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The Relationship of Illness Representation and

Self-Care Behaviors to Health-Related Quality of Life in

Older Individuals With Heart Failure

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The Relationship of Illness Representation and

Self-Care Behaviors to Health-Related Quality of Life in

Older Individuals With Heart Failure

by

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Dedication

I dedicate this dissertation to my wife, Glenda. She has helped make my dream a reality with her continuous support as my cheering section and offered support on every level of this research journey.

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The Relationship of Illness Representation and Self-Care Behaviors to Health-Related

Quality of Life in Older Individuals With Heart Failure

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This descriptive correlational study used a convenience sample of 98 individuals with Heart Failure (HF) ages 55 to 97 years ($M = 74.4$, $SD = 10.5$) to explore the relationships between the illness representations, HF self-care behaviors, and health-related quality of life (HRQOL). The majority of the sample was male (59%). While most of the participants were Anglo, 12% were African-American and 9% identified themselves as Latino/Hispanic. Participants had been living with their diagnosis for a median time of 3.5 years ($M = 6.1$ years, $SD = 8.12$). Each experienced, on average, at least one hospitalization due to HF in the past 12 months ($M = 1.1$ visits, $SD = 2.02$) with the median time since admission for the entire group at 1.1 years ($M = 2.1$ years, $SD = 3.13$). Approximately 65% of the group were functionally impaired (Class III/IV) according to the Specific Activity Scale (SAS).

The average-item Illness Perception Questionnaire-Revised (IPQ-R) scores indicated participants viewed their HF as having serious consequences ($M = 3.57$, $SD = .88$) and a chronic course ($M = 3.89$, $SD = 1.03$), being under their personal ($M = 4.11$,

SD = .55) and medical (*M* = 3.65, *SD* = .63) control but still exhibiting cyclical

disruptions in their lives (*M* = 2.84, *SD* = .90). Respondents were neutral on the internal

(*M* = 2.55, *SD* = .78) and external (*M* = 2.44, *SD* = .59) causal attribution subscales.

Scores on the Self-Care of HF Index (SCHFI) did not correlate significantly with the

IPQ-R subscales or scores on the Living with HF Questionnaire (LHFQ). Using

hierarchical regression, SAS functional classification (*B*=9.96, *p* <.01), identity (*B*

=2.01, *p* <.01), and consequences (*B*=1.20, *p* <.01) explained 64% of the total variance

in LHFQ scores. SCHFI total scores did not account for a significant increase in the

variance of the LHFQ scores. Implications and recommendations for future studies are

discussed.

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CHAPTER 1: INTRODUCTION

Heart failure (HF) is a chronic, progressive condition that affects an estimated 4.9 million individuals and impacts 1 out of every 10 elderly persons in the United States (American Heart Association [AHA], 2005). These individuals struggle to either control or prevent HF symptoms including fatigue, shortness of breath, persistent coughing, swelling of extremities, lack of appetite, confusion, and exercise intolerance (Hunt et al., 2005; Konstam et al., 1995; Pina et al., 2003) . The episodic, unpredictable, and gradual onset of these HF symptoms demands that each individual with HF be constantly vigilant in self-monitoring symptoms in order to implement appropriate self-care strategies. Otherwise, if someone overlooks the warning symptoms of HF, misinterprets the significance of a symptom based on incorrect information, or chooses an ineffective self-care behavior response, it may not be possible to maintain a lifestyle associated with an acceptable level of functioning and quality of life (QOL) (Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000).

The impact of HF on the United States' healthcare system is reflected in the 970,000 individuals hospitalized during 2002 at an estimated direct and indirect cost of $27.9 billion for 2005 (AHA, 2005). HF is the most common primary diagnosis for the elderly, with the number of cases expected to double over the next 40 years because of the increasing older population and the improvement in survival rate from underlying cardiovascular diseases (Haldeman, Croft, Giles, & Rashidee, 1999). HF is the cause of death for an estimated 264,900 individuals per year in the United States (AHA, 2005). The one-year mortality rate is extremely high with one out of every five persons expected

to die. The long-term survival for people diagnosed prior to the age of 65 is worse than cancer, with the expectation that at 8 years, 80% of the men and 70% of the women will have died (AHA, 2005).

HF has become a major public health problem from the standpoint of its impact on both morbidity and mortality (Levy et al., 2002). Although current advances in pharmacology and surgical interventions have allowed for some improvements in symptom management, individuals with HF continue to experience an accelerated deterioration in all aspects of quality of life as they age, in comparison to those with other common chronic disorders (Hobbs et al., 2002). Thus those individuals with HF and their healthcare providers (HCPs) need to maximize the tools at hand for increasing the effectiveness of self-care behaviors that would improve health-related quality of life (HRQOL). One proposed means to improve this effectiveness is to have a better understanding of how individuals perceive their HF in order to understand better their motivation for performance or avoidance of various self-care behaviors.

Examining the impact of HF from the perspective of the individual experiencing it allows a glimpse of that person's unique reality or "representation of illness danger" (Rachman, 1980). A basic premise of medical anthropology is that if the HCP has a better understanding of how the individual perceives his/her illness, then the HCP should be better equipped to address the client's specific biological and psychosocial needs in the most efficient and effective manner (Chrisman, 1977; Kleinman, 1980). Actively soliciting the individual's perception as to his/her unique reality of the illness encourages active participation and incorporation of treatment strategies toward self-care behaviors

that the person feels capable of successfully performing. This increase in the performance of effective self-care behaviors would be expected to result in a reduction of symptoms and an improvement in HRQOL (Leventhal, Leventhal, & Cameron, 2001).

Purpose

The primary purpose of this cross-sectional exploratory study was to examine the illness representations of a group of older community-dwelling individuals living with HF. The second purpose was to explore the relationship between the illness representations, HF self-care behaviors and HRQOL.

Background and Significance

HF occurs as the final pathway in a number of different cardiovascular disorders. Data from the Framingham Study shows that coronary heart disease and chronic hypertension are the two most common precursors (Levy, Larson, Vasan, Kannel, & Ho, 1996). Other risk factors associated with HF include cardiomyopathy, valvular dysfunction, cardiac arrhythmias or conduction disturbances, and pericardial infections (McMurray & Stewart, 2000). As individuals age, any of these multiple disorders may eventually manifest itself in the progressively disabling, fatal condition known as HF.

The progressive nature of HF is due to a process referred to as cardiac remodeling, which is brought on by a cascade of neurohormonal responses that cause adverse effects through increased blood pressure, sodium retention, structural changes to cardiac myocytes, and electrical instability (Carelock & Clark, 2001; Hunt et al., 2005). These circulating neurohormones are normally compensatory but become adverse because they eventually lead to increases in ventricular muscle mass, changes in the

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shape of the left ventricle, and impaired contractility (Carelock & Clark, 2001; Hunt et al., 2005).

Areas of HF Research

Research for the treatment of HF consists of three major approaches (Moser & Riegel, 2001). The first category deals with the development and testing of pharmacological agents to correct or minimize the problem of HF (Exner & Schron, 2001). The second area of research involves the various surgical interventions utilized for treatment of HF (Grady, Piccione, & Marcantonio, 2001). The third area is referred to as non-pharmacologic and includes such components as the identification of risk factors for worsening HF, biobehavioral training, and implementation of regular planned exercise to increase functional status (Moser & Dracup, 2001). Some aspects of each area of research are directed toward prevention strategies, while others are focused more on dealing directly with what is causing the HF. There are other instances, in particular with the surgical interventions, in which the purpose of the treatment is to replace the malfunctioning component or to assist the heart in its overall function.

Pharmacologic Research

Multi-site, randomized clinical trials evaluating pharmacological agents have been conducted in an effort to show evidence that medications actually correct or minimize the causes of HF (Ambrosioni, Borghi, & Magnani, 1995; Cohn et al., 1986; CONSENSUS Trial Study Group, 1987; Kober et al., 1995; Konstam et al., 1996; MERIT Investigators, 1999; Packer et al., 1996; Pitt et. al., 1999). One of the significant findings that emerged from this area of pharmacologic research is the development of

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effective agents to control hypertension (Konstam et al., 1996; SOLVD Investigators, 1991; SOLVD Investigators, 1992).

The Framingham Heart Study was initiated by the National Heart, Lung, and Blood Institute (NHLBI) in 1948 by enrolling 5,209 men and women without any pre-existing cardiovascular disease into a longitudinal study to determine what factors would be determinants of coronary artery disease (CAD) (NHLBI, 2000). The longitudinal study design has allowed the researchers to capture critical information about predictors of the development of HF and its natural progression (Ho, Anderson, Kannel, Grossman, & Levy, 1993; Ho et al., 1993; McKee, Castelli, McNamara, & Kannel, 1971; Vasan, Benjamin, & Levy, 1995). Findings from these data have been vital to researchers' understanding that HF can exist in an asymptomatic stage for a prolonged period prior to evolving into the symptomatic stage.

Untreated hypertension can lead to HF; therefore, effective control of high blood pressure is imperative to prevent the initial development of HF and to minimize progression of the disease process once it has been diagnosed (Levy et al., 1996; Wilhelmsen, Rosengren, Eriksson, & Lappas, 2001). The use of evidence-based protocols approved through national consensus panels allows the HCP to select the most appropriate and effective pharmaceutical agent to promote the best possible outcomes (Chobanian et al., 2003; Kostis et al., 1997).

A second significant finding in the area of pharmacological research related to the deceleration or prevention of cardiac remodeling. As understanding of the pathophysiology involved with HF became clearer over the past decade, new medications

were developed to diminish the negative impact that resulted from the neurohormonal compensatory process that resulted in the adverse affects of cardiac remodeling. Initially, it was believed that the loss of pumping power by the heart was due solely to a mechanical weakening of the muscle fibers from loss of cardiac cells during a heart attack or ischemic episode (Schlant & Sonnerblick, 1986). However, research over the past decade revealed that although the initial insult may be mechanical, when the heart begins to fail, it attempts to compensate with neurohormones released through activation of the renin-angiotensin-aldosterone system and the sympathetic nervous system (Hunt et al., 2005). The circulating neurohormones then contribute to the cardiac remodeling that results in the structural changes seen in the cardiac cells (Carelock & Clark, 2001). Based on evidence from multiple randomized clinical trials, several medications have shown effectiveness in reducing the symptoms and eventual ventricular remodeling associated with the influences of these circulating neurohormones. These include angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers, aldosterone antagonists, and beta-adrenoceptor blockers (Cleland et al., 2003; Cohn et al., 1991; CONSENSUS Trial Study Group, 1987; Dargie, 2001; Digitalis Investigation Group, 1997; Gottlieb et al., 1993; McKelvie et al., 1999; MERIT Investigators, 1999; Packer et al., 1996; Pitt et al., 1997, 1999, 2001; SOLVD Investigators, 1991; Swedberg, Kjekshus, & Snapinn, 1999).

Surgical Research

A second area of research for the treatment of HF is the surgical interventions developed over the past 30 years. These include coronary artery bypass surgery, mitral

valve repair, implantation of ventricular assist devices, implantation of pacemakers/cardiac defibrillators, and heart transplantation (Boehmer, 2003; Grady et al., 1995; Grady et al., 2005). With individuals with dysfunctional but still viable myocardium tissue or other appropriate conditions for treatment, coronary artery surgery will result in improved cardiac ability to pump blood, exercise performance, and quality-of-life scores (Pagano et al., 1998). Surgical repair of the mitral valve, or annuloplasty, has been found effective in treating HF caused by severe mitral regurgitation. In a recent study reported by Romano and Bolling (2003) following 167 participants who received annuloplasty, a significant improvement was noted over a 24-month time period in functional ability, ejection fraction (ability of the heart to pump blood effectively), reduction in mitral regurgitation, restoration of the normal left ventricular geometric relationship, and in many cases, reversal of the ventricular remodeling process.

The Randomized Evaluation of Mechanical Assistance Therapy as an Alternative in Congestive Heart Failure (REMATCH) study evaluated the use of left ventricular assist devices to improve survival, functional capacity, and symptoms (Richenbacher et al., 2003). Although only 5 of the 68 individuals initially implanted with the assist devices survived beyond 24 months, the usefulness of mechanical assist devices as a bridge for transplantation was established along with evidence that these devices could result in short-term improvements in QOL. Limited research regarding mechanical assistance through the use of a totally implantable artificial heart in 7 very high-risk HF participants revealed that artificial heart transplantation allowed for recovery of organ function and extended survival beyond that which was predicted (Boehmer, 2003).

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Human to human heart transplantation is also an ongoing surgical intervention used in the treatment of end-stage HF since 1967. Initial outcomes were poor due to rejection and infections, but with the introduction of cyclosporine in 1980 and continually improving surgical techniques, major success has been made in the area of survival and QOL (Grady et al., 2005).

In a meta-analysis of randomized controlled trials of cardiac resynchronization therapy (CRT) with implantable pacemakers, Bradley et al. (2003) reviewed 11 studies with 1,634 HF participants and found a reduction in deaths of 51% compared to controls, and a reduction in HF hospitalizations of 29%. Candidates for the procedure were individuals with dilated cardiomyopathy, interventricular conduction delays, and current classification as a New York Heart Association (NYHA) functional Class III or IV due to activity intolerance (Adamson & Abraham, 2003). Cardiac resynchronization therapy is a relatively new advance that is quickly gaining acceptance as a means to provide significant improvements for the person with HF, along with only the minimal risks of an outpatient procedure. An additional component of the ongoing trials is investigating the use of implantable cardioversion defibrillation (ICD) with CRT to prevent many of the lethal arrhythmias associated with HF (Young et al., 2003).

Nonpharmacologic Research

The third area of research encompasses a vast array of growing scientific literature that includes identification of those individuals at high risk for worsening HF outcomes (Konstam et al., 1996; Stewart et al., 1989), strategies to improve disease management to decrease mortality and morbidity and promote QOL (Rich, 1999; Rich et

al., 1995; Rich et al., 1993), biobehavioral training (Kostis, Rosen, Cosgrove, Shindler, & Wilson, 1994), and implementation of exercise as means of increasing both functional status and psychosocial outcomes (Belardinelli, Georgiou, Cianci, & Purcaro, 1999; Kavanagh et al., 1996; Martens, 2001; Quittan, Sturm, Wiesinger, Pacher, & Fialka-Moser, 1999; Tyni-Lenne, Gordon, Jansson, Bermann, & Sylven, 1997). Self-management strategies developed to meet the individual needs of the HF participants included personalized medication schedules, medication pillbox organizers, bathroom scales and logs to track daily weights, and educational components that stressed self-care behaviors directed at timely recognition of the warning signs for worsening HF (Martens, 2001; Moser & Riegel, 2001).

Summary for Areas of HF Research

New developments in technology suggest that surgical interventions and pharmaceutical therapy will continue to be a major focus of HF management. However, it is critically important to also have research addressing how the person with chronic HF can successfully live with the day-to-day self-management issues necessary to maintain an acceptable QOL. Few studies have explored how an individual with HF perceives his/her mental representations of illness and how these illness perceptions may be related to self-management behavior and subsequent QOL.

The diagnosis of HF carries with it a tremendous burden for the individual and the HCP to meet the complex demands of disease management. Clinical practice guidelines for HF (Bonow et al., 2005; Hunt et al., 2005) emphasize the importance of lifestyle recommendations that include medication regimens, diet restrictions, and exercise. Also

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included in these guidelines are suggestions to stop smoking, limit or abstain from alcohol, and daily monitoring for changes in symptoms that could indicate deterioration. The common thread in all of these recommendations is the requirement for individuals with HF to implement a change in their personal habits.

Improvement in perceived self-efficacy has been shown to promote personal change within elderly populations with chronic illness (Clark & Dodge, 1999; Lorig et al., 1999). In many ways, people with HF exemplify the challenges faced by most individuals living with a chronic illness because they must learn the health behaviors necessary for living with chronic illness and actively commit to monitor their health, set realistic goals, and persist with implementation and maintenance of healthy habits (Bandura, 1997; Stuifbergen & Roberts, 1997). This learning process is very complex and tenuous, but evidence indicates improvement in both physiological and psychosocial outcomes (Pollock, Christian, & Sands, 1990; Zauszniewski, 1996).

Unfortunately, there is no road map for those seeking to learn how to manage and live with a chronic illness such as HF. Each person goes through an exploratory trial-and-error process to discover what works best, many times without the benefit of useful guidance from providers in the formal healthcare environment (Hernandez, 1996; Kleinman, 1988). This process requires healthcare professionals to be sensitive to the illness perceptions and coping procedures of their clients and provide intervention when appropriate. It is anticipated that this proposed research will lead to a better understanding of the illness representations of individuals living with HF and how those representations are related to self-care behaviors. As individuals cope more effectively

with their illness, their QOL outcomes are expected to improve. Ultimately, it is anticipated that this research will help support the development of a more effective theory-based education program that facilitates self-care activities that include aspects of health maintenance and symptom management throughout the lifespans of community-dwelling individuals with HF.

Theoretical Framework

Social scientists have used multiple health behavior theories and models to study disease management in chronic illness. Several examples include the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), Social Cognitive Theory (Bandura, 1986), Theory of Reasoned Action (Ajzen & Fishbein, 1980), Theory of Planned Behavior (Ajzen, 1991; Ajzen & Madden, 1986), Health Belief Model (Hochbaum, 1958; Rosenstock, 1966), Social Support (House, Umberson, & Landis, 1988; Israel, 1982; Israel & Rounds, 1987), and Health Locus of Control (Lau, 1982; Wallston & Wallston, 1978). Approaching the study of health behavior from the perspective of the outside looking in, these theories and models have focused on variables such as susceptibility, stress response, intention, subjective norms, and self-efficacy.

Leventhal and colleagues have incorporated a unique "insider's" approach to understanding what is going on with the individual experiencing an illness by making extensive use of each person's unique illness reality in the Common Sense Self-Regulation Model (CSSRM) of illness representations (Leventhal et al., 2001). Their research continued earlier work done in social psychology by Kelly (1955) and Lewin (1935). It also built on the studies of folk illness reported by Chrisman (1977) and

Kleinman (1980) and took into account the mental representation the individual has of his or her health and illness. By utilizing this unique phenomenological viewpoint, the CSSRM allows the HCP to gain a better understanding of the individual's perspective on his or her disease and thus have a clearer assessment on how to provide support and guidance for improving self-management behaviors during an acute or chronic illness episode (Leventhal et al., 2001; Leventhal, Brissette, & Leventhal, 2003).

Common-Sense Self-Regulation Model: Basic Tenets

The first of the three basic assumptions underlying the CSSRM is the belief that the individual is an active problem-solver attempting to try to make sense out of the information being obtained (Leventhal et al., 2001; Leventhal et al., 2003). The initial stimuli or input that the individual becomes aware of may be from physical sensations of symptoms such as pain, emotional distress such as fear, or health-threatening laboratory results for an asymptomatic condition such as high cholesterol. The problem-solving process consists of three stages that are in response to symptoms or the health threat, as displayed in Figure 1. The first stage consists of representation of the health threat (mental and emotional reaction), the second stage is the coping procedures, and appraisal is the third stage. There is both a cognitive arm and an emotional arm to any health threat present in the model to represent the simultaneous and parallel process that occurs when the individual is confronted with reacting to the presence of a threatening symptom (Figure 1) (Leventhal, Nerenz, & Steele, 1984).
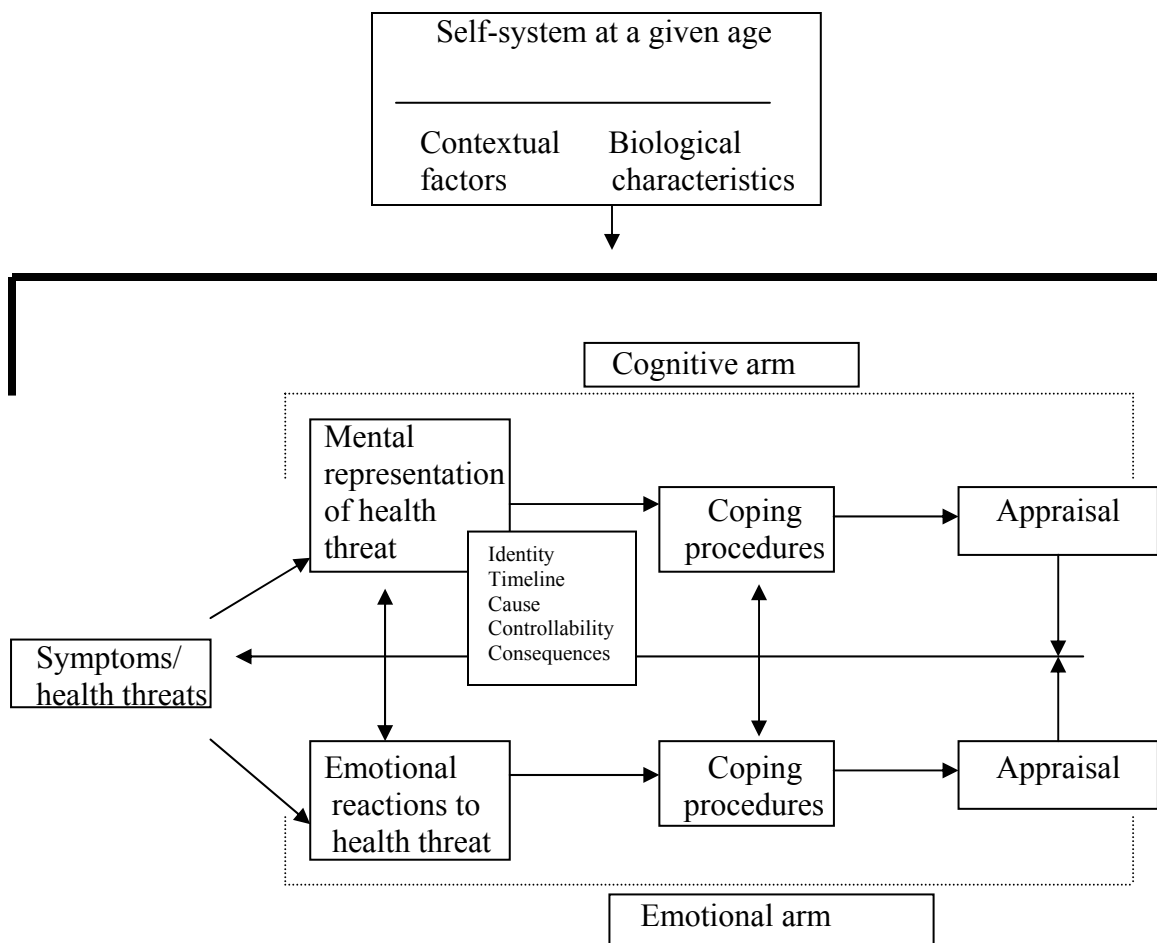
Figure 1. Illustration of the parallel process in the CSSRM. From "Women With Heart

Disease: Can the Common-Sense Model of Illness Help?" by K. Shifren, 2003, *Health

Care for Women International, 24(4)*, p. 360.

The second basic assumption of the CSSRM is that the adaptive process is based

on common-sense beliefs and appraisals (Leventhal et al., 2001; Leventhal et al., 2003).

This means that to understand the actions of an individual, it is necessary to look from the

person's perspective and take into account how the individual interprets the situation.

Even if the biomedical objective data are in disagreement, it is critical to remember that

an individual's actions are based on the person's common-sense beliefs and best

understanding of the situation. If someone does not choose to accept as real the objective biomedical data, or the person cannot understand it, then an individual must use only the resources and information already at hand to make decisions and act (Blackwell, 1992).

The third assumption of the CSSRM emphasizes the role of the socio-cultural context and its influence on the self-regulation process (Leventhal et al., 2001; Leventhal et al., 2003). The manner in which an individual visualizes a threat will be influenced by the person's environment, which consists of family, friends, HCPs, media, and the individual's socially defined roles.

Development and Use of CSSRM

The CSSRM was developed to identify factors involved with the processing of information by individuals regarding their illness or disease, how that information integrates into a coherent "lay" view of the illness, and how this lay view subsequently guides coping behaviors and outcomes (Hagger & Orbell, 2003). Multiple uses have been made of the CSSRM model in the medical research literature, many of them with persons with illnesses or conditions that were chronic and disabling. In a meta-analysis of 45 studies that utilized the theoretic framework of the common-sense model between 1989 and 2002, Hagger and Orbell (2003) found 16 conditions listed as the primary illness: myocardial infarction (MI), hypertension, atrial fibrillation, chronic obstructive lung disease, diabetes (type 1 and 2) rheumatoid and osteoarthritis, HIV, irritable bowel syndrome and disease, chronic fatigue syndrome, multiple sclerosis, Alzheimer's disease, breast cancer, oral surgery (extraction of 3rd molar), epilepsy, Addison's disease, psoriasis, cervical abnormalities, acute pain, and the common cold. The two articles

found utilizing CSSRM with individuals with HF were a published doctoral dissertation by Fox (2000) examining the congruence between 60 patients and their spouses on medication adherence in a cardiac rehabilitation program and a qualitative study of 19 older individuals conducted by Horowitz, Rein, and Leventhal (2004) describing their illness perceptions and lack of understanding of appropriate self-management strategies related to their most recent HF exacerbations.

Initially referred to as the parallel response model, the CSSRM originated from a group of experiments in the 1960s that Howard Leventhal (Leventhal, 1970) performed dealing with fear communications. Two major features of this model make it unique. The first feature is the simultaneous two-tier processing of the cognitive representation of the health threat and the emotional reaction to that health threat. Because these are working at the same time and are depicted in the model as an upper and lower arm, the term parallel response model is frequently applied to the CSSRM. The second feature is the three-stage process of a) illness representation, b) coping procedures, and c) appraisal (Leventhal et al., 2003). The upper arm of the model (Figure 1) demonstrates the processing of information for controlling danger, and the lower arm of the model represents controlling the emotional responses perceived as a result from the danger.

The Cognitive Arm (Problem-Solving Episode)

Illness representations.

According to the model, external and internal stimuli, represented in Figure 1 as symptoms or health threats, evoke illness representations when they come into contact with and are interpreted or decoded by schematic structures from prior health and illness

experiences. The speed and accuracy for the process of matching the health threat

stimulus with the illness meaning or representation will depend upon its similarity to

other previously experienced or imagined illness episodes (Leventhal et al., 2001). Five

dimensions of illness representations have been described: identity, timeline, cause,

controllability, and consequences. The dimension of identity is described as the label and

symptoms an individual associates with the health threat. When describing timeline,

Diefenbach and Leventhal (1996) stated that this dimension includes beliefs regarding the

amount of time elapsed by connecting the stimulus to an expected timeframe. It answers

the questions as to whether the stimulus is acute, chronic, or cyclic in nature. The

dimension of cause could include external agents such as bacteria and viruses, internal

susceptibilities such as genetic factors, or behavioral causes. The cause attribute gives

more definition to the stimulus by ruling out some of the options for illness

representations if the cause is known or suspected. The aspect of perceived controllability

of the stimulus pertains to how responsive the individual believes the illness will be to

self-treatment or expert intervention (Lau & Hartmann, 1983). The consequences or

anticipated and experienced personal repercussions of the disease may involve physical,

emotional, social, or economic outcomes.

These five attributes represent the basis of a lay model of illness representation

and guide the selection of coping procedures and evaluation of their effectiveness

(Leventhal et al., 2001). Representations are structured at two levels: abstract and

concrete. An example of something on an abstract level would be if a person could

cognitively "visualize" or think of a certain symptom or pain and what it must feel like,

e.g., severe chest pain. In contrast, the individual actually experiencing an acute MI with severe chest pain is having somatic stimulus input into the illness representation on a concrete, not abstract, level.

An illness representation is guided by three basic sources of information (Leventhal et al., 1984). The most common source of information is the general pool of lay information available that the individual is exposed to in everyday social activities and common knowledge of the illness. A second source of information is from authoritative sources such as doctors, nurses or a person's significant others. If the individual has already experienced the illness, the third source of information is available, which is taking into account his or her current illness experience (Hagger & Orbell, 2003).

Coping procedures for cognitive arm.

The second aspect of the problem-solving process involves the actual performance of health behavior that an individual adopts in response to a health threat. The illness representation influences the choice of the coping procedure for threat control, defining the goal for the procedure, and sustaining the performance of the procedure (Leventhal et al., 2001). Leventhal (Leventhal, Hudson, & Robitaille, 1997) points out that it is important to remember, when evaluating coping procedures for specific health threats, that individuals have various options they can select to address a health threat, and the very same objective may have multiple options of coping procedures at different points in time. It has been suggested that coping procedures have very similar attributes to the illness representation stage in that it can also be viewed as

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consisting of the same five dimensions: identity, cause, consequences, timeline, and controllability (Horne, 1997). Conscious thought and deliberate planning go into the performance of coping procedures to reduce health threats, but many times the coping reactions are performed automatically (Leventhal et al., 2001).

Appraisals for cognitive arm.

The third stage in the problem-solving process is the appraisal or outcomes evaluation. This stage is where feedback is given as to whether the health threat has been diminished or eliminated. Appraisal has been referred to as a matching process that checks the response outcomes against the specific coping procedures to see if they were effective (Leventhal, 1990). Although the initial primary focus is on the effectiveness of the coping procedures, based on expected outcomes, there is also the feedback loop possibility of reframing the illness representation to match the coping ability and outcome (Diefenbach & Leventhal, 1996; Leventhal, 1990). Information can flow in both directions from appraisal to representation and from representation to appraisal (Leventhal et al., 2001). To summarize, within the cognitive arm of the problem-solving episode, the illness representations function as the motivation, the coping procedures are the action plans, and the appraisals are outcome expectations of whether goals were met (Leventhal et. al., 1997).

The Emotional Arm (Problem-Solving Episode)

Emotional reaction.

The CSSRM proposes that a health threat will evoke any number of emotional responses in addition to the cognitive illness representations (Diefenbach & Leventhal,

1996; Leventhal et al., 1984). This "emotional arm" of the problem-solving episode is divided into three stages and has the same components as the cognitive arm: representation of the emotional reaction to the health threat, coping procedures, and appraisals (Rachman, 1980; Leventhal et al., 1984). The original derivation of the parallel model resulted from studies by Leventhal and colleagues (Leventhal, 1970) dealing with how individuals responded to fear messages in different ways. The emotions resulting from the fear messages were perceived and reacted to in a subjective manner, which made the two arms distinctly different from each other (Leventhal, 1990). The emotions that are represented in response to a health threat become the goal attainment for the coping procedure of emotional control (Leventhal et al., 2001).

Coping procedures for emotional arm.

Coping procedures represent the action plan for dealing with the emotional response to a health threat and the second stage of the emotional arm. To deal with emotional reactions, individuals employ a wide range of coping procedures including seeking out social support, cognitive reframing of the problem, and avoidance of the threat (Leventhal, 1990). There is a complex link between the mental and physiological systems of the body when an individual's emotional coping procedure impacts self-regulation. This can occur when emotional coping procedures affect the cognitive arm by altering feelings of vulnerability, perceptions of illness severity, expectations of successful outcomes, and beliefs of self-efficacy (Leventhal et al., 2001).

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Appraisal for emotional arm.

In the third stage of the emotional arm of the problem-solving process, the individual is evaluating whether the coping procedures put in place were appropriate and sufficient for the emotional reactions identified in the first stage (Leventhal, 1990). There is not a linear timeline to the resolution of health threats that are processed through the CSSRM. The emphasis is on inter-linkage and inter-play between the two parallel arms, in addition to non-linear timeline movement through the problem-solving process within each arm (Leventhal et al., 2001).

<center>*The Research Model*</center>

In summary, the CSSRM is a very appropriate model to explore the illness perceptions of individuals living with chronic HF. The problem-solving aspect of the model can be visualized as a three-stage process of illness representation, coping procedures, and appraisal aspects. This problem-solving aspect operates simultaneously on a dual track with the model's emotional component, which is made up of three stages similar to those of the problem-solving process.. The illness representation aspect consists of five dimensions that describe the identity, cause, consequences, timeline, and controllability of the health threat. Leventhal's CSSRM proposes that all coping procedures are the result of a "common-sense" approach from the standpoint of the layperson interpreting the information at hand.

Many of the self-care behaviors that are medically necessary to allow individuals with HF to live with fewer symptoms and a better QOL are not inherently "common-sense" or rational from a layperson's point of view. It requires the ability of the HCP or a

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support group to place themselves in the shoes of the clients and communicate to them in a meaningful and realistic manner as to what actions will make a difference and what those changes might be. Individuals with HF then have the option to choose whether they wish to adopt those self-care behaviors into their lifestyle. By actively soliciting the individuals' perception as to their unique reality of their illness, the HCP encourages active participation and the incorporation of self-care treatment strategies that persons feel capable of performing successfully. This increase in the performance of effective self-care behaviors would be expected to result in a reduction of symptoms and an improvement in HRQOL outcomes (Leventhal et al., 2001). It does not capture the essence of what Leventhal is trying to communicate with his model if HCPs presume individuals will be motivated to respond in a certain manner just because they have certain symptoms. Using the perspective of the individuals with HF, it is important to understand which one factor or combination of factors motivates their actions. This will in turn dictate how individuals will then respond to health threats on both a cognitive and emotional level through self-care health behaviors. In using information about illness representations, the HCP can act in concert with individuals and gain their active participation to accomplish mutual goals.

This study examined selected relationships within Leventhal's CSSRM's theoretical framework as outlined in Figure 2. Only the "Cognitive Arm" was addressed in this study. The five dimensions of the mental representation of health threat were assessed. HF self-care behaviors represented coping procedures and subjective perceptions of HRQOL served as the empirical indicator of appraisal.

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┌─────────────────────────────────────────┐
│        Self-system at a given age         │
│───────────────────────────────────────────│
│     Contextual        Biological          │
│     factors           characteristics     │
└─────────────────────────────────────────┘
```

Marital status		Age
Education		Gender
		Time since HF diagnosis
		Time since last HF admit
		Number of HF admits
		Comorbidity index
		Specific Activity Scale
		functional classification

Cognitive arm

Symptoms/ health threats → Mental representation of health threat → Coping procedures → Appraisal

Identity
Time-line
Cause
Controllability
Consequences

HF self-care behaviors

Health-related QOL

Figure 2. Illustration of research model. From "Women with Heart Disease: Can the Common-Sense Model of Illness Help?" by K. Shifren, 2003, *Health Care for Women International, 24(4)*, p. 360.

Research Model Scenario

For an older individual with HF, the experience of waking up with constant, severe coughing associated with extreme shortness of breath in the middle of the night can be influenced by contextual factors. For example, the person may attribute these symptoms to the room temperature being too hot and consequently believe that standing at the open window and cooling off will solve the problems. In reality, the biological

factor of decompensating HF is creating the health threat and resulting in the symptoms of cough and shortness of breath. When the symptoms continue, although somewhat abated, the individual investigates in more detail what might be causing the problem. As the person processes the symptoms, the initial label of "being too hot" becomes more defined; after stepping onto the bathroom scale, the individual realizes his weight is up four pounds from his normal dry weight; and he can feel wheezing in his lungs. These symptoms help the individual determine the new identity label of a "breathing problem due to excess fluid from HF." The cause, timeline, consequences, and controllability/cure dimensions are all unique to the person and should be elicited in each encounter with a HCP as part of the health assessment. In this instance, the individual felt the incident was caused by the half bag of salted chips he ate last evening; the timeline for the episode was acute, not chronic or cyclic; the consequences, although serious, were not life and death; and he could control the condition by immediately taking an extra diuretic, as his physician had instructed him previously, and maintaining his sodium intake to less than 2,000 mg on a daily basis.

Research Questions

Research Question 1

What are the levels of the illness representation dimensions for identity, cause, consequences, timeline, and cure/controllability as elicited by the Illness Perception Questionnaire-Revised (IPQ-R) for a group of older community-dwelling individuals with HF?

Research Question 2

What are the relationships among the illness representation dimensions as elicited by the Illness Perception Questionnaire-Revised (IPQ-R) for a group of older community-dwelling individuals with HF?

Research Question 3

What are the relationships between illness representation dimensions and HF self-care behaviors as measured by the Self-Care of HF Index (SCHFI)?

Research Question 4

Do illness representation dimensions and HF self-care behaviors add significantly to the prediction of HRQOL as measured by the Minnesota Living with Heart Failure Questionnaire (LHFQ) in older community-dwelling individuals with HF after controlling for selected individual contextual factors and biological characteristics such as age, marital status, co-morbidity, and length of time living with HF?

Definitions of Terms

The following definitions were used in this study:

Illness Representation

Illness representation is defined as the individual's integrated perceptual-cognitive model of a health threat that guides the person's coping with health events as well as evaluation of treatment effects (Leventhal et al., 2001). Five dimensions or attributes depict illness representation from the perspective of the lay individual. These five are described below (identity, timeline, cause, cure/controllability, and consequences) and together form the basis of the lay model of illness (Schober & Lacroix, 1991). Each of

these five dimensions was measured with the specific subscale from the IPQ-R (Moss-

Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002).

Identity

Identity is defined as the health threat label and the individual's ideas about the

somatic representation of that health threat (i.e., the label that defines the health threat

such as "heart failure" and its accompanying symptoms such as shortness of breath and

ankle swelling) (Lau & Hartmann, 1983; Leventhal et al., 1997).

Timeline

Timeline is defined as the individual's belief regarding the amount of time

expected for development of, duration of, and time of recovery from the health threat

(Croyle, 1992; Heidrich, Forsthoff, & Ward, 1994; Meyer, Leventhal, & Guttmann,

1985).

Cause

Cause is defined as the specific factor which the individual believes was

responsible for initiating the health threat (i.e., an external agent such as a germ, bacteria,

or virus; an internal susceptibility such bad genes; or a behavioral action such as poor

eating habits) (Diefenbach & Leventhal, 1996; Meyer et al., 1985).

Cure/Controllability

Cure/controllability is defined as the anticipated and perceived responsiveness of

the condition to self-treatment and expert intervention (Lau & Hartmann, 1983; Meyer et

al., 1985).

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Consequences

Consequences are defined as the anticipated and experienced outcomes of the disease that may be physical, emotional, social, or economic (Diefenbach & Leventhal, 1996; Leventhal et al., 2001).

HF Self-Care Behavior

HF self-care behavior is defined as the cognitive coping procedures that an individual with HF might perform to maintain health or control symptoms in response to a health threat (Leventhal et al., 2001). HF self-care behavior was measured with the SCHFI (Riegel, Carlson, & Glaser, 2000).

Health-Related Quality of Life (HRQOL)

HRQOL is defined as an individual's perception of the influence of HF on the physical, socioeconomic, and psychological aspects of his or her life. The HRQOL was measured with the LHFQ (Rector, Kubo, & Cohn, 1987).

Assumptions

In the current study, the following assumptions were made:

1. Participants answered the questionnaires in an honest and complete manner.

2. Individuals perceived the diagnosis and symptoms associated with HF to be a health threat.

3. Individuals with HF were able to identify the self-care behaviors they perform to maintain health and prevent illness.

4. A person's concept of a health threat was influenced in various and unknown ways by the attitudes and beliefs of his or her social and cultural environment. This

included the influence of family, friends, health practitioners (biomedical and traditional), mass media, and socially defined roles such as the active or passive patient.

Limitations

The possible limitations of this study included:

1. The findings from this study may not be generalized to all older individuals with HF because the sample was a non-random convenience sample drawn from the central Texas area.

2. All instruments were administered in the English language with no translator provided.

3. Individuals may have been hesitant to express their true feelings on a research instrument when it was contrary to popular belief or what they believed their HCP felt was appropriate.

4. Because a nonrecursive path model, a model with at least a two-directional arrow, cannot be used with cross-sectional data (Munro, 2001), a recursive path model was used in this study. However, the recursive model may not reflect phenomena in the natural setting because the relationships among variables are diagramed unidirectionally, allowing no interaction among variables; therefore, causality cannot be determined (Polit & Hungler, 1999).

Summary for Chapter 1

In this chapter, the impact of HF as a major health problem, along with the three major areas of current research, have been discussed. The primary purpose of this cross-sectional exploratory study was identified as the examination of illness representations of a group of older community-dwelling individuals living with HF. A second goal was to explore the relationship between the illness representations, HF self-care behaviors, and HRQOL. The remainder of the chapter explained the theoretical framework of the Common-Sense Self-Regulation Model utilized for this study and the definition of terms, assumptions, and limitations of the proposed study.

CHAPTER 2: REVIEW OF THE LITERATURE

This chapter will begin with a presentation of the literature associated with each of the five separate dimensions or attributes of illness representation. The next section will address the self-care behaviors of individuals with HF. The chapter will conclude with a brief review of the literature related to QOL for individuals with HF and address the impact HF has on HRQOL.

Illness Representation

The term *illness representation* is defined as the individual's integrated perceptual-cognitive model of a health threat that guides the person's coping with health events as well as evaluation of treatment effects (Leventhal et al., 2001). Illness representation has been used interchangeably throughout the research literature with terms such as *mental representations, lay cognitive models, common-sense representations, illness cognitions, illness concepts*, and *illness perceptions* (Scharloo & Kaptein, 1997). The five dimensions or attributes of illness representation are identity, timeline, cause, consequences, and cure/controllability (Leventhal et al., 1997; Leventhal et al., 2003). These five dimensions are important in regulating a person's health-related behavior from the standpoint of actual coping, entry into and use of medical treatment, and evaluation of treatment effects (Scharloo & Kaptein, 1997). Research related to each of these dimensions of illness representation in HF will be presented, followed by a discussion of findings from similar cardiovascular populations that have used the CSSRM.

Identity

The *identity dimension* is represented by the person's perception of the signs and symptoms associated with the illness including the name the individual uses to identify the illness (Leventhal et al., 1997). Most of the symptoms experienced by an individual with HF are subjective in nature and therefore difficult to quantify. Weight gain is one exception to this rule, but even it can go unnoticed if it is gradual, and the individual is not weighing daily or attributes the gain to increased caloric intake. The other difficult aspect of symptom monitoring for individuals with HF is the evolution and progression of the disease over a period of many years where there are no symptoms present to warn or signal the person of the impending illness ahead.

Participants' comments from a qualitative study (Stull, Starling, Haas, & Young, 1999) of persons with HF illustrate the words utilized by laypersons to express the symptoms they experience secondary to their HF.

> "I just ran out of breath, period." "When I went to bed I couldn't lay down and I figured I had pneumonia or something I didn't know...I couldn't lay down and go to sleep without coughing...it was classic." "I couldn't breathe, like I had to sit up to sleep and anything. They got 31 pounds of fluid off me in the first 2 days." "I think it got bad, not life-threatening exactly, but I certainly was not able to sleep very well. I got constantly tired, I was swollen, I had all the symptoms." (Stull, Starling, Haas, & Young, 1999, p. 287)

Common symptoms of HF were identified through a qualitative focus-group approach with 23 persons with HF (16 were men, 15 were white) and their 18 family members (17 were female, 12 were white) (Bennett et al., 2000). The primary symptoms identified by participants living with HF included dyspnea and fatigue, cognitive impairment, loss of balance and falling, chest pain; trouble sleeping, difficulty bending over, weight loss, and emotional symptoms (Bennett et al., 2000). Participants described their cognitive deficits as decreases in concentration, attention, and memory; they listed the three categories of emotional symptoms as fear, depression, and sadness (Bennett et al., 2000). The individuals with HF from each of the six focus groups consistently reported that dyspnea, the effects of diuretic therapy, and swelling were frequent problems; whereas the family members pointed out that impairments in attention, concentration, and memory, as well as falling and loss of balance, were of greatest concern to them.

<center>*Timeline*</center>

The timeline dimension is defined as the individual's belief regarding the amount of time expected for the development, duration, and recovery from a health threat (Diefenbach & Leventhal, 1996; Heidrich et al., 1994; Rachman, 1980; Meyer et al., 1985). Whether the individual views the timeline dimension as an acute, chronic, or episodic/cyclic model, this perceived time-frame is seen as a critical factor in guiding health behaviors (Horowitz, Rein, & Leventhal, 2004; Leventhal et al., 1984). The acute model relates to an illness that usually has a sudden, unexpected onset that is short in duration and self-limiting in nature, such as the flu or a cold. An illness categorized as

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episodic or cyclic is similar to the acute model except that the recurrent nature may not be predictable, as in a woman suffering from recurrent dysmenorrhea. The chronic model of the timeline dimension is usually associated with an illness such as arthritis, which has an insidious onset with no known cure. In addition, the individual is usually facing the expectation of worsening symptoms and serious consequences that negatively impact their QOL (Meyer et al., 1985).

Myer, Leventhal, and Guttman (1985), in a study of 180 individuals with hypertension, found that the choice the individual made to refer to the timeline of the illness as either acute or chronic was a significant predictor of whether the person would enter and remain in treatment. Those individuals who viewed their hypertension as chronic remained in treatment for the 6-month study and noted improved control of blood pressure. This was in contrast to those individuals who viewed their illness as acute or cyclic and who abandoned treatment at a significantly higher rate (Meyer et al., 1985). Similar findings were reported by Coutu, Dupuis, D'Antono, and Rochon-Goyer (2003) in a study of 208 individuals with high cholesterol who were assessed for illness representation at baseline and 3, 6, and 12 months. Also assessed were dietary intake, cholesterol lab tests, and biopyschosocial information. The misconception of high cholesterol being associated with an acute or cyclic timeline model was related to a significant rise in fat consumption over time and coincided with a 1.7 times increase in treatment drop-out at 3 months (Coutu, Dupuis, D'Antono, & Rochon-Goyer, 2003).

In a meta-analysis of 45 studies utilizing the CSSRM, Hagger and Orbell (2003) reported a positive correlation between a chronic timeline model and identity ($r = 0.16$)

and consequences ($r = 0.43$). That is, the perception of a chronic timeline model was associated with an increased number of symptoms and severity of negative outcomes. The negative correlation between timeline and cure/control ($r = -0.34$) indicates that the perception of an illness as chronic is associated with less possibility for cure/control. Research in chronic diseases dealing with pain indicate that the timeline model may be perceived more as constancy of the illness/symptoms, rather than duration (Scharloo & Kaptein, 1997).

In a study of 105 patients hospitalized for an MI or coronary angiography, Zerwic and colleagues (1997) found that 63% of those having suffered an MI and 43% of the individuals undergoing a coronary revascularization procedure indicated that they viewed their heart disease timeline model as chronic. Petrie, Weinman, Sharp, and Buckley (1996) also reported on illness perceptions within a group of 143 individuals who had experienced their first MI. The timeline dimension score was reported as the composite of three items and ranged from 5, which indicated an extreme acute model, to a maximum of 15 that represented a very chronic model. People who returned to work within 6 weeks had a timeline model more biased towards the acute direction than those who returned to work after 6 weeks (Petrie, Weinman, Sharpe, & Buckley, 1996).

There were only two studies in the literature that measured the illness perception attribute of timeline in a HF population. The first, by Fox (2000) in her study of congruence of illness representation between HF patients and their spouses, was based on a convenience sample of 60 individuals participating in a cardiac rehabilitation program. The patients and spouses scored their timeline models for HF as chronic. Horowitz and

colleagues (2004) conducted a qualitative study using a grounded theory approach to explore what community-dwelling individuals with HF ($N = 19$) understood about their illness perspectives, self-care, help-seeking behavior, attitude toward physicians, access to care, and their definition of and reaction to a worsening of their condition. The majority of individuals in this study described an acute model for their perception of the HF timeline. Most failed to demonstrate any clear understanding of the true chronic timeline of HF, its serious consequences, or its incurable nature. Those that perceived their illness as more acute were also less likely to perform the necessary monitoring and self-care behaviors that prevented or minimized an exacerbation of the illness.

The discrepancy found in the current literature on illness perceptions of the timeline dimension for HF indicates further need for study in this area. To obtain a more representative sample, this study actively recruited community dwelling older individuals living with HF but not currently enrolled in a cardiac rehabilitation program. A better understanding of how individuals with HF perceive the timeline of their illness may facilitate our understanding of their actions and self-care behaviors.

Cause

The *dimension of cause* is defined as the factor or factors the individual believes responsible for initiating the diagnosis of HF (AHA, 2005; Diefenbach & Leventhal, 1996). These causative factors could be viewed as either an internal susceptibility such as poor genetics or a vulnerability to external agents such as bacteria, viruses, and job stress. Medical literature identified coronary artery disease as the primary etiology for HF in 13 multicenter HF treatment trials involving over 20,000 patients over a 10-year time frame

(Gheorghiade & Bonow, 1998). Hypertension and valvular heart disease are the second and third most frequently seen reasons for HF in the literature, followed by myocardial toxins from alcohol or illegal drugs, myocarditis caused by a virus, and idiopathic dilated cardiomyopathy, a condition where no medical cause can be determined (Hunt et al., 2001). Research on the patient's causal attribution of HF is lacking in the scientific literature. It may be a question that is not asked because many times there is not a clear, definitive answer that can be given by the patient or explained by the HCP.

Attribution theory proposes that the majority of persons who experience a negative event such as the diagnosis of an MI or HF will engage in a search to understand what has happened, predict what the outcome will be, and attempt to gain some control over the threat (Heider, 1958; Kelley, 1967; Weiner, 1986). Findings from related studies with individuals who had experienced an MI revealed that greater than 80% of the participants provided attributions when asked (Affleck, Tennen, Croog, & Levine, 1987; Bar-On, Gilutz, Maymon, Zilberman, & Cristal, 1994; Gudmundsdottir, Johnston, Johnston, & Foulkes, 2001). It was also found that the number of causal attributions decreased over time. The number of causes elicited through cued attribution responses was shown to decrease by approximately 65% during the 12 months after discharge (Gudmundsdottir, Johnston, Johnston, & Foulkes, 2001). The investigators suggested that individuals may have narrowed down the possible causes over time or that they were less motivated to search for a cause over time. The process of focusing down from multiple to one or two specific causes may be beneficial in redirecting coping actions as individuals with chronic illness continue to learn to live with their disease.

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There are three dimensions within causal attribution theory that Weiner (1985, 1986) outlined as locus of causality, stability, and controllability. The locus of causality represents the aspect of an internal or external origin for the cause; stability refers to changeability of the cause over time; and controllability is linked to causes over which the subject has volitional control. In a review of 27 articles of causal attributions related to coping with illness, Roesch and Weiner (2001) found that when individuals who attributed their illness causation to an internal locus and saw the cause as changeable and controllable, they demonstrated a more positive psychological adjustment that was associated with the use of approach or emotion-focused coping techniques. In the same study, if individuals associated their illness causation with being unchangeable and uncontrollable, they had more negative psychological adjustment outcomes associated with the use of avoidance coping techniques (Roesch & Weiner, 2001).

Causal attributions are believed to influence the decisions individuals make in regards to following doctors' advice, performing self-care behaviors, and participating in rehabilitation programs. These attributions influence subjective health outcomes such as self-rated physical, social, and sexual functioning along with objective outcomes such as long-term prognosis, cardiac events, and NYHA classification (Agrawal & Dalal, 1993; Bar-On et al., 1994; Billing, Bar-On, & Rehnqvist, 1997; Petrie et al., 1996). Bar-On and colleagues (1994) studied causal attributions of 87 men who had experienced an MI 12 years previously. Within the 50 survivors of the original study, those who attributed the initial cause of the MI to an uncontrollable, external force such as fate or luck accounted for 24% of the self-reported decline of functional capacity, after controlling for age. The

authors suggested that the initial causal attributions associated with the MI might have

created a self-fulfilling prophecy because these persons with external views of causation

and negative perceptions of internal control over outcomes may have delayed the

implementation of better health practices that could support more positive outcomes

(Bar-On et al., 1994). Petrie and Weinman (1997) used factor analytic techniques to

analyze the causal attributions of 143 males who had experienced their first MI. The

initial 24 possible causes loaded onto three categories of attributions for the MI: lifestyle,

stress, and heredity. Only those individuals who attributed the MI to faulty lifestyle

showed significant improvement in diet and increased frequency of strenuous exercise 6

months after the MI (Petrie & Weinman, 1997).

In her study of the congruence of illness representations between 60 older HF

patients and their partners, Fox (2000) found that both were in agreement regarding the

attributed cause for the HF. Two-thirds of the participants identified external causes such

as heredity, stress, chance, germs/virus, pollution, other people, or poor medical care in

the past as reasons labeled "not their fault." Those attributing the cause to an internal

causation identified the following three categories: own behavior, diet, and state of mind

(Fox, 2000). The research also found no significant relationship between their perception

of cause of HF and adherence to therapeutic recommendations (Fox, 2000).

Although much is known about the causal attribution for individuals who have

experienced an MI, more study of the individual with HF is needed to determine if these

attributions are similar to the MI population's and whether there is a relationship between

causal attribution and self-care behavior. Future study to confirm Fox's initial findings of

causal attributions in HF will be important, along with the use of an instrument to measure more accurately the self-care behaviors associated with HF.

Consequences

Consequences are defined as the anticipated and experienced outcomes of the disease that may be physical, emotional, social, or economic (Diefenbach & Leventhal, 1996; Leventhal et al., 2001; Leventhal et al., 1984). The perception of consequences relates to the individual's judgment of severity based on the illness impact on that person's overall QOL and functional capacity (Rachman, 1980). Many of the statements related to consequence evaluation are comparative in nature, such as, "My life is worse than it was because of my illness" (Hagger & Orbell, 2003).

In a review of 101 empirical studies published between 1985 and 1995 dealing with illness perception in patients with chronic somatic illness, Scharloo and Kaptein (1997) identified 39 studies that measured the dimension of consequence as part of the CSSRM framework. In a study of 73 renal patients, researchers discovered that the perception of illness consequences was a better predictor of depression than the objective measurement of the illness severity (Sacks, Peterson, & Kimmel, 1990). In another study, 56 chronic pain patients reported a significant association between actual impairment and the belief that pain implies disability, independent of the amount of pain experienced by the individual (Riley, Ahern, & Follick, 1988). In several other studies, perceived consequences had a stronger relationship than self-rated severity of illness with these three outcomes: medical (Horowitz et al., 2004), psychological (Steed, Newman, & Hardman, 1999), and behavioral (Heijamns & de Ridder, 1998).

In a qualitative study of community-dwelling HF patients ($N = 19$), few participants described their underlying chronic HF condition as very serious (Horowitz et al., 2004). Participants did recognize the critical importance of seeking emergency care when a life-threatening exacerbation occurred with the onset of symptoms (difficulty breathing, chest pain, syncope) that usually necessitated an emergency hospitalization. The apparent lack of understanding of the consequences of HF and misconceptions regarding the timeline, causes, and self-management strategies available to control symptoms were thought to account for the absence of self-management behaviors to deal effectively with symptom exacerbations (Horowitz et al., 2004).

In a meta-analysis of 45 studies utilizing the CSSRM illness perception variables, Hagger and Orbell (2003) noted that the consequence dimension was significantly correlated in negative direction to physical function ($r = -0.18$, $p < .05$), psychological well-being ($r = -0.46$, $p < .05$), role functioning ($r = -0.43$, $p < .05$), social function ($r = -0.49$, $p < .05$), and vitality ($r = -0.45$, $p < .05$). There was a moderate positive relationship noted between consequences and psychological distress ($r = 0.50$, $p < .05$) that paralleled the findings in the dimensions of identity ($r = 0.36$, $p < .05$) and timeline ($r = 0.20$, $p < .05$).

Cure/Controllability

Cure/controllability is defined as the ideas the individual has about the anticipated and perceived responsiveness of the condition to self-treatment and expert intervention (Lau & Hartmann, 1983; Meyer et al., 1985). The attribute of cure/control was introduced initially by Lau and Hartman (1983) and was later added to the original four attributes of

the CSSRM by Leventhal and colleagues (1985). Although the medical community understands that HF is a chronic condition, often the layperson has developed a mental representation of HF that includes the unrealistic outcome of a cure. This inaccurate illness perception of the timeline, along with not understanding the serious consequences and causes actually responsible for the symptoms associated with the disease, makes it very difficult for many individuals with HF to establish effective strategies to manage or control the illness (Horowitz et al., 2004).

The control beliefs of an individual deeply influence the way a person experiences and tries to manage different areas of his or her life (Lachman, 1986; Rodin, 1987). Two of the components of control beliefs identified by researchers are *assimilation* and *accommodation*. Assimilation is represented by the individual placing responsibility for outcomes and achievements on either oneself, others, or fate/chance. This placement motivates efforts to counteract anticipated losses and influences QOL determinations based on how the outcomes are judged by that individual. Accommodation, also referred to as psychological adjustment, is the second component and takes into account the fact that a person's control beliefs are not based on just attaining preset outcomes and goals in order to be successful, but he or she also has the ability to realign those goals to meet a more realistic capability (Brandtstadter & Baltes-Gotz, 1990). An individual utilizing accommodation can achieve a desired outcome through cognitively reframing the situation.

Johnson and Morse (1990) found that regaining a personal sense of control was the core process involved in adjustment after experiencing an MI. The adjustment process

included four stages: defending oneself against a threatened loss of control; coming to terms with the MI; utilization of multiple strategies in an attempt to reestablish a sense of control; and if successful, movement to the final stage of adjustment that includes acceptance of limitations, resetting of goals, and a perceived sense of mastery. The inability to achieve this final stage resulted in the person experiencing cardiac invalidism and poor health outcomes (Johnson & Morse, 1990).

Researchers have found that an increased sense of personal control is associated with significant positive psychosocial outcomes for individuals undergoing major surgery and those with HF living in the community (Bohachick, Taylor, Sereika, Reeder, & Anton, 2002; Moser & Dracup, 1995; Tsay & Chao, 2002). In a 6-month follow-up study of individuals undergoing heart transplantation ($N = 28$), a sense of personal control during hospitalization was shown to be positively related to optimism ($r = .42$), satisfaction with life ($r = .49$), well-being ($r = .41$), lower levels of anger ($r = -.57$), and less depression ($r = -.52$) (Bohachick et al., 2002). In a study of 167 post MI, coronary artery bypass graft (CABG) surgeries, or combination of both, individuals were asked to rate perception of control related to their cardiac disease during hospitalization (Moser & Dracup, 1995). At the 6-month follow-up, those individuals indicating they perceived high control over their cardiac disease at baseline were significantly less anxious, less depressed, less hostile, and had better psychosocial adjustment (Moser & Dracup, 1995). Additional evidence in support of the positive influence that personal control beliefs have on psychosocial outcomes was seen in a study of 100 community-dwelling chronic HF subjects from Taiwan (Tsay & Chao, 2002). Perceived self-efficacy of being able to

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control and manage HF in the community had a direct effect on decreasing depressive symptoms. An indirect effect of perceived self-efficacy on depression through functional status was also demonstrated (Tsay & Chao, 2002).

Improvement in personal control beliefs as measured with specific self-efficacy scales has been shown to promote positive behavioral outcomes within elderly chronic illness populations (Clark & Dodge, 1999; Clark & Dodge, 1999; Lorig et al., 1999). In a one-year prospective study of 570 older women with heart disease, in which 22% of the sample reported HF as a primary diagnosis, Clark & Dodge (1999) demonstrated that a higher level of perceived self-efficacy at baseline was predictive of following a diet and maintaining an exercise program. These same women demonstrated significant decreases in their body weight and walked greater distances at both 4 months and one-year evaluations (Clark et al., 2000). A unique prospective study was reported that compared the general self-efficacy beliefs of individuals prior to the onset of HF with their functional decline 8 weeks later (Kempen, Sanderman, Miedema, Meyboom-de Jong, & Ormel, 2000). Among this sample of 134 Dutch elders, the individuals with higher levels of self-efficacy beliefs at baseline (prior to the HF hospitalization) had significantly less functional decline after onset of their disease compared to those with lower levels of self-efficacy (Kempen et al., 2000).

An individual's appraisal of control over an illness appears to influence both psychosocial and behavioral health behaviors. In general, those individuals who report a greater perception of personal control over their medical care and treatment demonstrated a more positive mood and exhibited a more positive adjustment to their illness through

the performance of appropriate self-care behaviors (Affleck et al., 1987; Bohachick et al., 2002; Moser & Dracup, 1995; Rodin, 1987). Those individuals who were more likely to take responsibility for personal control over day-to-day management of symptoms, as opposed to those who felt it was their HCP's responsibility, showed higher positive mood and psychosocial adjustment scores (Affleck et al., 1987). One theory offered in support of these findings is *participatory control* that emphasizes the active involvement of HCPs and chronically ill patients in a partnership to develop and implement treatment programs together (Lefcourt, 1984; Reid & Stirling, 1989).

Summary of Illness Representation Literature

The literature contains examples of each of the five dimensions of illness perception. The identity dimension is a primary concern for individuals with HF because of the difficulty associated with accurately monitoring and labeling the sometimes subtle and often complex symptoms of their illness. The lack of knowledge and skills to accomplish this accurate identification of symptoms becomes a challenge for HCPs and the individuals with HF to resolve in partnership. Understanding the individuals' beliefs regarding the timeline of their HF as acute, chronic, or episodic is critical because it may facilitate understanding of their actions and self-care behaviors. Just because HCPs understand the pathophysiology of a disease process and know the probable outcome, practitioners must not assume that individuals with HF will understand or accept that viewpoint. It has been shown that those individuals who do not treat HF as a chronic disease fail to perform the necessary monitoring and self-care behaviors that prevent or minimize an exacerbation of their illness (Horowitz et al., 2004).

To better understand the third illness dimension of *cause*, it can be contrasted with the medical term *etiology*. Cause is defined as the factors that the individual believes responsible for initiating the diagnosis of HF, whereas etiology is the study of the origin of a disease from the viewpoint of HCPs and the medical scientific literature. This highlights one of the basic assumptions of the CSSRM that emphasizes the importance of acknowledging an individual's perceptions of the health threat as being his or her reality, even if it goes against known medical evidence. If an individual with HF does not understand the actual cause, the person may choose not to comply with a prescribed medical regimen because the individual feels it is inappropriate or unnecessary. The mechanism of action identified in causal attribution studies with MI patients was that those individuals perceiving greater internal causation felt increased personal control that resulted in more positive outcomes. If individuals felt the cause of the illness was an issue they could do something about, they would be more likely to implement self-care behaviors that would result in positive outcomes. Fox (2000), the only researcher to study this particular issue in an older HF clinic population, reported 66% of this sample stated their HF was caused by external factors such as heredity, stress, chance, germs, and other people, with no significant association noted between causality and adherence behaviors. Further study of this variable in a community-dwelling population of elderly individuals with HF will be an important addition to the literature in relationship to self-care behaviors and QOL outcomes.

Although the dimension of consequences is related to individuals' judgment as to the severity of their illness, consequences focus on the anticipated and experienced

outcomes of the disease. Perceived consequences have been shown to be better predictors of depression and behavioral outcomes than self-reported severity-of-illness measures. In the qualitative study described by Horowitz, Rein, and Leventhal (2004), very few of the participants were able to describe their HF condition as having serious consequences. This lack of understanding of the consequences of HF and the misconceptions regarding the timeline and causes are thought to contribute to the failure of implementation of appropriate self-management behaviors to effectively deal with symptom exacerbations. Understanding individuals' illness experience from their perspective is critical. Individuals' perceptions of the consequences of a specific illness may motivate adherence to self-care behaviors that delay or prevent more serious outcomes to the disease. Although cure/controllability was not one of the five dimensions introduced in the original CSSRM, it is now recognized as a critical aspect that reflects individual, perceived responsiveness of the illness to self-treatment and/or medical interventions. The manner in which individuals perceive control over an illness appears to influence both psychosocial and behavioral health outcomes. Those individuals who have a higher sense of personal control over their illness demonstrate higher positive mood and psychosocial adjustment scores in addition to greater improvement in behavioral outcomes.

HF Self-Care Behaviors

The performance of self-care behaviors has been documented throughout history

and reflects the fact that individuals and families have always been the primary providers

of health care (Padula, 1992). Kleinman (1988), a medical anthropologist, points out that

even in modern industrialized societies 70% to 90% of all health care occurs in the

"popular sector" that is made up of the individual, family, social network, and community

health beliefs and activities. It is here that individuals first encounter disease and then use

their beliefs and values about illness to make decisions to forgo or institute treatment;

consult with friends, neighbors, relatives, and lay experts about what to do; or consult

with experts within the professional or folk sector.

Within the most recent health-related research literature, the term *self-care* has

frequently been used interchangeably with the term *self-management* (Deaton, 2000).

Self-care has come to mean different things to different people due to unique individual

perspectives on the multidimensional aspects of the self-care construct (Gantz, 1990).

Within the discipline of medicine, the medical treatment model views self-care as a minor

part of treatment, mainly involved with the performance of designated self-monitoring

activities along with simple treatment protocols. Pender (1996) notes that the discipline

of nursing regards self-care as involving the ability of the client to go beyond the level of

just monitoring symptoms and following treatments to the point of demonstrating the

knowledge and competencies that are useful in maintaining and enhancing health. Within

the nursing discipline, the meaning of self-care prior to 1976 involved just the simple acts

involved with activities of daily living, but that concept has grown to its present meaning

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that reflects individual actions directed towards both health maintenance and symptom management (Gantz, 1990). It is this philosophy that is incorporated into the foundation of the definition of HF self-care behaviors utilized in this dissertation. HF self-care behaviors are the coping procedures that an individual with HF performs to maintain health or control symptoms in response to a health threat. The performance of self-care behaviors in the HF population is seen as a means to improve outcomes such as the physical and emotional aspects of HRQOL.

The various ways in which self-care is measured complicates interpretations of current research literature. Some researchers have operationalized self-care as the score an individual receives reflecting the person's level of knowledge about HF self-management (Artinian, Magnan, Christian, & Lange, 2002; Artinian, Magnan, Sloan, & Lange, 2002) while others focus on listing the frequency with which an individual performs various known self-care behaviors (Artinian et al., 2002; Bennett et al., 2000; Bennett et al., 2001; Jaarsma, Stromberg, Martensson, & Dracup, 2003; Jaarsma et al., 2003). Others tend to focus on adherence to prescribed medical regimens and measure self-care in terms of compliance (Bennett et al., 2001; Ni et al., 1999; Wright et al., 2003). Recently, Riegel and colleagues have developed two instruments that are based on the naturalistic decision-making process involved in the choice of behaviors that maintain physiologic stability (self-care maintenance) and the response to symptoms when they occur (self-management) (Riegel et al., 2000; Riegel et al., 2004). Findings from 11 descriptive correlation studies related to self-care in the community-dwelling older individual with HF are discussed in the following section.

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HF Self-Care Behavior Operationalized as Knowledge

Artinian, Magnan, Christian, and Lange (2002) administered a 15-item, paper and pencil, self-report HF Knowledge Test to 123 people with HF and an average age of 65 (no standard deviation reported) but ranging in age from 36 to 84 years. The majority of participants were male (72%) and African American (60%) with the mean years of education being 11.69 (3.23). The majority was able to recognize symptoms of HF (67%), understand recommended alcohol restrictions (64%) and reasons for taking diuretics (60%), knew how to read labels for sodium content (52%), and could correctly identify the definition of an advanced directive (51%). However, more than half of the participants failed to identify the correct response for the appropriate self-care strategy to prevent rehospitalization (64%), the definition of HF (71%), or the need for routine weight monitoring (80%). Most of the participants were unable to correctly answer the knowledge questions concerning HF medications: diuretics (69%), digoxin (76%), and angiotensin-converting enzyme inhibitors (80%). Greater years of education were associated with higher knowledge levels ($r = .27$, $p = .002$,) and older age was negatively associated with HF knowledge scores ($r = -.20$, $p = .027$). The group of individuals who previously attended a health teaching or support group ($n = 15$) had significantly higher scores on the knowledge test than those who had not ($n = 108$, $U = 533[121]$, $z = -2.076$, $p = .038$). Findings must be interpreted with caution since the HF knowledge test was a new instrument with marginal internal consistency reliability ($\alpha = .70$) and limited evidence for validity.

A survey was conducted to determine level of HF knowledge and adherence to self-care behaviors in 113 patients referred to a specialized HF clinic for cardiac transplantation (Ni et al., 1999). The mean age was 51.0 (12.8) and the majority of participants were male (73%), Caucasian (86%), and had completed high school (85%). Approximately 40% of the sample was categorized as NYHA Class I or II and the remaining 60% fell into the categories of Class III and IV, which is to be expected with a cardiac transplant population. Three-fourths of the participants stated that they either had received written education materials regarding HF or had been provided verbal advice from their HCP about HF self-care, and 60% reported reviewing both written and verbal information. However, when asked how much they knew about HF, 38% of the participants stated they knew "little or nothing," and 49% said they only knew "some" about HF self-care. The mean of the CHF Knowledge Test was 11.6 (2.4) with a range of 3-16 out of a possible maximum score of 17. A significantly higher knowledge score was noted among those individuals who had been hospitalized in the past year, who had NYHA Class III or IV status, and who had received both written and verbal information about HF self-care from their HCP. The four symptoms of progressive HF that the majority of participants from this specialized HF clinic for cardiac transplantation could identify were increased shortness of breath (98%), fatigue after minor exertion (99%), swelling in the ankles (90%), and waking up at night coughing or short of breath (87%) (Ni et al., 1999). The symptoms not recognized by a large proportion of patients included the risk of weight gain (37%) and the need to go to the bathroom many times during the night (52%). A total of 39% of this population of advanced HF clients did not recognize

daily weight monitoring as an important health care strategy: 17% did not know they should weigh themselves daily, and an additional 22% thought that weighing themselves daily was not important. Thirteen percent of the respondents indicated that they were not aware they should restrict their sodium intake to less than two teaspoons a day and 21% of the group indicated that they were supposed to drink lots of water, as opposed to being on a fluid restriction of 1.5 to 2L a day.

HF Self-care Behaviors Operationalized as Adherence

In addition to the assessment of knowledge, Ni and colleagues (1999) also attempted to determine if the participants were adhering to their treatment regimen for HF. An 8-item adherence scale that assessed HF self-care behaviors in the area of medication dose compliance (two items), dietary sodium intake restriction (three items), weight monitoring (one item), and exercising (two items) was utilized to measure adherence to self-care recommendations. The maximum possible behavior score was 30. The majority (71%) of the participants stated they took their medication exactly as the physician prescribed. Less than half of the sample reported always avoiding salty food (35%) or always performing daily weights (44%). The mean for the adherence score was 16.6 (3.2) and it was significantly correlated with the knowledge score ($r = .33$, $p < .001$). In a multiple linear regression analysis, being unmarried, having lower self-efficacy, a lack of knowledge of self-care, no prior hospitalization, and not being referred to the clinic by a cardiologist explained 22% of the variance in poor adherence behaviors. Findings from this study regarding patients' limited knowledge about HF are especially

surprising given the advanced disease progression in this sample. Clearly, knowledge alone is not sufficient for action.

Using a qualitative focus group design method to determine what symptoms were experienced and what self-care strategies were employed to manage those symptoms, Bennett, Cordes, Westmoreland, Castro, and Donnelly (2000) studied 23 individuals with HF along with 18 of their family members. Seventy percent of the patient sample was male, and 65% identified themselves as Caucasian, with the remainder being African American. The participants in the focus groups were asked to think about symptoms that were caused by the heart disease and those that were caused by treatment for the heart disease.

The common symptoms reported by individuals with HF included diuretic-related symptoms such as urgency and frequency, shortness of breath, swelling, decreased concentration/attention span or loss of memory, loss of balance or falling, pain in chest, tiredness or weakness, trouble sleeping, difficulty bending over to perform an activity, and weight loss. The women expressed more negative emotional symptoms such as fear, depression, and worry. The 11 self-care categories that these individuals identified to manage HF symptoms included a change in physical activity levels, breathing assistance measures, position changes, temperature alterations, medication management, equipment or devices, adherence to a sodium-restricted diet, self-monitoring, distraction techniques, family support, and positive self-talk (Bennett et al., 2000).

Jaarsma and colleagues (Jaarsma, Abu-Sad, Dracup, & Halfens, 2000) conducted a randomized clinical trial ($N = 128$) to test the effects of education and support on self-

care behaviors for individuals hospitalized with exacerbation of HF. Participants in the intervention group ($n = 55$) received four in-hospital visits from the study nurse who provided standardized teaching, guidance, and support to the clients and their families regarding different aspects of HF and its treatment. The control group ($n = 73$) received usual care from the hospital nursing staff and their physicians. The average age of participants was 72 (9) years with 60% male, and all had either a NYHA Class III or Class IV classification. The intervention group reported significantly more self-care behaviors than the control group at one month, $t(126) = 3.8, p < .001$, and 3 months, $t(126) = 2.9, p = .005$. There was no significant difference in the group's scores at 9 months post-hospitalization, $t(126) = 1.6, p = .11$.

More than 75% of the participants responded that they failed to perform key self-care behaviors related to symptom monitoring of HF such as not reporting numerous symptoms including nausea, fatigue, a change in diuresis, weight change, or their failure to restrict fluids appropriately. While some reported thinking that these symptoms were not important to their health, many said they chose not to tell the doctor because they decided the symptoms were not related to their heart disease, or they believed the symptoms would go away in due time on their own. Even when an individual had an obvious sign of distress such as shortness of breath or leg edema, they chose more than half of the time not to notify the physician either because they did not want to upset others or they believed no one could do anything about it (Jaarsma et al., 2000).

Artinian, Magnan, Sloan, and Lange (2002) used a 29-item Revised Heart Failure Self-Care Behavior Scale to examine how frequently individuals with HF performed self-

care behaviors, the personal and environmental factors that affected self-care, and the relationship between HF knowledge and performance of self-care behavior. In the sample of 110 individuals, the average age was 64 (12), 78% were male, 63% were African American, and 60% were categorized as functionally impaired by their HF with 37% listed as NYHA Class III and 23% as Class IV. The HF self-care behavior items performed most frequently included taking prescribed medications and keeping doctor appointments. The least frequently performed behaviors included making contact with their physician concerning episodes of fatigue, nausea, or a sudden weight gain of 2 pounds or more in one day, not weighing every day, and drinking too much fluids.

Age was positively correlated to keeping doctor's appointments, taking pills as prescribed, refilling prescriptions on time, and getting a flu shot once a year. African Americans were more likely than Caucasians to report symptoms to the physician. Those individuals living with someone, as opposed to living alone, were more likely to ask for help when short of breath; contact their doctor after noticing symptoms of shortness of breath, edema, or weight gain; and not eat canned soups or TV dinners. Those who rated their health as poor were more likely to rest, limit activities, ask for help, and contact their physician regarding symptoms, compared to those who rated their health more positively. An intriguing finding was the inverse relationship between health status and performance of daily weighing. Those individuals who rated their shortness of breath as severe were the ones who were least likely to weigh on a daily basis. As the illness severity increased, the belief that the individual could lead a happy and good life with HF

decreased. Those individuals with lower annual incomes and lower levels of education were found to eat significantly more canned foods and TV dinners (Artinian et al., 2002).

A significant correlation ($r = 0.21$, p = .026) was noted between the scores reflecting a low level of knowledge and the total self-care behavior scores in this sample. Part of the reason for the poor performance of the HF self-care behaviors could be the lack of specific self-care knowledge. The authors point out that while knowledge may be necessary for self-care, it is not enough by itself (Artinian et al., 2002). For this reason it is important to understand the impact of both internal and external factors that influence the performance of HF self-care behaviors.

A randomized control trial performed by Wright and colleagues (2003) from Australia investigated the impact that patient education and self-management strategies such as daily recording of body weight and use of a patient diary would have on decreasing hospital readmission and improving QOL. The sample consisted of 197 individuals with either a first-time diagnosis or exacerbation of pre-existing HF. Those individuals randomized to the intervention group were given the opportunity to participate in a multidisciplinary heart management program which consisted of a HF clinic visit every 6 weeks with counseling by a HF nurse specialist and optimization of medication, planned primary care visits every 6 weeks, three planned patient education sessions, and provision of a diary and instructions on daily weighing. The 97 patients randomized to the usual-care group received standard post-discharge care without any structured patient education. Data were collected on both groups over a period of 12 months.

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The sample had an average age of 73 (12.5) years and most were male (64%) and Caucasians (77%). The NYHA classification was documented in only 176 of the 197 participants. It reflected a relatively functional group with 163 (93%) reporting Class I or II and only 13 (7%) reporting Class III. The measurement of self-care behavior in this study was based upon use of the HF diary that participants were to fill out and return to the researchers every three months. The diaries were to be utilized daily to annotate medication compliance, daily weights, and recordings of symptoms. Knowledge of self-management strategies was evaluated with a verbally administered four-item assessment that asked the following questions at the end of the 12 month study: 1) Do you have a way of monitoring your HF? If so, what? 2) Do you weigh yourself each day in order to monitor your condition? 3) Do you understand the significance of your weight increasing? 4) If your weight increased, what action would you take (Wright et al., 2003)?

Of the 100 individuals randomized to the intervention group, 76 chose to use the diary. Only 51 individuals (51% of the intervention group/ 67% of the control group) chose to keep a diary and consistently weighed themselves at least once a week. Those individuals who used the diary were found to have a significantly lower mortality rate (11% vs. 46%, $p < .0001$), were on more medications (median 9 vs. 6, $p < .006$), and attended more of their primary care physician follow-up visits (median 15 vs. 10, $p = .008$) than those not using the diary. Having scales in the home, an ejection fraction over 30%, and attendance to one or more education sessions were the three common issues for individuals who were successful with self-weighing within the intervention group. The

intervention group demonstrated a significant difference in knowledge over the control group in all four questions: method of self-monitoring (92 vs. 61, p = < .0001), use of self-weighing (87 vs. 29, p = < .0001), understands rationale for daily weighing (62 vs. 21, p = < .0001), and action plan (69 vs. 20, p = < .0001). The fact that only 20% of the participants in the control group were aware of what to do if their weight increased was a very alarming statistic. In summary, those individuals who attended the education sessions and used the diary made up three-fourths of the intervention group, and of this group approximately two-thirds (67%) adhered to the recommendations of monitoring their weight at least on a weekly basis. The positive outcomes of these behaviors resulted in a decrease in mortality, a higher rate of follow-up in visits with primary care physicians, and reporting of less severe HF symptoms (Wright et al., 2003).

HF Self-care Behaviors Operationalized as the Decision-Making Process

Carlson, Riegel, and Moser (2001) performed a cross-sectional descriptive study with 139 individuals aged 69.3 (13.9) years to describe their self-care abilities and the difficulties they experienced in achieving success in self-care. The study also compared the self-care abilities in those individuals experienced with HF to those who were inexperienced. The sample was comprised of 53% males, 73% retired from active employment, and 45% married. The degree of functional impairment was as follows: NYHA Class I = 28.1%, II = 29.9%, III = 39.5%, IV = 10.5%. The authors defined self-care as the active cognitive process undertaken by a person to maintain health or manage illness and disease (Riegel et al., 2000).

The most common HF symptoms reported by this sample were shortness of breath (94%), fatigue (80%), ankle edema (66%), difficulty breathing while sleeping (55%), palpitations (54%) and sudden weight gain (37%). Individuals who had suffered these symptoms were then asked to indicate how much difficulty they had in recognizing that each symptom was related to their HF. Over half of the sample indicated difficulty with recognizing the following four symptoms: sudden weight gain (61%), ankle edema (57%), difficulty breathing while sleeping (56%), and fatigue (52%). Newly diagnosed individuals with HF (less than two months) had significantly more difficulty recognizing the symptoms of HF than experienced individuals (Carlson, Riegel, & Moser, 2001).

Participants were asked to rate the importance of individual HF symptoms. Approximately two-thirds (63%) of the sample viewed shortness of breath with activity as very serious and needing critical response measures, in contrast to only 46% who rated shortness of breath at rest as very serious. The two symptoms rated as most important by the group overall were difficulty walking or climbing stairs and a decrease in energy level.

Individuals who had experienced shortness of breath were asked what self-care behaviors they performed to relieve symptoms. The primary self-care behavior strategies utilized by individuals with HF to relieve symptoms included resting, increasing their diuretic dose, decreasing sodium intake, decreasing fluid intake, grouping activities, sleeping with extra pillows or in a recliner, and utilizing self-calming techniques. Experienced individuals with HF were more likely than inexperienced to manage sudden

weight gain by reducing their sodium intake (75% vs. 45%) and taking an additional

diuretic dose (57% vs. 30%) (Carlson et al., 2001).

Self-efficacy was assessed within the four stages of self-care management that

include recognizing a change in signs and/or symptoms, evaluating the change,

implementing a self-care treatment strategy or taking action, and evaluating the

effectiveness of the treatment implemented. Only in the first stage where participants

responded that they felt very or extremely confident (54%) in recognizing signs and

symptoms of HF was a significant difference found when the newly diagnosed and

experienced groups were compared (p = .04). The remaining three self-efficacy scales did

not show any difference between new and experienced individuals when evaluating the

importance of signs and symptoms, taking action to relieve symptoms, or evaluating the

effectiveness of action taken (Carlson et al., 2001). These findings may indicate that as

individuals live with their HF they gain more self-confidence in recognizing the signs and

symptoms of the disease, but they fail to build their self-efficacy in the remaining three

areas of self-care management.

Several potential barriers to performing self-care behaviors also noted within the

findings of the development of this instrument included individuals with HF who

experienced symptoms from multiple co-morbidities and functional impairment with

basic activities of daily living such as walking up stairs and visual or hearing deficits

(Carlson et al., 2001). Many individuals with HF become very confused and

overwhelmed with the conflicting instructions about rest and exercise that are given by

various HCP and health agencies. For the same reason, the multiple diet instructions that

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an individual receives dealing with low sodium, low fat, low cholesterol, low sugar, and low calories become very difficult to understand and integrate into a realistic plan of action for a behavior change that affects major lifestyle habits.

Riegel and colleagues recently revised the original Self-Management of HF (SMHF) scale to decrease subject burden (Riegel et al., 2004). The new SCHFI instrument is only 18, rather than 65, items in length and requires 5-10 minutes to complete, as opposed to the original 20-30 minutes. Individuals are asked to indicate how often they perform six routine HF self-care maintenance activities. Self-care management ability, which is the active component of responding to symptoms and evaluating the effectiveness of treatment strategies, is then assessed. The questions for the self-care management are similar to those on the SMHF with the four-stage decision-making process, except only one symptom condition is being assessed rather than six separate scenarios. This format combination of self-care maintenance and self-care management into a single tool allows for the measurement of adherence of self-care behaviors and the evaluation of the decision-making process for self-care behavior. The SCHFI is comprised of three subscales (Self-Care Maintenance, Self-Care Management, and Self-Care Self-Confidence). The SCHFI also has potential for clinical application because it targets needed interventions more effectively and efficiently by identifying individuals who have difficulty recognizing their symptoms, those not adherent with recommended therapy, and those with a lack of knowledge about symptoms. This instrument was utilized for data collection in this study and its psychometric properties are addressed in Chapter 3.

Summary of HF Self-Care Behaviors

The concept of self-care behaviors has evolved in the nursing research literature from the simple measurement of knowledge level and compliance with prescribed medical practices to the more complex process of how individuals with HF make decisions regarding the management of their symptoms and illness. Although symptom recognition of an acute exacerbation of HF is very high in this population, the literature is clear that individuals with HF often fail to identify correctly the subtle, early warning signs of HF onset that require close self-monitoring. It is this higher level of complex self-care behavior that must be encouraged within the HF population to enable individuals to respond in an effective manner and produce positive health outcomes. Those individuals who do perform HF self-care behaviors that involve effective decision-making have decreased their risk of being readmitted to the hospital or death from HF. Additional research is needed to better understand the individual's perspective on HF and what motivates them to perform these HF self-care behaviors.

Quality of Life

As people live longer with HF due to improved treatment regimens and self-care behaviors, the research focus has shifted away from simply reducing mortality to issues related to preserving and improving QOL. Living longer with HF means a person may experience an impaired QOL as a consequence of physical symptoms, psychological distress, limitations of social activities, and treatment side effects (Berry & McMurray, 1999; Dracup, Walden, Stevenson, & Brecht, 1992; Konstam et al., 1995). Payers of health care are demanding QOL be measured and reported because it is becoming an

increasingly important indicator of successful treatment of a condition with climbing

costs because HF remains the most common reason for hospital admission for individuals

over the age 65. Healthcare researchers want QOL data because individuals with HF want

to see improvement in their personal QOL (Kinney, Burfitt, Stullenbarger, Rees, &

DeBolt, 1996). There is also the need to recognize what individuals with HF perceive as a

meaningful and acceptable change in their QOL (Revicki et al., 2000). This involves

assessment of the person's perception of whether the risks or effort expended to perform

the prescribed medical treatments to manage their HF was acceptable for the amount of

improvement in QOL they attained or maintained (Revicki et al., 2000).

The term QOL is a complex multi-dimensional concept that lacks a consensual

definition in the research community (Grady, 1993; Haas, 1999b). QOL has been referred

to as the excellence of one's life as a whole or the perceived happiness with one's life in

domains of importance to the individual (Campbell, Converse, & Rodgers, 1976; Cantril,

1965; Ferrans & Powers, 1985; Ferrans & Powers, 1992; Oleson, 1990). It is a phrase

that has taken on multiple meanings based on different instruments utilized to assess its

existence in various disciplines such as nursing, medicine, sociology, psychology, and

philosophy where research places individuals in dissimilar contexts (Farquhar, 1995).

QOL has been operationalized in the literature with measures of functional status, general

health, life satisfaction, well-being, adjustment, meaning of life, socioeconomic status,

self-esteem, and emotional factors (Farquhar, 1995; Ferrans & Powers, 1985; Zhan,

1992).

Attempts at describing aspects of QOL can be traced back to ancient times when Aristotle quantified happiness as a certain type of virtuous activity of the soul (McKeon, 1947). By defining health as being more than just the absence of disease and infirmity but also the presence of physical, mental, and social well-being, the World Health Organization, is credited with early development of the current QOL research framework within the medical community (World Health Organization, 1947). Day and Jankey (1996) presented an historical prospective on the evolution of QOL research in the U.S. following WWII. During the 1960s when crime and public disorder were becoming more prominent, researchers quantified the nation's QOL by collecting objective social indicators such as level of education, type of housing, and crime rates. In the 1970s, when it became obvious that this objective data would only predict approximately 15% of an individual's perception of personal QOL, researchers began to consider psychological or subjective indicators that included concepts such as happiness and satisfaction. By the 1980's, there emerged the gap theory of QOL that measured the difference between a person's present circumstance and a standard to which one compared oneself (Bach & Rioux, 1996). These same elements of objective-subjective indicators and gap theory principles continue to be the basis for the current QOL instruments (Bach & Rioux, 1996).

During the mid 1990s, the nursing research literature showed increasing work on the clarification of the concept of QOL with four critical attributes identified: (a) a general sense of satisfaction with one's life; (b) a mental capacity to assess one's own life; (c) an acceptable state of physical, mental, social, and emotional health; and (d) an

objective assessment by another that the person's living conditions are adequate (Haas, 1999a; Meeberg, 1993; Oleson, 1990; Zhan, 1992). Haas (1999a) proposed a conceptualization of QOL as primarily a subjective sense of well-being composed of the physical, psychological, social, and spiritual dimensions that are supplemented at times with objective indicators. These four subjective dimensions assess individuals' perceptions of their well-being and life satisfaction, while the objective data are identified through indicators labeled functional status. Haas (1999a) repeatedly stressed that the indicators are not true measures of QOL, but they function only as a means to assess the separate dimensions.

HRQOL

The term HRQOL was developed initially to differentiate between the umbrella term of QOL which encompasses such broad aspects as personal freedom, financial income, and quality of the environment (Guyatt, Feeny, & Patrick, 1993). Although HRQOL is related to the concept of QOL, HRQOL has a more narrow focus and reflects aspects of QOL sensitive to healthcare interventions. HRQOL is also considered more specific to research involving illness conditions than general QOL. HRQOL reflects the impact of the illness on the daily lives of individuals with chronic conditions such as HF (Nanda & Andresen, 1998). The importance of health in bringing about improvement in QOL has been shown to increase with age across the lifespan and varies individually based on multiple factors such as family, interpersonal relationships, finances, functional ability, and subjective feelings of happiness (Farquhar, 1995). Researchers use the phrase HRQOL to describe the aspects of QOL that they consider health care can modify.

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Unfortunately, there is no gold standard or strong theoretical basis to designate what aspects of QOL might be influenced by health conditions (Tully & Cantrill, 1999).

Similar to QOL, HRQOL is considered a multidimensional concept that at a minimum encompasses the physical and psychological domains by reflecting general health, physical symptoms, functional ability, well-being, and life satisfaction (Bennett, Baker, & Huster, 1998; Stull, Clough, & Van Dussen, 2001). Gill and Feinstein (1994) described HRQOL as "the uniquely personal perception of one's own health status" (p. 624). Unfortunately, the term HRQOL has taken on meanings similar to QOL, depending on how the researcher conceptualizes the term and what instrument is utilized to measure the outcome. Many times HRQOL and QOL are used interchangeably. The term HRQOL is preferred in this dissertation because it acknowledges a more focused approach towards assessment of outcomes (Bennett et al., 1998; Wenger, 1989).

In a study performed by Paul and Sneed (2002), individuals with HF were asked open-ended questions to define and give their perceptions of QOL. The sample of 17 males and 13 females had been involved in an outpatient multidisciplinary HF clinic for an average time period of 19.2 months ($SD = 9.9$). The majority of the participants were Caucasians (17) and the remainder African American (13) with an average age for the sample of 57.3 ($SD = 12.9$). Over 70% equated QOL with the ability to perform physical functions in the same way they did before developing HF (Paul & Sneed, 2002). Approximately 20% stated that QOL was equivalent to spiritual or mental health, and 10% of the group identified maintaining self-care activities and living longer. When asked about their reasons for living, individuals gave two major reasons for being alive: a

personal religion and having family such as children and grandchildren nearby. Other important reasons for living included doing things for others, helping society, maintaining social interactions, and remaining physically active. When questioned as to specific issues affected most by their HF, individuals emphasized the impact of symptoms causing physical limitations that resulted in disruption of family interactions and not being able to stay actively involved in the community. The presence of comorbid conditions such as arthritis and lung disease added to the symptom burden in addition to the individual expressing a loss of normalcy. Approximately half of the group indicated that if given a choice, they would prefer an improved QOL while 30% would choose an increased lifespan. However, of the 30% wanting to live longer, 50% qualified their response with comments indicating they would not want to be a burden to their families or be dependent on life support (Paul & Sneed, 2002).

For the purposes of this dissertation, HRQOL is defined as an individual's perception of the influence of HF on the physical, socioeconomic, and psychological aspects of life (Rector et al., 1987). The HRQOL is measured with the LHFQ (Rector et al., 1987), a disease-specific instrument based on the Wenger (1989) model that includes the three HRQOL dimensions of functional capacity, perceptions, and symptoms with their associated consequences. The first domain of HRQOL, functional capacity, involves physical activities that are necessary to perform the activities of daily living associated with an individual's occupation, recreation, and social or familial responsibilities. This also includes the assessment of the person's cognitive ability to make decisions and communicate. The second domain of the LHFQ is perceptions, which are the individual's

perceived life satisfaction and perceived health-related well-being. Evaluation of the individual's health perceptions also gives insight into their beliefs, value systems, and how the person with HF feels the disease has impacted personal ability to function on a daily basis(Wenger, 1989). The third domain of HRQOL associated with the Wenger model is symptoms. Wenger states that these symptoms may relate, not only to the disease, but also problems caused by comorbidities and side effects from treatments and/or medications (Wenger, 1989; Wenger, 1992).

Methodological Measurement Issues in HRQOL

Tully and Cantrill (1999) divided HRQOL outcome instruments into four groups: generic, disease specific, domain specific, and patient-centered. Generic outcome instruments focus on a broad range of aspects of the individual's life and, at a minimum, usually include the domains of physical, mental and social health (Bowling, 1995). Examples of generic HRQOL instruments include the Short Form 36 (SF 36) (Ware, 1993) and the Sickness Impact Profile (SIP) (Bergner et al., 1976). The major advantage of generic HRQOL instruments is that they allow for comparison across interventions and across a wide range of different disease states in addition to having a single number representing the net impact on quantity and quality of life (Guyatt et al., 1993; Mahoney & Barthel, 1965). The major weaknesses of generic instruments are that they may not focus adequately on the area of interest the researcher wishes to assess, and they may not be responsive to subtle changes over time (Guyatt et al., 1993; Tully & Cantrill, 1999). Disease specific outcome instruments tap into areas of the person's life that have been affected by the disease in question, such as disease-related symptoms that disrupt normal

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activities of daily living (Rector et al., 1987). This type of specificity accounts for the advantage found with improved responsiveness in the disease-specific instruments. Unfortunately, the narrow focus limits the possibility of detecting unexpected problems, such as side effects from medications. Consequently, several authors encourage simultaneous administration of both the generic and disease specific outcome measures, especially in longitudinal studies (Bowling, 1995; Tully & Cantrill, 1999).

Domain or dimension specific HRQOL instruments focus on very specific areas of health such as psychological well-being, activities of daily living, and pain (Tully & Cantrill, 1999). The Philadelphia Geriatric Center Morale Scale, Barthel Index, and McGill Pain Questionnaire are all examples of domain specific HRQOL instruments that have the advantage of allowing the researcher to concentrate on very specific areas of concern to collect data (Mahoney & Barthel, 1965; Melzack, 1975; Tugwell et al., 1987). The disadvantage of using a domain specific instrument is conceptually equating the importance of domain scores to overall HRQOL scores and trying to determine appropriate weights, such a determining how much impact the McGill Pain Questionnaire Scores should have in relationship to the Mini-Mental State Exam scores (Bowling, 1995).

Patient-centered HRQOL instruments seek the patient's viewpoint and allow the person to identify what is most important in his or her life (Tully & Cantrill, 1999). Scoring from a common baseline to measure change then follows individual selection. One example of this type of outcome instrument is the McMaster-Toronto Arthritis patient preference questionnaire. Respondents identify activities that are most affected by

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their arthritis and rank them according to their desire to do them without pain or discomfort. At a later time, the list of chosen activities is read back to the respondent, who self-reports whether there is a change in desire from baseline (Tugwell et al., 1987). The advantages of patent-centered HRQOL instruments are the unique patient perspective provided and the responsiveness that can come with individualized assessments. The significant disadvantages for implementation are the requirements for trained interviewers to administer questionnaires, in addition to a large time burden for the person completing the instrument. As with the disease-specific instruments, comparison between disease groups also becomes an issue.

Another aspect of debate in measurement of the HRQOL concept is utilization of multidimensional versus unidimensional instrumentation (Kaplan, 1988). The multidimensional approach allows for the separate measurement of the many dimensions of HRQOL such as seen in the Sickness Impact Profile that is made up of 136 items and yields 12 separate domain scores (Bergner et al., 1976). With the unidimensional approach, such as the Medical Outcomes Studies Short Form 36, an overall summary measure of HRQOL is provided (Ware, 1993).

Impact of HF on HRQOL

HF can significantly impact an individual's HRQOL by causing severe physical, role, and social impairment, as well as increasing psychological distress (Clarke, Frasure-Smith, Lesperance, & Bourassa, 2000; Dracup et al., 1992; Garg, Packer, Pitt, & Yusuf, 1993; MacMahon & Lip, 2002; Moser & Worster, 2000). Individuals with HF have the lowest physical functioning, social functioning, and health perceptions compared to

others with chronic illnesses such as hypertension, diabetes, arthritis, obstructive lung disease, or angina (Juenger et al., 2002; Stewart et al., 1989).

Age

HRQOL as measured by LHFQ scores has repeatedly demonstrated a significant inverse relationship in the HF population (Gottlieb et al., 2004; Grady et al., 1995; Worster, 2000). In a study of 155 community-dwelling individuals with HF ranging in age from 33 to 85 years ($M = 64$, $SD = 12$), younger patients had worse HRQOL scores on all three of LHFQ scores of total, physical subscale, and emotional subscale (Table 1) (Gottlieb et al., 2004).After a MI, younger individuals view their HRQOL as poorer than their elders view their own HRQOL. That finding may be explained by the older individuals' acceptance of symptoms and illness disruption as a natural occurrence associated with the aging process (Conn, Taylor, & Abele, 1991). Worster (2000) found in her study of 140 community-dwelling older individuals with HF that age alone explained 12.6 of the variance in a multiple regression predicting HRQOL, with the LHFQ total score as the dependent variable.

Symptom Severity

The NYHA functional classification system is the most common method utilized to measure the influence of symptoms on the functioning of cardiac patients (Riegel et al., 2002).The functional class system of I through IV was originally developed in 1928 and then revised in 1994 to include gradations of objective evidence for cardiovascular disease (classes A through D). Rector, Spencer, and Conn (1987), developers of the LHFQ, found in a population of 83 individuals with HF that the total score was

significantly correlated to the NYHA functional status ($r = 0.60, p < .01$). Similar

findings were reported from an outpatient HF program ($n = 61$) where individuals with a

decreased functional status perceived their HRQOL to be lower on their SF-36 physical

scores ($r = 0.36, p < .05$) and SF-36 mental scores ($r = 0.31, p < .05$)] (Westlake et al.,

2002). In other studies, significant differences in the LHFQ scores have been found

between the first three functional classification levels, but it is not as effective between

Class III and Class IV (Gorkin et al., 1993; Riegel et al., 2002). Worster (2000) found in

her studies involving 140 individuals with HF that adding NYHA classification as a

predictor to age as a predictor for QOL increased the explanation of variance by 5%.

Table 1

Age and Mean LHFQ Scale Scores

LHFQ scale	Age correlation (n=155)	Age<64yrs (n=74)	Age>64yrs (n=78)	t(df)	p Value
Total score	-0.269*	46.0 (27.7)	32.7 (24.0)	3.2 (150)	0.002
Physical	-0.226*	8.9 (8.0)	6.1 (6.5)	2.3 (140.8)	0.022
Emotional	-0.171*	20.1(12.6)	15.6 (14.4)	2.0 (150)	0.042

Note. A lower score on the LHFQ indicates increased HRQOL.

Adapted from S. S. Gottlieb, M. Khatta, E. Friedmann, L. Einbinder, S. Katzen, B. Baker

et al. (2004). "The Influence of Age, Gender, and Race on the Prevalence of Depression

in HF Patients." *Journal of the American College of Cardiology* , *43(9),* p.1546.

* $p < .05$.

Scores from the LHFQ were not sensitive to disease severity indicators such as ejection fraction (Berry & McMurray, 1999; Rector et al., 1987; Riegel et al., 2002). Individuals with relatively low ejection fractions of 20% to 30% tend to score similarly as those individuals with normal ejection fractions greater than 55% for both physical and emotional subscales on HRQOL tools (Riedinger et al., 2001).

Rehospitalization

Two separate studies focusing on the association of HRQOL and rehospitalization found that those individuals rehospitalized within six months of discharge demonstrated significantly lower baseline emotional subscale and total scores on the LHFQ and lower baseline physical, social, and perceived health perception scores on the SF 36 than those individuals who did not require rehospitalization (Bennett, Pressler, Hays, Firestine, & Huster, 1997; Konstam et al., 1996).

Social Support

The absence of emotional support among older hospitalized HF patients measured before admission is a strong predictor of the occurrence of fatal/nonfatal cardiovascular events in the year following the initial hospital admission (Krumholz et al., 1998). Single marital status was as a significant independent predictor demonstrating similar results with approximately one-third of the group having negative outcomes of death or readmission within 60 days of discharge (Chin & Goldman, 1997). Odds ratios were performed in both of these studies to determine the impact of being married as opposed to single/divorced/widowed when looking at the negative outcomes of cardiovascular events and rehospitalizations. It was found that those individuals who indicated they had some

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form of social support fared better than single individuals by odd ratios that ranged from 2.1 to 3.2 (Chin & Goldman, 1997; Krumholz et al., 1998). Although significant differences have been demonstrated with social support when looking at the specific outcomes outlined above, correlational studies involving marital status and LHFQ scores have not resulted in any significant findings (r = .08, p = ns) (Westlake et al., 2002).

Comorbidity

Frequently in clinical research trials, individuals with multiple comorbidities are eliminated from the study due to the potential complexity of interpreting results. In the studies where outcomes such as death or hospital readmissions were looked at, the adjusted hazard ratio was 1.3 (CI = 1.1-1.6) as measured by the Charlson Comorbidity Index (Chin & Goldman, 1997). There were no correlational studies found with HF patients that identified a quantifiable impact that the variable might have on the dependent variable of HRQOL, but Worster (2002) found in her study of predictors for HRQOL as measured by the LHFQ that comorbidity was not a contributing factor.

Gender

Men and women have a similar number and types of HF-related symptoms, level of depression, and rehospitalizations. However, women report significantly poorer HRQOL due to higher levels of impaired physical functioning (Bennett et al., 1998; Chin & Goldman, 1997; Friedman, 2003; Riedinger et al., 2001). A recent multi-site study of 640 men and women (50% each, matched for functional class, age, ejection fraction, and marital status) showed only minimal gender differences in scores at baseline (emotional

subscale only, p = .03) and no significant difference at three months on the physical

subscale, emotional subscale, and total scale scores (Riegel et al., 2003).

Depression

Significantly higher scores for mild to moderate depression were documented in

cross-sectional studies for as many as 85% of the hospitalized individuals with HF when

matched to control subjects (Havranek, Ware, & Lowes, 1999; Majani et al., 1999;

Zuccala, Cocchi, & Carbonin, 1995). The rates of major depression disorder in persons

currently hospitalized with HF ranged from 17% to 36.5% (Freedland, Carney, & Rich,

1991; Freedland et al., 2003; Koenig, 1998). Of particular interest was the finding that the

prevalence of major depression varied significantly within the group of individuals with

HF based on their functional classification of severity of illness. Only 8% of those with

NYHA Class I HF had major depression, while 40% of those with Class IV had major

depression (Freedland et al., 2003).

In a longitudinal study of an outpatient population of individuals with HF,

Murberg and colleagues found that depressed mood was a significant predictor of

mortality, when 25% of the depressed participants died within the 2 year study time

period compared to 11.3% of the nondepressed participants (MacMahon & Lip, 2002;

Murberg, Bru, Aarsland, & Svebak, 1998). In a study of depressive symptoms in a

community-dwelling sample of 6,1025 individuals over the age of 70, 11% of the 199

individuals suffering from HF met the criteria of depression based on a revised version of

the Center for Epidemiologic Studies Depression scale (CES-D). When the cohort with

HF was compared to a similar matched group of 1,856 persons with other heart

conditions (4.8%) and 4,070 persons with no heart condition (3.2%), their rate of depression was approximately twice that of the rest of the community (Turvey, Schultz, Arndt, Wallace, & Herzog, 2002).

Approximately half (48%) of the community-dwelling individuals participating in a study of the influence of age, gender, and race on the prevalence of depression in HF ($n = 155$) were identified as depressed based on scores of 10 or greater from the Beck Depression Inventory (BDI) (Gottlieb et al., 2004). The severity of depression was found to have a very strong positive correlation with the severity of impairment of HRQOL as reflected by the following correlation coefficients between the BDI and LHFQI scales that are all significant at $p < .05$: Total $r = 0.641$, Physical $r = 0.561$, and Emotional $r = 0.730$ (Gottlieb et al., 2004).

Interventions

Only within the last decade have the HF disease management research programs consistently included HRQOL as an outcome for research purposes (Moser & Dracup, 2001; Wenger, 1992). Examples of various program formats include the multidisciplinary team approach (Rich et al., 1995), HF clinics (Cline, Israelsson, Willenheimer, Broms, & Erhardt, 1998; Hanumanthu, Butler, Chomsky, Davis, & Wilson, 1997; Smith, Fabbri, Pai, Ferry, & Heywood, 1997), community case management (Jaarsma et al., 1999; Stewart, Marley, & Horowitz, 1999) and telephonic case management (Heidenreich, Ruggerio, & Massie, 1999; West et al., 1997). Overall trends in HRQOL outcomes of HF disease management programs included improvement in QOL scores as time from hospitalization increased, regardless of group assignment and improvement in the scores

of both the control and intervention groups. Overall, the degree of improvement in the intervention group was greater than the control by a magnitude of approximately 30% when comparing all types of disease management programs (Moser & Dracup, 2001). The main impact for several of these studies is on the physical functioning or symptom distress aspect of the HRQOL assessment (Stewart et al., 1999; West et al., 1997). For the remainder, a difference was shown in both physical and emotional/psychosocial functioning for improved QOL ranging from 15-39% (Hanumanthu et al., 1997; Rich et al., 1995; Smith et al., 1997). In a review article discussing the impact of nonpharmacological therapy on HRQOL for individuals with HF, Moser and Dracup (2001) speculated that the reason why different HF disease management programs are effective in improving HRQOL is because they decrease the symptomology associated with HF and its treatment. Other factors which these authors suggested were responsible for improvement in HRQOL included improved perceived control through education, decreased depression and anxiety through counseling, or increased social support which made more resources available for the person in need (Moser & Dracup, 2001).

Biobehavioral studies involving stress management and exercise training have shown promise within the HF population as a means to improve HRQOL. In a study involving 20 participants utilizing relaxation techniques as an intervention and QOL as an outcome (Heidenreich et al., 1999; West et al., 1997), it was noted that the stress management/coping intervention group demonstrated a reduction of depression (52%) and anxiety (39%) as opposed to the control group increasing in depression (25%) and anxiety (45%) (Kostis et al., 1994). Multiple studies have demonstrated the benefits of

exercise training on HRQOL with improvement ranging from 14-50% with disease-specific, general, and global change in well-being scales (Belardinelli et al., 1999; Kavanagh et al., 1996; Oka et al., 2000; Quittan et al., 1999; Tyni-Lenne et al., 1997; Wielenga et al., 1998; Willenheimer, Erhardt, Cline, Rydberg, & Israelsson, 1998). Positive improvements in HRQOL are thought to be exercise-related improvements in the ability to do more activities without the disabling symptoms of tiredness, breathlessness, and sleep disturbance (Witham, Struthers, & McMurdo, 2003) . This increase in functional capacity may bring about greater involvement in social interactions and escalated activity performance, resulting in an improvement of general health perceptions (Moser & Dracup, 2001). Other potential mechanisms of action proposed for HRQOL improvement include the impact of exercise on mood with the reduction of anxiety and depression that has been noted in other studies (Kavanagh et al., 1996; Kostis et al., 1994).

Summary of HRQOL

HRQOL is an important outcome to monitor in persons with HF. Individuals living with HF frequently appear to equate their level of HRQOL with the symptoms of fatigue and breathlessness that prevent them from participating in normal activities of daily living and social interactions. It is critical that researchers be very precise as to the aspects of HRQOL they are measuring and specify what instruments they utilize to obtain those scores. No studies were located that addressed the relationship of the CSSRM variable of interest in this study to HRQOL outcomes in the HF population. This study

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provides information about how individual perceptions of HF relate to self-care behaviors and HF HRQOL outcomes.

Summary for Chapter 2

This chapter reviewed the literature associated with the three primary variables related to the current study, which are illness representation, HF self-care behaviors, and HRQOL. The five dimensions of identity, timeline, consequences, control, and cause were discussed in conjunction with previous research utilizing the CSSRM theoretical framework. Information on the evolution and development of the measurement process for HF self-care behaviors were also discussed in this chapter under the headings of knowledge, adherence, and decision-making. The chapter concludes with a review of the impact HF has on the many aspects of an individual's life and discusses the measurement of HRQOL with in this population.

CHAPTER 3: METHODS

In this study, factors associated with the levels of the illness representation dimensions for a group of older community-dwelling individuals with HF were examined first to determine if there were relationships among the illness representation dimensions. These illness representation dimensions were then compared to HF self-care behaviors to determine if any relationships existed. The last step in the analysis was to determine if illness representation dimensions or HF self-care behaviors added significantly to the prediction of HRQOL in older community-dwelling individuals with HF after controlling for selected contextual factors such as the Specific Activity Scale (SAS) functional classification and number of ER visits/hospitalizations in the past year for HF. The following section will first present the design of the study and then address participant recruitment and data collection procedures. The chapter will conclude with a summary of each of the instruments utilized in the study.

Research Design

A descriptive correlational cross-sectional design was used to examine the relationship of illness representation dimensions, self-care behaviors, and HRQOL in older community dwelling individuals with HF after controlling for selected socio-demographic factors (e.g. age, marital status, medical comorbidity, and length of time living with HF). No previous studies were identified in which the interrelationships of these specific variables in the HF population were addressed.

This type of nonexperimental research design was chosen because it enabled the description and explanation of existing relationships without the manipulation of the

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independent variables (Fain, 1999). Reasons noted by Polit and Hungler (1999) for utilizing non-experimental research included (a) the measurement of human characteristics such as health beliefs or blood pressure that are not amenable to manipulation, (b) situations where ethical reasons prevent manipulation, (c) times in which it may be impractical to proceed with the resources available to the researcher, and (d) situations in which the researcher wishes to get a true picture of the everyday world of the participant. The purpose of a descriptive correlational research study is to describe the relationship among variables without inferring cause-and-effect relationships (Polit & Hungler, 1999).

Sample

The participants for this study were 98 community-dwelling individuals ages 55 years or older who had been diagnosed with HF by their physician or HCP for at least six months. Criteria for exclusion from the study were (a) that they could not understand and speak English and/or (b) were residing in a long-term-care facility where they required 24-hour supervision and assistance with activities of daily living.

The most complex analysis performed in this study was a multiple regression to predict the influence of the variables in the CSSRM and in self-care behavior on HRQOL (Cohen, 1988). Prior to initiating the study, a minimum size sample of 85 was established as the recruitment goal based on a regression power analysis using .30 R^2 of four covariates and .15 effect size for the 11 predictor variables with one dependent outcome variable (HRQOL) at an 80% power and .05 test significance level (Statistical Solutions, 1999). The number of covariates entered at Step 1 and predictor variables entered at Step

2 was based on the zero-order correlation with the dependent variable (LHFQ total score). Only those variables that demonstrated a significant correlation ($p < .05$) were to be entered into the regression.

Eighty-four individuals with HF were identified for the regression analysis after deletion of the 14 individuals who stated on the SCHFI they had not experienced any trouble breathing or ankle swelling due to HF. A zero-order correlation was performed between the dependent variable (LHFQ total score) and the variables representing the contextual factors and biological characteristics. SAS functional classification and the number of admits for HF/year were significantly related to the LHFQ total scores and thus entered as the covariates for Step 1 of the regression. The zero-order correlation was then performed between the dependent variable (LHFQ total score) and the IPQ-R subscales, which resulted in six significant findings of $p < .05$: identity (symptoms), timeline (acute/chronic), timeline (cyclic), consequences, internal cause, and external cause. Step 3 of the regression analysis required the inclusion of the SCHFI total score even though it was not significantly correlated with the dependent variable. A power analysis was performed for the subset of these 84 participants upon completion of the study utilizing the Nquery Advisor 5.0 software program (Nquery Advisor, 1999) with an alpha of .05 and adjusted $R^2 = .60$ for the nine predictor variables resulting in powe*r* = .80.

Procedures for Data Collection

This was a convenience sample drawn from multiple sites in central Texas (Table 2). The participants were recruited by flyers posted on public bulletin boards such as

churches, businesses, assisted living communities, and physician offices (A). Two 30-minute health seminars were developed and presented by the principal investigator at several assisted living and retirement facilities, At the seminars, a description of the ongoing research opportunity was explained, and flyers were available. The titles of these presentations were "Rehydration Strategies for Older Individuals: Are You Drinking Enough of the Right Stuff?" and "How to Make a Good Doctor's Visit Better." In addition, notices were placed in local publications of interest to the elderly such as church bulletins, community association newsletters, and via email. The protocols for recruitment procedures specific to each site are outlined in the Protocol for Participant Recruitment (Appendix B).

Table 2

Community Recruitment Sites for Data Collection ($N = 98$)

Recruitment Site	Frequency	Percent
VA outpatient clinic	37	37.8%
Physician office referral	28	28.6%
Email/personal contact	13	13.3%
Assisted living/retirement facility	7	7.1%
Home health agency	6	6.1%
Church	5	5.1%
Business	2	2.0%

Individuals who wished to participate in the study or wanted further information contacted the researcher by telephone or email. The researcher then answered all initial questions and performed an eligibility screening by asking the inclusion/exclusion criteria questions. If the participant met the entry criteria and wished to proceed with the study, arrangements were made for the researcher to meet with the individual in the person's home, place of business, or a convenient area such as a public library. The exceptions to this were the 37 participants from the VA outpatient clinic. Individuals recruited from the VA site who were participating in the research at the Austin Outpatient Clinic followed a process approved by the Central Texas Veterans Health Care System Institutional Review Board (IRB). Flyers were posted within the VA facility and several were handed to participants by their HCP. If the individual chose to be in the study, he or she then scheduled an appointment with the principal investigator at the same facility by calling the telephone number on the flyer. The protocol for completion of the questionnaire required that the principal investigator administer each questionnaire in person, rather than have each participant complete the forms at home and return by mail.

The informed consent was signed prior to initiating the administration of questionnaires and usually required approximately 10 minutes of discussion. The instructions for each of the questionnaires were explained, and any questions that arose were answered. Each participant was asked to complete a 21-item Demographic Data Sheet, the verbal 3 questions from the SAS, and three other instruments consisting of the 79-item IPQ-R measuring illness perceptions, the 18-item SCHFI assessing HF self-care behaviors, the 21-item LHFQ that evaluates HRQOL for individuals with HF, and a

question asking, "What it is like for people living with HF on a day-to-day basis"? The total time estimated for answering these questionnaires was approximately 40-50 minutes. Each participant received a 7-day pill organizer (retail value = approximately $7.00) upon completion of the interview.

Protection of Human Subjects

The University of Texas at Austin Institution Review Board (IRB) approved all forms of communication used to promote or advertise this study and the study protocol prior to the initiation of the study. Consents from the individuals who participated in this study were obtained following the guidelines of the School of Nursing Department Review Committee (DRC) and The University of Texas at Austin IRB to insure that their confidentiality was protected. An example of the consent is provided in Appendix C. Informed consent was obtained prior to initiating the collection of any data for this study. All data that were collected are maintained in a manner that cannot allow the names of the individuals to be identified with the data entered in the Statistical Package for the Social Sciences (SPSS) file. Confidentiality was protected with coded forms and questionnaires. Numbers were assigned to each individual, and the list linking these numbers to individual names was kept in a locked file accessible only to the principal investigator. Prior to any posting of information, approval through The University of Texas at Austin IRB was obtained. An additional IRB process was performed for participants recruited from the VA outpatient clinic.

Instruments

This study questionnaire included the following five instruments: Demographic

Data Sheet (developed by author), IPQ-R (Moss-Morris, Weinman, Petrie, Horne,

Cameron, & Buick, 2002), SCHFI (Riegel et al., 2004), LHFQ (Rector, Kubo, & Cohn,

1987), and an open-ended question requesting participants' comments about what living

with HF was like on a day-to-day basis (developed by author). The Cronbach's alpha

coefficients were calculated to determine the internal consistency of all subscale and total

scores. As shown on Table 3, the reliability coefficients for the two IPQ-R control

subscales and the SCHFI self-care management subscale were found to be lower than the

reported alphas.

Demographic Data Sheet.

The Demographic Data Sheet (Appendix D) prompted the participant to provide

his or her gender, age in years, marital status, number of years of education, approximate

date when first since diagnosed with HF, approximate last date admitted to ER or hospital

for HF, and number of times admitted to ER or hospital for HF over the past 12 months.

The Charlson Comorbidity Index was utilized to determine the number of coexisting

illnesses diagnosed for individuals by their physicians (Charlson, Pompei, Ales, &

McKenzie, 1987; Katz, Chang, Sangha, Fossel, & Bates, 1996). The Charlson

Comorbidity Index questionnaire was administered to 170 inpatients and then assessed

for accuracy against the medical records-based Charlson Comorbidity Index. Although

no interval between retest was reported, the test-retest intraclass correlation coefficient

assessed was 0.91 for the questionnaire and 0.92 for the chart-based Charlson

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Table 3

Summary of Internal Consistency for Scales ($N = 98$)

Scale	Number of items	Alpha	Literature alpha
IPQ-R			
Identity	19	.79	.75[a]
Consequences	6	.78	.84
Control (personal)	6	.60	.81
Control (treatment)	6	.65	.80
Timeline (acute/chronic)	6	.88	.89
Timeline (cyclical)	4	.77	.79
Causal attribution scale	18	.75	.71
Internal	11	.81	NR[b]
External	7	.47	NR[b]
SCHFI			
Self-care maintenance	6	.53	.56[c]
Self-care management	6	.48[d]	.70
Self-care self-confidence	6	.78	.82
SCHFI total	18	.75[d]	.76
LHFQ			
Physical dimension	8	.93	.92[e]
Emotional dimension	5	.84	.87
LHFQ total	21	.92	.92

Table 3 (continued)

[a]From "The Revised Illness Perception Questionnaire," by R. Moss-Morris, J. Weinman, K. Petrie, R. Horne, L. Cameron, & D. Buick, 2002, *Psychology and Health, 17(1)*, p. 5.

[b]NR = Not reported in literature.

[c]From "Psychometric Testing of the Self-Care of Heart Failure Index," by B. Riegel, D, Moser, M. Sebern, F. Hicks, & V. Roland, 2004, *Journal Cardiac Failure.10 (4),* p. 356..

[d]Calculation based on subset of 84 participants with symptoms of HF.

[e]From "The Minnesota Living With Heart Failure Questionnaire: Sensitivity to Differences and Responsiveness to Intervention Intensity in a Clinical Population," by B. Riegel, D. K. Moser, D. Glaser, B. Carlson, C. Deaton, R. Armola, et al., 2002, *Nursing Research, 51(4)*, p. 210.

Comorbidity Index (Katz et al., 1996). The Spearman correlation between the two measures was 0.63. The correlation was weaker with the less educated patients.

The Specific Activity Scale (SAS) measured the cardiac functional status of individuals derived from their response to survey questions related to common activities such as personal care, housework, occupation, and recreation (Goldman, Hashimoto, Cook, & Loscalzo, 1981). Based on the metabolic expenditure associated with the highest level of activity that can be performed to completion, individuals were categorized into one of four classifications (I = best, IV = worst) (Appendix E). The SAS differs from the NYHA functional classification system for categorizing cardiovascular disability because the NYHA classifies individuals according to degree of symptoms resulting from

ordinary or less than-than-ordinary physical activity (The Criteria Committee of the New York Heart Association, 1994) (Appendix F). The SAS has been shown to have acceptable inter-rater reliability between two observers (n = 75) (weighted kappa = .62) compared to the NYHA functional classification (weighted kappa = .41) (Goldman et al., 1981).

The SAS validity testing performed by the developers of the scale utilized the standard Bruce protocol treadmill exercise test as the gold standard. A true functional Class I was defined as the duration of exercise being more than 6 minutes. Class II was the duration of more than 3 minutes but less than 6 minutes, while class III was more than 1 minute and less than 3 minutes. Class IV was defined by the parameter of the individual not performing more than 1 minute of the Bruce protocol. The SAS demonstrated an acceptable agreement with the treadmill performances (n =150) (weighted kappa = .54, 68% agreement), compared to the NYHA classification (weighted kappa = .33, 51% agreement) (Goldman et al., 1981).

IPQ-R

The original Illness Perception Questionnaire (IPQ) was developed to assess the five components of illness representation from the CSSRM (Leventhal et. al., 1997; Leventhal, Nerenz, & Steele, 1984; Weinman, Petrie, Moss-Morris, & Horne, 1996). These five dimensions of identity, consequences, cause, control/cure, and timeline were the basis for the new instrument, the IPQ-R (Appendix G) that was utilized for this study. The changes to the IPQ-R included an expansion of the control and timeline subscales

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plus the addition of new illness coherence and emotional representation subscales (Moss-Morris et al., 2002).

The IPQ-R is a 78-item questionnaire; 64 items deal directly with the measurement of the five illness representation dimensions, 3 items list in rank-order the top three causal attributions, 5 items measure illness coherence, and 6 items determine emotional representation. Although the IPQ-R does contain questions related to illness coherence and emotional representation, data collected were not analyzed for this study. The authors of the questionnaire encourage each researcher to individualize the questionnaire to be disease-specific. In this study, references to "my illness" were changed to "my HF." This allowed the participants to focus their attention on relating how HF, specifically, affected them. The following paragraphs in this section will briefly describe the IPQ-R validation study and then explain the separate subscales, which were utilized to measure the various dimensions of illness representation.

Evidence in support of the validity for the IPQ-R was provided by a study involving seven illness groups performed in Auckland, New Zealand and an HIV patient group from Brighton, United Kingdom (Moss-Morris et al., 2002). To be included in the study, all individuals had to be capable of reading and writing English and have a medical diagnosis of their condition. The rheumatoid arthritis (RA), type II diabetes, and asthma groups were recruited from Auckland hospital outpatient clinics as they waited for their clinic appointments. Participation response rates to the survey were 90%, 92%, and 96% respectively. Recruitment was performed during treatment sessions for patients from a hospital-based chronic pain clinic (80% response rate) and for acute pain patients from a

private physical therapy practice (50% response rate). The chronic pain individuals had all experienced pain that was unexplained by medical signs alone for longer than 3 months, and the acute pain group presented with a first-time peripheral painful injury that had been present for less than 6 weeks. The individuals with multiple sclerosis were recruited from a mail-out questionnaire survey to two Auckland-based multiple sclerosis support groups (response rate 44%). The MI group was the only sample not derived from an outpatient setting because it consisted of consecutive admissions to the Coronary Care Unit at the Auckland Hospital with a confirmed diagnosis of acute MI (response rate 96%). These individuals completed the questionnaire within 1 week of their MI while in the hospital. The HIV sample was recruited from an HIV/AIDS clinic where all patients seeking treatment were asked to participate (60% response rate). The characteristics of participants in the eight illness groups are shown in Table 4.

Moss-Morris and colleagues (2002) performed two separate principal component analyses to validate the factor structure of the IPQ-R using the combined total off 711 individuals in the study. A varimax rotation and selection criteria of eigenvalues greater than 1.1 was utilized for both procedures, without the identity subscale being entered into either analysis. The first analysis dealt with the 50 items not associated with identity or causal attribution. These items initially fell into 11 factors that explained 68% of the variance, but 12 items that did not load or loaded onto more than one factor were deleted from the scale, and the analysis rerun. This resulted in 38 items that loaded on the seven factors of consequences, personal control, treatment control, timeline (acute/chronic), timeline (cyclical), illness coherence, and emotional representation. Almost all of the

items loaded exclusively onto one factor except for the consequences item "my illness is a serious condition" which loaded on the timeline factor (.49) in addition to the consequences factor (.57). There were also two personal control items that loaded onto the treatment control factor. These items were "there is a lot which I can do to control my symptoms" and "the course of my illness depends on me," which loaded .50 on treatment control and .51 on personal control (Moss-Morris et al., 2002).

Table 4

Characteristics of Illness Groups for IPQ-R Validation Study

Illness group	N	Gender (% Male)	Length of illness Mean (*SD*)	Age Years	Marital status (% married)
Asthma	86	28	26.6 (15.6)	41.9 (13.1)	53
Diabetes	73	59	9.8 (10.2)	57.4 (13.5)	59
Rheumatoid arthritis	76	24	16.3 (11.7)	59.0 (15.5)	53
Chronic pain	63	41	9.9 (9.0)	53.9 (11.1)	91
Acute pain	35	57	15.2 (13.5)[a]	35.7 (12.3)	71
Myocardial infarction	47	81	<1 week post MI	61.8 (13.4)	62
Multiple sclerosis	170	21	11.5 (10.0)	50.9 (13.0)	63
HIV	161	98	6.42 (4.1)	40.5 (8.8)	NA[b]

[a]Data for acute pain are given in days, not years. [b]NA = information not available.

Adapted from "The Revised Illness Perception Questionnaire (IPQ-R)," by R. Moss-Morris, J. Weinman, K. Petrie, R. Horne, L. Cameron, & D. Buick, 2002, *Psychology and Health, 17(1)*, p.3.

The principal components analysis conducted with the 18 causal attribution items

and varimax rotation resulted in a four-factor solution that accounted for 57% of the total

variance. After examining the contribution of the individual factors, the six items from

the psychological attributions factor explained 33% of the variance. The seven items in

risk factors accounted for 11%, and immunity contained three items that explained 7% of

the variance. The fourth factor was labeled accident/chance and accounted for only 6% of

the variance (Moss-Morris et al., 2002).

Identity Subscale

The identity dimension, which is comprised of the label of the illness and the

symptoms the patient views as being part of the disease, was measured by first having the

participants go through a list of 19 common illness symptoms and circle "yes" or "no" to

the statement "I have experienced the symptom *since my first congestive HF episode.*"

The participants were then asked to make a second determination and mark "yes" or "no"

for each symptom related to the statement "This symptom *is related to my congestive*

HF." The reason for the two-step process was to allow the participants to focus their

answers on the second determination of whether the symptom related to their HF, not just

that it occurred in the time frame following the first episode of HF. The yes-rated items

on this second rating were summed to obtain the identity subscale score, which ranged

from 0-19. A higher score on the identity subscale reflects a higher occurrence of

perceived HF symptoms. The 12 commonly experienced symptoms designated in the

original IPQ and two new symptoms from the IPQ-R are supplemented with six

additional new items identified in the review of the literature and added by the author for

this dissertation (Table 5) (Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000;

Dunbar & Dracup, 1996; Fox, 2000; Horowitz, Rein, & Leventhal, 2004).

Table 5

Identity Subscale Items (19 items)

IPQ identity items	IPQ-R identity items	Supplemental items
Nausea	Sore Throat	Chest Pain
Breathlessness	Wheeziness	Swollen feet and ankles
Weight loss		Weight gain
Fatigue		Difficulty concentrating
Stiff joints		Cough
Sore eyes		Loss of balance
Headaches		
Upset stomach		
Sleep difficulties		
Dizziness		
Loss of strength		
(Pain – replaced with Chest pain)		

Note. Supplemental items were added by author for this dissertation study.

In a test done by Moss-Morris and colleagues (2002) to support the construct

validity of the identity subscale from the new IPQ-R instrument, a paired samples t-test

was performed between the symptoms-experienced portion of the subscale and the

disease-specific sypmptom portion of the identity subscale. The t-test showed a significant difference $t(15.94)$, $p < .001$) (degrees of freedom not identified) providing support for a conceptual difference between symptoms associated with general illness and disease-specific symptomology. The second area of support for evidence of construct validity was the variance in the frequency that the individuals endorsed symptoms on the identity subscale. Fatigue was the most frequently stated symptom with 76% of individuals indicating its presence with their illness. Pain, loss of strength, sleep difficulties, and stiff joints were reported by over 50% of the individuals. Only 13% of the participants noted they had a sore throat, and the remaining symptoms were noted in approximately 25% of the individuals (Weinman et al., 1996). The internal consistency alpha for the current study ($N = 98$) was .79, higher than the .75 reported in the sample utilized for development of the IPQ-R ($N = 711$) (Moss-Morris et al., 2002). The test-retest reliability within a renal patient population (n=28) over a 3-week period was stable ($r = .80$, $p < .001$) (Moss-Morris et al., 2002).

Consequence Subscale

The consequences subscale (six items), which measures the expected effects and outcome of the illness, is rated on a 5-point Likert-type scale: strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree (Table 6). This same 5-point Likert scale is utilized for all the remaining IPQ-R subscales. For each subscale, the total is summed and divided by the number of items in the scale to obtain an average score. Scores can range from 1 to 5 with the higher score reflecting more negative outcomes resulting from the HF as perceived by the participant. The internal consistency reliability

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reported for the consequences subscale was a Cronbach's alpha = .84, and the test-retest

at 3 weeks reported as a Pearson correlation coefficient = .74 (Moss-Morris et al., 2002).

In this sample the Cronbach's alpha for the internal consistency was .78.

Table 6

Consequence Subscale Items
_____
My HF is a serious condition.

My HF has major consequences on my life.

My HF does not have much effect on my life.[a]

My HF strongly affects the way others see me.

My HF has serious financial consequences.

My HF causes difficulties for those who are close to me.
_____
[a]Reverse code response.

Personal Control Subscale

The cure/control dimension, which deals with how one recovers from or controls

the illness, is expanded in the new IPQ-R into two subscales to assess personal control

and treatment control. The personal control subscale was further clarified through factor

analysis to be comprised of six questions pertaining to self-efficacy beliefs, i.e., how

much confidence the individual has in his or her ability to perform the task at hand. The

same 5-point Likert-type scale is utilized for the personal control subscale with a range of

1 to 5 with the higher numbers reflecting a greater sense of personal control or self-

confidence (Table 7). The Cronbach's alpha measurement of .81 reflects a good stability

in the internal consistency of the subscale for the tested population. The test-retest over a 3-week time period was low, though, with a Pearson correlation of .46 (Moss-Morris et al., 2002).The alpha for this sample was .60, which was lower than the reported alpha in the literature. An inter-item correlation analysis was performed on this sample, and the two reverse-coded items were found to have the lowest corrected item-total correlation (ip15r Nothing I do will affect my HF = .14, ip17r My actions will have no effect on the outcome of my HF = .27). It may have been that the reverse-coded technique made answering these questions confusing for this medically compromised older population.

Table 7

Personal Control Subscale Items

There is a lot that I can do to control my symptoms.

What I do can determine whether my HF gets better or worse.

The course of my HF depends on me.

Nothing I do will affect my HF.[a]

I have the power to influence my HF.

My actions will have no affect on the outcome of my HF.[a]

---

[a]Reverse code response.

Treatment Control Subscale

　　　The treatment control subscale (five items) is the second component of the expanded control dimension for the new IPQ-R that focuses on the assessment of the individual's belief in the treatment or recommended advice. This concept has been

labeled as outcome expectancies by other social psychologists (Bandura, 1997). The scores for this subscale also range from 1 to 5 with higher scores reflecting the individual's belief that actions taken will result positive outcomes for making HF better (Table 8). The internal consistency reliability coefficient (Cronbach's alpha = .80) and the test-retest over a 3-week time period ($r = .63$) were both acceptable in the literature (Moss-Morris et al., 2002). The alpha for this sample was .65, which was also lower than the reported alpha in the literature (.80). As with the personal control inter-item correlation analysis, the two reverse-coded items were found to have low corrected item-total correlation (ip19r There is very little that can be done to improve my HF = .30, ip23r There is nothing which can help my condition = .43). There, the reverse-coded technique may have also accounted for the difference in the alphas reported between samples.

Table 8

Treatment Control Subscale Items

There is very little that can be done to improve my HF.[a]
My treatment will be effective in curing my HF.
The negative effects of my HF can be prevented (avoided) by my treatment.
My treatment can control my HF.
There is nothing that can help my condition.[a]

[a]Reverse code response.

Acute/Chronic Timeline Subscale

   The timeline dimension, which addresses how long the patient believes the illness will last, is measured with both the acute/chronic and the cyclical timeline subscales. The acute/chronic timeline subscale (six items) ranges in score from 1 to 5 with the higher score indicating a perception of the illness prognosis requiring greater time or being the equivalent to a chronic situation such as arthritis (Table 9). If the score for the timeline were a low number, this would indicate a perception of a short duration for the illness and be equivalent to a prognosis of an acute illness such as a cold or flu episode. Internal consistency in the literature was noted at .89 with Cronbach's alpha and the test-rest at 3 weeks was $r = .76$ (Moss-Morris et al., 2002). The Cronbach's alpha for this sample was .88.

Table 9

Acute/Chronic Timeline Subscale Items

My HF will last a short time.[a]
My HF is likely to be permanent rather than temporary.
My HF will last for a long time.
This HF will pass quickly.[a]
I expect to have this HF for the rest of my life.
My HF will improve in time.[a]

[a]Reverse code response.

Cyclical Timeline Subscale

The new aspect of cyclical timeline was added to the timeline dimension by the developers of the IPQ-R to capture this aspect of disease occurrence that was unique to some illnesses that reoccur at somewhat regular patterns. This can be applicable to either acute or chronic disease states but is probably more appropriate in the chronic timeline assessment. The cyclical timeline (four items) is also set up on the 5-point Likert scale that results in a score that ranges from 1 to 5 (Table 10). Higher scores on this subscale indicate the perception that the illness comes and goes and that it is very unpredictable and changes day to day. The Cronbach's alpha reported during the development of the IPQ-R instrument in evidence of internal consistency reliability was .79, and the test-retest was $r = .72$ (Moss-Morris et al., 2002). The Cronbach's alpha for this sample was .77.

Table 10

Cyclical Timeline Subscale Items

The symptoms of my HF change a great deal from day to day.
My symptoms come and go in cycles.
My HF is very unpredictable.
I go through cycles in which my HF gets better and worse.

Causal Attributions Subscale

The cause dimension, which assesses an individual's personal ideas about the etiology of his or her illness, is measured in a unique manner because of the desire to

make the instrument responsive to the needs of the researcher in varied cultural settings and populations with different illnesses. The subscale is comprised of 18 items that utilize the standard 5-point Likert scale with scores that range from 1 to 5. The suggestion of the authors is not to score the cause subscale if the study sample is less than 85 (Moss-Morris et al., 2002). For samples greater than 85, the suggestion is to start an analysis of separate items and rank by severity the causal factor identified for HF. The top 10 of this list is factored by principal component analysis to allow for consolidation of the items into groupings. This list of consolidated items then becomes the causal attribution scale (Hagger & Orbell, 2005; Weinman, Petrie, Sharpe, & Walker, 2000).

The instrument authors suggest that a factor analysis of the study results be performed to determine if the analysis coincides with the standard four-factor subscales suggested for scoring the causal attributions found in Moss-Morris and colleagues (2002)(Hagger & Orbell, 2005) (Table 11). Each factor is then treated as a unique individual subscale measuring the specific aspect of cause. The cause dimension is expanded into the four subscales of psychological attributions, risk factors, immunity, and accident/chance. Additional or different subscales may be identified unique to the population being studied. Within the population of 711 individuals studied for the validation of the IPQ-R, the following Cronbach's alphas were reported for internal consistency reliability coefficients and Pearson Correlations for 3-week test-retests: psychological attributions subscale (.86, .87), risk factors attributions subscale (.77, .88), immunity attributions subscale (.67, .78), and accident or chance attributions subscale (.23, .86) (Moss-Morris et al., 2002).

Table 11

Causal Attribution Subscale Items

Psychological	Risk factors	Immunity	Accident/Chance
Stress or worry	Hereditary	A germ or virus	Chance or bad luck
My mental attitude	Diet or eating habits	Pollution in the	Accident/injury
(e.g.,negative	Altered immunity	environment	
thinking)	My own behavior		
Family problems	Past, poor medical care		
Overwork	Aging		
My emotional state	Smoking		
(e.g., feeling down,	Alcohol		
lonely, anxious.)			
My personality			

In this study, the top 10 causes ranked by average-item means were diet or eating habits, heredity, aging, stress or worry, personal behavior, smoking, overwork, pollution in the environment, poor medical care in the past, and personal emotional state. These 10 items were then factored utilizing a principal components analysis with varimax rotation and eigenvalues set at 1.1. The analysis resulted in three factors explaining 55.8% of the variance (see Table 12). Because the inter-item correlation between aging and heredity was not strong ($r = .45$) it would be more appropriate to treat aging and heredity as two separate causes rather than two components of the same cause (Moss-Morris et al., 2002;

Weinman et al., 2000). The items on the cause subscale did not factor into categories similar to those presented by the instrument developers. The dissimilarities may be due to the older population and the influence of age and heredity on the analysis.

A decision was made to perform a two-factor principal components analysis with this sample, and it was found that a logical internal-external causal attribution scale was evident from the loading pattern (see Table 13). The advantage of utilizing this scale was also seen in having the input of all 18 items, rather than only the top 10. Unfortunately, the alpha for the external causal attribution subscale was not strong (Cronbach's alpha = .48), and, therefore, the external cause attribution subscale was eliminated from the final regression analysis.

<div align="center">SCHFI</div>

The SCHFI was developed to assess self-care ability of individuals in the HF population. The index measures both treatment adherence and decision-making aspects of self-care disease management (Riegel, Carlson, & Glaser, 2000; Riegel et al., 2004). The SCHFI is a self-report measure comprised of 15 items rated on a 4-point Likert-type scale that is divided into three subscales: Self-Care Maintenance (SC-MAINT), Self-Care Management (SC-MANAGE), and Self-Care Self-Confidence (SC-CONFID) (Riegel et al., 2004). The version of the SCHFI (R4 updated 8/21/03) that was utilized for this study contained three new test items, at the request of the tool developers, bringing the total to 18 items.

Table 12

Factor Analysis of Top 10 Causal Attributions (N = 98)

Causal attribution	Factor loadings	Alpha	Literature
Subscale groupings			
Psychological stress		.78	.86
Family problems	.85		
My emotional state (feeling down)	.77		
Overwork	.67		
Stress or worry	.61		
Poor medical care in my past	.47		
Lifestyle (risk factors)		.66	.59
Diet or eating habits	.79		
My own behavior	.71		
Smoking	.63		
Aging/Heredity		NC[a]	NA[b]
Aging	.81		
Heredity	.74		

[a] NC = Not computed due to only two items in grouping (Pearson r = .45).

[b] NA = Not available because the subscale was not reported in previous literature.

Table 13

Factor Analysis of 18 Causal Attributions ($N = 98$)

Causal attribution subscale groupings	Factor loadings	Alpha
Internal causal attribution		.79
Stress or worry	.66	
Alcohol	.61	
My mental attitude (negative attitude)	.60	
My own behavior	.59	
Smoking	.57	
My emotional state (feeling down)	.57	
Family problems	.55	
My personality	.53	
Overwork	.50	
Poor medical care in my past	.50	
Diet or eating habits	.45	
External causal attribution		.48
Chance or bad luck	.68	
Altered immunity	.63	
Pollution in the environment	.45	
Accident or injury	.40	
Germ or virus	.34	
Aging	.30	

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Table 13 continued

Causal Attribution Subscale Groupings	Factor Loadings	Alpha
Heredity	.04	

Psychometric testing for the 15-item SCHFI was performed using data from 760 individuals with HF located at seven clinical research sites in the United States (Riegel et al., 2004). The participants' ages in Riegel's study averaged 70.36 years (SD = 12.3) with 51% of the group comprised of males and 69% diagnosed with HF for a period of time greater than two months. The majority of the sample (65%) was retired with 51% indicating they were married and 28% stating they were widowed.

The instrument developers simplified the scoring difficulties encountered initially from an uneven number of items within the three subscales by transforming individual subscale scores to 100 points in order to allow them to be summed together for a total possible score of 300 points on the total SCHFI score (Riegel et al., 2004). A second problem was experienced when scoring persons who were asymptomatic for the prior three-month time frame or who were unable to respond appropriately to the self-care management subscale. In the previous versions of the instrument scoring instructions, asymptomatic individuals could be given credit for maintaining the symptom-free status. This was no longer allowed in the current version of the SCHFI (R4 updated 8/21/03), and the developers stated that no total score for the SCHFI could be computed for asymptomatic individuals with HF. It was recommended that investigators compare

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scores on the SC-MAINT and SC-CONFID subscales for these individuals with no data available on SC-MANAGE and SCHFI total (Riegel et al., 2004). Unfortunately, the impact of this constraint placed on the current study was the exclusion of 14 asymptomatic individuals from the data analysis of the final regression, resulting in a sample size of 84. A summary of the SCHFI subscale and total scores is located on Table 14. The reported levels of HF self-care behaviors (M = 213.1, *SD* = 32.5) for this sample (*n* = 84) were significantly greater than those reported by the instrument developers (*n* = 67) (M = 199.4, *SD* = 40.6) [*t*(83) = 3.85, *p* < .01 (two-sided)] .

Table 14

Summary of SCHFI Scores (*N* = 98)

Scale	Possible Range	Actual Range	Mean (*SD*)
Self-Care maintenance	0-100	33-100	76.72 (13.56)
Self-Care management	0-100	17-100	66.03 (17.22)[a]
Self-Care self-confidence	0-100	33-100	70.59 (13.83)
SCHFI total score	0-300	125-284	213.01 (32.52)[a]

[a]Calculation based on subset of 84 participants with symptoms of HF.

SC-MAINT

The first subscale of SC-MAINT consists of five items that the instrument

developers reported had the lowest coefficient alpha (.56) of the three subscales (n = 517)

(Riegel et al., 2004). Therefore the SC-MAINT is not desirable as a stand-alone

measurement scale. This extremely low alpha was explained by the authors as

understandable because health behaviors are unstable over time, independent of each

other, and controlled by different motivators. The raw scores for SC-MAINT can range

from 5 to 20 total, but with the transformation factor of 5, the maximum score of 100

points is achieved. The five common recommendations of HF maintenance which

individuals are asked to rate include: (a) Weigh yourself daily, (b) eat a low salt diet, (c)

take part in regular physical activity, (d) keep your weight down, and (e) get a flu shot

every year. The response set utilized for the SC-MAINT subscale includes the terms

never or rarely, sometimes, frequently, and *always*. A new item added by the authors of

the instrument to the subscale was "check your ankles for swelling". This increased the

total number of items to six with a point range of 6 to 24 and required transformation of

the final score to 100 with a factor of 4.17 (Riegel et al., 2004). The Cronbach's alpha for

this study (*N* = 98) was .53.

SC-MANAGE

The second subscale of SC-MANAGE consists of six items, which have shown an

acceptable internal consistency reliability coefficient of .70 (*n* = 98) determined by

Cronbach's alpha in the literature (Riegel et al., 2004). The internal consistency for the

current study was significantly lower with an alpha reported at .48 (*n* = 84). An inter-

item correlation analysis was performed, and several negative intercorrelations, ranging from $r = -.06$ to $r = -.23$, were noted between item 12 (call your doctor or nurse for guidance) and four of the five subscale items. The corrected item-total correlation for item 12 was -.09, with the remaining five items ranging from .21 to .39. Obviously, item 12 performed poorly with this population in this current study, which accounted partially for the low internal consistency. It may have been the demographic characteristics of a relatively experienced community-dwelling population that did not feel the need for calling the doctor or nurse to obtain guidance, as opposed to the population utilized by the developers (31% with less than two months since HF diagnosis and a majority recently discharged from a hospital).

The SC-MANAGE subscale breaks down into three separate sections (Table 15): (a) symptom recognition (one item scored 0-4), (b) treatment implementation (four items scored 1-4), and (c) treatment evaluation (one item scored 0-4) (Riegel et al., 2004). Each score is summed and then transformed with the transformation factor of 4.17 to obtain the maximum score of 100 points for the SC-MANAGE subscale. Before participants completed the SC-MANAGE section of the SCHFI, they answered the following question concerning their symptom status, even though it was not part of the final data analysis. The respondents were asked to mark "yes" or "no" whether they had trouble breathing or experienced ankle swelling related to their HF in the past three months (Riegel et al., 2004). This information was utilized to separate the symptomatic individuals from the asymptomatic for analysis purposes.

Table 15

Self-Care Management Subscale Items

_____

Symptom recognition: The last time you had trouble breathing or ankle swelling, how

quickly did you recognize it as a symptom of HF?

        Response options: N/A   Have not had these symptoms

                                  0   I did not recognize it

                                  1   Not quickly

                                  2   Somewhat quickly

                                  3   Quickly

                                  4   Very quickly

Treatment implementation: Listed below are remedies that people with HF use. If you

have trouble with breathing or ankle swelling, how likely are you to try one of these

remedies?

                1. Reduce the salt in your diet.

                2. Reduce your fluid intake.

                3. Take an extra water pill.

                4. Call your doctor or nurse for guidance.

        Response Options: 1   Not likely

                                  2   Somewhat likely

                                  3   Likely

                                  4   Very likely

Table 15 (continued)

Treatment evaluation: Think of a remedy you tried the last time you had trouble with

breathing or ankle swelling. How sure were you that the remedy helped or not?

        Response Option: N/A   I did not try anything

                                 1   Not sure

                                 2   Somewhat sure

                                 3   Sure

                                 4   Very sure

SC-CONFID

        The third subscale of the original SC-CONFID consisted of four items that were

scored on a 4-point Likert-type scale. The response set utilized for the answers included

not confident (1), somewhat confident (2), very confident (3), and extremely confident

(4). The SC-CONFID subscale had the best internal consistency reliability of the three

subscales with a Cronbach's alpha of .82 reported by the developers of the tool ($n = 758$)

(Riegel et al., 2004). Items in this subscale assessed the individual's self-efficacy towards

self-care ability in relation to each stage of the self-care management process, which

involved the steps of symptom recognition, symptom evaluation, treatment

implementation, and evaluation of treatment outcomes. The total raw points for the SC-

CONFID ranged from 4 to 16, but the transformation factor of 6.25 was utilized to obtain

the maximum score of 100 in order to provide standardization. The latest version of

SCHFI (R4 updated 8/21/03) included two new items in the SC-CONFID (Table 16),

which increased the subscale item total to six and resulted in an increased range of 6 to

24. The total score remained at 100 because the transformation factor was adjusted to

4.17 (Riegel et al., 2004). The alpha for the current study ($N = 98$) using the 6-item scale

was .78.

Table 16

Self-Care Self-Confidence Subscale Items

How confident are you that you can evaluate the importance of your symptoms?

Generally, how confident are you that you can recognize changes in your health if they

occur?

Generally, how confident are you that you can do something that will relieve your

symptoms?

How confident are you that you can evaluate the effectiveness of whatever you do to

     relieve your symptoms?

How confident are you that you can follow the treatment advice you have been given?[a]

How confident are you that you can keep yourself healthy and free of HF symptoms?[a]

[a]New items

Total SCHFI

     The total SCHFI score was computed only for those individuals who indicated

that they had been symptomatic with HF symptoms of difficulty breathing or ankle

swelling within the three months prior to test administration. Although psychometric

testing by the instrument developers demonstrated poor internal consistency with the SC-MAINT subscale, the SCHFI total internal consistency was adequate (alpha = .76) (n = 98) (Riegel et al., 2004). The alpha for the current study (n = 84) was .75. The tool developers provided evidence in support of construct validity with a confirmatory factor analysis that demonstrated the model hypothesis of self-care maintenance, self-care management, and self-care self-confidence (Riegel, Carlson, Glaser, 2000). When the model was run with 120 symptomatic patients, the model fit was adequate (comparative fit index = .73, non-normed index = .69), and the average absolute residual was small (.03). Construct validity was also supported with significant SCHFI and subscale differences (all < .05) between individuals experienced with HF and those newly diagnosed, which is consistent with the theoretical assumptions underlying the model (Table 17) (Riegel et al., 2004).

Individuals with HF are successful with self-care when they engage in healthy self-maintenance behaviors and also use problem-solving skills to address new symptoms quickly as a form of self-management. As self-maintenance and self-management improve, the person's self-confidence in their ability to control the outcome of the illness and treatment becomes stronger. The third test performed for evidence of construct validity by the tool developers was the assessment of intercorrelations among subscales (Table 18). All three subscales were significantly correlated, which supported construct validity. There were no subscales that demonstrated a high correlation (r > .42), which would have possibly indicated an overlap in measuring the same construct (Riegel et al., 2004).

Table 17

Differences of SCHFI Subscale Scores Based on Experience With Diagnosis.

| | Mean (SD) | |
| | Diagnosed < 2 months prior | Diagnosed > 2 months prior |
SCHFI score		
Self-care maintenance subscale*	66.1 (18.2) (*n* = 87)	70.3 (16.2) (n =296)
Self-care management subscale*	53.4 (20.7) (*n* = 26)	64.8 (20.5) (*n* = 67)
Self-care self-confidence subscale*	60.6 (18.3) (n =171)	66.9 (16.9) (n =378)
Total SCHFI score subscale*	179.5 (39.7) (*n* = 26)	199.4 (40.6) (*n* = 67)

Adapted from "Psychometric Testing of the Self-Care of Heart Failure Index" by Riegel, B, Carlson, B., Moser, D., Sebern, M., Hicks, F. D., & Roland, V., 2004, *Journal of Cardiac Failure,10(4),* p. 358.

*$p < .05$.

Table 18

SCHFI Subscales and Total Intercorrelations (*n* = 98)

	Self-care maintenance Subscale	Self-care management Subscale	Self-confidence Subscale
Self-care management	.39*		
Self-care self-confidence	.17*	.42*	
Total SCHFI score	.63*	.85*	.70*

Adapted from "Psychometric Testing of the Self-Care of Heart Failure Index" by Riegel, B, Carlson, B., Moser, D., Sebern, M., Hicks, F. D., & Roland, V., 2004, *Journal of Cardiac Failure,10(4),* p. 359.

p < .05.

LHFQ

The LHFQ was developed as a self-report disease-specific measure of HRQOL to assess perception of the influence of HF on the physical, socioeconomic, and psychological aspects of life (Rector et al., 1987). It was specifically designed to measure the effects of symptoms, functional limitations, and psychological distress on an individual's HRQOL. This 21-item self-report questionnaire required approximately 10-15 minutes to complete and was written at a 6th grade reading level. Many of the questions were drawn from the Sickness Impact Profile, a comprehensive assessment for the impact of illness in general. Participants responded to the 21 questions that covered symptoms and signs relevant to HF, physical activity, social interaction, sexual activity, work, and emotions (Berry & McMurray, 1999). An introductory question was read to

each person prior to administration of the survey that framed the questions to apply only to HF symptoms that had occurred during the past month. A 6-point Likert-type response scale (0 to 5) was utilized with response options of 0 = *no*, 1 = *very little*, and 5 = *very much*. There were no semantic descriptors associated with response options 2 through 4. By summing all the responses, a total score was obtained, which resulted in a range from 0 to 105. A lower score on the LHFQ reflected better HRQOL. Developers of the instrument reported that a decrease in LHFQ total score of 5 points or greater was considered a clinically significant indicator for improvement in symptoms (Rector et al., 1995). The responses of the LHFQ were also collated into two subscales reflecting physical and emotional dimension scores (Table 19) (Rector et al., 1987).

One study performed to provide evidence in support of construct validity for the LHFQ involved 198 individuals with HF (NYHA Class III) participating in a multicenter, randomized, double-blind, placebo-controlled study with the medication pimobendan (Rector & Cohn, 1992). After three months' follow-up, the intervention group receiving pimobendan therapy demonstrated significant improvements in median physical and total scores as compared to the placebo group. The LHFQ has also discriminated between NYHA functional Class I individuals and Class II individuals, although it is not as effective with Class III and IV (Riegel et al., 2002). Scores from the LHFQ were not sensitive to disease severity indicators such as ejection fraction (Berry & McMurray, 1999; Rector et al., 1987; Riegel et al., 2002).

Test-retest reliability has been reported at .84 (weighted Kappa coefficient) during a 7-21 day timeframe (Rector et al., 1987). In another sample with a one-week test-retest

period, the Pearson correlation for the total LHFQ was even higher ($r = .93$) (Rector & Cohn, 1992). During the same test-retest study, both the physical dimension Pearson correlation ($r = .89$) and the emotional dimension Pearson correlation ($r = .88$) were found to be acceptable (Rector & Cohn, 1992).

The psychometric properties of the LHFQ were recently assessed in an older sample of 1,136 individuals with HF from nine clinical trials representing eight different sites from the United States (Riegel et al., 2002). Each study involved an intervention study of HF patients that measured HRQOL with the LHFQ. Although approximately 72% of the participants were approached during their initial hospital stay, part of the exclusion criteria was that they could not be discharged to an institution requiring 24 hour nursing care. Therefore, the results of the data from one month represents more closely the community-dwelling population utilized for the current study. The average age of the participants was 68 years ($SD = 13.9$) with an evenly divided distribution by gender (female = 51%) and marital status (married = 48%, single/divorced/widowed = 52%). The majority (65%) had a high school education or higher, and NYHA Class III (44.5%) was the most common functional classification followed by Class IV (29.4%), Class II (20.9%), and Class I (5.2%). The internal consistency alpha coefficients reported for total LHFQ scores from this literature ranged from .92 at baseline to .96 one month later (Riegel et al., 2002). A Cronbach's alpha was also calculated for both the Physical

Table 19

LHFQ Subscale Items

Introductory question:

Did your HF prevent you from living as you wanted during the last month by:

Physical subscale:

making you sit or lie down to rest during the day?

making your walking about or climbing stairs difficult?

making your working around the house or yard difficult?

making your going places away from home difficult?

making your sleeping well at night difficult?

making your relating to or doing things with your friend or family difficult?

making you short of breath?

making you tired, fatigued, or low on energy?

Emotional subscale:

making you feel you are a burden to your family or friends?

making you feel a loss of self-control in your life?

making you worry?

making it difficult for you to concentrate or remember things?

making you feel depressed?

Subscale at baseline (.92) and one month (.95) and the Emotional Subscale at baseline

(.87) and one month (.92) (N = 1,136) (Riegel et al., 2002).

The internal consistency alpha coefficients for this study were similar to the

literature. The Cronbach's alpha for the total LHFQ score was .93, physical dimension

was .84, and emotional dimension was .92 for a sample of 98 individuals. A summary of

the subscales and total scores from the LHFQ can be viewed in Table 20.

Table 20

Summary of LHFQ Scores (N =98)

Scale	Possible Range	Actual Range	Mean (*SD*)
LHFQ physical	0-40	0-40	19.44 (12.14)
LHFQ emotional	0-25	0-25	7.29 (6.99)
LHFQ total	0-105	0-90	37.49 (23.45)

Note. Lower scores indicate a higher HRQOL.

Of interest, the reported levels of HRQOL in the current (N = 98) (M = 37.49,

SD = 23.45) were significantly better than baseline clinical trial scores reported by Riegel

(N = 1,136) (M = 50.71, SD = 23.25), [t(97) = -5.58, p < .01 (two-tailed)] (Riegel et al.,

2002). When comparing the HF self-care levels of the present sample (N = 98) (M =

37.49, SD = 23.45) with individuals who participated in low intensity interventions and

were assessed at the six-month time period (M = 47.87, SD = 22.9), they reported better

HRQOL [t(97) = -4.38, p < .01, (two-sided)]. With a high intensity intervention level, the

results reversed, and the current sample reported significantly lower HRQOL ($N = 98$)

($M = 37.49$, $SD = 23.45$) than the intervention group at the six-month time period of

assessment ($M = 32.07$, $SD = 23.08$) [$t(97) = 2.29$, $p = .02$, (two-sided)].

Data Analysis Procedures

Data were entered in the SPSS 12.0 statistical software program using numerical

coding for categorical variables. Checks were conducted to insure accurate data entry.

The data were examined for out-of-range values prior to analysis. After the data file was

cleaned, Cronbach's alphas were calculated to determine the internal consistency of all

total and subscale scores. Each total and subscale score was examined for normal

variance, skewness, and kurtosis. Descriptive statistics (frequency, means, and standard

deviation) were used to describe the sample. Correlation and hierarchical multiple

regression analysis were utilized to answer the research questions discussed below.

Research Question 1: What are the levels of the illness representation dimensions for

identity, cause, consequences, timeline, and cure/controllability as elicited by the IPQ-R

for a group of older community-dwelling individuals with HF?

Descriptive statistics (frequency, means, and standard deviation) were used to

describe the level of each illness representation as measured the IPQ-R subscales

(identity, acute/chronic timeline, cyclical timeline, consequences, personal control,

treatment control, internal causal attribution, and external causal attribution). Qualitative

data in response to the open-ended question were analyzed using conceptual and thematic

descriptions, referred to under the typology of qualitative descriptive (Sandelowski &

Barroso, 2003).

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Research Question 2: What are the relationships among the illness representation

dimensions as elicited by the IPQ-R for a group of older community-dwelling individuals

with HF?

This question was analyzed by computing the zero-order Pearson's correlation

coefficients to determine the relationships among the illness representation subscales

(identity, acute/chronic timeline, cyclical timeline, consequences, personal control,

treatment control, internal causal attribution, and external causal attribution).

Research Question 3: What are the relationships between illness representation

dimensions and HF self-care behaviors as measured by the SCHFI?

This question was analyzed by computing zero-order Pearson's correlation

coefficients to determine the relationships among the illness representation subscales

(identity, acute/chronic timeline, cyclical timeline, consequences, personal control,

treatment control, internal causal attribution, and external causal attribution) and the

SCHFI total score along with its three subscales (self-care maintenance, self-care

management, and self-care self-confidence).

Research Question 4: Do illness representation dimensions and HF self-care behaviors

add significantly to the prediction of HRQOL as measured by the LHFQ in older

community-dwelling individuals with HF after controlling for selected individual

contextual factors and biological characteristics such as age, marital status, co-

morbidity, and length of time living with HF?

A zero-order Pearson correlation was performed initially between the dependent

variable (LHFQ total score) and all the potential variables for the regression as a

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preliminary analysis of the data for the inclusion of regression variables on the basis of a significant correlation ($p < .05$). The hierarchical multiple regression was used to determine the relationship between the outcome variable (LHFQ total score), six predictor variables (the SCHFI total score and five illness representation subscales that met inclusion criteria with a significant Pearson correlation coefficient), and the two covariates consisting of biological characteristics (SAS functional classification and number of HF admits/year). Elimination of the "months since diagnosed with HF" variable occurred after an analysis of tolerances was performed to determine if any multicollinarity was present among the proposed covariates and predictor variables. Assessment for significant findings of missing data and for non-normal distribution of data showed no need for removal of any additional variables from the equation. A check for linearity was performed by doing a scatter plot matrix of the independent variables and the dependent variable with no non-linear patterns noted. A check for normality was performed by viewing a stem-leaf plot and histogram of the studentized residuals in addition to computing tests for normality plots with SPSS 12.0 software that demonstrated a good Q-Q plot along the line for each variable.

It was necessary to recode one variable "number of HF admits/year" by collapsing extreme outliers to minimize skewness prior to proceeding forward with the regression analysis. This was done by grouping the four individuals who indicated their number of admissions during the past year for HF were 4, 5, 10, and 15 within the category of "Four or more admit/year." This recoding minimized skewness from 4.4 to 1.2. The illness representation variable "external causal attribution" was excluded from the regression

after meeting entry criteria of Pearson correlation coefficient $p < .05$ due to a poor internal consistency alpha $= .46$. A scatter plot of the leverage, standardized dfbetas, and Cook's Distance against an arbitrary sequence number was performed to check for influential points.

The scores for the individual biological characteristics of SAS functional classification and number of HF admits/year were entered as the first block of the regression analysis. The scores of the six illness representations subscales were entered as the second block, and the SCHFI total score were entered as the third block. In this way, the degree to which HF self-care behaviors add to illness representations in the prediction of HRQOL after controlling for contextual factors and biological characteristics could be determined.

Summary for Chapter 3

This methodology section describes a descriptive correlational research design that was used to study the illness representation, self-care behaviors, and HRQOL of older individuals with HF living in the community. A description of the target population and proposed sample size are given along with the procedures involved with data collection. Each of the instruments in the study is discussed in detail followed by a summary of the statistical data analysis plan.

CHAPTER 4: RESULTS

This chapter presents the results of the analysis of the data. The findings include the demographic information for the final sample, and findings specific to each of the four research questions. Alpha was set at .05 for all statistical analyses. Themes identified in the qualitative data are also presented.

Description of Sample

One hundred and four individuals initially agreed to participate in the study. The final sample of 98 participants is the result of three participants who did not meet the minimum age criteria, two individuals not diagnosed with HF for a minimum of 6 months, and one person who was excluded from the study. This individual was excluded from the analysis based on his lack of attentiveness (he had to be awakened by his wife four times during the interview) and a response-set bias. His answer to each opinion question resulted in "*strongly agree*," even to reverse-coded items. This individual reported a 5th grade education level, and his wife stated he had co-existing medical conditions of sleep apnea and had suffered a recent stroke with possible cognitive deficits. Two individuals refused to sign the informed consent documents and therefore were not enrolled into the study.

The demographic data obtained for the final sample ($N = 98$) are summarized in Table 21. The age for the sample ranged from 55 years to 97 years ($M = 74.4$, $SD = 10.5$). The majority of the sample was male (59%), and almost half (49%) reported greater than a high school/GED level of education. While most of the participants were Anglo, 12%

were African-American, and 9% identified themselves as Latino/Hispanic. Almost half

(44%) of the participants reported they were presently married, and 34% were widowed.

Table 21

Demographic Characteristics of the Study Sample (*N* = 98)

Variable	Frequency	Percent
Gender		
Male	58	59.0%
Female	40	40.8%
Race		
White	86	87.8%
African American	12	12.2%
Ethnicity		
Latino/Hispanic	9	9.2%
Age (*M* = 74.4, *SD*= 10.5)		
55-64 yrs	20	20.4%
65-74 yrs	26	26.6%
75-84 yrs	33	33.7%
85-94 yrs	18	18.3%
95-104 yrs	1	1.0%

Table 21 (continued)

Variable	Frequency	Percent
Marital Status		
Married/Living with significant other	45	45.9%
Never married	5	5.1%
Divorced/Separated	15	15.3%
Widowed	33	33.7%
Education (highest grade level achieved) (M = 12.9, SD = 2.7)		
Less than 7th grade	1	1.0%
7th to 11th grade	16	16.3%
High school diploma/GED	33	33.7%
Some college (13 to 15 years)	28	28.6%
College degree (16 years or greater)	20	20.4%

Participants in this study had been living with their diagnosis for a median time of

3.5 years (M = 6.1 years, SD = 8.12). Over half of the group (52%) reported they were

diagnosed with HF for at least 3 years and a third (36%) for longer than 5 years. They

experienced, on average, at least one ER/hospitalization due to HF in the past 12 months

(M = 1.1 visits, SD = 2.02) with the median time since admission for the group as a

whole also at 1.11 years (M = 2.1 years, SD = 3.13). Approximately 65% of the group

fell into the functionally impaired category with classification at Class III or Class IV (as

determined by the SAS), and 57% of the group reported a Charlson Comorbidity Index of

3 or greater (M = 3.6, SD = 2.6). Health-related characteristics of the participants are summarized in Table 22.

Table 22

Health-Related Demographic Characteristics (N = 98)

Variable	Frequency	Percent
Time since diagnosed with HF (M = 6.1 years, SD = 8.12)		
6 months to one year	17	17.3%
One year	19	19.4%
2 to 5 years	34	34.7%
6 years or greater	28	28.6%
Number of ER visits/hospitalizations/12 months for HF (M = 1.1 visits, SD = 2.02)		
No ER visit/hospitalization	48	49.0%
One visit to ER/hospital	26	26.5%
Two visits to ER/hospital	11	11.2%
Three visits to ER/hospital	9	9.2%
Four or more visits to ER/hospital	4	4.1%
Time since last admission to ER/hospital for HF (M = 2.1 years, SD = 3.13)		
Less than 3 months	13	13.3%
3 to 6 months	17	17.3%
7 to 12 months	17	17.3%
2 years	22	22.4%
3 years or greater	29	29.7%

Table 22 (continued)

Variable	Frequency	Percent
Charlson Comorbidity Index (M = 3.6, SD = 2.6)		
One	16	16.3%
Two	26	26.5%
Three	24	24.5%
Four	8	8.2%
Five	8	8.2%
Six or greater	16	16.2%
SAS functional classification		
Class I (7-10 METs) [a]	8	8.2%
Class II (5-6 METs)	27	27.6%
Class III (2.5-4 METs)	60	61.2%
Class IV (2-2.3 METs)	3	3.1%
Co-existing diagnoses		
Hypertension	74	75.5%
Myocardial infarction	51	52.0%
Diabetes mellitus	31	31.6%
Cerebrovascular accident/TIA [b]	29	29.6%

[a]METS = metabolic equivalents. [b]TIA = transient ischemic attack

Research Questions

This section presents the results of the analysis of the data for each research question. Each question is listed with the results of the data analysis described. The scores for each illness representation scale are presented below. Table 23 presents findings related to Illness Identity, and Table 24 provides a summary of the scores in the IPQ-R cognition dimensions. The scoring method for the Illness Identity scale is different from the others since it consists only of adding the *yes* symptoms acknowledged by the individual as related to their HF. The average-item scores for the remaining illness representation scales are comprised of items that are rated 1 to 5 on a Likert-type scale reflecting *strongly disagree* to *strongly agree*, respectively. The causal scale is also unique in its calculation since it starts with the rating of 18 items on a 5-point Likert-type, followed by selection of the top 10 causes based on rank-order of item-average, which are then factor analyzed to allow for grouping into the most concise listing of causes (Table 25).

Research Question 1. What are the levels of the cognitive illness representation dimensions for identity, cause, consequences, timeline, and cure/controllability as elicited by the IPQ-R for a group of older community-dwelling individuals with HF?

Illness Identity

Higher scores on the Illness Identity scale mean the respondents had the perception of more symptoms being related to their HF condition. Within the study sample, the top three symptoms recognized as related to their HF by approximately 75% of the study sample were breathlessness, fatigue, and edema of the lower extremities.

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Table 23

Symptoms Recognized as Related to HF (*N* = 98)

Variable	Frequency	Percent
Breathlessness	86	87.8%
Fatigue	83	84.7%
Swollen feet and ankles	78	79.6%
Loss of strength	65	66.3%
Chest pain	58	59.2%
Dizziness	57	58.2%
Weight gain	55	56.1%
Sleep difficulties	50	51.0%
Wheeziness	49	50.0%
Cough	39	39.8%
Loss of balance	30	30.6%
Difficulty concentrating	28	28.6%
Weight loss	19	19.4%
Nausea	18	18.4%
Upset stomach	17	17.3%
Headaches	15	15.3%
Stiff joints	10	10.2%
Sore eyes	3	3.1%
Sore throat	1	1.0%

Table 24

Summary of IPQ-R Scores ($N = 98$)

Scale	Possible Range	Sample Range	Total Score Mean (*SD*)	Average Item Mean (*SD*)
Illness Identity	0-19	0-17	7.8 (3.64)	NA
Consequences	6-30	6-30	21.4 (5.29)	3.57 (0.88)
Control (personal)	6-30	15-30	24.7 (3.30)	4.11 (0.55)
Control (treatment)	6-30	9-25	18.3 (3.15)	3.65 (0.63)
Timeline (acute/chronic)	6-30	6-30	23.3 (6.16)	3.89 (1.03)
Timeline (cyclic)	4-20	4-20	11.3 (3.62)	2.84 (0.90)
Cause (internal)	11-50	11-50	25.5 (7.78)	2.55 (0.78)
Cause (external)	7-35	8-32	19.5 (4.71)	2.44 (0.59)

Consequences

The average item score on the six-item consequences subscale was 3.57 (*SD* = .88). Higher scores on this scale indicate the individual perceived the HF as having more serious negative outcomes or bad effects. The three items ranked as having the most serious consequences for the current study were"My HF is a serious condition" (M = 4.28, SD = 1.07), "My HF does not have much effect on my life (reverse-coded)" (M = 4.0, SD = 1.26), and "My HF has major consequences in my life" (M = 3.97, SD = 1.22).

Table 25

Causal Attributions of HF

Variable	Frequency	Percent
Internal causal attributions	Agree or strongly agree	
Diet or eating habits	61	62.3%
Stress or worry	57	58.1%
My own behavior	55	56.1%
Smoking	33	33.3%
Poor medical care in my past	31	31.6%
My emotional state (feel down, lonely, anxious, empty)	28	28.5%
Overwork	25	25.5%
Family problems or worries caused my illness	24	24.5%
My personality	14	14.3%
Alcohol	13	13.2%
My mental attitude (thinking about life negatively)	13	13.2%
External causal attributions		
Aging	66	67.3%
Hereditary - it runs in my family	60	61.2%
Pollution in the environment	24	24.5%
Chance or bad luck	17	17.3%
Altered immunity	15	15.3%

Table 25 (continued).

Variable	Frequency	Percent
		Agree or strongly agree
Germ or virus	12	12.2%
Accident or injury	12	12.2%

Control (Personal)

The control dimension, which deals with how one recovers from or controls the illness, is expanded in the IPQ-R into two subscales to assess personal control and treatment control. Higher scores reflect a greater sense of personal control or self-confidence. The average item score on this six-item subscale was 4.11 ($SD = .55$).

Control (Treatment)

The treatment control subscale is the second component of the expanded control dimension for the IPQ-R that focuses on assessment of the individual's belief in the treatment or recommended advice. Higher scores reflect individuals' beliefs that actions taken will result in positive outcomes for making their HF better. The group had an average item score of 3.65 ($SD = .63$) on the five-item treatment control scale.

Timeline (Acute/Chronic)

The timeline dimension, which addresses how long the patient believes the illness will last, is measured with both the acute/chronic and the cyclical timeline subscales. The acute/chronic timeline subscale is comprised of six items; higher scores indicate a perception of the illness prognosis requiring greater time or being the equivalent to a

chronic situation such as arthritis. Low scores indicate a perception of a short duration for the illness (e.g., an acute illness such as a cold or flu episode). This study sample had an average item score of 3.89 ($SD = 1.03$) on the acute/chronic subscale.

Timeline (Cyclical)

The cyclical timeline captures whether or not there are symptoms within the illness that reoccur at somewhat regular patterns or if they appear unpredictably. This can be applicable to both acute and chronic disease states but is probably more appropriate in the chronic timeline assessment. Higher scores on this subscale indicate the perception that the illness comes and goes and that it is very unpredictable and changes day to day. The average item score for this four-item subscale was 2.84 ($SD = .90$).

Cause (Internal and External)

The cause dimension, which assesses an individual's personal ideas about the etiology of the illness, is comprised of two subscales in this study: the 11-item Internal Cause subscale (areas within the individual's control) and the 7-item External Cause subscale (areas outside the individual's control). The individuals who rate high on the Internal scale would see their cause of illness to be something that was the result of actions within their control. The average item score for this 11-item subscale was 2.55 ($SD = 0.78$). The individuals who rate high on the External scale would see their cause of illness to be something that was the result of an action or an event outside of or beyond their control. The average item score for this 7-item subscale was 2.44 ($SD = 0.59$).

Research Question 2. What are the relationships among the cognitive illness representation dimensions as elicited by the IPQ-R for a group of older community-dwelling individuals with HF?

Table 26 presents the correlations among the subscale scores on the IPQ-R. There were several significant correlations of moderate strength noted. The identity subscale positively correlated with cyclical ($r = .35, p < .01$), consequences ($r = .40, p < .01$), and external cause ($r = .35, p < .01$). The strongest negative intercorrelations were between timeline (acute/chronic) and treatment control ($r = -.50, p < .01$), and the strongest positive intercorrelations were between timeline (acute/chronic) and consequences ($r = .43, p < .01$). The scores on the consequences subscale were correlated in a positive direction with identity ($r = .40, p < .01$), timeline (.43, $p < .01$), cyclical ($r = .36, p < .01$), internal cause ($r = .25, p < .05$), and external cause ($r = .26, p < .01$). Personal control had only one significant correlation, which was in a positive direction with treatment control ($r = .43, p < .01$). The internal cause dimension was positively correlated with timeline ($r = .32, p < .01$), and the external cause dimension was positively correlated with cyclical ($r = .35, p < .01$).

Research Question 3. What are the relationships between illness representation dimensions and HF self-care behaviors as measured by the SCHFI?

The main variable utilized to measure HF self-care behavior (SCHFI total score) did not correlate significantly with any IPQ-R subscale, as noted in Table 27. There were several small but significant correlations between the IPQ-R subscales and the subscale

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Table 26

Correlations Among IPQ-R Subscales ($N = 98$)

	Subscale	1	2	3	4	5	6	7	8
1.	Identity	--	.17	.35**	.40**	-.12	-.10	.07	.35**
2.	Timeline		--	.12	.43**	-.13	-.50**	.04	.03
3.	Time (cyclic)			--	.36**	.01	-.08	.32**	.35**
4.	Consequences				--	-.03	-.22*	.25*	.26**
5.	Control (personal)					--	.43**	.13	-.12
6.	Control (treatment)						--	.07	-.09
7.	Cause (internal)							--	.29**
8.	Cause (external)								--

*p < .05 level (two-tailed). **p < .01 level (two-tailed).

scores on the SCHFI. The SCHFI self-maintenance subscale was negatively correlated with the IPQ-R external cause subscale (r = -.22, p < .05). The SCHFI self-management subscale score was positively correlated with the IPQ-R subscales of identity (r = .23, p < .05), cyclical (r = .28, p <.01), consequences (r = .26, p < .05) and internal cause, (r = .32, p < .01). The SCHFI self-confidence subscale was positively correlated with the IPQ-R subscales of personal control (r = .31, p < .01) and treatment control (r = .25, p < .01) and negatively correlated with the timeline (r = -.23, p < .05) and consequences (r = .25, p < .05) subscale scores.

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Table 27

Correlations Among IPQ-R and SCHFI (*n* = 84)

Subscale	9	10	11	12
1. Identity	.04	.23*	-.03	.08
2. Timeline	-.03	.10	-.23*	-.12
3. Time (Cyclic)	.07	.28*	-.01	.19
4. Consequences	-.09	.26*	-.25*	.03
5. Control (Personal)	.17	.07	.31**	.20
6. Control (Treatment)	.05	-.01	.25*	.13
7. Cause (Internal)	-.15	.32**	-.02	.09
8. Cause (External)	.05	-.01	.25*	.13
9. SCHFI Maintenance Subscale		.17	.37**	.64**
10. SCHFI Management Subscale		--	.42**	.78**
11. SCHFI Self-Confidence Subscale			--	.78**
12. SCHFI Total Score	--			

* $p < .05$ level (two-tailed). ** $p < .01$ level (two-tailed).

Research Question 4. Do illness representation dimensions and HF self-care behaviors add significantly to the prediction of HRQOL as measured by the LHFQ in older community-dwelling individuals with HF after controlling for selected individual contextual factors and biological characteristics such as age, marital status, comorbidity, and length of time living with HF?

Initially, the zero-order correlations between the dependent variable (LHFQ total score) and all the continuous demographic variables were examined to select the covariates for Step 1 of the hierarchical regression (Table 28). Based on these correlations, the SAS functional classification, time since last HF admit, and number of admits/year were selected for inclusion on Step 1. None of the four proposed covariates (age, Charlson Comorbidity Index, marital status, and length of time diagnosed with HF) were significantly related to the LHFQ scores and were excluded from the analysis.

Table 28.

Correlations Between LHFQ Total Scores and Contextual Factors/Biographical Characteristics Variables ($N = 84$)

Variable	LHFQ total score
Specific Activity Scale functional classification	.50**
Time since last HF	-.32**
Number admits for HF/year	.28**
Time diagnosed with HF	.11
Charlson Comorbidity Index	.16
Age in years	-.13
Highest year of education	-.16
Marital status[a]	.04

[a]Marital status is dummy-coded as a dichotomous variable (0 = never married, widowed, separated, divorced; 1 = married or living with significant other).

*$p < .05$ level (two-tailed). **$p < .01$ level (two-tailed).

Because of the concern for multicollinarity between the two variables of time since last HF admission and the number of admits for HF/year variable, as noted with their initial moderate correlation ($r = -.56$, $p < .01$), a model was first specified with both variables included to determine collinarity diagnostics. It was found that they both accounted for the same dimension. When the tolerance and variance inflation factors (VIF) were compared for the variable time since last HF admission (tolerance = .616, VIF = 1.623) and number of admits for HF/year (tolerance = .669, VIF = 1.495), it was decided to exclude the first and keep the latter.

In determining the selection of variables for Step 2 of the regression analysis, a second zero-order correlation was performed with the LHFQ total scores and six IPQ-R subscales (Table 25). Based on these correlations, the identity, timeline (acute/chronic), cyclical timeline, consequences, and internal causal attribution subscales were selected for inclusion on Step 2. The personal and treatment control variables were eliminated because they were not significantly correlated to the dependent variable (Table 29). The external causal attribution subscale was also eliminated from the regression due to a concern for the poor internal consistency (alpha = .46). The theoretical model stipulated that Step 3 of the regression analysis require the inclusion of the SCHFI total score, which was not significantly correlated with the dependent variable ($r = .04$, $p =$ ns) (Table 29).

Table 29

Correlations of IPQ-R and SCHFI between LHFQ Total Scores (*n* = 84)

Subscale	LHFQ total score
1. Identity	.57**
2. Timeline (acute/chronic)	.32**
3. Time (cyclic)	.51**
4. Consequences	.61**
5. Control (personal)	-.08
6. Control (treatment)	-.05
7. Cause (internal)	.29**
8. Cause (external)	.36**
9. SCHFI Maintenance Subscale	-.08
10. SCHFI Management Subscale	.25*
11. SCHFI Self-Confidence Subscale	-.13
12. SCHFI total score	.04

*p < .05 level (two-tailed). **p < .01 level (two-tailed).

A hierarchical multiple regression was run with the variables entered on three steps. The results are located in Table 30. The SAS functional classification scale and number of admits for HF/year were entered in the first set and accounted for 27% of the variance ($p < .01$) associated with contextual factors. With the addition of the IPQ-R subscales of identity, timeline (acute/chronic), cyclical timeline, consequences, and the internal causal attribution subscale scores to the second step, the $R^2 = .64$ and accounted for an additional 37% of the variance ($p < .01$). SCHFI total score was entered in the third step but did not account for significantly more variance in LHFQ scores (p = ns). Overall, the variables entered in the three steps accounted for 64% of the variance in HRQOL scores reported by this group of older individuals with HF.

Table 30.

Summary of Hierarchical Regression Analysis for Predicting HRQOL Scores ($n = 84$)

Variable	B	SE B	β
Step 1			
(Constant)	-5.93	8.95	
SAS	15.79	3.41	.45**
Number of admits for HF/year	3.41	1.94	.17
Step 2			
(Constant)	-58.80	10.03	
SAS	9.87	2.62	.28**
Number of admits for HF/year	2.24	1.44	.12
Identity (symptoms)	1.99	.53	.30**
Timeline (acute/chronic)	.33	.30	.09
Timeline (cyclic)	.91	.53	.14
Consequences	1.20	.42	.26**
Internal cause	.37	.22	.13

Table 30. (continued)

Variable	*B*	SE *B*	β
Step 3			
(Constant)	-49.78	14.71	
SAS	9.96	2.62	.29**
Number of admits for HF/year	2.29	1.44	.12
Identity (symptoms)	2.01	.53	.30**
Timeline (acute/chronic)	.29	.30	.08
Timeline (cyclic)	.98	.54	.15
Consequences	1.20	.42	.26**
Internal cause	.37	.22	.13
SCHFI	-.05	.05	-.06

Note. $R^2 = .27**$ for Step 1; $R^2 = .64$ for Step 2; $\Delta R^2 = .37**$ for Step 2; $R^2 = .64$ for Step 3; $\Delta R^2 = .004$ for Step 3.

*p < .05 level. **p < .01 level.

Themes from Open-ended Question

At the end of the interview, each individual was given the opportunity to share any comments they believed "might help nurses and doctors better understand what it is like for people living with HF on a day to day basis." Individuals were given the choice of either writing their own responses on the survey themselves or dictating their responses to the interviewer and allowing him to write it on the survey. Of the 88 comments provided by the 80 individuals, 5 individuals transcribed their own responses, and the remainder dictated their responses to the principal investigator.

The data were grouped into multiple categories after several readings. From these categories, the principal investigator and a second researcher jointly developed seven distinct categories and then independently placed each of the 88 responses into one of the seven categories. Each response was reviewed to compare the agreement between the two researchers as to category placement. There were 17 initial disagreements (86% agreement). Each response was discussed until 100% agreement was obtained about placement of each response. The principal investigator then developed the four general themes, which are based on the seven categories. The theme most commonly referred to was *learning to cope with HF* (31 responses), which was comprised of three components. The first component of *learning to cope with HF* addressed specific self-care actions to manage HF (14 responses). Exemplars included: "I have to be very careful about salt intake so I can overcome this new breathlessness," "You need to surround yourself with people that know and understand your limitations," "I have spent many nights in a recliner where I was able to sleep, as opposed to restless nights in bed," and "What has

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gotten me through this is reading the Bible and going to church every week." The second component of *learning to cope with HF* dealt with having a positive attitude, which was represented with comments such as: "A person's attitude has as much to do with heart failure as medicine," "I can get through anything with a positive attitude and faith in God," and "You can make yourself sick, or you can make yourself well." The third component was described as *acceptance of the limitations associated with the illness* (10 responses). Exemplars of this element included: "You have to accept everyday as it is. God is not punishing me–. This is what I've got, so live with it," "I don't let the condition take over my life," "I know it is not going to get any better," and "Just accepting it. Everybody goes through trials. It has made me stronger."

The second most common theme discussed by the group was the *impact of HF symptoms on personal relationships and everyday activities* (23 responses). Comments that were representative of this theme included: "I can't walk and talk at the same time," "Disappointed I can't take care of the house. Have to have help twice a week," "I want to please my ladies, and I love sex, but since I got heart failure I am limp," "I can't drive anymore," and "You always have to have someone helping you; you can't even walk your dog. You have to rely on other people. There is such a loss of independence -- the doctor does not want me to live alone."

The third theme addressed by the participants in the current study dealt with issues related to *communication with HCPs* (21 responses) and was comprised of two elements: improved listening skills (12 responses) and better exchange of medical information (9 responses). In the first component of improved listening skills, 10 of the

12 responses dealt with the HCPs' need to be more attentive with their listening skills on an interpersonal basis, and two individuals suggested using terminology other than "*failure*" when referring to their illness. Examples of comments representative of this component include: "Doctors and nurses need to actually really listen to the patient. You may not agree with it, but listen to it and work around it," "If you don't know how to express yourself, how do you tell someone you need help? If you don't hurt, then you don't have a problem (except my BP was 180/100)," and "You need to use another word other than failure because it connotes such complete distress. It says, 'I don't care what you do, but you are going to die anyway.' Maybe use *disability*, *inability*, something that is not so finalized." The second component, which dealt with better exchange of medical information, was represented by the following exemplars: "As soon as the condition is diagnosed, the health care team needs to spend time showing people how to deal with the illness and how to best control it," "Make for sure your patient knows what they are getting into. Don't just tell them what to do, but why they are supposed to do them," "The doctors used medical terms that we didn't understand. If they would educate patients better in the beginning, then people won't be as afraid when things start going wrong," and "There needs to be more education from the doctor to the patient about what is going on with congestive heart failure. Nobody explained the first time about how important it was to monitor fluid and salt."

The fourth theme identified within the comments made by these participants was a description of *the emotional reactions associated with HF* (13 responses). These reactions included depression, frustration, uncertainty, anger, and fear. Comments that

were representative of this theme included, "At night I feel really worried and alone," "The uncertainty of not knowing what was going on in my case," "You feel like a time bomb. You never know when you are going to go off," "I feel like I am a bother to my family sometimes," and "I feel depressed because I can not do the things I use to be able to do."

Summary for Chapter 4

Data were analyzed using SPSS 12.0. Descriptive statistics (frequencies, means, and standard deviations), Pearson correlations, and a hierarchical multiple regression were used to answer the four research questions. The average-item scores for the subscales of the IPQ-R indicated that participants tended to view their HF as having serious consequences ($M = 3.57$, $SD = .88$); being under their personal ($M = 4.11$, $SD = .55$) and medical ($M = 3.65$, $SD = .63$) control with a disease that has a chronic course ($M = 3.89$, $SD = 1.03$), but still exhibits episodic and cyclical disruptions in their life ($M = 2.84$, $SD = .90$). Respondents had neutral average-item scores on both the internal ($M = 2.55$, $SD = .78$) and external ($M = 2.44$, $SD = .59$) causal attribution subscales. All intercorrelations between the IPQ-R subscales were in the expected directions and anticipated strength. Total scores on the SCHFI, the measure used to operationalize HF self-care behavior, did not correlate significantly with any of the IPQ-R subscales or the LHFQ scale, which was the measure of HRQOL. A three-step hierarchical multiple regression was run to predict LHFQ scores. In the first step, the two contextual factors of the SAS functional classification scale and number of admits for HF/year accounted for 27% of the variance ($p < .01$). The addition of identity, timeline (acute/chronic), cyclical

timeline, consequences, and the internal causal attribution scores in the second step

accounted for an additional 37% of the variance ($p < .01$), resulting in a total $R^2 = .64$.

The SCHFI total score was entered in the third step, but it did not account for any

significant increase in the variance of the LHFQ score. Overall, the three sets of variables

accounted for 64% of the variance in HRQOL scores reported by this group of older

individuals with HF.

The 88 responses to the question at the end of the interview, when each individual

was given the opportunity to share any comments the person believed "might help nurses

and doctors better understand what it is like for people living with HF on a day to day

basis," were categorized into four major themes utilizing qualitative descriptive

methodology. The most common theme, *learning to cope with HF* (31 responses), was

comprised of three components: (a) specific self-care actions to manage HF, (b) having a

positive attitude, and (c) acceptance of the limitations associated with the illness. The

second most commonly discussed theme by the group was the *impact of HF symptoms on

personal relationships and everyday activities* (23 responses). The third theme addressed

by the participants dealt with issues related to *communication with HCPs* (21 responses)

and was comprised of two elements: improved listening skills and better exchange of

medical information. The fourth theme was a description of *the emotional reactions

associated with HF* (13 responses).

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

This chapter summarizes the study and the findings, considers implications of these findings, and makes recommendations for future research and practice.

Summary of the Study

Purpose

The purpose of this descriptive correlational study was to examine the illness representations of a group of older community-dwelling individuals living with HF and then explore the relationships between illness representations, HF self-care behaviors, and HRQOL. The theoretical framework for this study was the cognitive arm of the CSSRM.

Procedures

The participants for this study were 98 community-dwelling individuals age 55 years or older who had been diagnosed with HF by their physician or HCP for at least 6 months. Criteria for exclusion from the study were: (a) that they could not understand and speak English and/or (b) were residing in a long-term-care facility where they required 24-hour supervision and assistance with activities of daily living. This was a convenience sample drawn from multiple sites in central Texas.

Informed consent was obtained prior to initiating the administration of questionnaires. Each participant was asked to complete a 21-item Demographic Data Sheet, 3 questions from the SAS, the 79-item IPQ-R measuring illness perceptions, the 18-item SCHFI assessing HF self-care behaviors, the 21-item LHFQ that evaluates

HRQOL for individuals with HF, and an open-ended question asking, "What it is like for people living with heart failure on a day-to-day basis?" The total time for answering these questionnaires was approximately 60 minutes for each person. Each participant received a 7-day pill organizer upon completion of the interview.

Sample Characteristics

The participants ranged in age from 55 years to 97 years ($M = 74.4$, $SD = 10.5$). The majority of the sample was male (59%), and almost half (49%) reported greater than a high school/GED level of education. While most of the participants were Anglo, 12% were African-American, and 9% identified themselves as Latino/Hispanic. Almost half (44%) of the participants reported they were presently married, and 34% were widowed.

Participants in this study had been living with their diagnosis for a median time of 3.5 years ($M = 6.1$ years, $SD = 8.12$). Over half of the group (52%) reported they had been diagnosed with HF for at least 3 years and a third of the group (36%) for longer than 5 years. They experienced, on average, at least one ER/hospitalization due to HF in the past 12 months ($M = 1.1$ visits, $SD = 2.02$) with the median time since admission for the group as a whole also at 1.11 years ($M = 2.1$ years, $SD = 3.13$). Approximately 65% of the group fell into the functionally impaired category with classification at Class III or Class IV, and 57% of the group reported a Charlson Comorbidity Index of 3 or greater ($M = 3.6$, $SD = 2.6$).

Analysis and Findings

Data were analyzed using SPSS 12.0. Descriptive statistics (frequencies, means, and standard deviations), Pearson correlations, and a hierarchical multiple

regression were used to answer the four research questions. The average-item scores for the subscales of the IPQ-R indicated that participants tended to view their HF as having serious consequences ($M = 3.57$, $SD = .88$), being under their personal ($M = 4.11$, $SD = .55$) and medical ($M = 3.65$, $SD = .63$) control, and having a chronic course ($M = 3.89$, $SD = 1.03$), but still exhibiting episodic and cyclical disruptions in their life ($M = 2.84$, $SD = .90$). Respondents had neutral average-item scores on both the internal ($M = 2.55$, $SD = .78$) and external ($M = 2.44$, $SD = .59$) causal attribution subscales. All intercorrelations between the IPQ-R subscales were in the expected directions and anticipated strength. Scores on the SCHFI, the measure used to operationalize HF self-care behavior (SCHFI total score), did not correlate significantly with any of the IPQ-R subscales or the LHFQ scale, the measure of HRQOL.

A three-step hierarchical multiple regression was run to predict LHFQ scores. In the first step, the two contextual factors of the SAS functional classification scale and number of admits for HF/year accounted for 27% of the variance ($p < .01$). The addition of identity, timeline (acute/chronic), cyclical timeline, consequences, internal causal attribution, and the external causal attribution subscale scores in the second step accounted for an additional 37% of the variance ($p < .01$), resulting in a total $R^2 = .64$. The SCHFI total scores were entered in the third step but did not account for any significant increase in the variance of the LHFQ scores. Overall, the three sets of variables accounted for 64% of the variance in HRQOL scores reported by this group of older individuals with HF. The participants' 88 comments explaining what it was like to live with HF on a day-to-day basis were initially placed into seven categories utilizing

descriptive methodology. Similar categories were merged to form the four major themes of *learning to cope with HF* (31 responses), *impact of HF symptoms on personal relationships and everyday activities* (23 responses), *communication with HCPs* (21 responses) and *the emotional reactions associated with HF* (13 responses).

Discussion of Findings

Sample Characteristics

Characteristics of the study sample must be carefully considered when interpreting the findings from this study. This sample was unique from many found in the literature because it was recruited from a variety of community sites and therefore reflects an experienced group living with their diagnosis for an average period of 6 years. Most studies in the literature represent samples whose recruitment are associated with an exacerbation of their HF requiring hospitalization or participation in a formal outpatient HF clinic (Fox, 2000; Heo, Moser, Riegel, Hall, & Christman, 2005; Rich et al., 1995; Riegel et al., 2002). The average experience of the participants for the current study of 1.1 hospitalizations during the past year and median of 1.1 years since their last admission are similar to those of other studies. There were 84 (86%) symptomatic individuals in the current study who experienced shortness of breath or swelling of their lower extremities during the previous 3 months, compared to 606 (79%) in the sample utilized for psychometric testing of the SCHFI instrument (Riegel et al., 2004). Fewer individuals in the current study had difficulty in recognizing shortness of breath or swelling of their lower extremities as symptoms of HF (26%), compared to Riegel's sample (49%), and the sample for this study also reported significantly greater HF self-

care behaviors as measured by the SCHFI total score (*M* = 213.07, *SD* = 32.52) than the sample utilized by the instrument developers (*N* = 760) (*M* = 191.9, *SD* = 41.5) [*t*(83 = 5.97, *p* < 01 (two-sided)] (Riegel et al., 2004). The HF self-care self-confidence scores for this study (*M* = 70.6, *SD* = 13.8) were also noted to be significantly higher than the previously cited study (*M* = 64.9, *SD* = 17.2) [*t*(97) = 4.98, *p* < .01 (two-tailed)]. This greater level of self efficacy may partially explain why the individuals in the current sample were able to score higher on the SCHFI (Riegel et al., 2004).

Of interest, the scores reported for HRQOL in the current sample (*M* = 37.49, *SD* = 23.45) were significantly better than baseline clinical trial scores found in the literature (*M* = 50.71, *SD* = 23.25), [*t*(97) = -5.58, *p* < .01 (two-tailed)] (Riegel et al., 2002). In a comparison of LHFQ scores of the current study (*M* = 37.49, *SD* = 23.45) to the results of the secondary analysis performed by Riegel and colleagues (2202) utilizing a sample of 1,136 individuals with HF from nine clinical sites, the most similar group were those persons who had participated in a moderate intensity intervention and were evaluated at the 3-month time period (*M* = 35.77, *SD* = 25.7) [*t*(97) = .71, *p* = .48 (two-sided)] (Riegel et al., 2002).

Research Question 1: Levels of each illness representation dimension

Identity

The identity dimension is represented by the person's perception of the signs and symptoms associated with the illness including the name the individual uses to identify the illness (Leventhal et. al., 1997). Utilizing the illness identity subscale in this study (*M* = 7.8, *SD* = 3.4), the number of symptoms identified as related to HF was found to be

very similar to that reported by Fox (2000) (M = 7.8, SD = 3.9). In this current study, the three most frequently-reported symptoms of breathlessness (87.8%), fatigue (84.7%), and edema of the lower extremities (79.6%) were consistent with the universal symptoms associated with HF reported in previous studies (Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000; Grady et al., 1995; Ni et al., 1999). The following six symptoms reported by at least a majority of the study participants included loss of strength (66.3%), chest pain (59.2%), dizziness (58.2%), weight gain (56.1%), sleep difficulties (51.0%), and wheezing(50.0%). Previous studies found diuretic-related symptoms such as urinary urgency or frequency (Bennett et al., 2000), but none were reported in this study, possibly because there was no option to indicate such symptoms on the IPQ-R identity subscale.

Most of the symptoms experienced by an individual with HF are subjective in nature and therefore difficult to quantify. Weight gain is one exception, but even this can go unnoticed if it is gradual and the individual is not weighing daily or attributes the gain to increased caloric intake. The other difficult aspect of symptom monitoring for individuals with HF is the gradual evolution and progression of the disease over a period of many months or years when there are no symptoms present to warn the person of the impending illness ahead. In this study, an identity subscale item showed approximately half of the sample (56.1%) reported weight gain as a symptom related to their HF. For clarity, the principal investigator gave each participant this information: "Weight gain means a sudden increase of your weight of 3-5 pounds that occurs over a 24-hour time period or 10 pounds over one week."

Even with this seemingly obvious piece of information, 44% of the study participants indicated they did not see weight gain as a symptom related to their HF. This may indicate that they personally did not experience any fluid overload symptoms or they were not aware that a weight increase of 3-5 pounds occurs during their HF exacerbations because they did not know to weigh themselves and were unaware of any changes occurring. This is similar to the study reported by Ni and his colleagues (1999) where 39% of the advanced HF clients did not recognize daily weight monitoring as an important health care strategy: A total of 17% did not know they should weigh themselves daily, and the remaining 22% thought that weighing themselves daily was not important (Ni et al., 1999).

It was an interesting coincidence that 56% of the current study identified weight as a symptom related to HF as part of their illness representation, and 68.3% indicated on the SCHFI that they performed daily weights always ($n = 36, 36.7\%$) or frequently ($n = 31, 31.6\%$). A Pearson chi square was performed between the two variables of identity (weight gain related to HF) and SCHFI self-care maintenance (performance of daily weight, dichotomized), but no significant findings were noted [$\chi^2 (4, N = 98) = .07, p = .86)$]. This was an unexpected finding since the illness representation developed was based on symptoms they recognized as related to weight gain related to their HF and therefore would be expected to result in the performance of HF self-care behaviors such as the performance of daily weights.

From the comments made by participants describing what it was like to live with HF on a day-to-day basis, four themes were developed that could possibly address certain

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aspects of the CSSRM. The comments from the theme of *communication with HCPs* could be related to the identity dimension and the individual's attempt to gather information about his or her illness in the most efficient and effective manner. Improved communication and better exchange of medical information could cause an improvement in the recognition of the symptoms that are associated with their illness and an increase in the ability to describe their symptoms to others, which would then lead to finding the best strategy for managing each symptom. An example of the identity dimension and its influence on mental representation of an illness was demonstrated vividly with one person's comments concerning the initial impact of the term *failure* as a label: "You need to use another word other than *failure* because it connotes such complete distress. It says, 'I don't care what you do, but you are going to die anyway.' Maybe use *disability, inability* –or something that is not so finalized."

Consequences

In this study, consequences subscale average item scores (3.57, *SD* = .88), which are representative of the anticipated and experienced physical, emotional, social or economic outcomes of the illness, were found to be almost identical to those reported in the Fox (2000) study (3.57, *SD* = .47). The tendency for participants in this study to perceive HF as having serious negative outcomes or bad effects is different than Horowitz, Rein, & Leventhal (2004) found in their qualitative study involving 19 individuals with HF who demonstrated a total lack of understanding of the serious negative impact of their HF symptoms.

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The consequences dimension of the CSSRM was represented by the major theme, derived from comments about the open-ended question, concerning *impact of HF symptoms on personal relationships and everyday activities.* Comments reported by participants relating what they perceived as consequences of their HF included: "I can't fly where I want to go to because of oxygen," "I can't attend church," "I can't take care of my house," "My children insisted I live in a controlled environment (assisted living facility)," "You always have to have someone helping you – you can't even walk your dog," and "I can't drive anymore." These statements bring an illness from a textbook case study to the reality of a living, human being. This is also what brings an illness into focus for the individual dealing with it. These critical factors define what is important in the person's life and represent the challenges faced on a daily basis due to the impact of the illness.

The theme of *learning to cope with HF* contained many comments that were related to the coping-procedures aspect of the CSSRM because they addressed strategies that an individual utilized to manage the illness. The participants listed several very specific self-care actions including limiting salt intake, sleeping in a recliner, exercising regularly, and staying active in the community. The two other areas of self-care identified as important to these participants were having a positive attitude and acceptance of the limitations of the illness. They appeared to be utilizing these positive strategies to minimize the negative aspects of serious consequences.

Control (Personal)

The IPQ-R measures the control dimension utilizing two separate subscales to assess personal control and treatment control. Because of this revision, it was not possible to compare the original treatment control score obtained by Fox (2000) with the personal control subscale from this study. The scores reported on the personal control scale reflect a possible range of agreement choices from *strongly disagree* to *strongly agree* (1 to 5). When the resulting average item score (4.11, *SD* = .55) on this subscale was referenced to the 1 to 5 range, the original score ranked above the 80[th] percentile relative to possible scores. The scores reported by these participants reflect a high sense of personal control and self-confidence within the context of their own personal illness. This high value of 4.11 is the perception these individuals with HF have of how much control they believe they have to manage the symptoms associated with their HF. The medical professional needs to be aware of this key aspect of personal control. Whether an individual with HF has a perception of personal control that is true or illusionary, the nurse needs to be aware that most individuals are highly motivated and have the personal conviction that they can control their HF. Unfortunately, when a HF exacerbation occurs due to illness progression to the point of hospitalization, many times the individual feels loss of personal control and failure. HCPs also might assume lack of personal control caused an individual's frequent hospitalizations, and it was the fault of the individual for not adhering to treatment protocols or diet.

The high personal control scores may also be a reflection of the fact that this was a community-residing sample not presently experiencing difficulties, compared to

individuals in the other samples in the literature who were frequently recruited during an exacerbation of their HF requiring hospitalization. In this study, comments made by individuals demonstrating aspects of personal control include, "I can no longer run, but I can still ride a bike," "Do things slowly and pace myself," and "I got back into my old routine."

Control (Treatment)

The treatment control subscale, the second component of the expanded control dimension for the IPQ-R, focused on assessment of the individual's belief in the treatment or recommended advice. The average item score of 3.65 ($SD = .63$) on the treatment control scale reflected the individuals' beliefs that actions taken would result in positive outcomes for making their HF better. Demonstrating aspects of treatment control, individuals in this study made comments such as, "I have always considered my heart trouble as a challenge to overcome…but lately my breathing has really become a problem and now I get afraid that the end could come much quicker than I ever thought," and "I am not getting new heart or lungs, but we can maintain what you got."

Although both of the control scales had acceptable internal consistency reported in the literature (personal control = .81, treatment control = .80), the Cronbach's alphas for this study sample were low (personal control = .60, treatment control = .65). It may be that the individuals with HF viewed treatment choices as personal control decisions because of the requirement that almost everything prescribed by the physician necessitated the individual to self-monitor and perform self-care procedures to carry out the treatments such as limiting salt intake, medication adherence, exercise, and

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monitoring weight. The reliability of both scales may have decreased because individuals may have answered the items on the IPQ-R control subscales within the context of personal control only, rather than keeping them separate as personal and treatment.

Timeline (Acute/Chronic)

The timeline dimension, which addresses the onset, duration, and recovery time of the illness, was measured with both the acute/chronic and the cyclical timeline subscales. This study sample had an average item score of 3.89 (*SD* = 1.03) on the acute/chronic subscale. This was not significantly different from the timeline subscale scores reported by Fox (2000) (4.0, *SD* = .83) that also reflected higher scores indicating a perception of HF as chronic illness rather than acute [*t*(97) = -1.07, *p* = .29]. Horowitz, Rein, and Leventhal (2004) highlighted the problem of individuals not recognizing HF as a chronic illness, which then brought about issues of proper self-management decision-making. Unfortunately, it is not possible to compare these studies since different quantitative measures were used.

Timeline (Cyclical)

The cyclical timeline scale assesses whether or not there are symptoms within the illness that reoccur at somewhat regular patterns or if they appear unpredictably. Although the average item score for this subscale (2.84, *SD* = .90) was not as high as the previous acute/chronic timeline, it was still above the midline, indicating a stronger perception of a cyclic pattern than a regular predictable pattern. One of the comments from the open-ended question that was related to the timeline (cyclical) dimension was found in the major theme *the emotional reactions associated with HF*: "It is not good.

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You feel like a time bomb. You never know when you are going to go off." Although this is categorized as an emotional response to the illness, it also represents the unpredictable nature and volatile disruption that HF exacerbations have on an individual's life. Since no previously published research has been located utilizing the new IPQ-R subscales for cyclical timeline in a sample of individuals with HF, this study was able to contribute new data to the literature.

Cause (Internal and External)

The average item score for the internal cause subscale in this study population was 2.55 (SD = 0.78). The three top-ranked internal causal attributions for this study were "diet or eating habits" (n = 61, 62.3%), "stress or worry" (n = 57, 58.1%), and "my own behavior" (n = 55, 56.1%). The three top ranked internal causal attributions in the Fox (2000) study were *my own beh*avior (n = 28, 46.7%), *diet or eating habits* (n = 25, 41.7%), and *state of mind* (n = 8, 13.3%).

The individuals who rate high on the external cause subscale would see their cause of illness to be something that was the result of action or an event outside of or beyond their control. The average item score for this subscale was 2.44 (SD = 0.59). The three top ranked external causal attributions for this study were *aging* (n = 66, 67.3%), *heredity* (n = 60, 61.2%), and *pollution in the environment* (n = 24, 24.5%). The three top-ranked external causal attributions in the Fox (2000) study were *heredity* (n = 34, 56.7%), *stress* (n = 32, 53.3%), and *chance* (n = 15, 25%).

Research Question 2: Relationships among illness representation dimensions

In general the pattern of correlations between the IPQ-R subscales was similar to that reported in other studies with previous chronic illness representation literature (Hagger & Orbell, 2003; Heijamns & de Ridder, 1998; Holliday, Wall, Treasure, & Weinman, 2005; Moss-Morris et al., 2002; Scharloo & Kaptein, 1997). A common finding in the illness representation literature is a strong negative association between the personal control and consequences dimensions, but this relationship was not present in this study ($r = -.03$). As was mentioned earlier, the internal consistency Cronbach's alpha reported for this subscale was low (.60) and may account for the discrepancy. Another possibility could be that the individuals in this sample initially recognized HF as a serious illness and put in place adequate self-care behaviors to address disease management issues that now have led them to the point of believing that the consequences of the disease are not going to be as serious. The significantly positive skew of the personal control response scores may explain both the lower coefficient alpha and correlations with other scales. There was a weak but significant correlation between the treatment control subscale and the consequences subscale ($r = -.22, p < .05$).

Research Question 3: Relationships between illness representation dimensions and HF self-care behaviors

Symptomatic participants in this study ($n = 84$) had significantly higher scores (213.07, $SD = 32.52$) [$t(83) = 5.97, p < .01$ (two-sided)] on the SCHFI than participants in the psychometric study reported by Riegel and colleagues (2004) ($N = 760$) (191.9, $SD = 41.5$). When participant scores from this study ($n = 84$) (213.07, $SD = 32.52$) are

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compared to those from a subset from the psychometric study who had greater experience

with their HF diagnosis ($n = 67$) (191.9, $SD = 41.5$), the current study sample had

significantly greater scores on the SCHFI score [$t(83) = 3.85$, $p < .01$ (two-sided)]

(Riegel et al., 2004). Little information was provided about the sample in Riegel's (2004)

study, described only as being diagnosed greater than 2 months with HF; so it is difficult

to quantify any difference of experience between these two groups to explain the

variation in scores. There were no significant correlations noted between the SCHFI total

score and any IPQ-R subscale scores. This was an unexpected finding, since the CSSRM

theorizes that illness representations lead to the actual performance of health behavior. A

possible explanation is that the SCHFI is not sufficiently sensitive to capture the subtle,

ongoing daily behavioral changes that actually structure the "action plans" of individuals

with HF, which are derived from their mental representations and ultimately affect their

HRQOL.

Research Question 4: Prediction of HRQOL with illness representation

dimensions and HF self-care behaviors after controlling for selected contextual factors

and biological characteristics

Although a substantial percentage of variance in the LHFQ scores was

accounted for with variables in this study ($R^2 = 64\%$), scores on the SCHFI did not add

significantly to the variance accounted for in LHFQ scores as predicted by the model.

Possible alternative explanations could be that the SCHFI instrument was not sensitive

enough or there were unaccounted-for variables not included the model. It is also possible

that the HF self-care behaviors may have been acting as a moderator rather than a

mediator as proposed in the model, but no evidence was found to support this. The SCHFI scores were split at the median to determine if low performers of self-care behavior (M = 187.5, SD = 20.9) or high performers (M = 238.6, SD = 19.0) would affect a change in the LHFQ scores, but there was no significant difference noted between the LHFQ scores of low performers (M = 39.3, SD = 22.4) and those of high performers (M = 38.4, SD = 24.9) [$t(82)$ = .18, p = .86 (two-sided)].

Although the HF self-care behaviors variable did not demonstrate a significant impact on HRQOL, the three variables that did explain 64% of the variance were functional status, symptoms, and consequences. All three of these concerns for older individuals with HF have the potential to be significantly influenced by self-care. The stories told through the qualitative data gave very detailed examples of how individuals benefited from self-management actions. They spoke of the process of learning to live with HF and listed specific acts they performed that resulted in their ability to "overcome this new breathlessness, "be able to sleep," and "make yourself stronger."

Limitations

Limitations of this study involve the use of a small convenience sample confined to one geographic area, which does not allow for variations that may exist in medical treatment and climate differences. There may have been a bias with the sample due to self-selection of individuals choosing to participate who were more successful in managing their illness compared to those who did not participate who may have been in denial or found it difficult to control their condition. Another limitation noted was the lack of input from the spouse. There were several instances when the spouse was present

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with the participant during the interview and wished to add comments or suggest a different response option be selected for the questionnaire, but no formal protocol was in place to allow for such participation. In addition, only the cognitive representations were evaluated. Inclusion of the emotional representation arm of the model and the impact of emotional reactions and appraisal might add to the prediction of HRQOL. An important note to remember in regards to additional limitations for this study include the use of the new IPQ-R instrument for a patient population in which it had not been utilized before and employment of the new SCHFI instrument to measure self-care in a more experienced population than previously tested by the developers.

This older sample had a relatively high comorbity presence of diabetes (32%) and cerebralvascular accidents/transient ischemic attacks (30%); and therefore had an increased possibility of exhibiting a cognitive deficit. A limitation of this study was the absence of a cognitive screening instrument to verify that no deficits existed. Although the interview format gave some insight into the participant's cognitive ability, a standardized assessment would have been preferable.

Implications and Recommendations for Nursing Practice

The implications for nursing practice based on the results of this study start with the focus on the significant correlates of HRQOL in this sample: the SAS functional classification, the identity subscale, and the consequences subscale. In addition, it is important to approach the practice recommendations utilizing the theory-based approach of the CSSRM, which focuses on active partnership between the individual with HF and the HCP. Another key implication for nursing practice is the recognition of the

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importance of the individuals' perception of their illness. Whether their perception is right or wrong to the nurse, it is what individuals think about their illness that will frame their responses.

One suggestion would be to implement strategies or procedures, such as participation in an outpatient cardiac exercise program that could improve the individual's ability to function at a higher level or to maintain the present level of function with less effort. Because of the importance of symptoms in the self-care management of HF, it is critical that the nurse adequately assess this aspect of the health history. The nurse should encourage the individual with HF to describe in detail the symptoms experienced with an exacerbation of HF and the actions the person took in response. This will give the nurse valuable insight into the depth of understanding the individual has of the illness and may indicate potential areas for further education. Associated with this improved communication is the opportunity for the nurse to educate an individual with HF on objective recognition and description of fluid overload symptoms. One specific method of objective assessment for fluid overload is daily monitoring of weight at home. As more individuals with HF become aware of this assessment technique, it will provide yet another tool for the person with HF to use in managing his or her illness.

The impact that a word such as *failure* has on individuals with a recent diagnosis of HF can sometimes be difficult to comprehend from the perspective of a HCP when it is used every day as a common descriptor. To be sensitive to the use of this word with newly diagnosed individuals and allow for the reinforcement of correct ideas or the

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sharing of factual medical information that may alter negative perceptions, the nurse should ask persons with HF to explain the meaning of the term in their own words. Whenever medical terminology is utilized within a conversation between the nurse and individuals with HF, there needs to be a clear understanding of the meaning of terms.

Another practice opportunity would be the implementation of a HF discharge program built around the basic components of the CSSRM. This could include the basic components of identity (recognition of symptoms associated with exacerbation of HF), timeline (recognition that illness is chronic in nature with episodic exacerbations), consequences (individualized, symptom-management strategies such as moving to an assisted living facility, implementing energy conservation techniques, and eating a low-salt diet), control (to encourage personal self-efficacy, self-management skills), and causal attributions (individualized behavioral change strategies for reduction of risk factors).

Implications and Recommendations for Nursing Research

There are several recommendations for further research involving older individuals diagnosed with HF and residing within the community. Better measures of HF self-care behavior are needed for this unique population because the SCHFI was unable to differentiate between the low and high performance of HF self-care behaviors when compared to HRQOL total scores. The self-care construct is difficult to operationalize with many unique individualized components. Although the developers of the SCHFI instrument were able to demonstrate significant differences in HRQOL scores between recently diagnosed individuals with HF (< 2 months) and those more

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experienced (> 2 months), the instrument did not appear to be sensitive enough to detect differences in HRQOL scores within this older, community-dwelling group that had no participants with less than 6 months experience with the diagnosis.

Another suggestion for nursing research would be the recruitment of a larger sample from multiple geographic areas to provide a more representative sample of the general population. The implementation of a cognitive screening tool to assess for any deficits that would warrant exclusion of participants from the study would also be an appropriate recommendation for this sample. Examples of possible tools for consideration could be the clock test or the Mini Mental State Exam. Utilization of a research design that allows data to be collected over several time points, rather than the current cross-sectional study approach, might provide a greater understanding of how individuals cope with HF symptoms over the course of the disease. This would also afford the opportunity to track for change over time. An additional research implication from this study is the need for future exploration of the illness representation dimensions and their impact on QOL as a basis for an intervention study. Examples of this could be seen in the implementation of a hospital discharge program established with educational material based on the theoretical principles of the CSSRM.

Summary for Chapter 5

This chapter discussed the findings of the descriptive correlational study that examined the illness representation dimensions, self-care behaviors, and HRQOL of older, community-dwelling individuals with HF and made comparisons to previous research. Limitations to the study and recommendations for nursing practice and research

were addressed. This study serves as a preliminary step in developing interventions to

improve self-care management of HF.

APPENDIX A

Recruitment Flyer

CONGESTIVE HEART FAILURE STUDY

"What Does Congestive Heart Failure Mean to You

and How Do You Live With It?"

Purpose of study: To understand how people with heart failure deal with their illness.

Who is eligible to be in this study?
√   Are you 55 years of age or older?
√   Have you been told by your doctor that you have Congestive Heart Failure, CHF or Heart Failure?
√   Has it been at least six months since you were first told you have Heart Failure?
√   Are you residing in the community (home, apartment, senior retirement home, or assisted living facility)?

What is involved?
- Phone or email to sign up for the study.
- Set a meeting time and place.
- Complete a form that contains simple questions about what your illness means to you, how you deal with it, in addition, how it affects your life. (Approximately one hour time commitment).
- All survey information is anonymous and will be kept confidential.
- Upon completion of the form, you will receive a 7- day medication pill organizer.

Contact:
Wayne Voelmeck RN, MS (Doctoral Candidate)
The University of Texas at Austin School of Nursing

Phone: (512) 964-3794   Email: **wvoelmeck@mail.utexas.edu**

Note: This recruitment flyer was printed with the background watermark colors light blue and the heart colors a light red. A full border of bright red hearts outlined the perimeter of the flyer, but is not pictured here.

APPENDIX B

PROTOCOL FOR PARTICIPANT RECRUITMENT

Protocol for Senior Retirement Homes and Assisted Living Facilities

 (Rationale for selection: expectation of large number of individuals over the age of 55 that may have the diagnosis of HF and may be interested in participating in the study)

1. Meet with onsite manager of facility and outline details of research project.

2. Request permission to post flyer in public access areas such as bulletin board, lobby, laundry room, or hallway. Inquire as to a central information system utilized by the facility such as residential mailboxes, group emails, or a newsletter where they would be willing to allow the posting of the flyer.

3. Offer to provide a health seminar presentation or a routine health screening for all interested residents of the facility that included tests commonly conducted by nurses in the community such as blood pressure assessment, heart rate, weight assessment with body mass index (BMI) calculation, and oxygen saturation as measured by finger pulse oximeter. Any abnormal findings would be referred to their regular family physician. If preferred, demonstrations could also be performed on self-management strategies for the proper use of automatic blood pressure equipment, proper filling of 7-day medication pill organizers, and/or selection of the appropriate bathroom scales/weighing devices.

4. If an individual with heart failure contacts the researcher during a health screening and wishes to participate in the study, coordination will be made at that time for a mutually convenient time and place to collect the data. Otherwise, any

resident with heart failure in the facility who wishes to participate in the study may contact the researcher by phone or email and set up the meeting time and place for the data collection.

Protocol for churches or local religious organizations

(Rationale for selection: expectation of large number of individuals over the age of 55 that may have the diagnosis of HF; or have family members, neighbors, or friends that have the diagnosis of HF and may be interested in participating in the study)

1. Meet with the pastor or individual in charge of the organization and ask permission to post a flyer in public access areas such as bulletin board, lobby, or hallway. Inquire as to a central information system utilized by the organization such as group emails or a newsletter that they would be willing to allow the posting of information concerning the study also.

2. Church member distribution: EMAIL TEXT:

My name is Wayne Voelmeck and I am a graduate nurse at UT School of Nursing. I am conducting a Congestive Heart Failure Study looking at "What Does Congestive Heart Failure Mean to You and How Do You Live With It?" It focuses on how people with heart failure deal with their illness and requires about 60 minutes to complete the questionnaire.

To be eligible for the study you must be 55 years of age or older, speak and understand English, and have been diagnosed with Congestive Heart Failure for at least six months.   (You may have been short of breath

and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.) You also must be residing in the community (home, apartment, senior retirement home, or assisted living facility).

If you are interested in participating, please phone or email me at the contact references below to set up a meeting time and place. You will be asked to answer very simple questions on a paper form about what your illness means to you, how you deal with it, and how it affects your life. All information is anonymous and will be kept confidential. You will receive a 7-day medication pill organizer for completion of the questionnaire.

I am requesting that you please forward the contact information below to any family members, neighbors, or friends that have been diagnosed with congestive heart failure for at least six months if they are interested in participating in the study. Due to time and financial restraints, I need to restrict my driving range to within a 90 minute time-frame from central Austin.

Thank you for your consideration,
Wayne Voelmeck, RN
Phone: (512) 964-3794
email:wvoelmeck@mail.utexas.edu

3. If an individual with heart failure is interested in participating in the study, they would be responsible for contacting the researcher by phone or email to arrange a convenient meeting time and place for the data collection.

Protocol for Newsletters

(Rationale for selection: expectation that readership of the newsletter would include a large number of individuals over the age of 55 of whom some may have the diagnosis of HF and which to participate in the study)

1. Meet with the individual in charge of the organization responsible for publishing the newsletter or placement of announcements and outline details of the research project.

2. Submit announcement for Congestive Heart Failure Study to Shady Hollow Community Newsletter, Eldercare Newsletter and other similar local community newsletters.

3. The announcement would consist of the flyer in a reduced sized. If the newsletter was unable to reproduce graphics, then only the printed contents would be displayed with the Title, purpose, who is eligible, what is involved, and contact information.

4. If individuals with heart failure are interested in participating in the study, they would be responsible for contacting the researcher by phone or email to arrange a convenient meeting time and place for the data collection.

Protocol for Emails

(Rationale for selection: expectation that fellow academic peers might have family members, neighbors, or friends over the age of 55 that may have the diagnosis of HF and would be interested in participating in the study)

1. Utilization of email to ask academic peers at the University of Texas to assist in the recruitment of individuals with heart failure.

2. After obtaining permission from the webmasters of the UT Austin dissertation listserve, UT School of Nursing Listserve, and Association of Nurses in Graduate School Listserve, post the following text and the flyer in electronic form as an attachment.

3. EMAIL TEXT:

"Fellow UT students: My name is Wayne Voelmeck, and I am a doctoral student in the UT School of Nursing. I am currently recruiting community-dwelling individuals with Congestive Heart Failure who are 55 years of age or older to participate in a study dealing with illness perceptions, self-care behaviors, and health-related quality of life. The purpose of the study is the gain insight into how healthcare providers can more effectively co-partner with the individuals that are living with heart failure and help them to be more successful in managing their disease process.

I am requesting that you please forward the contact information in the attached flyer to any family members, neighbors, or friends that have been diagnosed with congestive heart failure for at least six months if they are interested in participating in the study. Due to time and financial restraints, I need to restrict my driving range to within a 90 minute driving time from central Austin. I will coordinate a one-time data collection meeting with the individual at a time and place of their choosing which is expected to take approximately one hour. Upon completion of the questionnaire, participants will be given a 7-day pill organizer.

Thank you for your consideration,

Wayne Voelmeck, RN

Phone: (512) 964-3794

email:wvoelmeck@mail.utexas.edu

4. If the individual with heart failure is interested in participating in the study, they would be responsible for contacting the researcher by phone or email to arrange a convenient meeting time and place for the data collection.

Protocol for Health Care Providers (HCPs)

(Rationale for selection: expectation that HCP will encounter large number of individuals over the age of 55 that may have the diagnosis of HF and may be interested in participating in the study)

1. Meet with individual (HCPs) or the onsite manager of office (example: physician's office, dentist's office, or outpatient pharmacy) and outline details of

the research project. If the employer for which the HCP works requires that a

separate Institution Review Board Committee approve the research prior the

collection of data in the facility, all necessary steps will be taken to address this

requirement and an addendum will be filed with the University of Texas IRB.

2. Request permission to post the flyer in a public access area such as a bulletin

board in the waiting area or to leave multiple copies available in the waiting

room. Another suggestion would be to make multiple copies of the flyer available

to the HCP and allow the HCPs to distribute them to those individuals known to

have heart failure.

3. Any individuals with heart failure interested in participating in the study would

be responsible for contacting the researcher by phone or email to arrange a

convenient meeting time and place for the data collection.

Protocol for Senior Community Activity Centers and Health Fairs (Rationale for

selection: expectation of large number of individuals over the age of 55 that may have

the diagnosis of HF and may be interested in participating in the study)

1. Meet with individual in charge or the onsite program director and outline

details of the research project.

2. Request permission to post the flyer in a public access area such as a bulletin

board.

3. Offer to provide a health seminar presentation or a general routine health

screening for all interested participants of the program that included tests

commonly conducted by nurses in the community such as blood pressure

assessment, heart rate, weight assessment with body mass index (BMI) calculation, and oxygen saturation as measured by finger pulse oximeter. Any abnormal findings would be referred to their regular family physician. If preferred, demonstrations could also be performed on self-management strategies for the proper use of automatic blood pressure equipment, proper filling of 7-day medication pill organizers, and/or selection of the appropriate bathroom scales/weighing devices.

4. If an individual with heart failure contacts the researcher during a health screening and wishes to participate in the study, coordination will be made at that time for a mutually convenient time and place to collect the data. Otherwise, any participant with heart failure in the program who wishes to participate in the study may contact the researcher by phone or email and set up the meeting time and place for the data collection.

APPENDIX C

Informed Consent

The Relationship of Illness Representation and Self-Care Behaviors

to Quality of Life in Older Individuals with Heart Failure

Conducted By: Wayne Voelmeck, RN, MS   IRB PROTOCOL #2004060097

University of Texas at Austin, School of Nursing (512) 232-4761

(wvoelmeck@mail.utexas.edu)

Faculty Sponsor: Alexa Stuifbergen, RN, Ph.D., (512) 232-4710

(astuifbergen@mail.utexas.edu)

       You are being asked to participate in a research study. This form provides you with information about the study. The person in charge of this research will also describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part. Your participation is entirely voluntary and you can refuse to participate without penalty or loss of benefits to which you are otherwise entitled. You can stop your participation at any time by simply telling the researcher.

The purpose of this study is to understand how people with heart failure deal with their illness. If you agree to be in this study, we will ask you to do the following things:

- Provide background information such as your age, gender, ethnicity, year when first diagnosed with heart failure, how many times you were admitted to the ER for heart failure, activity level, and medical conditions.

- Complete three questionnaires that contain simple questions about what your illness means to you, how you deal with it, and how it affects your life.

- Total estimated time to participate in study is approximately one hour.

Risks and Benefits of being in the study:

• The risk associated with this study is no greater than everyday life.

• There are no direct benefits expected for participation in this study, but indirectly individuals with heart failure are expected to benefit from the knowledge gained by healthcare providers.

• Compensation: You will receive a 7-day pill organizer upon completion of the questionnaires.

The records of this study will be stored securely and kept private. Authorized persons from The University of Texas at Austin and members of the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. All publications will exclude any information that will make it possible to identify you as a subject.

Contacts and Questions:

If you have any questions about the study please ask now. If you have questions later or want additional information, call the researchers conducting the study. Their names, phone numbers, and e-mail addresses are at the top of this page. If you have questions about your rights as a research participant, please contact Clarke A. Burnham, Ph.D., Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects, (512) 232-4383.

You will be given a copy of this information to keep for your records

Statement of Consent:

I have read the above information and have sufficient information to make a decision about participating in this study. I consent to participate in the study.

Signature:_____   Date: _____

Signature of Investigator:_____   Date: _____

Demographic Data Sheet

Thank you for your participation in this study. All information will be kept confidential.

1. Birthdate_____
                    (month/day/year)

2. Gender: ☐ Male
☐ Female

3. Highest year of education completed _____
(example: completed grade school=6 yrs, completed high school=12 yrs)

4. Current marital status:
            ☐ Never Married   ☐ Widowed
            ☐ Married   ☐ Separated
            ☐ Divorced   ☐ Living with a Significant Other

5. Approximate date when your heart failure first occurred _____
                                                            (Month/Year)

6. Approximate last admission date to the hospital or emergency room for
Heart Failure_____
             (Month/Year)

7. How many times in the past 12 months have you gone to the emergency room for heart failure? ___

8. Which best describes your racial group?
☐ African American/Black   ☐ Asian American
☐ Indian American   ☐ White
☐ Other (please describe)_____

9. Are you Hispanic/Latina?   ☐ No   ☐ Yes

10. Have you ever had a heart attack?   No_____Yes_____

11. Have you ever been treated for heart failure? (You may have been short of breath and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.)   No_____ Yes____

12. Have you had an operation to unclog or bypass the arteries in your legs
No_____Yes_____

13. Have you had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack (TIA)? No_____ Yes_____

13a. Do you have difficulty moving an arm or leg as a result of the
                stroke or cerebrovascular accident? No_____ Yes_____

14. Do you have asthma?
      No_____ Yes_____→If yes, do you take medicines for your asthma?
                          No_____
                          a) Yes, with flare-ups of asthma only   _____
                          b) Yes, I take medicines regularly, even when I'm not
                              having a flare-up _____

15. Do you have emphysema, chronic bronchitis, or chronic obstructive lung disease?
      No_____Yes_____→If yes, do you take medicines for your lung disease?
                          No_____
                          c) Yes, only with flare-ups _____
                          d) Yes, I take medicines regularly, even when I'm not
                              having a flare-up_____

 16. Do you have stomach ulcers, or peptic ulcer disease?
      No_____ Yes_____ →If yes, has this condition been diagnosed by endoscopy
      (where a doctor looks into your stomach through a scope) or an upper GI or barium
      swallow study (where you swallow chalky dye and then x-rays are taken)?
      No_____ Yes_____

17. Do you have diabetes (high blood sugar)? No_____ Yes_____
          a) Is it treated by medications taken by mouth? No_____ Yes_____
          b) Is it treated by insulin injections?   No_____ Yes_____

17a. Has the diabetes caused …
          a) problems with your kidneys?   No_____ Yes_____
          a) problems with your eyes,
              treated by an ophthalmologist?   No____   Yes_____

18. Have you ever had the following problems with your kidneys?

Poor kidney function (blood tests show high creatinine)? No____Yes____

Have used hemodialysis or peritoneal dialysis?   No____Yes____

Have received kidney transplantation   ?   No____Yes____

19. Do you have rheumatoid arthritis that you take medications for regularly?

No_____   Yes_____

Do you have Lupus (systemic lupus erythematosus)?   No_____   Yes_____

Do you have Polymyalgia rheumatica?   No_____   Yes_____

20. Do you have …..

Alzheimer's Disease, or another form of dementia?   No_____   Yes_____

Cirrhosis, or serious liver damage?   No_____   Yes_____

Leukemia or polycythemia vera?   No_____   Yes_____

Lymphoma?   No_____   Yes_____

Cancer, other than skin cancer, leukemia, or lymphoma? No_____   Yes_____
If yes, has the cancer spread, or metastasized to other

parts of your body?   No_____   Yes_____

If the cancer has NOT metastasized, was the cancer first

treated less than 5 years ago?   No_____   Yes_____

Hypertension:

21. Do you have hypertension?   No_____   Yes_____

APPENDIX E

Specific Activity Scale

If the participant states that s/he did not perform or is incapable of performing the activity in the stem question, then the principal investigator will substitute in subsequent order the remaining choices alphabetically starting with "a".

"I am going to ask you some questions concerning your level of activity. Please indicate which activities that you have been able to perform in the past four weeks or that you feel you are capable of performing."

Questions:	**Any Yes**	**No**
1. Can you walk down a flight of steps without stopping (4.5-5.2 METs)?	Go to #2	Go to #4

2. Can you carry anything up a flight of eight steps without stopping (5-5.5 METs)?
 	
  (a) garden, rake, weed (5.6 METs);
 	
  (b) roller skate, dance fox-trot (5-6 METs); or
 	
  (c) walk at a 4 mph rate on level ground (5-6 METs)?
	Go to #3	Class III

3. Can you carry at least 24 lb up eight steps (10 METs) Or can you:
 	
  (a) carry objects that are at least 80 lbs (8METs);
 	
  (b) do outdoor work-shovel snow, spade soil (7 METs)
 	
      (c) do recreational activities such as skiing, basketball,
 	
touch football, squash, handball, (7-10 METs) or
 	
  (d) jog/walk 5 mph (9 METs)
	Class I	Class II

Questions:	**Any Yes**	**No**

4. Can you shower without stopping (3.6-4.2 METs)? Or can you
 	
  (a) strip and make a bed (3.9-5 METs);
 	
  (b) mop floors (4.2 METs)
 	
  (c) hang washed clothes (4.4 METs)
 	
  (d) clean windows (3.7 METs)
 	
  (e) walk 2.5 mph (3-3.5 METs)
 	
  (f) bowl (3-4.4 METs)
 	
  (g) play golf (walk and carry clubs) 4.5 METs); or
 	
  (h) push a power lawn mower (4 METs)?
	Class
	
	III
		Go to
		
		#5

5. Can you dress without stopping because of symptoms (2-2.3 METs)?	Class III	Class IV

From "Comparative Reproducibility and Validity of Systems for Assessing Cardiovascular Functional Class: Advantages of a New Specific Activity Scale" by Goldman, L., Hashimoto, B., Cook, E. F., & Loscalzo, A., 1981, *Circulation*, *64*(6), p. 1228.

Comparison Chart Between NYHA and SAS Functional Classification

Class	NYHA	SAS
I	Patients with cardiac disease but without resulting limitations of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.	Can perform to completion any activity requiring ≥ 7 METS (i.e. jog/walk at 5mph or carry at least 24 pounds up a flight of eight steps without stopping.)
II	Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.	Can perform to completion any activity requiring ≥ 5 METs (i.e. walk 4 mph or carry anything up flight of eight steps without stopping) but can not perform acts requiring ≥ 7 METs.
III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain.	Can perform to completion any activity requiring ≥ 2 METs (e.g., walk 2.5 mph or shower without stopping) but can not perform to activities requiring ≥ 5 METs.

Class	NYHA	SAS
IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of HF or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.	Cannot or do not carry out to completion activities requiring ≥ 2 METs.

Adapted from "Comparative Reproducibility and Validity of Systems for Assessing Cardiovascular Functional Class: Advantages of a New Specific Activity Scale" by Goldman, L., Hashimoto, B., Cook, E. F., & Loscalzo, A., 1981, *Circulation, 64*(6), p. 1229.

APPENDIX G

Illness Perception Questionnaire-Revised (IPQ-R)

YOUR VIEWS ABOUT YOUR CONGESTIVE HEART FAILURE

Listed below are a number of symptoms that you may or may not have experienced since you were first diagnosed with Congestive Heart Failure. Please indicate by circling Yes or No, whether you have experienced any or these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom since my first Heart Failure episode			This symptom is **related to** my Heart Failure	
Chest Pain	Yes	No	- - - - - - - - - - - - -	Yes	No
Loss of Balance	Yes	No	- - - - - - - - - - - - -	Yes	No
Sore Throat	Yes	No	- - - - - - - - - - - - -	Yes	No
Nausea	Yes	No	- - - - - - - - - - - - -	Yes	No
Weight Gain	Yes	No	- - - - - - - - - - - - -	Yes	No
Breathlessness	Yes	No	- - - - - - - - - - - - -	Yes	No
Cough	Yes	No	- - - - - - - - - - - - -	Yes	No
Weight Loss	Yes	No	- - - - - - - - - - - - -	Yes	No
Fatigue	Yes	No	- - - - - - - - - - - - -	Yes	No
Stiff Joints	Yes	No	- - - - - - - - - - - - -	Yes	No
Swollen Feet and Ankles	Yes	No	- - - - - - - - - - - - -	Yes	No
Sore Eyes	Yes	No	- - - - - - - - - - - - -	Yes	No
Wheeziness	Yes	No	- - - - - - - - - - - - -	Yes	No

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	Headaches	Yes	No	- - - - - - - - - - - - -	Yes	No
	Difficulty Concentrating	Yes	No	- - - - - - - - - - - - -	Yes	No
	Upset Stomach	Yes	No	- - - - - - - - - - - - -	Yes	No
	Sleep Difficulties	Yes	No	- - - - - - - - - - - - -	Yes	No
	Dizziness	Yes	No	- - - - - - - - - - - - -	Yes	No
	Loss of Strength	Yes	No	- - - - - - - - - - - - -	Yes	No

We are interested in your own personal views of how you now see your current illness of Congestive Heart Failure. Please indicate how much you agree or disagree with the following statements about your illness of Congestive Heart Failure by checking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP 1	**My heart failure will last a short time**					
IP 2	My heart failure is likely to be permanent rather than temporary					
IP 3	My heart failure will last for a long time					
IP 4	This heart failure will pass quickly					
IP 5	I expect to have this heart failure for the rest of my life					
IP 6	My heart failure is a serious condition					
IP 7	**My heart failure has major consequences on my life**					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP 8	My heart failure does not have much effect on my life					
IP 9	My heart failure strongly affects the way others see me					
IP 10	**My heart failure has serious financial consequences**					
IP 11	My heart failure causes difficulties for those who are close to me					
IP 12	There is a lot which I can do to control my symptoms					
IP 13	What I do can determine whether my heart failure gets better or worse					
IP 14	The course of my heart failure depends on me					
IP 15	Nothing I do will affect my heart failure					
IP 16	I have the power to influence my heart failure					
IP 17	My actions will have no affect on the outcome of my heart failure					
IP 18	My heart failure will improve in time					
IP 19	There is very little that can be done to improve my heart failure					
IP 20	My treatment will be effective in curing my HF					
IP 21	The negative effects of my heart failure can be prevented (avoided) by my treatment					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE/OR DISAGREE	AGREE	STRONGLY AGREE
IP 2 2	My treatment can control my heart failure					
IP 2 3	There is nothing which can help my condition					
IP 2 4	Their symptoms of my condition are puzzling to me					
IP 2 5	My heart failure is a mystery to me					
IP 2 6	I don't understand my heart failure					
IP 2 7	My heart failure doesn't make any sense to me					
IP 2 8	I have a clear picture or understanding of my condition					
IP 2 9	The symptoms of my heart failure change a great deal from day to day					
IP 3 0	My symptoms come and go in cycles					
IP 3 1	My heart failure is very unpredictable					
IP 3 2	I go through cycles in which my HF gets better and worse					
IP 3 3	I get depressed when I think about my heart failure					
IP 3 4	When I think about my heart failure I get upset					
IP 3 5	My heart failure makes me feel angry					
IP 3 6	My heart failure does not worry me					
IP 3 7	Having heart failure makes me feel anxious					

		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP 3 8	My heart failure makes me feel afraid					

CAUSES OF MY HEART FAILURE

We are interested in what <u>you</u> consider may have been the cause of your heart failure. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your heart failure. Please indicate how much you agree or disagree that they were causes for you by checking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary – it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behavior					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Aging					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

On the three lines below, please list in rank-order the three most important factors that you now believe caused YOUR illness of HF. You may use any of the items from the box above, or you may have additional ideas of your own.
The most important causes for me:

1. _____

2. _____

3. _____

GLOSSARY

Glossary of Acronyms

Acronym	Words or Phrase Represented
CSSRM	Common Sense Self-Regulation Model
ER	Emergency Room
HCP	Healthcare Provider
HF	Heart Failure
HRQOL	Health-Related Quality of Life
IPQ-R	Illness Perception Questionnaire-Revised
IRB	Institutional Review Board
LHFQ	Living with Heart Failure Questionnaire
NYHA	New York Heart Association
QOL	Quality of Life
SAS	Specific Activity Scale (functional classification status)
SC-MAINT	Self-Care Maintenance (subscale of SCHFI)
SC- MANAGE	Self-Care Management (subscale of SCHFI)
SC-CONFID	Self-Care Confidence (subscale of SCHFI)
SCHFI	Self Care of Heart Failure Index
VA	Veteran Administration

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VITA

Wayne Francis Voelmeck was born in Eureka, Kansas on February 1, 1952, the son of Andrew Francis Voelmeck and Elsie Poe Voelmeck. He graduated from Ottawa High School in Ottawa, Kansas in 1970 and attended the University of Kansas before beginning his nursing education at Marymount College School of Nursing in Salina, Kansas where he received the degree of Bachelor of Science in Nursing. After graduation in 1974 Wayne began a military service over the next 20 years as a U.S. Army nurse corps officer. He had duties as a CCU/MICU staff nurse at Ft. Sill, OK; staff nurse at the Research Institute for Infectious Diseases, Ft. Detrick, MD; ER head nurse at Schofield Barracks, HI; Cardiovascular CNS and Director, Cardiac Rehabilitation Program at Denver, CO; and Director, Continuing Education and Staff Development at Stuttgart and Landstuhl, Germany. In May 1986 he obtained his Masters in Science in Nursing from Boston University School of Nursing, Boston, MA. Upon leaving the military in May of 1994, Wayne developed and managed the Cardiopulmonary Specialty Program within a home healthcare agency in Austin, Texas until 1999. Wayne has worked part-time since 1999 as ER staff, consultant to home health care agencies in the community, and teaching/research assistant at The University of Texas at Austin while completing course requirements for his PhD.

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