing variables of self-concept, health beliefs and perceptions were examined using open-ended interviews. The underlying complexity concerning these factors was evident in patient responses. Some patients were optimistic, self-confident and positive regarding self-care, while others did not feel in control of their illness and were reluctant to participate fully in self-care activities.

Although the enabling variable, social support was not significantly associated with self-maintenance, self-confidence, self-care management or SCHFI, in the interviews social support along with satisfaction with care were identified as influential factors for self care practices. In the quantitative analysis it was demonstrated that other enabling variables of psychological status and co-morbidity were correlated with self-care maintenance behaviors. Individuals with severe psychological distress and with more than four co-morbid conditions engaged in fewer self-maintenance behaviors.

Only the patient characteristic of ethnicity was associated with self-care maintenance behaviors. Individuals with an Aboriginal background in this

investigation engaged in significantly less self-care maintenance behaviors than individuals with a European background.

Although individuals without shortness of breath had higher scores for self-efficacy than those with this symptom, both groups in this study engaged in similar self-care practices. Individuals in this study with higher self-efficacy scores had fewer hospital admissions for heart failure compared to other study participants.

Nursing implications emerging from the study suggest that development of an individualized teaching plan with frequent follow-up assessment of both self-care behaviors and decision-making related to self-care be undertaken with clinic patients.

This study has added to the limited body of knowledge on self-care for heart failure patients in an ambulatory care setting. Specific recommendations for future research include the need for further self-care model testing and randomized longitudinal studies to determine the effect of educational interventions on variables such as symptom management by patients and hospital admissions.

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Appendix A

New York Heart Association Functional Classification

Class	New York Heart Association Functional Classification	Corresponding Activities (Specific Activity Scale)
I	Patients with cardiac disease but without resulting limitations of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations, dyspnea or chest pain.	Patients can perform to completion any activity requiring ≥ 7 metabolic equivalents (such as carry 25 lb up eight steps; carry objects that weigh 80 lb; do outdoor work); do recreational activities (such as skiing, basketball, jog/walk 5 mph).
II	Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, dyspnea, palpitations or chest pain.	Patients can perform to completion any activity requiring ≥ 5 metabolic equivalents (such as gardening, roller skating, dance fox trot, walk at 4 mph on level ground) but cannot perform to completion activities requiring metabolic equivalents requiring ≥ 7 metabolic equivalents.
III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary levels causes fatigue, palpitations, dyspnea or chest pain.	Patients can perform to completion any activity requiring ≥ 2 metabolic equivalents (such as shower without stopping, make the bed, clean windows, play golf, dress without stopping, walk 2.5 mph) but cannot perform activities requiring ≥ 5 metabolic equivalents.
IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of cardiac insufficiency or of the anginal syndrome may be present at rest. If any physical activity is undertaken, discomfort is increased.	Patients cannot perform to completion activities requiring ≥ 2 metabolic equivalents. Cannot carry out activities listed above.

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Golman, L., Hashimoto, B., Cook, E. F., & Loscalzo, A. (1981). Comparative reproducibility and validity of systems for assessing cardiovascular functional class: Advantages of a new specific activity scale. *Circulation*, *64*, 1227.

Appendix B

Heart Failure Staging SystemStage A

Patients at risk for developing heart failure because of co-morbidity conditions that are strongly associated with the development of heart failure. Such patients have no signs or symptoms of heart failure and have never manifested signs or symptoms of heart failure. There are no structural or functional abnormalities of the valves or ventricles. Examples: patients with systemic hypertension, coronary artery disease, or diabetes mellitus.

Stage B

Patients who have developed structural heart disease that is strongly associated with the development of heart failure but have no symptoms of heart failure and have never manifested signs or symptoms of heart failure. Examples: patients with left ventricular hypertrophy, enlarged, dilated ventricles, asymptomatic valvular heart disease or previous myocardial infarction.

Stage C

Patients who have current or prior symptoms of heart failure associated with underlying structural heart disease.

Stage D

Patients with marked symptoms of heart failure at rest despite maximal medical therapy and who require specialized interventions. Examples: patients, who cannot be safely discharged from the hospital, are recurrent hospitalized, are in the hospital awaiting heart transplantation, are in a hospice setting with a mechanical circulator assist device.

Francis, G. S. (2001). Pathophysiology and diagnosis of heart failure. In Fuster, V., et al. (Eds.), *Hurst's the heart*. (10th ed.) (pp. 657-568). New York: McGraw-Hill.



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Appendix C

RESEARCH SERVICES &
PROGRAMS
Office of the Vice-President (Research)

244 Engineering Bldg.
Winnipeg, MB R3T 5V6
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APPROVAL CERTIFICATE

13 May 2003

TO: Karen Schnell (Advisor B. Naimark)
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2003:040
"Determinants of Self-care for Heart Failure Patients within an
Ambulatory Care Setting"

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.

The following are approved for use:

- Protocol, dated April 7, 2003
- Informed Consent Form, dated May 9, 2003

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 that, 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.

Get to know Research ...at your University.

Appendix D

i n t e r o f f i c e
M E M O R A N D U M

Local:

Fax:

TO: Ms. Karen Schnell
372 Lockwood St.
Winnipeg, MB R3N 1S4

FROM: Dr. M. Tétreault
Chairperson, Research Review Committee

DATE: May 30, 2003

SUBJECT: **Experimental Protocol Submission - Response**

This is to inform you that I have reviewed your response regarding the protocol entitled "Determinants of Self-Care for Heart Failure Patients in an Ambulatory Care Setting", Ref # RRC/2003/0460.

As the recommendations by the Research Review Committee have been met, final approval is now granted.

Thank you for your cooperation.

MT/mh

cc: Dr. Barbara Naimark, Supervisor
Dr. B. MacDougall, Clinical Director - Medicine
Ms. B. Petrowski, Program Director - Medicine
Ms. K. Neufeld, Director - Chief Nursing Officer
Dr. I. White, President of the Medical Staff
Mr. D. Mestdagh, Pharmacy Department
Ms. D. Halhead, Financial Services
Ms. S. Guinn, Health Records
Ms. A. Lemieux, Manager, Quality, Research & Evaluation

Appendix E

Invitation to Participate

Research Project Title: **Determinants of self-care for heart failure patients in an ambulatory care setting.**

Researcher: **Karen Schnell, graduate student, University of Manitoba, Master of Nursing Program.**

Progressive heart failure is a heart condition associated with symptoms that severely limit an individual's daily activity level. Within North America, heart failure is being seen with increasing frequency, as approximately 350, 000 Canadians and 4.8 million Americans are affected by this condition. The use of self-care activities is an important way to manage symptoms and improve a person's daily activity level.

Purpose of the Study:

This research study will be conducted by Karen Schnell as part of the course work for the Master of Nursing program at the University of Manitoba. This study will examine the self-care activities most commonly used by individuals diagnosed with heart failure and identify factors associated with these activities.

Voluntary Participation:

Your participation in the study is voluntary and you can change your mind and withdraw from the study whenever you choose. Taking part in this study will not affect the care that you are currently receiving in the clinic.

Study Procedures:

You will see that the study is divided into two parts. The first part involves completing questionnaires that take about 25 minutes. The second part involves an optional 30 to 40 minute telephone interview.

1. Part One:

- You will be given questionnaires about: how you function in your daily life, how you feel about yourself and your health, what health behaviors you tend to undertake if you have symptoms, how you decide what self-care activities to use and personal information about yourself, such as occupation and age.
- The researcher will ask for permission to review your Heart Failure Clinic chart to obtain information about your heart condition, other medical conditions you may have, and your history of hospitalization.

- Either you will complete the questionnaire package with the researcher at the time of your clinic appointment or the researcher will set up a time convenient for you where she will telephone you and help you fill out the questionnaires. It should take about 25 minutes to complete.
- At the end of the call, you will be asked to mail the completed questionnaires in the return self-addressed stamped return envelope that is provided. You are not obligated to continue with part two of the study and can end your participation by mailing back the completed questionnaires.

2. Part Two:

- The interview part of the study is completely optional.
- If you wish to take part, a telephone interview appointment will be made.
- Five questions about factors related to your health behaviors will be asked. The interview should take 30 to 40 minutes of your time.

Confidentiality

Your specific responses on the questionnaire will be kept strictly confidential. Only the researcher and her study advisor, Dr. Barbara Naimark will have direct access to the data. All information will be identified by code number and not your name. Your name will not appear in any report about this study, or in any future publications. Your personal health information and medical records will be treated confidentially in accordance with the Personal Health Information Act of Manitoba. During and after the project, all data will be stored in a secure place in the researcher's home office and kept for 7 to 10 years and then discarded as confidential waste.

Risks and Benefits

There are no known risks or monetary costs involved with taking part in the study. You will not receive any direct benefit or monetary payment, but taking part in this study may provide information to others with heart conditions.

Questions

If you have additional questions, please feel free to contact the researcher, Karen Schnell at _____ or her study advisor, Dr. Barbara Naimark at _____

A copy of the results of the study will be available on written or verbal request to the researcher.

You are free to ask any questions you may have about this study. For questions about your rights as a research participant, please contact the University of Manitoba, Fort Garry Campus, Research Ethics Secretariat Office at _____

Thank you for considering taking part in the study.

Appendix F



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Faculty of Nursing

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

Consent Form

Research Project Title: Determinants of self-care for heart failure patients in an ambulatory care setting.

Researcher: Karen Schnell, graduate student, University of Manitoba, Master of Nursing Program.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

You are invited to take part in a study about self-care for people with a heart condition called heart failure. The results of the study may be helpful to health care providers (like nurses) who want to understand the reasons why self-care is performed. This study will be conducted by Karen Schnell as part of the course work for the Master of Nursing program at the University of Manitoba.

Having read the *Invitation to Participate* sheet, I understand that:

- in the questionnaire part of the study, I will be asked about: how I function in my daily life, how I am feeling about myself and my health, what health behaviors I tend to undertake if I have symptoms, how I decide what self-care activities to use, and personal information about myself, such as age and marital status;
- either I will complete the questionnaire package with the researcher at the time of my clinic appointment or I will take the questionnaire package home and the researcher will telephone me and help me fill out the health questionnaires. It will take about 25 minutes to complete. At the end of the call, I will be asked to mail the completed questionnaires in the return self-addressed stamped envelope that will be provided to me;
- the researcher will ask for permission to review my Heart Failure Clinic chart to obtain information about my heart condition, other medical conditions I may have, and my history of hospitalizations;
- the interview part of the study is optional. If I wish to take part, a 30 to 40-minute telephone interview appointment will be made. Five questions will be asked about factors related to my health behaviors;

Determinants of Self-Care for Heart Failure Patients in an Ambulatory Care Setting

- there are no known risks or costs involved with taking part in the study;
- there is no payment or direct benefit to me for taking part in the study, but doing so may provide information to help other people with heart conditions;
- taking part in this study is voluntary and if I do not participate it will not affect my care;
- my specific responses on the questionnaire will be kept confidential. Only the researcher and her study advisor, Dr. Barbara Naimark will have direct access to the data. All information will be identified by a code number and not my name;
- my personal health information and medical record will be treated confidentially in accordance with the Personal Health Information Act of Manitoba. The study results will be kept in a secure space for a period of seven to ten years and then destroyed. A copy of the results will be available on written or verbal request.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions for 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 consequence. Your continued participation should be as informed as you initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you have questions at any time during the study, you can contact the researcher, Karen Schnell at _____ or her study advisor, Dr. Barbara Naimark at _____.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at _____. A copy of this consent has been given to you to keep for your record and reference.

We recognize the importance of your participation. Thank you.

I, _____ (print) agree to participate in this project.

Participant's Signature Date

Researcher's Signature/Name (print) Date

A copy of the study results will be available on written or verbal request to the researcher.

Appendix G

SELF-CARE OF HEART FAILURE®*All answers are confidential.*

SECTION A: How often do you do the following?

	Never or rarely	Sometimes	Frequently	Always
1. Weigh yourself daily?	1	2	3	4
2. Keep the salt in your diet lower than 2000 – 3000 mg (2-3 Gm) each day?	1	2	3	4
3. Exercise at least 3 times each week?	1	2	3	4
4. Take medications as prescribed?	1	2	3	4
5. Keep your weight within 10% of your ideal weight?	1	2	3	4
6. Talk to your doctor whenever you need guidance?	1	2	3	4
7. Get immunizations (like a flu shot) every year?	1	2	3	4

SECTION B:

Listed below are symptoms that people with heart failure may have. If you had a change in any of these symptoms, how worrisome or troubling would it be?

(circle **one** number for each symptom)

	Not worrisome	Somewhat worrisome	Worrisome	Very worrisome
8. Trouble breathing	1	2	3	4
9. Tired or fatigued	1	2	3	4
10. Sudden weight gain	1	2	3	4
11. Swelling	1	2	3	4
12. Dizziness, loss of balance, or passing out	1	2	3	4
13. Trouble sleeping because of trouble breathing	1	2	3	4
14. Just didn't feel well	1	2	3	4

Many patients have symptoms due to their heart failure. **Trouble breathing** is the most common symptom of heart failure.

15. In the past three months, have you had trouble breathing?

Circle one.

- 1) No
- 2) Yes

SECTION C:

If you have NOT had trouble breathing in the last 3 months, SKIP 16-18 AND GO TO SECTION D.

16. The **LAST TIME** you had trouble breathing, how quickly or easily did you recognize it as a symptom of heart failure? Circle one.

- 1) I didn't
- 2) It took me a while
- 3) Fairly quickly
- 4) Immediately

7. The **LAST FEW TIMES** you had trouble breathing, what did you do to relieve it?
Circle ALL that apply.

- 1) Reduced the sodium (salt) in your diet
- 2) Reduced your fluid intake
- 3) Took an extra water pill
- 4) None of the above

18. **IF YOU TRIED** reducing salt in your diet, reducing your fluid intake, or taking an extra water pill, did any of these things help relieve your trouble breathing? Circle one.

- 1) No, it did not help
- 2) Yes, it helped
- 3) I'm not sure if anything helped

SECTION D:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
19. How confident are you that you can <u>evaluate</u> your symptoms?	1	2	3	4
20. Generally, how confident are you that you can <u>recognize changes</u> in your health if they occur?	1	2	3	4
21. Generally, how confident are you that you can <u>do something</u> to relieve your symptoms?	1	2	3	4
22. How confident are you that you can <u>evaluate the effectiveness</u> of whatever you do to relieve your symptoms?	1	2	3	4

Please fill in the date you completed this survey _____

Did someone help you complete this survey? **Yes** **No**

Appendix I

THE GENERAL WELL-BEING SCHEDULE

READ – The questionnaire contains questions about how you feel and how things have been going with you. For each question, mark (X) beside the answer which best applied to you.

1. How have you been feeling in general?
(DURING THE PAST MONTH)
- 1 In excellent spirits
2 In very good spirits
3 In good spirits mostly
4 I have been up & down in spirits a lot
5 In low spirits mostly
6 In very low spirits

2. Have you been bothered by nervousness
or your nerves?
(DURING THE PAST MONTH)
- 1 Extremely so, to the point where I
could not work or take care of things
2 Very much so
3 Quite a bit
4 Some- enough to bother
5 A little
6 Not at all

3. Have you been in firm control of your
behavior, thoughts, emotions, or feelings?
(DURING THE PAST MONTH)
- 1 Yes, definitely so
2 Yes, for the most part
3 Generally so
4 Not too well
5 No, and I am somewhat disturbed
6 No, and I am very disturbed

4. Have you felt sad, discouraged, hopeless, or
had so many problems that you wondered
if anything was worthwhile?
(DURING THE PAST MONTH)
- 1 Extremely so –to the point that I have
just about given up
2 Very much so
3 Quite a bit
4 Sometimes- enough to bother me
5 A little bit
6 Not at all

5. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)	<input type="checkbox"/> 1 Yes- almost more than I could bear to stand <input type="checkbox"/> 2 Yes- quite a bit of pressure <input type="checkbox"/> 3 Yes- some more than usual <input type="checkbox"/> 4 Yes- some but about usual <input type="checkbox"/> 5 Yes- a little <input type="checkbox"/> 6 Not at all
6. How happy, satisfied or pleased have you been with your personal life? (DURING THE PAST MONTH)	<input type="checkbox"/> 1 Extremely happy-could not have been More satisfied or pleased <input type="checkbox"/> 2 Very happy <input type="checkbox"/> 3 Fairly happy <input type="checkbox"/> 4 Satisfied- pleased <input type="checkbox"/> 5 Somewhat dissatisfied <input type="checkbox"/> 6 Very dissatisfied
7. Have you had any reason to wonder if you you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory? (DURING THE PAST MONTH) concerned	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 Only a little <input type="checkbox"/> 3 Some- but not enough to be concerned Or worried about <input type="checkbox"/> 4 Some and I have been a little <input type="checkbox"/> 5 Some and I am quite concerned <input type="checkbox"/> 6 Yes, very much so and I am concerned
8. Have you been anxious, worried, or upset? (DURING THE PAST MONTH)	<input type="checkbox"/> 1 Extremely so- to the point of being sick or almost sick <input type="checkbox"/> 2 Very much so <input type="checkbox"/> 3 Quite a bit <input type="checkbox"/> 4 Some- enough to bother me <input type="checkbox"/> 5 A little bit <input type="checkbox"/> 6 Not at all
9. Have you been waking up fresh and rested? (DURING THE PAST MONTH)	<input type="checkbox"/> 1 Everyday <input type="checkbox"/> 2 Most every day <input type="checkbox"/> 3 Fairly often <input type="checkbox"/> 4 Less than half the time <input type="checkbox"/> 5 Rarely <input type="checkbox"/> 6 None of the time

10. Have you been bothered by any illness, bodily disorder, pain, or fear about your health? (DURING THE PAST MONTH)	1 <input type="checkbox"/> All the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
11. Has your daily life been full of things that were interesting to you? (DURING THE PAST MONTH)	1 <input type="checkbox"/> All the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
12. Have you felt down-hearted and blue? (DURING THE PAST MONTH)	1 <input type="checkbox"/> All of the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
13. Have you been feeling emotionally stable and sure of yourself? (DURING THE PAST MONTH)	1 <input type="checkbox"/> All the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time
14. Have you felt tired, worn out, used up, or exhausted? (DURING THE PAST MONTH)	1 <input type="checkbox"/> All of the time 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> A good bit of the time 4 <input type="checkbox"/> Some of the time 5 <input type="checkbox"/> A little of the time 6 <input type="checkbox"/> None of the time

For each of the four scales below, note that the words at each end of the 0 to 10 scale describe opposite feelings. Circle any number along the bar which seems closest to how you generally feel DURING THE PAST MONTH.

15. How concerned or worried about your HEALTH have you been? (DURING THE PAST MONTH)	0 1 2 3 4 5 6 7 8 9 10
	<hr/> Not concerned at all Very concerned
16. How RELAXED or TENSE have you been? (DURING THE PAST MONTH)	0 1 2 3 4 5 6 7 8 9 10
	<hr/> Very relaxed Very tense
17. How much ENERGY, PEP, VITALITY, Have you felt? (DURING THE PAST MONTH)	0 1 2 3 4 5 6 7 8 9 10
	<hr/> No energy at all Very energetic
18. How DEPRESSED or CHEERFUL have you been? (DURING THE PAST MONTH)	0 1 2 3 4 5 6 7 8 9 10
	<hr/> Very depressed Very cheerful

Appendix J

Personal Information
(Demographic Questionnaire)

Please complete the following questions by marking a "X" by the line that answers the questions best for you. Any information that you give is completely confidential. At no time will your name be used in connection with this questionnaire.

1. Sex Male _____ Female _____

2. Age (years) _____

3. When were you diagnosed with heart failure? Approximate Date _____

4. Ethnic Background

What is your main ethnic background (ie. Asian, German, French, Spanish)?

5. Marital Status

What is your current marital status?

_____ Single

_____ Widowed/Divorced

_____ Married

_____ Common-law

6. Living Situation

With whom do you live with now?

_____ live alone

_____ live with spouse or common-law partner

_____ live with spouse and other family (e.g. children)

_____ live with other friends or family

_____ other (please specify) _____

7. Social Support

Most people have one or more individuals they can count on for help in time of need (ie. help or support you). Can you think of someone like this in your life? _____ no _____ yes → How many such persons? _____

If yes, what is the relationship of each of these helpers to you (ie. son/daughter).

8. Level of Education

What is the highest school grade you have completed?

- _____ Grade 6 or less (Elementary School)
 _____ Grade 7 to 11 (High School)
 _____ Grade 12 (High School Diploma)
 _____ Some College or University
 _____ College or University Degree
 _____ Graduate Degree

9. Occupational Status

- _____ full-time _____ medical leave
 _____ part-time _____ unemployed
 _____ retired

Has your occupational status changed due to your heart condition? _____

10. Most recent occupation.

- _____ laborer _____ retail
 _____ clerical _____ professional
 _____ management _____ homemaker
 _____ not applicable _____ other (please specify) _____

11. Family Income level

What is your family annual income?

- _____ less than \$20, 000
 _____ \$20, 000 to \$39,000
 _____ \$40, 000 to \$59, 000
 _____ \$60, 000 to \$79, 000
 _____ \$80, 000 and over

Number of people in your household? _____

Thank you for taking the time to complete these questions. It is very much appreciated.