

A Perspective Taking Intervention to Enhance Family Caregiver Symptom Assessment and
Improve Symptom Management for the Heart Failure Patient

by

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Abstract

Community care of heart failure (HF) requires ongoing management often involving family caregivers (FCG) who make decisions based on their level of skill in symptom assessment. FCGs who misunderstand patients' (PT) symptom experiences may contribute to poor management of patient symptoms resulting in repeat hospital admissions. This study tested for improved perceptual agreement between the FCG and the PT with HF after FCG's were instructed to actively engage in PT-oriented perspective-taking, in the context of assessing the PT's symptoms. In addition, change in FCG empathic responding was measured. Davis' (1990) organizational model of empathy guided this one-group pre-test/post-test interventional pilot study (n=14 dyads). Non-parametric Wilcoxon signed-rank test evaluated PT/FCG discrepancy scores on the Heart Failure Symptom Survey (HFSS) and the Empathic Responding Scale (ERS). A qualitative interview captured PT and FCG responses to the intervention. Six of 14 HFSS symptoms demonstrated significantly improved PT/FCG perceptual agreement along at least one of four symptom dimensions: frequency, severity, interference with physical activity, and interference with enjoyment of life. The ERS did not capture improved post intervention empathic responding in the FCG likely due to ceiling effect. Interviews revealed PT/FCG participants focus on similar themes from their unique perspective. Study findings provided ongoing evidence in support of a perspective-taking intervention that has a promising effect on improving or sustaining FCG's sensitive understanding of the PT's symptom experiences. This simple, non-invasive technique is worthy of further study, development, and implementation to promote early, PT-oriented attention to avert exacerbations of HF that cost the wellbeing of not only PT's and FCG's, but also the health care system.

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Note: HFSS = Heart Failure Symptom Survey; ERS = Empathic Responding Scale

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Note: HFSS = Heart Failure Symptom Survey

Chapter One - Introduction

Statement of the Problem

As our population ages, Canadians increasingly feel the growing impact of chronic illness in their daily lives. The effects of personal interaction with chronic illness are seen in the daily demands of self-care or the shared care of a family member, the periodic absence or struggle of a co-worker, and the mounting financial strain of our health care programs (Conference Board of Canada, 2013).

Heart disease remains the second most common cause of death in Canada (Statistics Canada, 2007) encompassing many long-term illnesses such as chronic angina, hypertension, arrhythmias, and cardiomyopathy. Heart disease is also closely associated with many other chronic illnesses such as diabetes, chronic obstructive lung disease and renal disease. The Public Health Agency of Canada (2009) stated that in 2007, 1.3 million Canadians reported having been formally diagnosed with heart disease and, of that group, 43.5 percent rated their health as fair or poor specifically related to heart disease. Furthermore, 68.8% of the group reported activity restrictions related to heart disease, while 30.3% indicated the limitation was severe enough to warrant help with daily activities (Public Health Agency of Canada, 2009).

Success rates for treating acute cardiac events have greatly improved in the past decade, allowing survivors to live on despite permanent cardiac damage. Advancing age and myocardial injury open the door for the development of heart failure (HF) – a chronic progressive syndrome fraught with acute episodes of decompensation and hospitalization, deteriorating quality of life and escalating healthcare costs (Gardetto, 2011; Green, 2009; Heart and Stroke Foundation, n.d.). HF syndrome results in a continual worsening of the heart's ability to maintain an adequate forward movement of blood to meet the metabolic demands of the body. HF can begin quickly, or slowly develop over many years. The end result is an over accumulation of fluid in the body,

generally in the lungs, abdomen, and lower legs typically manifesting in the classic symptoms of shortness of breath, fatigue and leg swelling (Public Health Agency of Canada, 2009; Soine, 2010).

HF afflicts more than half a million Canadians and requires continuous complex medical management and resource utilization. Twenty-four percent of HF patients will require hospitalization within the first year of diagnosis: each hospital stay averages eight days at an estimated cost in 2001 of one billion dollars annually. Despite headway in treatment, mortality remains between five and 50% in the first five years following diagnosis (Canadian Cardiovascular Society, 2006).

With no cure, symptom control is a critical part of HF management (Gallagher, 2010; Luttik, Jaarsma, Moser, Sanderman, & van Veldhuisen, 2005; Riegel & Carlson, 2002; White, Howie-Esquivel, & Caldwell, 2010). Evidence indicates that early diagnosis and treatment along with continuous symptom monitoring and management can lessen acute deteriorations and decrease the need for hospitalization (Gallagher, 2010; Luttik, Jaarsma, et al., 2005). Lee, Moser, Lennie, and Riegel (2011) demonstrated that patients achieving an above average degree of self-management are able to enjoy event-free survival rates similar to symptom free HF patients (Lee, Moser, Lennie, & Riegel, 2011). More than ever clinical management has become the responsibility of interdisciplinary clinics utilizing advanced practice nurses specializing in the care of HF patients (Henry, Hull, Litwinovich & Doxakis, 2013). Nurses are well positioned to invest the time and expertise necessary to help patients develop effective symptom management skills (Case, Haynes, Holaday, & Parker, 2010; Gardetto, 2011).

Most HF management programs acknowledge the critical role that the patient's social support systems play in their care (Luttik, Jaarsma, et al., 2005). More and more, family

caregivers are relied upon to play an increasingly active role in symptom assessment and management of chronic illness including HF (McPherson, Wilson, Lobchuk, & Brajtman, 2008; Quinn, Dunbar, & Higgins, 2010). Family and friend social support has been linked to lower readmission rates and improved medication adherence in HF patients (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008). The challenge to patients and caregivers alike rests in achieving the high level of self-management necessary to maximize functional status and quality of life for the HF patient.

Since family caregivers are active participants in the care and management of HF patients in the community, efforts should be made to support their important contribution. As family caregivers become increasingly expected to monitor, interpret, and report their findings to healthcare providers, it becomes increasingly important that their perceptions reflect the true nature of the patient's symptom experience (McPherson et al., 2008). Misjudgments in symptom assessment by family caregivers of HF patients may contribute to poor symptom management resulting in untimely hospitalizations. One way to support the family caregiver and patient is to enhance caregiver skills in perceiving the patient's symptoms. The closer the family caregiver can come to approximating the symptom experience of the patient themselves, the more valuable their contribution to symptom management will become.

Examining symptom assessment congruence between family caregivers and HF patients, Quinn, Dunbar and Higgins (2011) found moderate agreement among dyads. There were some significant symptoms such as leg edema for which family caregivers consistently rated the symptom lower than the patient's self-assessment indicating room for improvement in caregiver assessment in the HF population. Among cancer patients and their caregivers the opposite has been reported, with a tendency for the caregiver to overestimate symptom severity, more so on

psychological symptoms than on physical ones (Lobchuk & Degner, 2002; McPherson et al., 2008). The literature demonstrates a need to improve this important communication exchange between family caregiver and patient.

In the 1980's, the communications researcher, Mark V. Redmond demonstrated that competent communication closely shared a set of perceptual and expressive skills with empathic perception (Redmond, 1985). Based on this connection, it is reasonable to assume that improving empathic perception may also improve communication competence between family caregivers and patients, resulting in shared understanding of the patient's symptom experience.

One promising method to enhance empathy and achieve improved perceptual agreement between two individuals, employs what psychologist Mark Davis (1996) refers to as an advanced cognitive processes of empathy: role-taking, also known as perspective taking. When clinically employed, perspective taking is an empathic process that involves the observer (e.g., the family caregiver) imaginatively putting themselves into the other person's (e.g., the patient) 'shoes' in order to accurately estimate the patient's symptom experiences (Davis, 1996).

In the context of family caregiving, perspective taking is a learned process where the family caregiver engages actively and deliberately in an attempt to access and understand the inner thoughts and feelings of the patient from a sensitive, patient-oriented point of view. This definition differs from the self-oriented perspective taking where the family caregiver may imagine him- or herself in the patient's situation and how he or she would think and feel as an individual in the same predicament. This process suggests a type of projection process where the caregiver assumes that his or her beliefs or feelings are similar to the patient's beliefs or feelings. On the other hand, 'other' or patient-oriented perspective taking requires the family caregiver to

temporarily suppress their egocentric point of view, placing him- or herself within the situation, as the patient (Batson, 2011; Davis, 1996).

Lobchuk and colleagues' findings suggested that the other-oriented, or 'imagine-patient' perspective-taking approach was effective in narrowing the degree of disagreement (for six common symptoms) and produced higher concordance on ratings of patients' symptoms between cancer patients and their family caregivers (Lobchuk, McClement, Daeninck, Shay, & Elands, 2007a). These encouraging results suggest that the active, deliberate process of perspective taking may offer one method of enhancing empathic perception and improve perceptual agreement between family caregivers and HF patients, ultimately improving symptom assessment and health outcomes.

Purpose of the Study

The main purpose of this pilot study is to examine the impact of a perspective taking instructional prompt as a means to enhance a family caregiver's ability to assess the HF patient's symptom experiences.

Theoretical Perspective

In order to better understand the connection between empathic perspective taking, perceptual agreement, and helping behavior, it is beneficial to review literature and theory on the broader concept of empathy. Psychologist Mark H. Davis (1996) spent 15 years studying the origins and characteristics of empathy. Davis developed a comprehensive, inclusive organizational model to encompass the many facets of this complex concept including process and outcome components, as well as emotional and cognitive components of empathy (Davis, 1996). Discussion of Davis' model will be limited to concepts directly relevant to the purpose of this study.

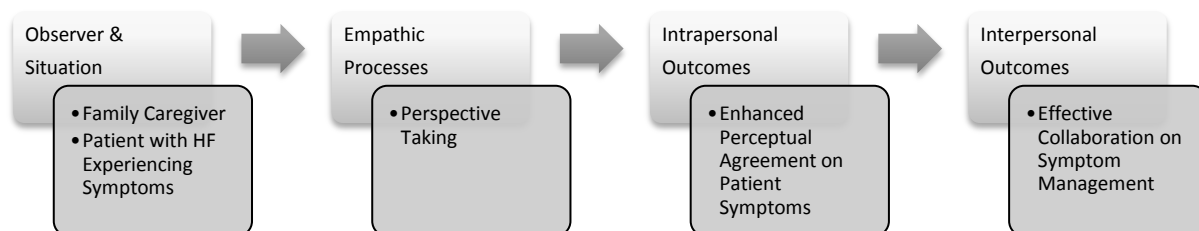
Davis' (1996) model of empathy flows in one direction (i.e., no feedback loops) beginning with two antecedents: the observer, and the situation they witness. Characteristics of the observer (e.g., past-experiences) and the situation (e.g., intensity or duration) influence the observer's unique empathic response. Once the observer is exposed to the situation, they may choose to first engage in an empathic process, or to move immediately to an outcome, either intrapersonal (i.e., an emotional or cognitive response occurring within themselves) or interpersonal (i.e., behavior directed toward the situation).

Figure 1.1 Flow of Davis' (1996) model (adapted).



The purpose of the study intervention will be to encourage the family caregiver to move through Davis' model, deliberately employing the empathic process of perspective taking in order to experience the intrapersonal outcome of enhanced perceptual understanding, directed at achieving the interpersonal outcome of helping behavior. Further exploration of these constructs within the context of family caregiving and symptom assessment will demonstrate the hypothesized application of Davis' organizational model of empathy.

Figure 1.2 Flow of Davis' (1996) model as employed in study.



The observer is the family caregiver who responds to the HF patient experiencing HF symptoms (the situation). In response to the perceived symptoms, the family caregiver will be

encouraged to actively engage in the advanced cognitive process of perspective taking. Davis (1996) described perspective taking as a deliberate, active, learned process in which one individual attempts to access and understand the inner thoughts and feelings of another individual. Citing the works of Dymond (1950), and Derr and Speroff (1954) (as cited in Davis, 1996) Davis believed that the intrapersonal outcome of perceptual agreement is largely the result of the cognitive process of perspective taking. Perspective taking requires the developmental ability to suppress one's own egocentric point of view and actively consider the point of view of another individual. (Davis, 1996). Caregivers who engage in the empathic process of perspective-taking may attain the interpersonal outcome of perceptual agreement and enhance their understanding of the patient's suffering from the patient's point of view. Perceptual agreement between the family caregiver and the HF patient over the patient's distressing symptom experiences will potentially allow the family caregiver to offer the patient more effective cooperative assistance in symptom management (an interpersonal outcome).

As guided by Davis (1996), this study will test the effect of an instructional set that prompts the caregiver to engage in the empathic process of perspective-taking and helping behaviors that are sensitive and responsive to the patient's symptom needs from the patient's point of view.

Definition of Terms

The following constructs are defined as they will be operationalized within the parameters of the study and derived from the work of Davis (1996).

Empathic process. An empathic process is a learned, cognitive empathic response, deliberately employed by a caregiver in response to the patient experiencing HF symptoms in

order to achieve intrapersonal and interpersonal outcomes. Perspective-taking is an empathic process.

Empathic response. An empathic response is any reaction, emotional or cognitive, internal or expressed that reflects the caregiver's efforts to achieve an understanding of the patient's internal state of being from the patient's viewpoint of the situation.

Family caregiver. A family caregiver is any unpaid person identified by the patient who shares in activities of daily living with the patient, including participation in HF symptom assessment, as well as symptom management (i.e., helping behaviour).

Interpersonal outcome. An interpersonal outcome is the caregiver's outward helping behaviour directed at ameliorating or palliating the patient's HF symptoms as a result of the caregiver's patient-oriented understanding of the situation.

Intrapersonal outcome. An intrapersonal outcome is the result of the caregiver's empathic response to the patient's symptom experiences manifest in the caregiver's patient oriented understanding of the situation. Patient oriented understanding, also known as perceptual agreement, occurs when the caregiver and the patient experiencing the HF symptoms arrive at a similar understanding of the inner thoughts and feelings experienced by the patient at that moment.

Perspective taking. A deliberate, active, learned empathic process in which the family caregiver attempts to access and understand the inner thoughts and feelings of the patient about symptom experiences from a sensitive, patient-oriented point of view. This definition differs from the self-oriented perspective taking in which the caregiver imagines him- or herself within the patient's situation and how he or she would think and feel. The patient-oriented perspective

taking requires the caregiver to suppress temporarily their egocentric point of view, placing him- or herself within the patient's symptom experiences, as the patient.

Research Questions

As guided by Davis' (1996) organizational model of empathy this pilot study aims to answer the following research questions:

1. Is there improved perceptual agreement between family caregivers and HF patients after family caregivers are instructed to engage in patient-oriented perspective-taking in the context of assessing the patient's symptoms?
2. Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to engage in a patient-oriented perspective-taking process in the context of assessing and managing the patient's symptoms?
3. What are the perceptions of HF patients and their family caregivers in response to the patient-oriented perspective-taking intervention in the context of assessing and managing the patient's symptoms?

Significance of the Study

The patient-oriented perspective taking intervention has the potential to positively impact the family caregiver's ability to support and maintain the HF patient within the community setting through better symptom assessment and symptom management. If shown to be effective in this project, this simple, non-invasive intervention could be tested in a larger experimental design study. If shown to be effective in future experiments, the patient-oriented perspective taking instruction could be incorporated into current HF symptom assessment teaching guidelines for family caregivers at HF clinics, inpatient facilities, community health offices and private clinics. This pilot project will add to the cumulative knowledge regarding the impact of

patient-oriented perspective taking instructional prompts already explored in existing research (Lobchuk et al., 2007a, Lobchuk, McClement, Daeninck, Shay & Elands, 2007b; Lobchuk & Vorauer, 2003; Quinn et al, 2011). If a positive significant effect can be shown in the investigator thesis project with a homogenous sample of family caregivers of individuals with HF, then it is plausible that the perspective taking prompt will have a similar effect and wide applicability in other chronic diseases.

Improved symptom management is known to enhance the wellbeing and quality of life for both the patient and the family caregiver (Lee et al., 2011). Long-term effects of the imagine-patient perspective-taking intervention could include decreased morbidity, decreased mortality, and decreased need for acute hospitalizations with the added benefit of a reduced healthcare burden and caregiver satisfaction and confidence in managing patients' symptoms in HF.

Chapter Two – Review of the Literature

Understanding Heart Failure (HF)

HF is not a disease but rather a wide range of clinical pathologies resulting in a limited array of clinically recognizable signs, symptoms and characteristics producing a complex progressive clinical syndrome (Green, 2009; Soine, 2010). Classic manifestations of HF are shortness of breath, fatigue, and fluid retention attributable to cardiac ventricular dysfunction from a progressive remodeling of the heart's architecture.

Etiology. An estimated two-thirds of all HF cases are a result of coronary artery disease (CAD), with the remaining one-third believed to be non-ischemic (Hunt, Baker, Chin, Cinquegrani, Feldmanmd, Francis...Smith, 2001; Soine, 2010). Advances in the treatment of CAD have led to greater survival rates and longer lives for this patient population. Improved CAD treatment is of course, good news and welcome progress. However, the cost of survival often involves some degree of permanent injury to the heart, setting the stage for development of heart failure syndrome. Discovering the etiology of an individual's HF is an early step in diagnosis and management as the potential reversal of causative factors, such as ongoing cardiac ischemia, impacts symptom experience, and illness progression (Canadian Cardiovascular Society, 2006; Hunt et al., 2001).

Ventricular dysfunction in HF may result from any number of conditions which chronically increase ventricular pressure load (such as hypertension) or volume load (such as aortic valve incompetence), place overwhelming metabolic demands on the heart (such as anemia), or result in direct injury to the myocardium (such as infarction; cardiotoxins) leading to cardiac remodeling (Soine, 2010). In cardiac remodeling, initially adaptive changes within the ventricle, eventually become exaggerated and dysfunctional resulting in ventricular dilatation and hypertrophy. Neural hormonal mechanisms and sympathetic nervous system activation

contribution to HF have gained widespread attention in the past decade as researchers strive to understand better their contribution to the failing myocardium (Soine, 2010).

Ventricular dilatation is a result of cardiac muscle cell (myocyte) elongation in response to the need for the over-taxed heart to increase left ventricular end diastolic volume (the amount of blood in the heart just before contraction) in order to increase stroke volume (amount of blood ejected with each contraction) to meet the body's metabolic demands. Ultimately, ongoing ventricular dilatation causes the dimensions of the heart to permanently remodel with diminished ventricular contractility and diastolic relaxation. This results in diminished forward movement of blood, while simultaneously increasing oxygen demand within the heart muscle (Soine, 2010).

Under the strain of increased afterload (the force against which the heart pumps) or increased preload (the volume of blood in the heart immediately before contraction), ventricular hypertrophy occurs: the myocytes thicken, increasing their mass and the thickness of the ventricular wall. Initially hypertrophy allows the ventricle to increase the force of contraction thereby increasing stroke volume to satisfy metabolic demands. In due course, the hypertrophied myocyte is believed to undergo dysfunctional internal changes leading to diminished systolic contraction and delayed diastolic relaxation. If the heart is unable to relax adequately during the diastolic filling phase, its end-diastolic volume and stroke volume will be diminished. This remodeled, bulky, stiff ventricle has higher oxygen demands and offers greater impedance to coronary perfusion placing further strain on the heart muscle (Soine, 2010).

Systemic neurohormonal changes and sympathetic nervous system activation, adaptive in the short term, in the long term are believed to perpetuate cardiac remodeling. Mobilizing cardiac reserve in times of need, catecholamine release stimulates the heart to increase its rate and contractility thereby increasing stroke volume and cardiac output (the amount of blood

pumped forward per minute). In addition, arteriole vasoconstriction occurs resulting in increased return of blood to the heart and higher filling pressure, increasing end-diastolic volume, stroke volume, and cardiac output. This tightening of the arterioles results in a rise in systemic blood pressure. By increasing preload and afterload, sustained catecholamine stimulation contributes to cardiac remodeling (Soine, 2010).

Diagnosis. As an acknowledged Canadian authority on heart disease, the Canadian Cardiovascular Society (CCS) regularly publishes and updates cardiac practice guidelines. These guidelines are based on meta-analyses of the most current research evidence reviewed by expert practitioners, leading to professional consensus on diagnosis and management targeted for practical application by physicians, nurses, and allied health care practitioners (Canadian Cardiovascular Society, 2006). In 2006, the CCS published their most recent update of consensus conference recommendations on HF diagnosis and management. Recently there has been a necessary clarification in the terminology used to define heart failure. Separating cases by "systolic dysfunction" and "diastolic dysfunction" has been replaced by the distinction of "left ventricular systolic dysfunction" (LVSD) or "preserved systolic function" (PSD) in recognition that systolic and diastolic dysfunction may occur simultaneously (Green, 2009).

The following diagnostic recommendations are based on the CCS 2006 guidelines, with the understanding that individual circumstances will dictate application. When HF is suspected, initial investigation begins with a focused clinical history including risk factors, prior cardiac diseases in the patient and their family, comorbid conditions (especially diabetes and renal disease), current, and significant past drug regimens (including known cardiotoxins), any functional limitations as well as symptoms, and any aggravating factors. Physical examination involves standard vital signs, focused cardiac, pulmonary and abdominal exam, and a vascular

assessment with a determination of volume status including baseline weight and jugular venous distension. Baseline New York Heart Association (NYHA) functional status and American College of Cardiology/American Heart Association (ACC/AHA) HF staging should be documented (discussed in detail under “Illness Trajectory”) (Canadian Cardiovascular Society, 2006; Hunt et al., 2001). Other initial investigations include chest radiography, electrocardiogram, B-type natriuretic peptides (not routine in Manitoba), standard complete blood count, electrolytes, renal function, glucose, lipids, liver enzymes and function, thyroid function, as well as urinalysis. If initial investigations indicate a possible diagnosis of HF syndrome, transthoracic echocardiography is recommended to assess for structural abnormalities in the heart allowing for examination of size and function of the ventricles, estimation of ejection fraction (the percentage of blood present in the heart that is “ejected” forward with the hearts contraction), and identification of valvular abnormalities (backflow leakage during contraction if incompetent or a narrowed exit from the heart chamber if stenosed). If the results are inconclusive or ongoing ischemia is a concern, additional diagnostic investigations may include radionuclide imaging, cardiac angiography, cardiopulmonary exercise testing, or if necessary, magnetic resonance imaging, computed tomography or direct biopsy of the heart muscle (Canadian Cardiovascular Society, 2006).

Symptom Experience

Symptoms are the subjective experience of the individual (Gallagher, 2010). Symptoms indicate subjectively perceived changes in a condition that are not measured in the same objective way as signs such as temperature and blood pressure (Farlex, 2012). Symptoms are often changeable and the gold standard for their assessment is patient self-report (Gallagher, 2010). The clinical manifestation of HF varies significantly in both the frequency and severity of

any given symptom and changes over time. Although dyspnea and fatigue are generally considered the primary symptoms experienced by HF patients, the CCS (2006) identified other common clinical manifestations such as orthopnea, paroxysmal nocturnal dyspnea, weakness, exercise intolerance, dependent edema, cough, abdominal distension, nocturia, and cool extremities, as well as the less common manifestations of nausea, abdominal discomfort, anorexia, and cyanosis. Cognitive impairment and altered mentation or delirium, also less common symptoms, tend to occur more often in the elderly HF patient (Canadian Cardiovascular Society, 2006). To date, the mechanism and progress of cognitive impairment in HF is not well understood (Bauer & Pozehl, 2011).

Illness Trajectory

Over time, the early syndrome of heart failure evolves into perceived illness by the individual with an ensuing chronic, progressive trajectory (Soine, 2010). In 2001, the ACC and the AHA Task Force published a new method of examining this trajectory in the form of four HF stages (Hunt et al., 2001).

Acknowledging the importance of the pre-symptomatic period, the ACC/AHA HF 'Stage A' includes individuals who are at greater risk for developing HF, but currently do not manifest structural heart disease or any of the symptoms of HF syndrome. Examples of high risk factors include hypertension, arteriosclerosis, diabetes, obesity, treatment with cardiotoxins, or a family history of cardiomyopathy. 'Stage B' includes those individuals with structural heart changes but still no outward signs or symptoms. 'Stage C' identifies the period traditionally recognized as HF where measurable structural changes in the heart are evident along with past or ongoing symptoms of HF. 'Stage D' captures end-stage heart disease in which the individual is refractory to maximal medical treatment, requiring such extraordinary treatment as mechanical support,

inotrope infusion, transplantation, or the addition of hospice care to relieve or palliate HF symptoms. 'Stage D' individuals experience symptoms at rest and are recurrently hospitalized (Hunt et al., 2001; Soine, 2010).

The intent of the ACC/AHA Task Force was to create a system complimentary to the traditional HF classification system of the NYHA which is based on the patient's perceived symptoms (Hunt et al., 2001). NYHA Class I includes patients experiencing no symptoms with normal activity, Class II, those with symptoms during ordinary activity, Class III, individuals with symptoms during less than ordinary activity, and Class IV, individuals experiencing symptoms while at rest or with minimal activity (American Heart Association, 1994). Although the NYHA system offers an excellent ongoing gauge of the individual's functional status at a given point in time, it is sensitive to acute variation and therefore does not map the overall illness trajectory. For example, a patient could experience NYHA Class IV symptoms during an acute decompensation then return to their baseline functional status of NYHA Class II for a long period of time. In the ACC/AHA staging system, the individual moves forward in a predetermined direction but with a trajectory amenable to diligent care (Soine, 2010). The ACC/AHA noted that their staging system does not seek to address acute exacerbations, the care of children, or HF due to primary valvular disease or congenital malformations, but rather, the adult individual with chronic left ventricular dysfunction. The ACC/AHA Stages provide a useful template for mapping an individual's progression on the illness trajectory of most adults experiencing chronic heart failure, and recognize early accepted risk factors and the existence of an asymptomatic phase (Hunt et al., 2001).

Recognition of high risk factors allows for mediation of the heart failure trajectory before damage to myocardial structures occurs. Building prevention and early intervention into the

treatment model could serve to minimize or delay cardiac remodeling and the onset of HF symptoms. While prevention is a worthy goal, developing methods to moderate the effect of existing cardiac damage and ongoing symptom management is an ongoing concern.

Treatment

Following diagnosis, treatment of HF begins with the reversal of any causative or contributing factors such as ongoing ischemia, untreated hypertension, or ongoing exposure to cardiotoxins. The next step involves a lifetime commitment to careful optimization of pharmaceutical management, lifestyle modification, and symptom management (Artinian, Magnan, Sloan, & Lange, 2002; Edwardson, 2007).

The CCS regularly updates and publishes an algorithm for the treatment of clinically stable HF on their website (www.ccsguidelineprogram.ca) and in a pocket guide format. Pharmaceutical treatment begins with angiotensin converter enzyme inhibitors (ACEI) (or angiotensin II receptor blocker (ARB) if ACEI is not tolerated) and a beta blocker (BB) (or ARB if beta blocker is not tolerated). These two medications are titrated up to the maximum therapeutic dosage as tolerated by the individual's blood pressure and heart rate with the goal of strengthening pump function and reducing the load on the heart. The patient must self-monitor for symptoms of hypotension and bradycardia such as weakness, light-headedness, fainting, and postural light-headedness. The patient's kidney function must also be monitored as these medications may induce renal insufficiency and hyperkalemia. If HF symptoms persist (NYHA Class II – IIIa) while on maximum dosages of ACEI and BB, an additional ARB or Digoxin/Nitrate dosage combination may be added. If symptoms persist or worsen over time, the patient may require the addition of one or more diuretics, typically Furosemide and Spironolactone to reduce the fluid load on the heart (Canadian Cardiovascular Society, 2006).

If a patient has an ejection fraction of less than 30%, he or she may be considered for implantation of an implantable cardiac defibrillator (ICD) due to a high risk for sudden death secondary to arrhythmias. If the patient has an electrocardiogram QRS complex greater than 120 milliseconds (prolonged transmission of the electrical impulse through the ventricles), they may be considered for cardiac resynchronization therapy (CRT): CRT involves a specialized implanted pacemaker with an additional ventricular lead to enhance coordination of the ventricles during contraction compensating for prolonged transmission of the electrical impulse through the ventricles. Many HF patients experience bradycardic and tachycardic arrhythmias that require implanted pacemakers. Medications, such as BB, that reduce the patient's heart rate to a therapeutically slower rate may lead to the implantation of a pacemaker as a safety feature to prevent symptomatic bradycardia (Canadian Cardiovascular Society, 2006).

Lifestyle changes that involve entrenched behavior can prove challenging for the HF patient (Edwardson, 2007; Gallagher, 2010). Dietary changes, smoking cessation, and regular exercise take time and perseverance on the part of the patient. Psychological counselling, a referral to a dietitian, and a referral to a medical rehabilitation recreation center are standard practices at the SBGH Heart Failure Clinic. A reduced sodium diet and often times, fluid restrictions of 1500 milliliters per day are common in the HF population. Mounting evidence points to the importance of a guided regular exercise program as tolerated, even in advanced HF (Downing & Balady, 2011; O'Connor et al., 2009; Whellan et al., 2011). Diligent follow-up by health care providers is necessary to facilitate these often-difficult changes for the long-term.

Symptom management goes beyond the day-to-day care routines demanded by many chronic illnesses sometimes referred to as self-maintenance. HF patient self-maintenance activities include medication compliance, maintaining a low sodium diet, partaking in regular

exercise, and monitoring daily weights. Many HF patient educational programs, often interdisciplinary, help prepare the patient for these self-care routines. However, self-care also involves the constant and careful assessment of subjective symptoms which may point to a chronic deterioration in the patient's condition or the onset of an acute deterioration that requires immediate professional attention (Edwardson, 2007). Such symptoms include fatigue, shortness of breath, orthopnea, paroxysmal nocturnal dyspnea, and dependent edema usually of the lower legs or abdomen. When regular self-maintenance leaves the patient experiencing an increase in the frequency, duration, or intensity of any of these symptoms, the patient must engage in a more active process of self-management, also referred to as symptom management. Symptom management activities may include short-term fluid restriction, the addition of prescribed short-term supplementary diuretics or a reduction in activity or exertion. Most often, a self-assessment of increased HF symptoms should trigger the patient to contact the health care provider who is responsible for the care of their HF. Early professional intervention can help prevent a severe acute episode and treat any underlying causes. Diligent symptom assessment and management lead to fewer emergency room visits, fewer hospitalizations, and increased functional status (Gallagher, 2010).

Patient Self-Care

In the Heart and Stoke Foundation's (2011) patient handbook, "Managing Congestive Heart Failure" an emphasis is placed on the patient's need to identify areas of control over illness. HF demands involvement of the patient on a daily basis to make informed lifestyle choices to mitigate the impact of their illness on quality of life and functional status (Gallagher, 2010; Granger, Sandelowski, Tahshjain, Swedberg, & Ekman, 2009; Riegel et al., 2011). A widely-held belief is that patients who actively participate in self-care have better quality of life

than their counterparts (who do not partake in self-care) and are hospitalized less often (Granger et al., 2009; Riegel et al., 2011). Ironically, it is also well established that heart failure patients exhibit poor adherence to many self care behaviors (White, Howie-Esquivel, & Caldwell, 2010).

White et al. (2010) tested the use of a diary as a concrete measure to record daily weights, HF symptoms, and hospitalizations. White was able to demonstrate increased adherence in monitoring daily weights using the diary but she also noted that only one in 20 patients responded to a change in weight by contacting their physician. Webel and colleagues (2007) examined the variability of daily weights along with common symptoms of dyspnea and edema, and found that the greatest variability occurred with dyspnea over the 30 day study (Webel, Frazier, Moser, & Lennie, 2007). Edema however remained relatively stable with periodic large variations. There was a stronger positive relationship between dyspnea and edema than either symptom and body weight (Webel et al., 2007).

A significant factor in the early treatment of heart failure exacerbations is the patient's hesitation in disturbing or bothering their family caregiver with changes in symptom severity or frequency, leading to a delay in treatment (Dunbar et al., 2008). The heart patient's desire to avoid worrying family members resulted in an ineffective response to escalating symptoms that should have been treated early to avoid hospitalizations (Dunbar et al., 2008; Jurgens, Hoke, Byrnes, & Riegel, 2009).

Role of Family Caregivers

Informal care is often complex and poorly understood. Clark, Reid, Morrison, Capewell, Murdock and McMurray (2008), in their descriptive study of informal care, described what they termed "invisible caring". Invisible caring, either obvious or covert, involves ongoing monitoring and symptom assessment, and estimations of energy levels compared to anticipated

energy use (Clark et al., 2008; Kang, Li, & Nolan, 2011). Often these assessments were described as subtle, difficult to explain, and born of many years of experience with the patient. These activities often influenced patient and family caregiver decisions regarding when to seek professional help for an exacerbation in symptoms, lead the caregiver to curb the patient's activities, or influenced the caregiver to take over certain activities or roles. Accuracy of assessment was seen as very important by the informal caregiver (Clark et al., 2008). Facilitating accurate symptom assessment by family caregivers could avoid reliance on the patient's self-reported symptom assessment as the sole impetus for seeking care.

Other researchers examined 'shared care' with the aim of understanding the role of congruence in symptom assessment between patients and family caregivers in decreasing caregiver strain on the supportive family member. Horowitz, Goodman, and Reinhardt (2004) and Sebern and Riegel (2009) found that patient-family caregiver disagreement about symptom experiences increased tension and depressive symptoms for both the patient and the caregiver.

Historically health care providers have turned to family caregivers for surrogate decision-making when patients are unable to decide for themselves, recognizing their special relationship and intimate understanding of the patient. In a meta synthesis of family caregivers' experiences with HF, Kang and another fellow researcher identified the theme of 'Enjoying a Good Relationship' that captured a special closeness with the patient in which the family caregiver would engage in activities, such as maintaining a low salt diet along with the patient as a form of solidarity. This theme also depicted the positive effects for both partners in having someone close to share problems indicating a natural, ongoing communication of concerns between the dyad (Kang et al., 2011). It is reasonable to accept that involved family caregivers, who

participate in the patient's health care decisions on a regular basis, often assume the role of an advocate for, or an advisor to the patient.

Perceptual agreement on symptom assessment between the patient and the family caregiver ultimately relies on how well the patient is willing or able to communicate their inner symptom experiences to their family caregiver. How the patient conveys their symptom experiences to their family caregiver, and how the family caregiver perceives and understands the inner subjective world of the patient's symptom experiences involves a complex, poorly understood communication process between the patient and the family caregiver.

Communication, Empathy and Perspective-Taking

Simple dictionary definitions of communication describe it as an imparting or transmitting of knowledge in order to achieve understanding or share thoughts, ideas or feelings (Dictionary.com, 2012). Implicit to this definition of communication is that another individual is on the receiving end of the transmission of knowledge. Communication often involves non-verbal cues and observations that the receiving individual must actively perceive in order to successfully share the other person's inner thoughts and feelings. Shared understanding or perceptual agreement is the result of successful communication. Family caregivers cannot effectively participate in shared decision making in symptom management with the patient if they are not receiving reliable information about the patient's symptom experience.

In 1985, researcher Mark Redmond was able to demonstrate a strong relationship ($r = .98$) between communication competence and empathy when university students evaluated 27 conversational sets of personal crisis. This finding suggested that empathy and communication are not discrete concepts (Redmond, 1985). In his later work, Redmond (1989) described what he saw as empathy's role in competent communication: it allows us to achieve better

understanding (perceptual agreement), but also enhances our ability to predict another person's actions and to adapt to a situation. Empathic responding is an essential tool for the family caregiver to achieve perceptual agreement with the patient, to better step inside their subjective world of symptom experiences in order to predict the patient's reactions to symptoms, and help the patient adapt to, or manage their circumstances.

The definition of empathy has been a subject of debate for many years (Batson, 2011; Davis, 1996). Batson described eight concepts of empathy that commonly appear in the literature. Two of these concepts are useful in our discussion of empathy: understanding the inner thoughts, feelings and ideas of another person, and the act of taking on the position or perspective of another individual in order to understand or imagine their inner thoughts, feelings and ideas (Batson, 2011). When conceptualized in this manner, Davis' organizational model of empathy (described in Chapter 1) demonstrates how active empathic processes may be employed to enhance an individual's empathic response in order to communicate a higher degree of understanding, or perceptual agreement between two individuals. Within the context of caregiving, Davis's model predicts that when the family caregiver is exposed to the HF patient who is experiencing symptoms, the caregiver may choose to invoke the active empathic process of perspective-taking to achieve a higher level of understanding (perceptual agreement) of the patient's symptom experience (Davis, 1996). If Redmond's (1989) assertions regarding the role of empathy in competent communication are valid, the caregiver will not only gain better perceptual agreement, but also predict better the patient's reactions and adapt to the patient, potentially leading to more effective helping behavior. The promising effects of empathic responding on enhanced perceptual understanding and helping behaviors have drawn the interest of researchers in family caregiving.

First, let us examine in detail the fundamental groundwork conducted on empathy by social psychologists. Batson, Early and Salvarani (1997) were interested in the relationships among perspective-taking, empathy, and personal distress. In Batson et al.'s study, 60 university students were exposed to the distressing situation of a young student whose parents died leaving her to care for younger siblings. Batson et al. employed three different perspective-taking prompts: an objective stance, imagine-other, and imagine-self perspective-taking. Employing their own empathy index and distress index (differentiating direct personal distress and distress for another), Batson et al. were able to demonstrate a significant difference in the responses between the 'objective' group and the two 'imagine' groups. The two 'imagine' groups showed a similar degree of distress, however the target of their emotion or distress differed (direct personal distress versus distress for the young student). The 'imagine-self' group experienced more distress for the young student than the 'objective' group, but also more direct personal distress than either the 'imagine-other' or 'objective' groups. On the other hand, the 'imagine-other' group demonstrated more distress for the young student than the 'objective' group and the 'imagine-self' group. As captured on Batson et al.'s (1997) empathy index, the 'imagine-other' group had exhibited significantly greater empathy than distress, and the distress they felt correlated higher with distress for the young student than direct distress within themselves. The 'imagine-self' group had both high empathy and high overall distress; however, the distress was highly correlated with direct personal distress but only weakly correlated with distress for others. The 'imagine-other' group had the clear advantage of experiencing a lower degree of personal distress. Batson et al. concluded that both 'imagine' perspectives would invoke empathy in the observer, however, the 'imagine-self' group would choose to act to alleviate their own distress whereas the 'imagine-other' group would experience more altruistic motivation (Batson et al.,

1997). Testing the impact of an 'imagine-other' prompt in evoking empathy responses is therefore warranted in reality based settings. In the context of caregiving, further studies could examine the impact of an 'imagine-other' prompt with family caregivers to invoke enhanced empathic responding toward their loved one who is experiencing illness related symptoms. Based on the seminal work of Batson et al., an 'imagine-other' prompt has potential to enhance caregivers' competent communication, perceptual agreement, and helping behavior toward the HF patient while limiting the harm of personal distress.

Lobchuk, McClement, Daeninck, Shay, and Elands (2007 a) tested the different effects of three perspective taking prompts (imagine-self, imagine-patient, and neutral) on reducing perceptual disagreement between patients and family caregivers on patient symptom experiences in the context of cancer care. The most discordance between patients and caregivers on ratings of patient symptoms occurred when caregivers responded to the imagine-self prompt. On the other hand, the imagine-patient perspective-taking prompt was more effective in reducing patient-caregiver disagreement on patient symptoms and resulted in higher concordance between the patient and the family caregiver on six common symptoms (lack of energy, worrying, pain, lack of appetite, weight loss, and change in taste) (Lobchuk et al., 2007 a).

Similar research has been done in the cardiac population with HF patients. Quinn et al. (2011) completed a pilot study where they tested the effect of an 'imagine-other' perspective-taking intervention on the empathic response of family caregivers toward community dwelling patients with HF. At the 2011 Heart Failure Society of America conference, Quinn et al. reported an increase in perceptual agreement on six of 14 symptoms (shortness of breath (SOB) lying down, SOB waking up at night, chest pressure, irregular heartbeat, difficulty sleeping, and difficulty concentrating) captured on the Heart Failure Symptom Survey (Quinn, Dunbar, &

Higgins, 2011). Quinn et al. (2011) concluded that family caregivers were actively employing the patient-oriented empathic process of perspective-taking after they received an instructional prompt to entertain the patient's viewpoint on symptom experiences over a two-week time frame in the home. A growing body of research supports the belief that imagine-other perspective-taking is an effective process for enhancing empathic responding and perceptual agreement. The work of Lobchuk et al. (2007 a) and Quinn et al. (2011) strongly suggested that imagine-other perspective-taking is not only an active, conscious process, but that it can be learned by family caregivers in a relatively short period of time with simple instructions.

Summary

The investigator's literature review demonstrated that there is growing evidence that supports respective linkages among caregiver perspective-taking, empathic responding, perceptual agreement, competent communication, or motivation to engage in helping behavior toward patients who suffer from serious illness. Based on the investigator's review of empathy theory by Davis (1996) and studies on perceptual understanding in social psychology (Batson et al., 1997) and nursing literature (Lobchuk et al., 2007 a, b; Quinn et al. 2011), interventions that aim to bolster caregivers' skills in empathy can result in enhanced patient-caregiver agreement in symptom assessment and symptom management for the HF patient. In turn, improved symptom management for the HF patient has the potential in the long-term to decrease morbidity, increase patient quality of life, slow the progression of heart failure, and lessen the need for emergent care and hospital admission. Due to the paucity of studies on the effects of an imagine-patient perspective-taking intervention on patient-caregiver perceptual agreement in symptom assessment, further research is needed before widespread adoption and application occurs.

Chapter Three - Methodology

Introduction

The purpose of this chapter is to describe the study design and research methodology utilized to examine the impact of a perspective taking instructional prompt as a means of enhancing the family caregiver's ability to assess the heart failure (HF) patient's symptom experience, and support the patient's symptom management behavior. This section will include a discussion of the study design, sample and setting, instrumentation, methods and procedures including a description of time frames. This section will conclude with a description of the data analysis plan to answer the study's research questions.

Design, Sample and Setting

This pilot study utilized a prospective one-group pre-test/post-test interventional design with dependent dyads of patients with HF and their family caregivers to address the first two research questions:

1. Is there improved perceptual agreement between the family caregiver and the patient with HF after family caregivers are instructed to engage in patient-oriented perspective-taking in the context of assessing the patient's symptoms?
2. Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to actively engage in a patient-oriented perspective-taking process in the context of assessing and managing the patient's symptoms?

Following the quantitative portion of the study, the investigator engaged in a qualitative semi-structured interview to explore the third research question:

3. What are the perceptions of the patient with HF and their family caregiver in response to the patient-oriented perspective-taking instructional set as employed by the family caregiver in the context of assessing and managing the patient's HF symptoms?
-

The population of interest was adult patients with HF living in the community who regularly engage in HF symptom monitoring and management along with a family caregiver. To ensure the occurrence of symptoms during the study period, sample selection included HF patients who experienced symptoms with ordinary activity (NYHA Class II), less than ordinary activity (NYHA Class III) or symptoms at rest or with minimal activity (NYHA Class IV) (Canadian Cardiovascular Society, 2006) for a minimum of three months prior to enrollment (to allow for some experience with assessing HF symptoms). The target sample of patients with HF included those with a family caregiver who assisted in their care for a minimum of three months. Both the patient and family caregiver: spoke and read English, were over the age of 18 years, had access to a telephone, and had no evidence of cognitive impairment precluding them from informed consent as determined by clinical staff. Patients excluded from participating in the study included those with ongoing cardiac ischemia that requires acute treatment (however, they would have been eligible to enroll in the study once they were stable), and those with a major psychiatric disorder or significant cognitive dysfunction.

Protection of human subjects. Written permission to conduct the study was obtained from the Winnipeg Regional Health Authority ACCESS ethics board, the Education/Nursing Research Ethics Board at the University of Manitoba, St. Boniface Hospital Office of Research and Grace Hospital Research Ethics Board. SBGH site permission for the study was obtained from the Director of the SBGH Heart Failure Clinic, Dr. S. Zieroth; Program Team Managers of SBGH in-patient units E5 and E6, Ms. S.A. Hobbs and Ms. M. Damm; and the Program Director of the Medicine Program, SBGH, Ms. Heather Carlsson. Grace Hospital site permission for the study was obtained from the Program Director of the Adult Medical Clinic and the inpatient medical unit, Mrs. Monica Warren.

Only those participants who voluntarily agreed to participate in the study were included. A verbal explanation of the purpose of the study and its risks and benefits was given to each participant. The investigator stressed that patients and family caregivers could withdraw at any time during the study with no effect on their care or treatment. A written explanation of the study was included in the consent forms for patients and family caregivers (Appendices B and C).

All information was gathered from patients and family caregivers. Permission to speak with the patient's health care provider was sought in the patient consent form for instances where a lack of clarity in medical information existed. Demographic data was obtained to describe the representativeness of the sample (Appendices D and E). Confidentiality of the information was guaranteed by the investigator. In any instance, where demographic variables had a frequency lower than five, data was reported with the larger group to protect the anonymity of participants. A code number for each patient and family caregiver was assigned and written on all questionnaires and interview transcripts. Participants were instructed not to write their names on the forms and were reassured that no names will appear in written reports of the study. Participants' names in audio-recorded transcripts were replaced with pseudonyms. The list connecting participants with code numbers is being kept separately under lock and key in the investigator's University of Manitoba office. The investigator's advisor and thesis committee were the only ones having access to the data.

Procedures for Recruitment and Participation. The population under scrutiny consisted of 14 pairs of patients and family caregivers dealing with HF in the home setting. The original aim of this study was to have 20 patient-family caregiver dyads comprise the sample for this study. Sample size was based the recommendation of Mr. Brenden Dufault, biostatistician,

Manitoba Centre for Nursing and Health Research, University of Manitoba for conducting tests of two-group differences.

All participants were sought from SBGH HF Clinic, SBGH internal medicine units E5 and E6, Grace Hospital Adult Medical Clinic, and Grace Hospital acute medicine unit. All 15 participants (15 dyads signed consents, 14 dyads completed all questionnaires, one dyad's data collection was incomplete due to death of patient during the study interval) in this convenience sample were invited to participate in this study by SBGH HF Clinic staff. Patients and caregivers who were in the HF Clinic and met the study inclusion and exclusion criteria (i.e., patients were dealing with New York Heart Association (NYHA) Class II-IV HF for a minimum of 3 months; family caregivers were in the caregiving role for a minimum of 3 months; both patient and the caregiver were English speaking, over the age of eighteen years, had access to a telephone, and had no evidence of cognitive impairment precluding them from informed consent as determined by clinical staff), were given a brief verbal description of the study's purpose and provided with the letter of invitation by the clinic nurse or physician (Appendix A). Copies of the letter of invitation were stored on a counter within the clinic where staff reviewed patient charts prior to entering the consulting rooms. Although the letter of invitation included a response option for patients to indicate their interest in being approached by the investigator to tell them more about the study, due to time constraints in the clinic the staff did not retain records on which eligible participants declined the invitation. It was the preferred practice of clinic staff to ask the patient if they were interested, then, if the patient and their caregiver agreed to be contacted by the investigator, the staff nurse provided the patient with the letter of invitation and emailed the patient's contact information to the investigator for follow-up by telephone. In addition, during routine follow-up phone calls, the HF Clinic nursing staff verbally

invited individuals meeting the criteria by using the letter of invitation as a guide (Appendix A); if interested, the patient's contact information was forwarded to the investigator by email or telephone for follow-up. When contacted by telephone the investigator reviewed the purpose of the study, inclusion and exclusion criteria, the risks and benefits of the study, voluntary participation, right to withdraw at any time without penalty, and participation requirements. If the participants were in agreement, a time and place for their first visit was set and if the participants requested, copies of the patient and caregiver consents were mailed to their home in advance of the scheduled home visit.

When in the clinic setting, the investigator was invited into the clinic consulting room by clinical staff to speak with any interested patients (and if available, their caregivers). These patients (and sometimes caregivers) would complete the letter of invitation and return it directly to the investigator when arriving in the consulting room. The investigator would further discuss the purpose of the study, inclusion and exclusion criteria, the risks and benefits of the study, voluntary participation, right to withdraw at any time without penalty, and participation requirements. If the participants were in agreement, a time and place for their first visit was set and copies of the patient and caregiver consents were provided to them to review. If time permitted, the consent was thoroughly reviewed in the clinic and signed. However, due to time constraints within the clinic typically the participants took the consents home for review.

Upon arrival at the first visit, if the consent was not already signed at the clinic, participants were given a more thorough explanation of the study with a review of the consent and were provided answers to any of their questions or concerns. All consents were signed by both participants prior to the initiation of any study procedures or instruments.

The presence of the investigator onsite at SBGH HF Clinic was an approach that appeared to ‘boost’ successful recruitment of study participants. The presence of the investigator served as a reminder to busy clinicians about the study, helped to clarify inclusion and exclusion criteria for staff, assisted in building rapport between the investigator and the nursing and medical staff, and provided opportunities for the investigator to meet and speak directly with eligible patient and caregiver participants about the study while in the clinic setting. On-site visits by the investigator were supported by the clinic manager.

During the recruitment phase, several barriers were encountered at two additional recruitment sites. At the SBGH medical units, the primary contact, Kim Jabusch, had an unexpected extended leave of absence. At Grace Hospital, the clinic manager, Monica Warren, had unexpectedly left her position. The investigator had conducted several site visits at Grace Hospital Adult Medical Unit that included making contact with the clinic coordinator and a meeting with the nursing staff to introduce the study at that recruitment site. However, the investigator was not able to build a successful rapport with staff and no recruitment protocol for the setting had emerged. The investigator left her telephone and email contact information with the clinic coordinator at Grace Hospital so she could follow-up with eligible participants who expressed an interest in the study. The clinic coordinator identified that ‘physician hesitancy’ was the major reason for no invitations being offered to eligible study participants at the Grace Hospital Adult Medical Clinic. As well, the clinic coordinator indicated that, although a few candidates met the inclusion criteria, they were deemed unsuitable for the study based on the opinion of clinic practitioners.

It remains unknown how many patients and caregivers in total were approached by practitioners to participate in the study as the letters of invitation for those not interested were not

completed by staff or patients due to clinical time constraints. It was not possible to estimate the total number of letter of invitations distributed as staff provided letters of invitation to some potential participants without recording their names and some letters of invitations were taken to clinic offices for reference while speaking to eligible participants over on the telephone.

In total, 21 eligible participants submitted to staff a completed letter of invitation at the SBGH HF Clinic indicating their interest in speaking with the investigator about the study. After the investigator spoke further with eligible participants who agreed to hear more about the study (either by telephone or in-person in the clinic), 15 of 21 eligible patient-caregiver dyads agreed to participate and were fully consented: one patient died between the first and second data collection visits leaving a final sample of 14 dyads who completed all study measures at two time points. Thirteen patients and 12 caregivers participated in the post-intervention interview: one caregiver declined the final audio-recorded interview that was scheduled to occur at the SBGH HF Clinic as the Handi-Transit ride arrived early and the second caregiver and patient pair declined due to fatigue (i.e., the patient was recently hospitalized and the caregiver did not wish to reschedule). Table 1.1 describes participants' reasons for non-participation.

Table 1.1

Patient and caregiver reason for non-participation after initial interest expressed (n = 7)

	Phase	Reason for Non-participation
1	Invitation signed at HF Clinic Follow-up Telephone Call	Patient declined; No longer interested
2	Invitation signed at HF Clinic Follow-up Telephone Call	Patient ineligible due to poor short term memory
3	Invitation signed at HF Clinic Follow-up Telephone Call	Patient declined; The patient was in the process of moving further away from the FCG
4	HF Clinic forwarded name by email Follow-up Telephone Call	Patient declined; No longer interested
5	Invitation signed at HF Clinic Follow-up Telephone Call	No response; Several telephone messages left with caregiver
6	HF Clinic forwarded name by email Follow-up Telephone Call	Patient declined; Booked first appointment and cancelled, no longer interested
7	Invitation signed at HF Clinic Completed First Visit	Notified by family of patient's death

Instruments and Measurement

Four instruments were administered during this study: a Demographic Data Form developed by the investigator (Appendices D and E), the Heart Failure Symptom Survey (HFSS) (Appendices F and G), the Empathic Responding Scale (ERS) (Appendices H and I), and a semi-structured Interview (Appendices J and K). Each instrument and interview script was a version designed respectively for the patient and the family caregiver.

The investigator-developed Demographic Data Form captured the socioeconomic characteristics of the participating patients and family caregiver, as well as the extent and duration of the patient's heart failure, and the degree interaction between the patient and the caregiver. Missing or incomplete data regarding diagnosis and stage of heart failure was clarified verbally with the patient's healthcare professional treating their HF. Permission to speak with the patient's healthcare provider was obtained in the patient's informed consent form. All patients provided approval for the investigator to access his or her healthcare provider.

The HFSS measured the patient and family caregiver's perceptions of the patient symptom experiences at baseline and two weeks after the intervention to determine changes in perceptual agreement on ratings between patients and family caregivers on the patient's symptoms (Research Question #1). The HFSS is a 14 item Likert-type scale that was developed by Pozehl, Duncan, and Hetzog (2006) to assess four dimensions (frequency, severity, interference with physical activity, and interference with the enjoyment of life) of 14 common heart failure symptoms over the prior seven days. The four dimensions are measured on a 0 to 10 point scale for such symptoms as shortness of breath and peripheral edema. Pozehl et al. (2006) tested the tool's validity and reliability with a sample of 300 heart failure patients. The Cronbach's alpha reliability coefficient was .80 for the frequency subscale and .87 for the

severity subscale: both estimates indicated good internal consistency (Pozehl, Duncan, & Hertzog, 2006) and established the HFSS as an acceptable instrument for the assessment of common symptoms experienced by HF patients. Quinn, Dunbar and Higgins (2011) adapted Pozehl et al.'s HFSS for use in dyadic research with heart failure patients and their family caregivers to assess heart failure symptom congruence. Their efforts resulted in the two versions of the tool (patient and family caregiver versions) that were utilized in this study (Appendices F and G) (Quinn, Dunbar, & Higgins, 2011).

The ERS was administered to measure and compare patients' and family caregivers' perceptions of the family caregiver's use of cognitive and affective efforts, as well as their behavioural strategies in empathic responding to address Research Question #2. O'Brien and Delongis (1996) originally designed and tested ten empathic responding items examining relationship-focused coping in psychology students. These empathic responding items were rated on a three-point scale and had a reliability alpha estimate of .93 (O'Brien & Delongis, 1996). In her thesis project, Bokhari (2008) adapted the ERS to a five-point scale for use in a descriptive correlational pilot study involving only ovarian cancer patients who reported on their family caregiver's empathic responses in their caregiving relationship (i.e., not dyadic). A Cronbach's alpha estimate of .93 was reported for the ERS as employed in Bokhari's thesis project (Lobchuk & Bokhari, 2008). Bokhari's (2008) five-point scale version of the ERS was used in this study with the patient and the family caregiver who reported on the family caregiver's empathic responding toward the patient.

To address Research Question 3, the final instrument was a three item, semi-structured interview (Appendices J and K) developed by the investigator with the guidance of Dr. M. Lobchuk, Dr. S. McClement, and Dr. C. Quinn (thesis committee members), for independent

administration to the patient and the family caregiver. A qualitative methodology was appropriate as the investigator's goal was to obtain a description of a naturally occurring phenomena (Sandelowski, 2000 a). The interview script sought to elicit participants' descriptions of their experiences with symptom assessment over the two-week post-intervention period. The investigator's aim was to gather a rich description by the patient and the family caregiver about their reactions and receptivity to the patient-oriented perspective-taking intervention that was administered to family caregivers to enhance their patient-oriented understanding and collaboration with the patient in assessing and managing the patient's symptoms in the home (Cresswell, 2007). Consistent with the qualitative approach, interview questions were revised as guided by the emerging interview data.

Procedures and Time Frames

Following enrollment, delivery of the study tools and intervention occurred within a two-week period according to the following schedule (Table 1.2):

Participant	Enrollment	Study Day 1	Study Day 14
Heart Failure Patient	Patient Demographics Form	Heart Failure Symptom Survey Empathic Responding Scale	Heart Failure Symptom Survey Empathic Responding Scale Semi-Structured Interview
Family Caregiver	Family Caregiver Demographics Form	Heart Failure Symptom Survey Empathic Responding Scale Perspective Taking Intervention	Heart Failure Symptom Survey Empathic Responding Scale Semi-Structured Interview

The duration of the study included enrollment and data collection over a two month time period with completion of data collection one month after, and a further two months to complete data analysis (5 month total study period).

Data Analysis Plan

The preliminary data analyses plan was reviewed with Mr. Brenden Dufault, biostatistician, Manitoba Centre for Nursing and Health Research, University of Manitoba. All instruments were scored according to the procedures outlined with each questionnaire and statistical significance was set at $p < 0.05$. Initial data analyses included descriptive statistics (means, frequencies, and range) of sample characteristics (demographics and medical characteristics), and study variables as captured on study questionnaires. All research tools were thoroughly reviewed onsite resulting in no missing data. Data was determined not to meet the assumptions for parametric tests and therefore, non-parametric statistical treatments were employed as recommended by the biostatistician.

Research Question 1. Is there improved perceptual agreement between the family caregiver and the patient with HF after family caregivers are instructed to actively engage in patient-oriented perspective-taking, in the context of assessing the patient's symptoms?

Improved perceptual agreement was assessed by calculating the absolute differences between dyad ratings on each symptom as measured by the HFSS. The data appeared strongly non-normal and the sample size was small, therefore the non-parametric Wilcoxon signed-rank test was used (Polit, 2010). Guided by Davis' model (1996), the investigator predicted that there would be a significantly smaller absolute difference between the dyad's scores two weeks after the intervention when compared to baseline scores. This would demonstrate improved perceptual agreement between the family caregiver and the HF patient after family caregivers are instructed to actively engage in patient-oriented perspective-taking, in the context of assessing the patient's symptoms

Research Question 2. Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to actively engage in a patient-oriented perspective-taking process, in the context of assessing and managing the patient's symptoms?

Patient and family caregiver perceptions of improved empathic responses by family caregivers were assessed by calculating the absolute differences between the ERS scores for each participant at baseline and at two-weeks post intervention. The non-parametric Wilcoxon signed-rank test was employed as the data appeared to be non-normally distributed and the sample size was small (Polit, 2010).

Research Question 3. What are the perceptions of the patient with HF and their family caregiver in response to the patient-oriented perspective-taking instruction, in the context of assessing and managing the patient's symptoms?

An inductive qualitative content analysis was used to interpret and report the data collected by audio-recorded semi-structured interviews with patients and family caregivers two-weeks after the intervention (Elo & Kyngäs, 2008; Sandelowski, 2000 b). This method was chosen because it provided an in-depth understanding and identification of patients' and family caregivers' perceptions of patient and family caregivers responses to the empathy-enhancing intervention, in the context of family caregivers' trying to understand and assess patients' symptoms. Delivery of the perspective-taking intervention and its use over the subsequent two-weeks enhanced purposive sampling by ensuring a common experience for each dyad. Audio-recorded interviews were transcribed verbatim and analyzed using content analysis and constant comparison techniques to identify, code, categorize, classify, and label the primary patterns in the data until no new themes emerge and data saturation had been achieved with the sample (Cresswell, 2007; Elo & Kyngäs, 2008). We identified and explored commonalities and

differences between patients' and family caregivers' responses. Qualitative analysis was guided by the experience of Dr. Michelle Lobchuk and Dr. Susan McClement (thesis committee members).

Trustworthiness was strengthened by pre-planned attention to credibility, dependability and transferability and was largely guided by the 1985 seminal work of Lincoln and Guba. Measures to enhance credibility strengthened the link established between the data and its interpretation, and the intended focus of the inquiry increasing confidence in the worth of the results (Graneheim & Lundman, 2004). The investigator spent eight months prior to the study observing and interacting with HF patients and their family caregivers, documenting and discussing empathic interactions and communication. Persistent observation helped to avoid distortions based on prior knowledge of the investigator (Lincoln & Guba, 1985). No relationship restrictions (e.g., spouse only) were placed on the dyads to ensure rich variation in caregiving experience. Peer debriefing was employed by the investigator, discussing preliminary findings and hypothesis testing with a peer knowledgeable in empathic responding to provide constructive feedback and challenge thought processes surrounding deconstruction, coding, synthesis, and personal bias. Informal member checking occurred throughout the interview process by verbally confirm the respondent's intention allowing for the immediate correction of misinterpretations, and volunteering of additional information to clarify the communication of their perceptions. Summary statements were used for confirmation of interpretation and data points (Graneheim & Lundman, 2004; Lincoln & Guba, 1985).

Dependability relies on consistent data collection and treatment of data during the analysis process. Dependability was supported by audio-recording the interviews, verbatim transcription, consultation with members of the thesis committee to audit coding procedures,

detailed field notes to record the interview environment and conditions, as well as recognition and containment of researcher bias (Graneheim & Lundman, 2004; Lincoln & Guba, 1985).

Three interview questions with associated prompts were used in the semi-structured interviews by the investigator to aid consistency in data collection.

Transferability is the degree to which the study findings may be transferred to other individuals, groups, or settings. Transferability was enhanced through a clear, in-depth representation of the findings, and the circumstances and individuals from which the findings were derived so the results may be suitably utilized. Appropriate, representative quotations were used to exemplify the study's findings, allowing them to retain their unique character and avoid blending them into common-place experience (Graneheim & Lundman, 2004; Lincoln & Guba, 1985).

Summary

A combination of quantitative and qualitative data collection and analyses served to strengthen the analytic power of the pilot study (Sandelowski, 2000 b). The deductive process as guided by relationships depicted in Davis' (1996) organization model of empathy allowed us to detect a measurable change in the behavior of the family caregiver toward the patient experiencing HF symptoms. The inductive process allowed the investigator to uncover insights into how participants perceive their own responses (behavioral and emotional) to the perspective-taking intervention that was administered to family caregivers to enhance their understanding of patients' symptom experiences in HR.

Chapter Four – Results

The main purpose of this thesis project was to examine the impact of a perspective taking instructional prompt as a means to enhance family caregiver ability to assess the patient with heart failure's (HF) symptom experiences. This chapter reviews the data collection protocol, describes the characteristics of paired patient and family caregiver sub-group samples, offers descriptive statistics of the study variables, and reports on the reliability of study instruments with each participant group. Quantitative analyses of data for research questions #1 and #2, as well as inductive qualitative content analyses of data for research question #3 are presented in conjunction with a report of the findings. The specific research questions were:

Research Question 1: Is there improved perceptual agreement between family caregivers and patients with HF after family caregivers are instructed to engage in patient-oriented perspective-taking in the context of assessing the patient's symptoms?

Research Question 2: Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to engage in a patient-oriented perspective-taking process in the context of assessing and managing the patient's symptoms?

Research Question 3: What are the perceptions of patients with HF and their family caregivers in response to the patient-oriented perspective-taking intervention in the context of assessing and managing the patient's symptoms?

Data for this study were collected over a 2 month period between January 2013 and March 2013. Sites for recruitment of participants in this study included: St. Boniface General Hospital (SBGH) HF Clinic, SBGH internal medicine units E5 and E6, Grace Hospital Adult Medical Clinic, and Grace Hospital acute medicine unit. Data collected from each of the participants included pre-intervention measures (patient and caregiver versions of the Demographic Survey, Heart Failure Symptom Survey (HFSS), and Empathic Responding Scale

(ERS)) and post-intervention measures (patient and caregiver versions of the HFSS, and ERS). Following the completion of the pre-intervention questionnaires, family caregivers were instructed by the investigator about an empathic perspective-taking intervention to employ over the following two weeks. Patients and family caregivers were also invited to participate in a post-intervention audio-recorded interview (approximately 20 minutes) with the investigator. The data from the questionnaires were entered into a computer file by the investigator. Audio-recorded interviews were transcribed and analyzed by inductive qualitative content analysis. The computer package SPSS 21.0 for Windows was utilized to analyze the quantitative data.

Data Collection Protocol

Twelve of the 14 dyads completed the study within their home, one dyad at the SBGH HF Clinic, and one dyad with an initial visit in the patient's workplace office and the second visit in a nearby restaurant (at the patients request). The following will describe the consent and data collection protocol for the pre- and post-intervention phases of measurement.

Pre-intervention data collection. Prior to commencing the data collection protocol, the investigator provided study participants with the informed consent to read (Appendix B, and C). Once participants read, understood and signed the respective consent forms for the patient and the caregiver, they were asked to complete the questionnaires. As described in Chapter Three, patients and caregivers completed either the patient or caregiver version of three questionnaires pre-intervention: the Demographic Survey, the Heart Failure Symptom Survey (HFSS), and the Empathic Responding Scale (ERS) (Appendix D, E, F, G, H and I). If participants were unable to be in separate rooms for completion of the questionnaires, a file folder was placed standing up between them to maintain independence in response. Upon completion of the questionnaires the investigator met alone in a quiet room with the caregiver for 10 to 15 minutes to deliver the

Empathic Perspective-Taking Intervention (Appendix K) and answered any caregiver questions regarding employment of the intervention. Total time for the initial visit varied in length from approximately 30 minutes to three hours depending on the preference of the patient and caregiver in establishing rapport.

Post-intervention data collection. Two weeks post-intervention patients and caregivers repeated their respective versions of the two questionnaires: the HFSS, and the ERS (Appendix E, F, G, and H). For the majority of dyads the post-intervention audio-recorded interviews were completed individually in separate rooms within their home, however, three dyads had alternate arrangements: one dyad was in a restaurant with the alternate participant waiting outside in their vehicle (at their suggestion), one dyad was interviewed while the patient was in hospital (using the hospital room for the patient, and a quiet sitting area for the caregiver). An attempt was made to conduct one interview in the SBGH HF Clinic but the patient interview was incomplete due to competing demands to complete clinical tasks and time constraints (i.e., Handi-Transit schedule); the caregiver declined to reschedule interviews for self and the patient).

All participants expressed satisfaction with the research process with no participant displaying distress beyond a normal emotional response to the study's protocol of pre- and post-questionnaires, intervention, and the post-intervention interview questions. The investigator deemed that it was not necessary to seek outside support or counselling for any participant and no related request was made by study participants or their respective practitioners.

Profile of the Participants

A convenience sample of 14 pairs of patients and their family caregivers were included as participants. Table 4.1 summarizes the general demographic characteristics of the patients and caregivers.

Characteristic	Patient Frequency (%)	Caregiver Frequency (%)
Gender		
Male	10 (71.4)	2 (14.2)
Female	4 (28.6)	12 (85.7)
Age Range		
40 years of age or under	1 (7.1)	1 (7.1)
41-50 years of age	-	-
51-60 years of age	1 (7.1)	2 (14.3)
61-70 years of age	6 (42.8)	7 (35.7)
71-80 years of age	3 (21.4)	2 (14.3)
81 -90 years of age	3 (21.4)	2 (14.3)
Marital Status		
Married	10 (71.4)	12 (85.7)
Common-law	2 (14.3)	2 (14.3)
Widowed	2 (14.3)	-
Ethnic Heritage		
Canadian	6 (42.9)	2 (14.3)
French Canadian	1 (7.1)	4 (28.6)
British	1 (7.1)	2 (14.3)
German	3(21.4)	2 (14.3)
Polish	2 (14.3)	1 (7.1)
Scottish		1 (7.1)
Ukrainian	1 (7.1)	2 (14.3)
Education Level		
Less than High School	5 (35.7)	3 (21.4)
High School Graduate	3(21.4)	4 (28.6)
At least one year College or University	3(21.4)	1 (7.1)
College or University Graduate	1 (7.1)	4 (28.6)
Graduate/Professional Training	2 (14.3)	2 (14.3)
Occupational Status		
Employed Full-time	1 (7.1)	2 (14.3)
Employed Part-time	-	2 (14.3)
Medical leave	3 (21.4)	-
Retired	10 (71.4)	8 (57.1)
Unemployed	-	2 (14.3)
Occupational Type (current or previous)		
Clerical	2 (14.3)	4 (28.6)
Labourer	3 (21.4)	1 (7.1)
Homemaker	1 (7.1)	2 (14.3)
Professional/Management	4 (28.6)	4 (28.6)
Skilled Trades	4 (28.6)	3 (21.4)

Household Income (Gross Annual)		
Below \$40,000	3 (21.4)	
\$40,000 - \$79,000	5 (35.7)	
Over \$80,000	3 (21.4)	
Prefer not to answer	3 (21.4)	

Number of Individuals Living in Home		
Live alone	2 (14.3)	-
Two	10 (71.4)	11 (78.6)
Three	1 (7.1)	1 (7.1)
Four	1 (7.1)	2 (14.3)

*no missing data

**no missing data

Demographic characteristics of the patients. Of the fourteen patients 71% were male, had an overall mean age of 69 years and an age range of 38 to 86 years with most patients (64%) ≥ 65 years. All male patients were married and resided with their caregiver. Two of the four female patients were married and lived with their caregiver while the remaining two were widowed and lived alone. Half of the patients self-identified as Canadian or French-Canadian while the other half indicated European descent. The majority (64%) indicated that they had a high school education or higher (43% had some college or university education). Eleven of 14 patients divulged their household income with the majority being \$40,000 or over. Half of the patients historically worked in physically demanding positions (Labourer: 21%, Skilled Trades: 29%); only one patient maintained full-time employment in a reduced capacity at the time of the study while the remaining patients were either retired or on medical leave.

Demographic characteristics of the caregivers. Of the fourteen caregivers, 86% were female, they had an overall mean age of 65 years, and an age range of 31 to 89 years with the majority (64%) of caregivers being ≤ 65 years. All caregivers were in a marital or common-law relationship and resided with their spouse. All male caregivers and most female caregivers were married to the patient; two female caregivers were in a non-marital relationship with the patient and did not live with them. Forty-three percent of caregivers self-identified as Canadian or French-Canadian while 57% indicated European descent. The majority (79%) of caregivers indicated that they had a high school education or higher (50% had some college or university education). Seventy-one percent of caregivers were retired or unemployed at the time of the study; the majority had worked in clerical or professional/management positions. Of note, three caregivers were registered nurses (one practicing, one in management, and one retired).

Characteristics of the patient HF care routines pre-study. Approximately two-thirds of patients (64%) were diagnosed with heart failure more than five years ago. Although HF acuity level varied, 71% of patients sought HF counsel of their family doctor or HF specialist three or more times in the six months prior to the study, 43% visited the ER in the prior six months, while 29% experienced a HF related admission in that period. Although 93% of patients were prescribed a diuretic, only 64% weighed themselves daily. All patients were prescribed daily medication with 79% managing the administration independently at home, and 100% confirming they always take their medications as prescribed. Further details are provided in Table 4.2.

Table 4.2

Characteristics of the Patient HF care routines (n = 14)*

Characteristic	Patient Frequency (%)
Length of time since HF diagnosis	
Less than 6 months	1 (7.1)
6 months < 5 years	4 (28.6)
5 years or longer	9 (64.3)
Approximate number of visits to family doctor/heart specialist, heart failure clinic due to HF symptoms in past 6 months	
None	-
1 to 2 times	4 (28.6)
3 or more times	10 (71.4)
Approximate number of Emergency Room visits due to HF in past 6 months	
None	8 (57.1)
1 time	3 (21.4)
2 or more times	3 (21.4)
Approximate number of hospital admissions due to HF in past 6 months	
None	10 (71.4)
1 time	2 (14.3)
2 or more times	2 (14.3)
Frequency of measuring weight	
Never	-
Once a day	9 (64.3)
Once every 2-3 days	3 (21.4)
Once every week	1 (7.1)
Once every month	1 (7.1)
Take a diuretic or “water pill”	
Yes	13 (92.9)
No	1 (7.1)
Prescribed daily medication	
Yes	14 (100)
No	-
Medications are pre-packaged or “bubble packed” by a pharmacist	
Yes	3 (21.4)
No	11 (78.6)
Consistency in taking medication as prescribed	
Never	-
Rarely	-
Sometimes	-
Frequently	-
Always	14 (100)

*no missing data

Characteristics of caregiver HF care involvement and knowledge. The majority (71%) of caregiving relationships were five years or longer: only one caregiving relationship was below six months. In 86% of dyads, contact between patients and family caregivers was daily as most caregiving couples resided together. Both the patient and the caregiver reported a high degree of caregiver assistance with HF management (79% and 71% respectively). Interestingly, most patients gave a higher rating than caregivers on their joint willingness to discuss the patient's thoughts and feelings about HF as well as on the caregiver's knowledge of the patient's thoughts and feelings regarding their HF symptoms. More than half of caregiving partners reported receiving less than two hours of formal HF teaching. Of note, 86% of patients indicated that they were not required to assist their caregiver with any chronic medical condition. Further details are provided in Table 4.3.

Characteristic	Patient Frequency (n=14)* (%)	Caregiver Frequency (n=14)** (%)
Caregiver relationship to the patient		
Wife		10 (71.4)
Husband		2 (14.3)
Daughter		1 (7.1)
Friend		1 (7.1)
Length of caregiving relationship		
Less than 6 months	1 (7.1)	
6 months to < 5 years	3 (21.4)	
5 years or longer	10 (71.4)	
Caregiver contact with the patient		
Daily, Pt and CG live together	12 (85.7)	12 (85.7)
Daily, Pt and CG do not live together	1 (7.1)	1 (7.1)
More than weekly, Pt and CG do not live together	-	1 (7.1)
Weekly, Pt and CG do not live together	1 (7.1)	-
Less than weekly, Pt and CG do not live together	-	-
Caregiver assistance with HF management		
Never	-	-
Rarely	1 (7.1)	-
Sometimes	2 (14.2)	4 (28.6)
Frequently	3 (21.4)	3 (21.4)
Always	8 (57.1)	7 (50.0)
Patient and caregiver share thoughts and feelings about HF		
Never	-	1 (7.1)
Rarely	-	-
Sometimes	1 (7.1)	4 (28.6)
Frequently	5 (35.7)	5 (35.7)
Always	8 (57.1)	4 (28.6)
Caregiver knows the patient's thoughts and feelings about their symptoms		
Not at all	-	1 (7.1)
Not very well	-	-
Has some knowledge	-	2 (14.3)
Somewhat well	4 (28.6)	7 (50.0)
Very well	10 (71.4)	4 (28.6)

Formal HF teaching sessions		
None	6 (42.9)	5 (35.7)
Less than 2 hours	2 (14.2)	3 (21.4)
2 hours to 8 hours	5 (35.7)	3 (21.4)
More than 8 hours	1 (7.1)	3 (21.4)
<hr/>		
HF related healthcare professionals contact in the past year		
Cardiologist	14 (100)	8 (57.1)
Family Doctor	12 (85.7)	9 (64.3)
Nurse	14 (100)	6 (42.9)
Physiotherapist	2 (14.3)	-
Dietician	3 (21.4)	2 (14.3)
Pharmacist	6 (42.9)	7 (50.0)
<hr/>		
Patient regularly assists caregiver with a chronic medical condition		
Yes	2 (14.3)	
No	12 (85.7)	

*no missing data

**no missing data

Descriptive Statistics of Study Variables

HFSS frequency of symptoms. Both patients (n = 14) and caregivers (n = 14) provided frequency ratings for all 14 HFSS symptoms (occurrence over the last 7 days) at pre- and post-test. Although many HFSS symptoms varied in frequency (on a scale of 0 to 10, where 0 = Never and 10 = Very frequently) between the pre- and post-test measures, for three symptoms, the greatest proportion of patients and caregivers reported occurrence at both time points as well as the highest mean frequency rates as follows: fatigue, tiredness or lack of energy was reported by 86 to 100% of patients and caregivers with mean frequency rating of 4.7 to 6.0 (scale of 0 to 10, where 0 = Never and 10 = Very frequently), difficulty sleeping was reported by 86 to 93% of patients and caregivers with a mean frequency rating of 4.5 to 6.2, and shortness of breath with activity was reported by 71 to 93% of patients and caregivers with a mean frequency rating of 3.1 to 5.8. On the other hand, only 29% to 36% of patients and caregivers reported the occurrence of chest pressure or heaviness in the patient's chest. Other symptoms that had the least proportion of patients and caregivers who reported report their occurrence in the pre-test and post-test conditions were: irregular heart beat or fluttering feeling in your chest (29 to 43% of patients and caregivers) worsening cough (21 to 57% of patients and caregivers), and shortness of breath when you wake up at night (29 to 50% of patients and caregivers). For nine of the 14 HFSS symptoms the patient mean symptom frequency rating was lower on both pre- and post-test than the caregiver mean symptom frequency rating including all four types of shortness of breath, fatigue, tiredness or lack of energy, dizziness or lightheadedness, difficulty sleeping, forgetfulness or difficulty concentrating, and depressed or feeling down. Both forms of edema, swelling in your feet, ankles or legs, and Full or bloated feeling in your abdomen were

consistently rated as more frequent by the patients than the caregivers (i.e. higher mean frequency ratings on both pre- and post-test). Further details are provided in Table 4.4.

Table 4.4
Frequency of each HFSS as rated by the Patient (n=14) and Caregiver (n=14)

HFSS	Pt Pretest %	Pt Pretest Mean (SD)	CG Pretest %	CG Pretest Mean (SD)	Pt Posttest %	Pt Posttest Mean (SD)	CG Posttest %	CG Posttest Mean (SD)
1.Shortness of breath at rest	43	1.6(3.0)	57	3.6(3.6)	43	1.3(2.3)	64	3.1(3.2)
2.Shortness of breath with activity	**71	4.2(3.7)	**93	*5.8(3.4)	**71	3.1(2.7)	**86	*4.6(3.2)
3.Shortness of breath when lying down	57	2.7(3.3)	57	4.2(4.3)	36	2.4(3.8)	57	3.1(3.7)
4.Shortness of breath when you wake-up at night	29	1.6(3.0)	36	2.2(3.7)	43	1.9(3.1)	50	3.0(3.6)
5.Swelling in your feet, ankles or legs	64	*4.4(4.6)	57	3.9(4.5)	71	*4.6(4.4)	50	3.2(3.6)
6.Full or bloated feeling in your abdomen	**71	3.8(3.7)	57	2.7(3.2)	**71	4.1(4.1)	57	2.4(3.2)
7.Fatigue, tiredness or lack of energy	**93	*5.4(3.4)	**100	*6.0(3.4)	**86	*4.7(3.7)	**93	*5.8(3.8)
8.Chest pressure or heaviness in your chest	36	1.7(3.0)	36	1.8(3.1)	29	0.9(2.0)	36	1.4(2.6)
9.Irregular heart beat or fluttering feeling in your chest	43	2.1(3.2)	29	1.3(2.9)	36	1.5(2.7)	29	0.8(2.1)
10.Worsening cough	36	1.3(2.0)	21	1.2(2.5)	57	1.6(1.7)	36	1.6(2.4)
11.Dizziness or lightheadedness	57	2.4(2.9)	57	2.9(3.4)	64	2.1(2.5)	79	2.9(2.8)
12.Difficulty sleeping	**86	*5.7(3.9)	**93	*6.2(3.7)	**93	*4.5(3.2)	**86	*5.9(4.3)
13.Forgetfulness or difficulty concentrating	50	2.5(3.2)	64	2.6(2.9)	50	1.9(3.0)	57	2.7(3.0)
14.Depressed or feeling down	57	2.4(2.8)	64	4.2(3.7)	57	2.1(2.7)	71	2.6(3.2)

Abbreviations: Pt=Patient; CG=Caregiver

*the three highest mean frequency ratings by patients or caregivers for the frequency of the symptom on a scale of “0” to “10”

**the greatest proportion of patients and caregivers provided a frequency rating of “1” to “10” across 14 HFSS symptoms over the last 7 days.

HFSS severity of symptoms. There were three symptoms that were given the highest mean severity rating (on a scale of 0 to 10, where 0 = no severity and 10 = very severe) by both patient and caregiver at both pre- and post-test: fatigue, tiredness or lack of energy (mean = 4.6 (SD 2.9) to 6.1 (SD 3.4)), and difficulty sleeping (mean = 4.3 (SD 3.4) to 5.9 (SD 3.5)), shortness of breath with activity (mean = 3.5 (SD 3.5) to 4.9 (SD 3.2)). For patients and caregivers the least mean severe symptom in the pre-test and post-test conditions were for irregular heart beat or fluttering feeling in your chest (mean = 0.8 (SD 2.2) to 2.0(3.0)), chest pressure or heaviness in your chest (mean = 1.0 (SD 1.7) to 2.1(SD 3.5)), and worsening cough (median = 1.1 (SD 2.3) to 1.7(SD 1.8)). For 10 of the 14 HFSS symptoms the patient mean symptom frequency was lower on both pre- and post-test than the caregiver mean symptom severity rating including all four types of shortness of breath, fatigue, tiredness or lack of energy, chest pressure or heaviness in your chest, dizziness or lightheadedness, difficulty sleeping, forgetfulness or difficulty concentrating, and depressed or feeling down. Full or bloated feeling in your abdomen, irregular heart beat or fluttering feeling in your chest, and worsening cough were consistently rated as more severe by the patients than the caregivers (i.e. higher mean frequency ratings on both pre- and post-test). Further details are provided in Table 4.5.

Table 4.5

Severity of each HFSS Symptom as rated by the Patient (n=14) and Caregiver (n=14)

HFSS Symptom	Patient Pretest Mean (SD)	Caregiver Pretest Mean (SD)	Patient Posttest Mean (SD)	Caregiver Posttest Mean (SD)
1.Shortness of breath at rest	1.4(3.0)	3.4(3.8)	1.4(2.2)	2.9(3.2)
2.Shortness of breath with activity	*3.5(3.5)	*4.9(3.2)	3.6(3.0)	*4.1(3.1)
3.Shortness of breath when lying down	2.7(3.3)	4.0(4.1)	2.2(3.5)	2.7(2.8)
4.Shortness of breath when you wake-up at night	1.9(3.3)	2.3(3.8)	1.6(2.5)	2.8(3.2)
5.Swelling in your feet, ankles or legs	2.7(3.4)	3.9(4.2)	*3.9(3.6)	3.1(3.7)
6.Full or bloated feeling in your abdomen	3.3(3.4)	2.6(3.2)	2.8(2.9)	1.8(2.5)
7.Fatigue, tiredness or lack of energy	*4.8(3.4)	*6.1(3.4)	*4.6(2.9)	*5.7(3.5)
8.Chest pressure or heaviness in your chest	1.6(3.0)	2.1(3.5)	1.0(1.7)	1.4(2.5)
9.Irregular heart beat or fluttering feeling in your chest	2.0(3.0)	1.4(3.1)	1.4(2.5)	0.8(2.2)
10.Worsening cough	1.5(2.6)	1.1(2.3)	1.7(1.8)	1.6(2.6)
11.Dizziness or lightheadedness	2.5(3.2)	4.1(4.3)	2.2(2.9)	3.0(3.0)
12.Difficulty sleeping	*5.1(3.8)	*5.9(3.5)	*4.3(3.4)	*5.4(4.0)
13.Forgetfulness or difficulty concentrating	1.8(2.8)	2.5(3.1)	1.8(3.2)	2.1(2.7)
14.Depressed or feeling down	2.0(2.7)	3.9(3.9)	2.1(2.7)	2.9(3.0)

Abbreviation: SD=Standard Deviation

* highest ratings for severity.

HFSS symptom interference with physical activity. The three symptoms given the highest mean ratings for interference with the patient's day to day physical activity (scale of 0-10, where 0 = no interference) by both the patient and the caregiver at both pre- and post-test were fatigue, tiredness or lack of energy (mean = 4.3 (SD 4.0) to 5.8 (SD 3.6)), shortness of breath with activity (mean = 3.9 (SD 3.4) to 5.4 (SD 3.3)), and difficulty sleeping (mean = 3.5 (SD 3.6) to 5.7 (SD 4.0)). Five symptoms with the lowest mean rating (mean = 0.8 (SD 2.0) to 2.8 (SD 3.7)) for both the patient and the caregiver at pre- and post-test for interference with physical activity were: shortness of breath when you wake-up at night, chest pressure or heaviness in your chest, irregular heart beat or fluttering feeling in your chest, worsening cough, and forgetfulness or difficulty concentrating. For eight of the 14 HFSS symptoms the patient mean symptom interference with physical activity was lower on both pre- and post-test than the caregiver mean symptom interference with physical activity rating including all four types of shortness of breath, fatigue, tiredness or lack of energy, chest pressure or heaviness in your chest, dizziness or lightheadedness, difficulty sleeping, and depressed or feeling down. Full or bloated feeling in your abdomen, and irregular heart beat or fluttering feeling in your chest were consistently rated as having greater interference with physical activity by the patients than the caregivers (i.e. higher mean frequency ratings on both pre- and post-test). Further details are provided in Table 4.6.

Table 4.6
Degree of Interference with Physical activity of each HFSS Symptom as rated by the Patient (n=14) and Caregiver (n=14)

HFSS Symptom	Patient Pretest Mean (SD)	Caregiver Pretest Mean (SD)	Patient Posttest Mean (SD)	Caregiver Posttest Mean (SD)
1.Shortness of breath at rest	1.9(3.7)	3.1(3.9)	1.3(2.6)	2.1(3.0)
2.Shortness of breath with activity	*4.5(3.9)	*5.4(3.3)	*3.9(3.4)	*4.4(3.4)
3.Shortness of breath when lying down	2.5(3.6)	3.3(4.2)	1.8(3.3)	2.7(3.9)
4.Shortness of breath when you wake-up at night	1.3(2.9)	2.5(4.2)	0.9(1.6)	1.9(3.1)
5.Swelling in your feet, ankles or legs	2.1(3.6)	3.6(4.1)	3.2(4.1)	2.7(3.9)
6.Full or bloated feeling in your abdomen	2.8(3.7)	1.9(2.9)	2.4(2.9)	1.5(2.2)
7.Fatigue, tiredness or lack of energy	*4.8(3.9)	*5.8(3.6)	*4.3(4.0)	*5.3(4.1)
8.Chest pressure or heaviness in your chest	1.6(3.0)	2.7(4.2)	0.8(1.5)	1.5(2.5)
9.Irregular heart beat or fluttering feeling in your chest	2.1(3.1)	1.5(3.3)	1.6(2.7)	0.9(2.4)
10.Worsening cough	1.1(2.9)	1.2(2.5)	1.6(3.0)	1.1(2.9)
11.Dizziness or lightheadedness	2.6(3.4)	4.3(4.5)	2.0(3.0)	2.8(3.3)
12.Difficulty sleeping	*3.9(3.8)	*5.7(4.0)	*3.5(3.6)	*4.0(4.4)
13.Forgetfulness or difficulty concentrating	0.8(2.0)	2.8(4.2)	1.3(2.6)	0.8(2.2)
14.Depressed or feeling down	2.2(2.9)	4.3(4.2)	1.6(2.4)	2.0(3.1)

Abbreviation: SD=Standard Deviation

* Three highest rated symptoms for interference with physical activity.

HFSS symptom interference with enjoyment of life. The three symptoms given the rated highest mean for interference with the patient's day to day physical activity (scale of 0-10, where 0 = no interference) by both the patient and the caregiver at both pre- and post-test were fatigue, tiredness or lack of energy (mean = 3.9 (SD 3.8) to 8.1 (SD 8.1)), difficulty sleeping (mean = 3.6 (SD 4.3) to 6.1 (SD 4.3)), and shortness of breath with activity (mean = 2.9 (SD 3.3) to 5.5 (SD 3.2)). Five symptoms with the lowest mean ratings (mean = 0.8 (2.7) to 2.7 (SD 4.2)) for interference with enjoyment of life by both the patient and the caregiver in the pre- and post-test condition were: shortness of breath when you wake-up at night, full or bloated feeling in your abdomen, chest pressure or heaviness in your chest, irregular heart beat or fluttering feeling in your chest, and worsening cough. Further details are provided in Table 4.7.

Table 4.7

Degree of Interference with Enjoyment of Life of each HFSS Symptom as rated by the Patient (n=14) and Caregiver (n=14)

HFSS Symptom	Patient Pretest Mean (SD)	Caregiver Pretest Mean (SD)	Patient Posttest Mean (SD)	Caregiver Posttest Mean (SD)
1.Shortness of breath at rest	2.1(3.7)	3.6(3.9)	1.4(3.0)	3.1(3.5)
2.Shortness of breath with activity	*3.7(4.2)	*5.5(3.2)	*2.9(3.3)	*5.1(3.6)
3.Shortness of breath when lying down	2.5(3.6)	3.6(4.0)	1.4(2.5)	3.2(3.9)
4.Shortness of breath when you wake-up at night	0.8(2.7)	2.5(4.2)	1.0(1.7)	2.1(3.5)
5.Swelling in your feet, ankles or legs	2.1(3.7)	3.6(4.2)	*2.9(3.9)	2.4(3.7)
6.Full or bloated feeling in your abdomen	2.4(3.8)	1.9(3.0)	2.1(2.6)	1.6(2.7)
7.Fatigue, tiredness or lack of energy	*4.3(4.4)	*8.1(8.1)	*3.9(3.8)	*4.9(4.0)
8.Chest pressure or heaviness in your chest	1.3(3.0)	2.7(4.2)	0.9(1.7)	1.9(3.2)
9.Irregular heart beat or fluttering feeling in your chest	1.4(2.9)	1.7(3.3)	1.2(2.5)	0.9(2.4)
10.Worsening cough	1.2(3.0)	1.6(3.3)	1.6(2.9)	1.4(3.1)
11.Dizziness or lightheadedness	2.1(3.1)	4.4(4.6)	1.6(3.1)	2.8(3.4)
12.Difficulty sleeping	*3.6(4.3)	*6.1(4.3)	*3.7(3.7)	*4.1(4.6)
13.Forgetfulness or difficulty concentrating	1.1(2.7)	3.0(4.0)	1.2(2.5)	1.6(2.8)
14.Depressed or feeling down	2.5(3.3)	4.6(4.0)	1.9(2.6)	3.4(3.3)

Abbreviation: SD=Standard Deviation

* Three highest rated symptoms for interference with enjoyment of life.

Empathic responding scale. For the ERS total mean scores (Likert type scale range of scores from 0 to 4, where 0 does not describe the caregiver very well), caregivers rated their own empathic responding lower than the patient rated the caregiver's empathic responding in the pre-test (means = 3.49, 3.51) and post-test (means = 3.39, 3.48) conditions, respectively. In addition, both patients and caregivers rated caregiver empathic responding lower post-intervention than pre-intervention (patient mean rating of 3.51 decreased to a mean rating of 3.48; caregiver mean rating of 3.49 decreased to a mean rating of 3.39). The ERS item rated the highest by patients in both pre- and post-test conditions was, "my caregiver tries to accept me as I am now". The ERS item rated highest by caregivers in both pre- and post-test conditions was, "I try to understand their concerns". The ERS item rated lowest by both patients and caregivers in both pre- and post-test conditions was, "my caregiver tries to experience what I was feeling" (patient mean rating of 3.00 in both pre- and post-test conditions; caregiver mean rating of 3.07 in both pre- and post-test conditions). Further details are provided in Table 4.8.

Table 4.8
ERS Items and Total Score for Patient (n=14) and Caregiver (n=14)

ERS Items (Patient version evaluating caregiver empathic response; Caregiver version is shown in Table 4.14)	Patient Pretest Mean (SD)	Caregiver Pretest Mean (SD)	Patient Posttest Mean (SD)	Caregiver Posttest Mean (SD)
1. My CG tries to understand my concerns.	3.57 (.76)	*3.79 (.43)	3.43 (.76)	*3.71 (.50)
2. My CG tries to understand how I felt.	3.64 (.50)	3.64 (.50)	3.50 (.52)	3.50 (.65)
3. My CG tries to experience what I was feeling.	**3.00 (1.04)	**3.07 (1.27)	**3.00 (.78)	**3.07 (1.00)
4. My CG tries to imagine being in my shoes.	3.21 (.80)	**3.07 (1.21)	3.21 (.70)	3.29 (.91)
5. My CG tries to see things from my point of view.	3.29 (.91)	3.57 (.51)	3.36 (.63)	3.36 (.75)
6. My CG tries to accept me as I am now.	*3.71 (.61)	3.64 (.50)	*3.79 (.43)	3.50 (.65)
7. My CG tries to help me by listening to me.	*3.71 (.83)	3.57 (.51)	3.57 (.76)	3.50 (.65)
8. My CG tries to help me by doing something for me.	3.64 (.63)	3.64 (.50)	3.71 (.61)	3.43 (.65)
9. My CG tries to figure out what will make me feel better.	3.64 (.50)	3.57 (.51)	3.57 (.51)	3.36 (.75)
10. My CG tries to provide comfort to me by telling me about their positive feelings for me.	3.64 (.63)	3.29 (.73)	3.64 (.50)	3.14 (.66)
Total Mean Score	3.51 (.49)	3.49 (.44)	3.48 (.46)	3.39 (.54)

Abbreviations: CG=caregiver; SD=Standard Deviation

* Highest rated ERS item.

**Lowest rated ERS item.

Note: ERS response items ranged from 0 to 4 where 0 'does not describe the caregiver well' and 4 'describes the caregiver very well'.

Instrument Reliability

Internal consistency reliability of the HRSS and the Empathic Responding Scale were estimated for both patient and caregiver sub-groups using Cronbach's alpha coefficient reliability estimates. The criterion for adequate reliability was established at $> .70$ (Polit, 2010). HFSS subscale reliability coefficient estimates for the patient and caregiver sub-groups in the pre- and post-test condition on frequency, severity, interference with physical activity, and interference with enjoyment of life ranged from .86 to .95 (Table 4.9). For the total Empathic Responding Scale, Cronbach's alpha coefficient reliability estimates of .86 and .90 were obtained on pre-test and post-test respectively for patients, and .80 and .91 were obtained in the pre- and post-test conditions respectively for family caregivers. Cronbach's alpha coefficient reliability estimates are summarized in Table 4.10 and indicate excellent internal consistency (Polit, 2010) for both the HFSS and ERS in both pre- and post-test.

Table 4.9

Cronbach's alpha coefficient reliability estimates for HFSS Subscales

HFSS Subscale	Patient Pre-test	Patient Post-test	Caregiver Pre-test	Caregiver Post-test
Frequency	.91	.87	.91	.93
Severity	.90	.87	.93	.94
Interference with Physical Activity	.89	.83	.91	.92
Interference with Enjoyment of Life	.92	.86	.89	.95

Table 4.10

Cronbach's alpha coefficient reliability estimates for the total ERS

ERS Reliability Coefficient	Patient Pre-test	Patient Post-test	Caregiver Pre-test	Caregiver Post-test
Cronbach's Alpha	.86	.90	.80	.91

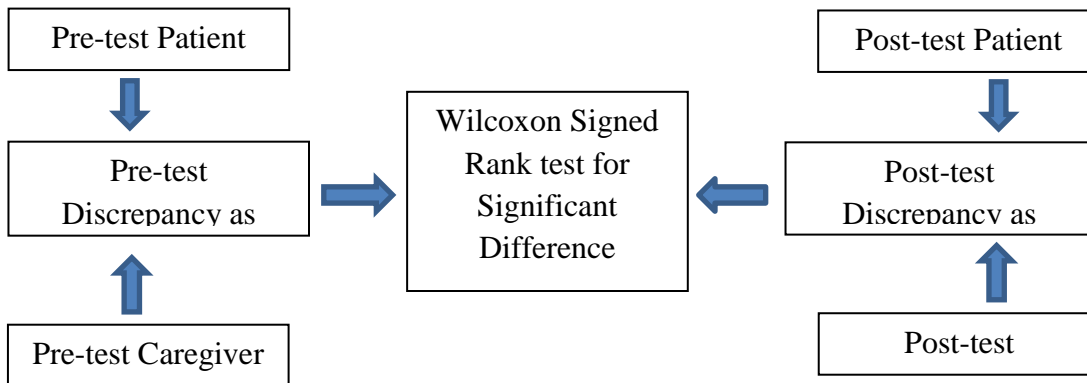
Analysis of Research Questions

Research question 1. Is there improved perceptual agreement between the family caregiver and the patient with HF after family caregivers are instructed to actively engage in patient-oriented perspective-taking, in the context of assessing the patient's symptoms?

The investigator's hypothesis was that there would be less of a perceptual discrepancy between the dyad HFSS item scores two weeks after the intervention when compared to the baseline discrepancy scores of patients and caregivers. To support this hypothesis, two conditions must be met by the data: first, there must be a statistically significant difference between the absolute discrepancy scores in the pre- and post-test conditions on the HFSS (Figure 4.1). Second, the post-test discrepancy score on the HFSS must be smaller than the pre-test discrepancy score to indicate an improvement in perceptual agreement. These conditions were examined individually and under the supervision of the statistician, Mr. Brendan Dufault.

Condition 1: Presence of significant difference. There must be a statistically significant difference when comparing the absolute discrepancy scores for the pre- and post-test scores on the HFSS (Figure 4.1). A statistical test of difference will demonstrate any statistically significant change in the size of the patient-caregiver discrepancy between the pre- and the post-test scores on the HFSS.

Figure 4.1 Test of differences on pre- and post-test absolute discrepancy scores on the HFSS.



The following steps were taken by the investigator to examine whether any significance differences existed between the pre-test and post-test discrepancy scores on the HFSSs:

1. Calculated the difference between the patient rating of a symptom on the HFSS with the identical item on the caregiver HFSS. This was first done with pre-test responses and then with post-test responses, respectively.
2. Calculated the absolute value of the discrepancy score between the patient's and the caregiver's responses on individual items on the HFSS. The absolute discrepancy score was employed to avoid positive and negative results from canceling each other out. Moreover, the investigator was interested in the degree of discrepancy and not the direction of biased reporting on the HFSS by patients and family caregivers for Research Question 1.
3. To test the difference in the absolute value of discrepancy between patient and family caregiver responses on pre- and post-test HFSS scores for each item, the Wilcoxon signed rank non-parametric test was employed with respect to each of the four domains on the HFSS: frequency, severity, interference with physical activity, and interference with enjoyment of life (e.g. shortness of breath at rest (symptom) rated for frequency

(domain)). Since the ordinal data on the HFSS tool was from a small sample ($n=14$) and the distribution appeared non-normal, the non-parametric Wilcoxon sign-ranks test was the most appropriate test of median differences in discrepancy scores. The Wilcoxon sign-ranks test examines the differences between related pairs of data such as the study dyad scores and relies on the use of median values rather than mean values; median values are more appropriate as they are less influenced by non-normally distributed data in the current study (Polit, 2010).

4. In addition to an item-by-item examination of HFSS responses, overall performance on each domain (subscale) was examined by first calculating the median value for each participant's rating across all 14 symptoms on each subscale: frequency, severity, interference with physical activity, and interference with enjoyment of life. Using these median scores, pre- and post-test patient-caregiver median discrepancy scores were calculated. The Wilcoxon signed rank test was used to examine for significant difference between the pre-test subscale scores and post-test subscale scores.
5. The results were captured in Appendix M.

Several statistically significant ($p < .05$) differences emerged from the HFSS discrepancy score data (Appendix M). In total, seven of 14 HF symptoms demonstrated a statistically significant change in patient-caregiver discrepancy scores post-intervention. Each HFSS subscale (frequency, severity, interference with physical activity, and interference with enjoyment of life) contained at least two to four occurrences of significant pre-test to post-test differences in patient-caregiver discrepancy scores. In addition, of the four subscales totals, three demonstrated statistically significant differences when comparing each dyad's pretest and posttest median patient-caregiver discrepancy scores: frequency, severity, and interference with

physical activity. Significant findings for each HFSS symptom will be organized by subscale and individually described below. Both significant and non-significant findings are summarized in Appendix M.

HFSS frequency subscale.

- i. Full or bloated feeling in your abdomen – frequency: The medians of pre- and post-intervention discrepancy scores were 3.0 and 1.0 with semi-interquartile ranges (SIQR) of 2.0 and 1.0 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the frequency with which the patient experienced a full or bloated feeling in their abdomen ($z = -2.62, p = .009$) (Appendix M).
 - ii. Chest pressure or heaviness in your chest – frequency: The medians of pre- and post-intervention discrepancy scores were 1.5 and 0.5 with SIQRs of 2.0 and 0.5 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the frequency with which the patient experienced chest pressure or heaviness in their chest ($z = -2.05, p = .041$) (Appendix M).
 - iii. Median Score of the Frequency Subscale: The medians of pre- and post-intervention discrepancy scores were 2.0 and 1.0 with SIQRs of .88 and .75 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention patient-caregiver median discrepancy scores across 14 symptoms on the frequency subscale ($z = -2.37, p = .018$) (Appendix M).
-

One additional symptom that approached a statistically significant difference between pre- and post-intervention patient-caregiver median discrepancy scores on frequency was depressed or feeling down ($z = -1.90$; $p = .058$; Appendix M).

HFSS severity subscale.

- i. Shortness of breath with activity – severity: The medians of pre- and post-intervention discrepancy scores were 3.5 and 2.0 with SIQRs of 2.0 and 2.0 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the severity with which the patient experienced shortness of breath with activity ($z = -2.10$, $p = .036$) (Appendix M).
 - ii. Shortness of breath when lying down – severity: The medians of pre- and post-intervention discrepancy scores were 4.5 and 1.0 with SIQRs of 3.5 and 1.5 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the severity with which the patient experienced shortness of breath when lying down ($z = -2.39$, $p = .017$) (Appendix M).
 - iii. Worsening cough – severity: The medians of pre- and post-intervention discrepancy scores were 0 and 1.0 with SIQRs of .75 and 1.1 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the severity with which the patient experienced a worsening cough ($z = -2.00$, $p = .046$) (Appendix M).
 - iv. Depressed or feeling down – severity: The medians of pre- and post-intervention discrepancy scores were 3.0 and 1.0 with SIQRs of 3.0 and 1.6 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention
-

median patient-caregiver discrepancy scores of the severity with which the patient experienced feeling depressed or feeling down ($z = -2.39$, $p = .011$) (Appendix M).

- v. Median score of the severity subscale: The medians of pre- and post-intervention discrepancy scores were 2.3 and 1.0 with SIQRs of 1.3 and .75 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention patient-caregiver discrepancy scores of the median of each individual's ratings of all 14 symptoms in the severity subscale ($z = -2.70$, $p = .007$) (Appendix M).

Two additional symptoms that approached having statistically significance differences in medians of pre- and post-intervention discrepancy scores were: shortness of breath at rest ($z = -1.96$, $p = .050$); full or bloated feeling in your abdomen ($z = -1.91$; $p = .056$).

HFSS interference with physical activity subscale:

- i. Full or bloated feeling in your abdomen – interference with physical activity: The medians of pre- and post-intervention discrepancy scores were 2.0 and 1.0 with SIQRs of 2.8 and 2 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the interference with physical activity which the patient experienced related to shortness of breath with activity ($z = -1.98$, $p = .048$) (Appendix M).
 - ii. Depressed or feeling down – interference with physical activity: The medians of pre- and post-intervention discrepancy scores were 5.0 and 2.0 with SIQRs of 3.1 and 1.8 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the interference with physical activity which the patient experienced related to feeling depressed or feeling down ($z = -2.15$, $p = .032$) (Appendix M).
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- iii. Median score of the interference with physical activity subscale: The medians of pre- and post-intervention discrepancy scores were 1.5 and .50 with SIQRs of .81 and .75 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention patient-caregiver discrepancy scores of the median of each individual's ratings of all 14 symptoms in the interference with physical activity subscale ($z = -2.82, p = .005$) (Appendix M).

Two additional symptoms that approached a statistically significant difference in pre- and post-intervention median discrepancy scores: shortness of breath with activity ($z = -1.89, p = .059$) and shortness of breath when you wake up at night ($z = -1.95; p = .051$).

Interference with enjoyment of life subscale.

- i. Short of breath at rest – interference with enjoyment of life: The medians of pre- and post-intervention discrepancy scores were 2.0 and 2.0 with SIQRs of 3.6 and 1.5 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the interference with enjoyment of life which the patient experienced related to shortness of breath at rest ($z = -1.98, p = .048$) (Appendix M).
 - ii. Depressed or feeling down – interference with enjoyment of life: The medians of pre- and post-intervention discrepancy scores were 4.5 and 2.0 with SIQRs of 3.0 and 1.8 respectively. A Wilcoxon signed rank test showed a significant difference between pre- and post-intervention median patient-caregiver discrepancy scores of the interference with enjoyment of life which the patient experienced related to feeling depressed or feeling down ($z = -2.15, p = .022$) (Appendix M).
-

It is noted that only “depressed or feeling down” exhibited a statistically significant reduction in discrepancy scores between patients and caregivers after the intervention across three HFSS dimensions: severity, interference with physical activity, and interference with enjoyment of life. As well, “a full or bloated feeling in the abdomen” revealed a reduction in discrepancy scores between patients and caregivers on HFSS frequency and HFSS interference with activity ($p = .048$). The HFSS item, “shortness of breath at rest” revealed less pre- and post-intervention median score discrepancies in severity ($p = .050$) and interference with enjoyment in life ($p = .048$) following the caregiver intervention.

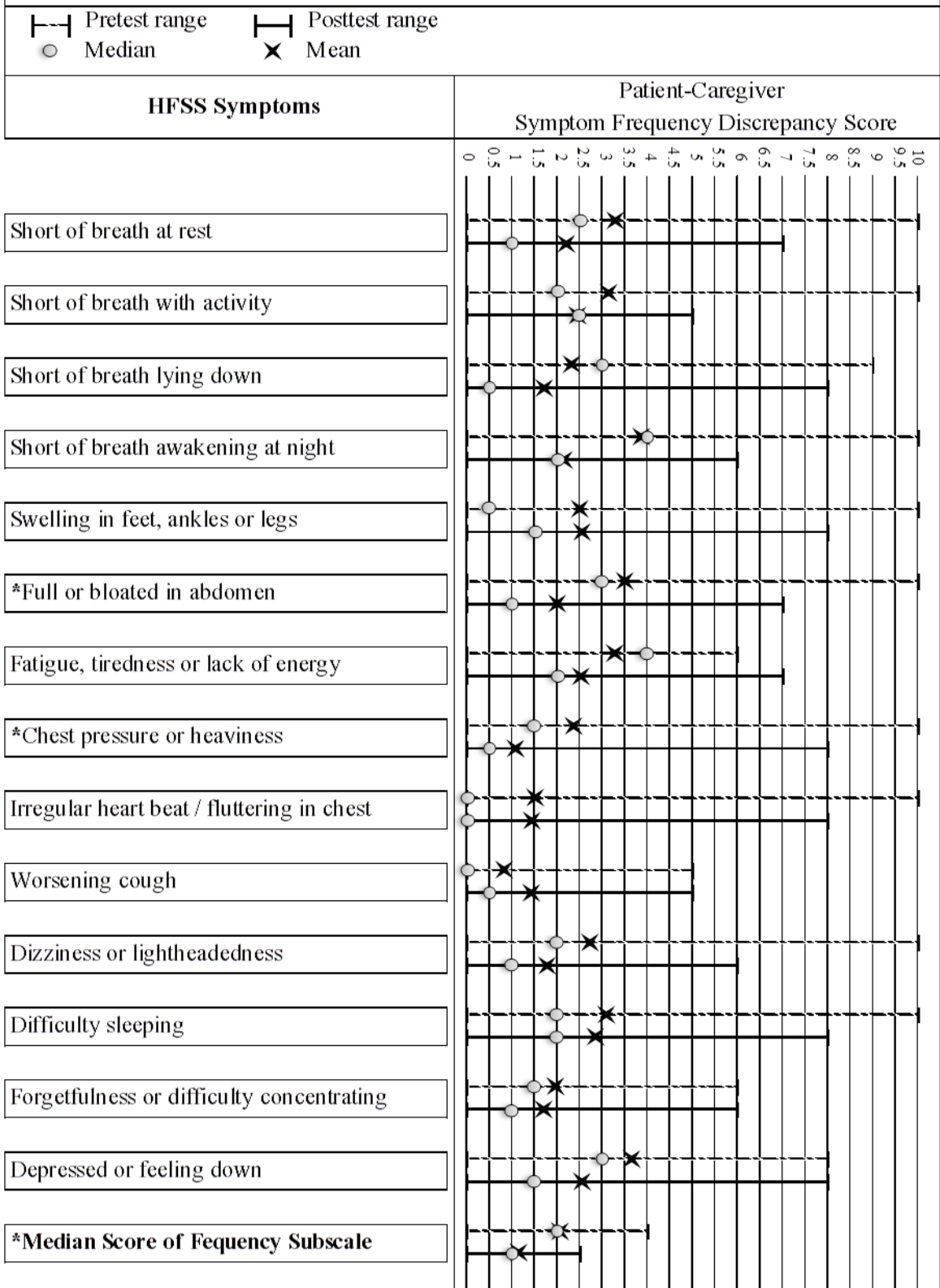
Condition 2: Direction of the change. The Wilcoxon Signed Rank test was employed by the investigator to identify statistically significant differences as evidence that that condition #1 was met for several symptoms across four HSFF dimensions. In other words, there were statistically significant changes in patient-caregiver post-discrepancy scores in comparison to the pre-intervention scores for: shortness of breath at rest interference with enjoyment of life, shortness of breath with activity severity, shortness of breath when lying down severity, full or bloated feeling in their abdomen frequency and interference with physical activity, chest pressure or heaviness in their chest frequency, worsening cough severity, and depressed or feeling down severity, interference with physical activity and interference with enjoyment of life.

To establish whether condition 2 was met, the investigator conducted an examination of the direction of change in median post-intervention discrepancy scores in comparison to the pre-intervention discrepancy scores across HSFF sub-scale items. The hypothesis was there will be lower discrepancy scores at the time of post-test (two weeks after the family caregiver was instructed on patient-oriented perspective-taking) when compared to the pretest measurement of HSFF scores.

The direction of change in median discrepancy scores are displayed graphically for: frequency (Figure 4.2), severity (Figure 4.3), interference with physical activity (Figure 4.4), and interference with enjoyment of life (Figure 4.5). In addition, mean discrepancy scores and the range of discrepancy scores are displayed alongside median scores for sub-scale items for all four dimensions on the HFSS.

In Figure 4.2 for ‘frequency’, a cursory examination revealed that there was a decrease in median discrepancy scores in the post-test in comparison to median responses in the pre-test condition for nine out of 14 HSFF items. However, there was a statistically significant decrease in post-test discrepancy scores for only: a full or bloated feeling in the abdomen, chest pressure or heaviness, and on the overall median discrepancy score for ‘frequency’. Out of interest, these frequency items also had a corresponding decrease in mean and range of discrepancy scores when comparing the pre-test to the post-test measures. Although not statistically significant, several post-test HSFF discrepancy score medians were lower in comparison to pre-test HFSS-discrepancy score medians including: short of breath at rest, short of breath lying down, short of breath awakening at night, fatigue, dizziness or lightheadedness, forgetfulness, and depressed or feeling down. For short of breath at activity, swelling in feet, ankles, or legs, irregular heart beat or fluttering in chest, worsening cough, and difficulty sleeping there was either no significant change in discrepancy scores, or that the discrepancy score was greater in the post-test condition.

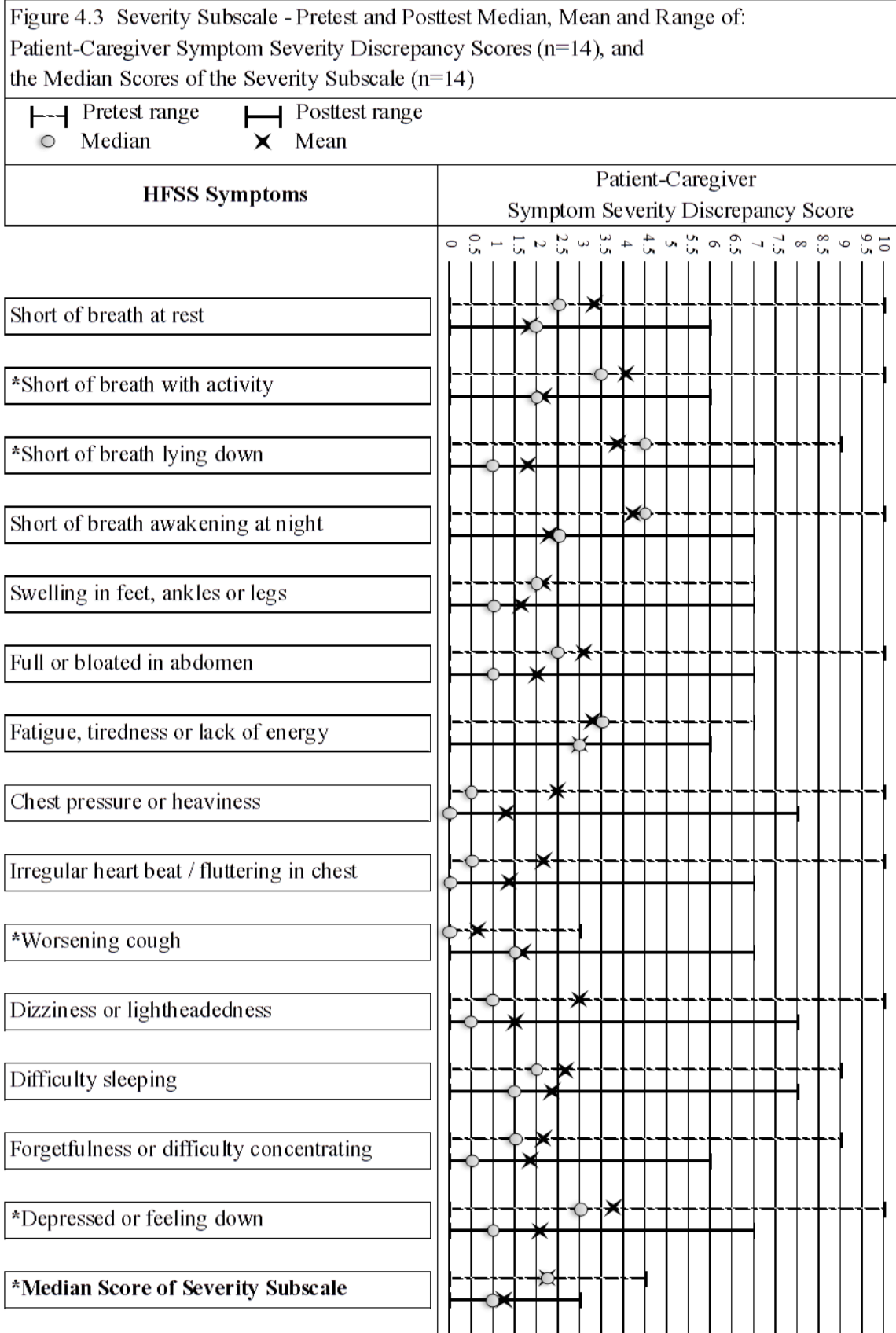
Figure 4.2 Frequency Subscale - Pretest and Posttest Median, Mean and Range of: Patient-Caregiver Symptom Frequency Discrepancy Scores (n=14), and the Median Scores of the Frequency Subscale (n=14)



*Indicates statistically significant findings for Wilcoxon signed rank test of differences

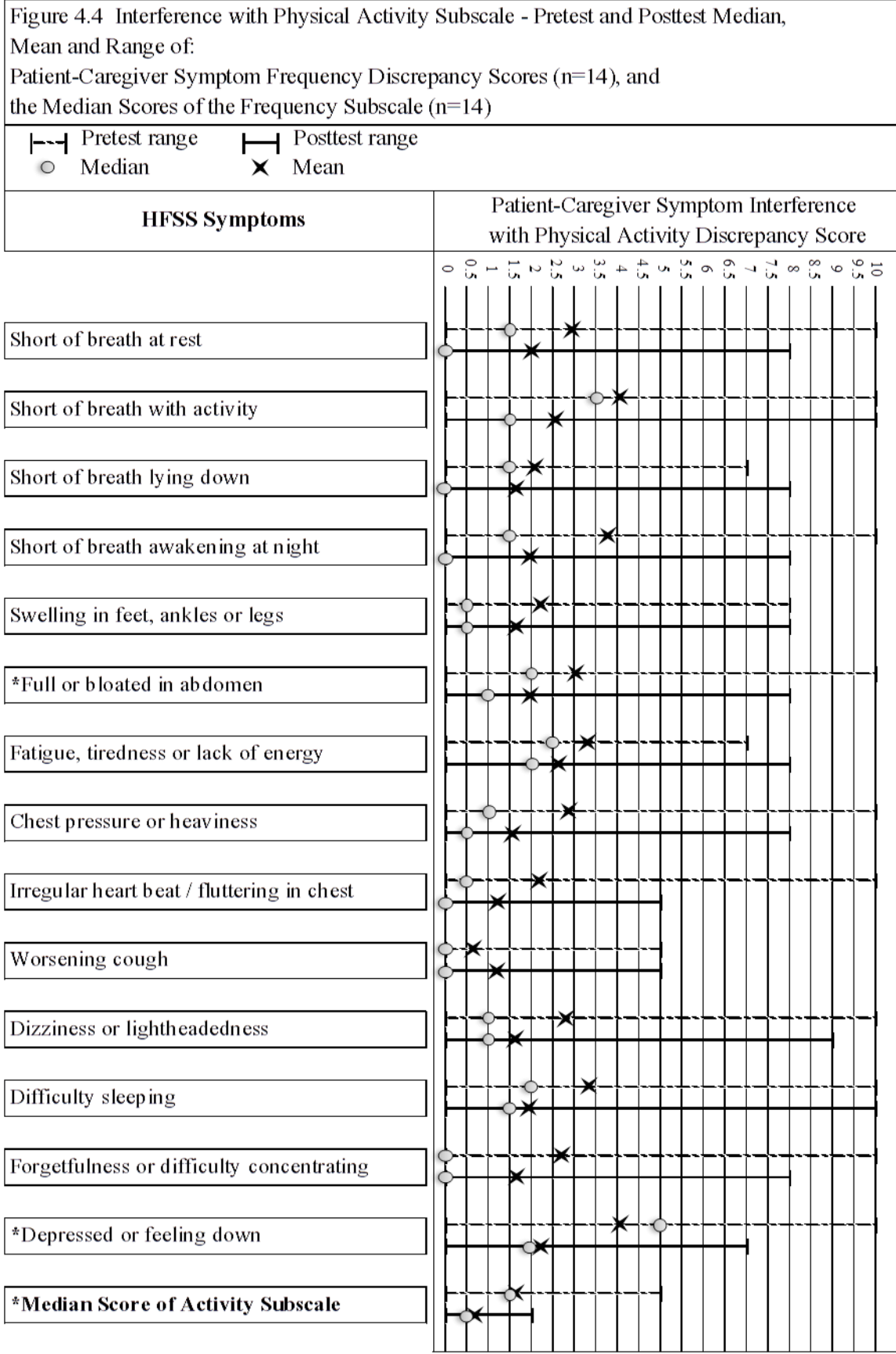
In Figure 4.3 for “severity”, a cursory examination of median discrepancy scores indicated a decrease in post-intervention measurement on 13 of 14 symptoms. More specific, there was a statistically significant decrease in post-test discrepancy scores for short of breath with activity, short of breath lying down, depressed or feeling down, and overall median discrepancy subscale score. Although not statistically significant, several post-intervention HFSS median discrepancy scores were lower in comparison to pre-intervention HFSS median discrepancy scores for: short of breath at rest, short of breath awakening at night, swelling in feet, ankles, or legs, full or bloated feeling in abdomen, fatigue, chest pressure or heaviness, irregular heartbeat or fluttering in chest, dizziness or lightheadedness, difficulty sleeping, and forgetfulness or difficulty concentrating. The only symptom that had a significant increase in median discrepancy scores at post-intervention was on worsening cough.

When the severity of “shortness of breath” is considered overall, two of four shortness of breath items (i.e., shortness of breath with activity, and lying down) had a statistically significant decrease in discrepancy scores while shortness of breath at rest showed a borderline significant decrease in discrepancy score ($p = .05$) indicating an overall improvement in patient-caregiver perceptual agreement on the “severity” of shortness of breath items.



*Indicates statistically significant findings for Wilcoxon signed rank test of differences

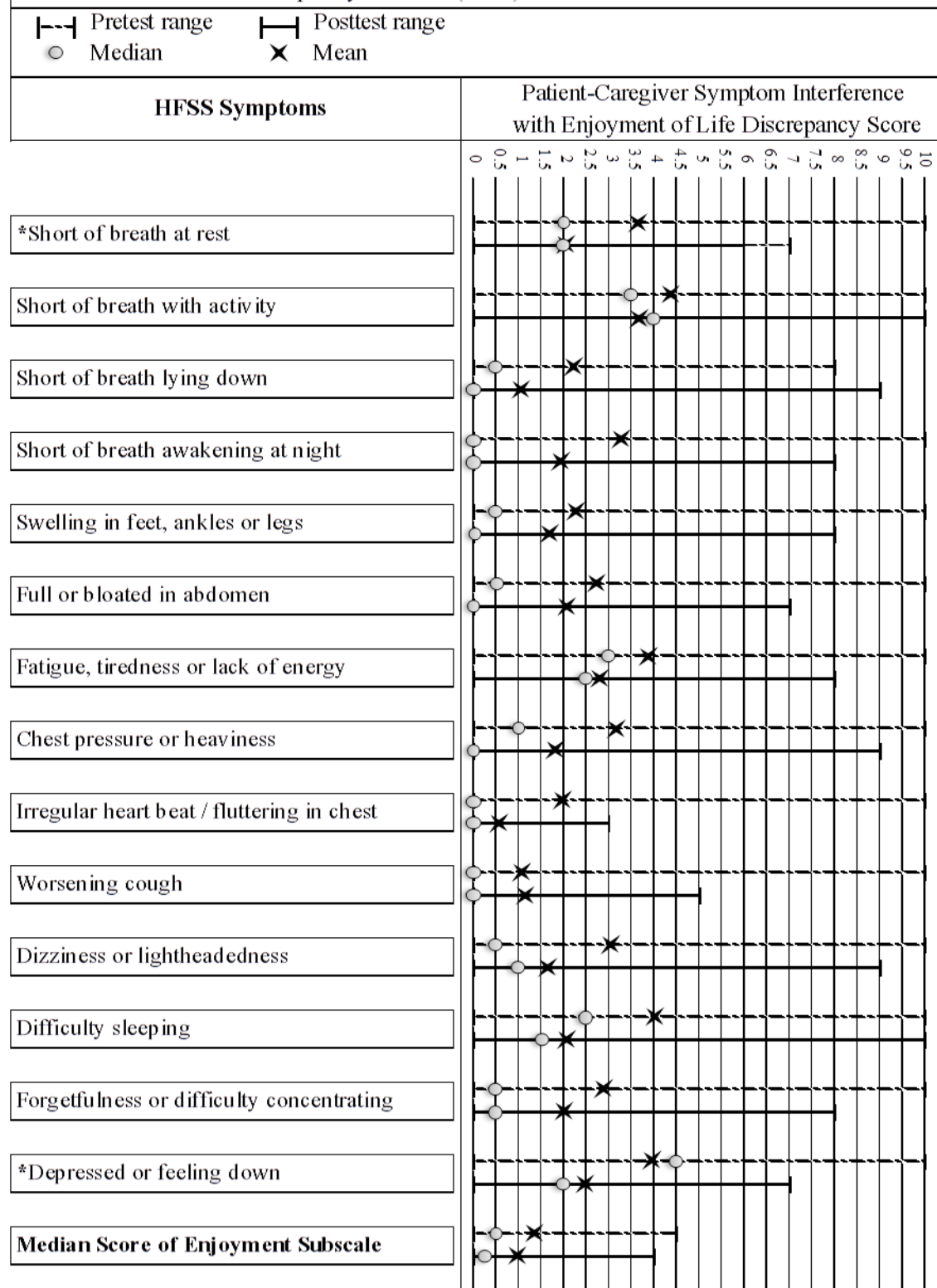
In Figure 4.4 for “interference with physical activity”, a cursory examination of median discrepancy scores indicated a decrease in the post-test condition for 10 of 14 symptoms and four ties. More specifically, there was a statistically significant decrease in post-test discrepancy scores for full or bloated in abdomen, depressed or feeling down, and total median discrepancy score. Although not statistically significant, several post-intervention HSFF discrepancy scores were lower in comparison to pre-intervention HSFF discrepancy scores for: short of breath at rest, short of breath with activity, short of breath lying down, short of breath awakening at night, fatigue, chest pressure or heaviness, irregular heart beat/fluttering in chest, and difficulty sleeping. There were no significant changes in median discrepancy scores in the post-intervention condition for: swelling in feet, ankles or legs, worsening cough, dizziness or lightheadedness, and forgetfulness.



*Indicates statistically significant findings for Wilcoxon signed rank test of differences

In Figure 4.5 for “interference with enjoyment of life”, a cursory examination of median discrepancy scores indicated a decrease in the post-test condition for seven of 14 symptoms and five were tied. More specific, there was a statistically significant decrease in post-test median discrepancy scores for HFSS item “depressed or feeling down”. Of note, although the HFSS item “short of breath” demonstrated a statistically significant difference between pre- and post-test discrepancy scores despite an unchanged median discrepancy score, both the mean score and the range of discrepancies decreased. Although not statistically significant, several post-intervention HSFF mean discrepancy scores were lower in comparison to pre-intervention HSFF discrepancy scores for: shortness of breath lying down, swelling in feet, ankles or legs, full or bloated in abdomen, fatigue, chest pressure or heaviness, and difficulty sleeping. Although the overall median pre- and post-test scores on the interference with enjoyment of life subscale did not have a significant difference, the median, mean, and range results revealed a post-intervention decrease in scores. Two symptoms had an increase in discrepancy score median at post-intervention: shortness of breath with activity (albeit a decrease in mean score and no change in range score) and dizziness or lightheadedness (albeit a decrease in mean and range scores).

Figure 4.5 Interference with Enjoyment of Life Subscale - Pretest and Posttest Median, Mean and Range of: Patient-Caregiver Symptom Frequency Discrepancy Scores (n=14), and the Median Scores of the Frequency Subscale (n=14)



*Indicates statistically significant findings for Wilcoxon signed rank test of differences

Summary of research question 1. Is there improved perceptual agreement between the family caregiver and the patient with HF after family caregivers are instructed to actively engage in patient-oriented perspective-taking, in the context of assessing the patient's symptoms?

The investigator's hypothesis was that there would be less of a perceptual discrepancy between the dyad HFSS item scores two weeks after the intervention when compared to the baseline discrepancy scores of patients and caregivers. Several HFSS items met the two conditions (statistically significant difference between the absolute discrepancy scores on pretest and post-test on the HFSS, and the post-test discrepancy score on the HFSS must be smaller than the pre-test discrepancy score to indicate an improvement in perceptual agreement).

For the "frequency" dimension of HF symptoms, in the post-test condition caregivers demonstrated a statistically significant lower perceptual discrepancy from the patient when assessing the frequency with which the patient experienced a full or bloated feeling in their abdomen, and the patient experiencing chest pressure or heaviness. A comparison of each dyad's pre- and post-intervention median scores for frequency revealed an overall statistically significant lower perceptual discrepancy in the caregiver's ability to match the patient's self-report of frequency across 14 HFSS symptoms.

For the 'severity' dimension of symptoms, in the post-test condition caregivers demonstrated a statistically significant lower perceptual discrepancy from the patient when assessing the severity of the patient's experience of shortness of breath with activity, shortness of breath lying down, and when the patient felt depressed or feeling down. A comparison of each dyad's pre- and post-intervention median scores for severity revealed an overall statistically significant lower perceptual discrepancy in the caregiver's ability to match the patient's self-report of severity across 14 HFSS symptoms.

For the ‘interference with physical activity’ dimension of symptoms, in the post-test condition caregivers demonstrated a statistically significant lower perceptual discrepancy from the patient when assessing degree in which the patient was experiencing interference with physical activity related to a full or bloated in the abdomen, and when the patient was feeling depressed or feeling down. A comparison of each dyad’s pre- and post-intervention median scores for ‘interference with physical activity subscale’ revealed an overall statistically significant lower perceptual discrepancy in the caregiver’s ability to match the patient’s self-report of interference with physical activity across 14 HFSS symptoms.

For the “interference with enjoyment of life” dimension of symptoms, in the post-test condition caregivers demonstrated a statistically significant lower perceptual discrepancy from the patient when assessing degree in which the patient was experiencing interference with enjoyment of life related to feeling depressed or feeling down. A comparison of each dyad’s pre- and post-intervention median scores for “interference with enjoyment of life subscale” revealed an overall non-statistically significant ($p = .058$) lower perceptual discrepancy in the caregiver’s ability to match the patient’s self-report of interference with enjoyment of life across 14 HFSS symptoms.

Summary of research question 2. Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to actively engage in a patient-oriented perspective-taking process, in the context of assessing and managing the patient's symptoms?

The Wilcoxon Signed Rank test was employed to test for significant differences between the pre- and post-test Empathic Responding Scale (ERS) scores (used as a repeated-measure at two time points) of patients and caregivers, respectively. The investigator determined that the

ordinal data in this small sample ($n = 14$ dyads) was non-normal, therefore the Wilcoxon Signed Rank Test was deemed appropriate (Polit, 2010). The Wilcoxon Signed Rank Test was employed to test for differences in the total ERS score, as well as in the individual ERS item scores between two time points for patients and family caregivers, respectively. Of note, both the patient and the family caregiver provided their respective perceptions of the family caregiver's empathic responses toward the patient. To determine changes in the respective perceptions of the caregiver's empathic responses toward the patient after the intervention, the patient's pre-test scores were compared to the patient's post-test scores, and the caregiver's pre-test scores were compared to the caregiver's post-intervention scores on the ERS. Both the patient and the caregiver rated the caregiver's empathic behaviours on an ordinal scale of 0 to 4: "0", if the item does not describe the caregiver's behaviour well to "4", if the item describes the caregiver's behavior very well.

Presence of significant difference. Table 4.11 displays the p-value results of the Wilcoxon Signed Rank test of differences in median scores for patients and family caregivers, respectively for individual items and the ERS total score. Across all items, there were no statistically significant changes in how patients and family caregivers respectively perceived the empathic responses of family caregivers toward the patient at pre- and post-intervention. As well, respective to the patient's and the caregiver's total ERS scores at two time points, there were no statistically significant differences found across ERS items. In the following, the investigator conducted a cursory examination of the data with a view to identifying possible patterns of change in the caregivers' empathic behaviours toward the patient in the post-intervention condition.

Table 4.11
Comparison of Patient and Caregiver ERS* Discrepancy Scores

ERS Items**	Patient Pre-test to Post-test Wilcoxon p-value	Caregiver Pre-test to Post-test Wilcoxon p-value
1. My CG tries to understand my concerns.	.41	.56
2. My CG tries to understand how I felt.	.48	.41
3. My CG tries to experience what I was feeling.	1.0	1.0
4. My CG tries to imagine being in my shoes.	1.0	.26
5. My CG tries to see things from my point of view.	.76	.18
6. My CG tries to accept me as I am now.	.56	.16
7. My CG tries to help me by listening to me.	.41	.66
8. My CG tries to help me by doing something for me.	.66	.08
9. My CG tries to figure out what will make me feel better.	.71	.18
10. My CG tries to provide comfort to me by telling me about their positive feelings for me.	1.0	.32
Total Score	.58	.22

*Abbreviation: ERS=Empathic Responding Scale of 0 to 4 where “0” does not describe the caregiver very well and “4” describes the caregiver very well

**Patient version evaluating caregiver empathic response; Caregiver version is shown in Table 8
Abbreviations: CG=Caregiver

Patterns of directional change in patient pre- and post-intervention ERS responses.

The investigator's cursory examination of patterns of change in the patient's pre- and post-intervention perceptions of their caregiver's empathic responses revealed the following. The patient median total ERS score decreased from 3.70 (pre-intervention) to 3.40 (post-intervention) (see Table 4.13; Figure 4.6). As well, eight out of 10 ERS median item scores remained unchanged in the post-intervention condition and three ERS median item scores decreased in the post-condition as reported by patients. No ERS items revealed an increase in median item ratings by the patient on the caregiver's empathic responses in the post-intervention condition. Additional cursory analysis of mean scores on the ERS for patients revealed that three ERS items had a minimal increase in ratings: "my CG tries to see things from my point of view" (pre-test mean = 3.29 to post-test mean = 3.36), "my CG tries to accept me as I am now" (pre-test mean = 3.71 to post-test mean = 3.79), and "my CG tries to help me by doing something for me" (pre-test mean = 3.64 to post-test mean = 3.71) (see Table 4.12). Given the non-normal distribution of the data collected in this small study sample, the reader's interpretation of changes in median and mean scores must be considered with caution.

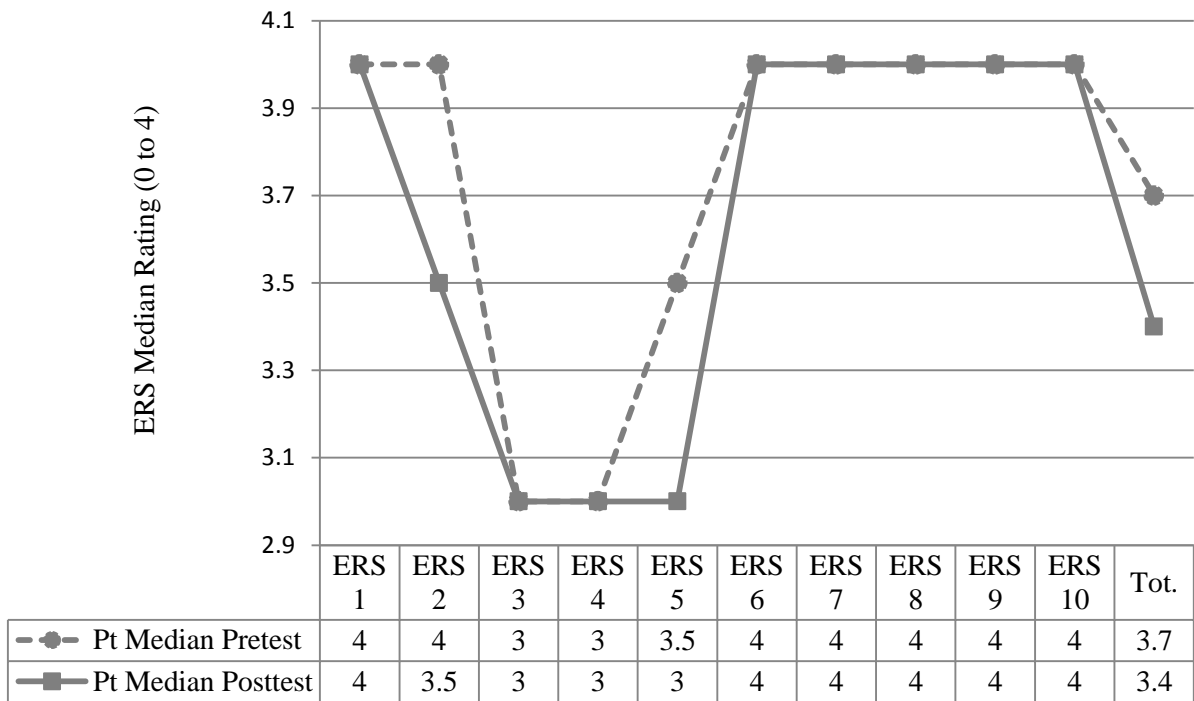
Table 4.12
Patient and Caregiver ERS* Mean, Median, and Range

ERS Items**	Pt Pretest (Posttest) Mean Score	Pt Pretest (Posttest) Median Score	Pt Pretest (Posttest) Range of Scores
1. My CG tries to understand my concerns.	3.57 (3.43)	4.00 (4.00)	2-4 (2-4)
2. My CG tries to understand how I felt.	3.64 (3.50)	4.00 (3.50)	3-4 (3-4)
3. My CG tries to experience what I was feeling.	3.00 (3.00)	3.00 (3.00)	1-4 (2-4)
4. My CG tries to imagine being in my shoes.	3.21 (3.21)	3.00 (3.00)	2-4 (2-4)
5. My CG tries to see things from my point of view.	3.29 (3.36)	3.50 (3.00)	1-4 (2-4)
6. My CG tries to accept me as I am now.	3.71 (3.79)	4.00 (4.00)	2-4 (3-4)
7. My CG tries to help me by listening to me.	3.71 (3.57)	4.00 (4.00)	1-4 (2-4)
8. My CG tries to help me by doing something for me.	3.64 (3.71)	4.00 (4.00)	2-4 (2-4)
9. My CG tries to figure out what will make me feel better.	3.64 (3.57)	4.00 (4.00)	3-4 (3-4)
10. My CG tries to provide comfort to me by telling me about their positive feelings for me.	3.64 (3.64)	4.00 (4.00)	2-4 (2-4)
Total Score (mean on scale)	3.51 (3.48)	3.70 (3.40)	2.1-4.0 (2.6-4.0)

*Abbreviation: ERS=Empathic Responding Scale of 0 to 4 where “0” does not describe the caregiver very well and “4” describes the caregiver very well

**Patient version evaluating caregiver empathic response; Caregiver version is shown in Table 8
Abbreviations: CG=Caregiver

Figure 4.6 Patient ERS Ratings (n=14)



Abbreviations: ERS=Empathic Responding Scale; Pt=Patient; Tot.=Total

*Empathic Responding Scale of 0 to 4 where “0” does not describe the caregiver very well and “4” describes the caregiver very well

Patterns of directional change in caregiver pre- and post-test condition ERS responses.

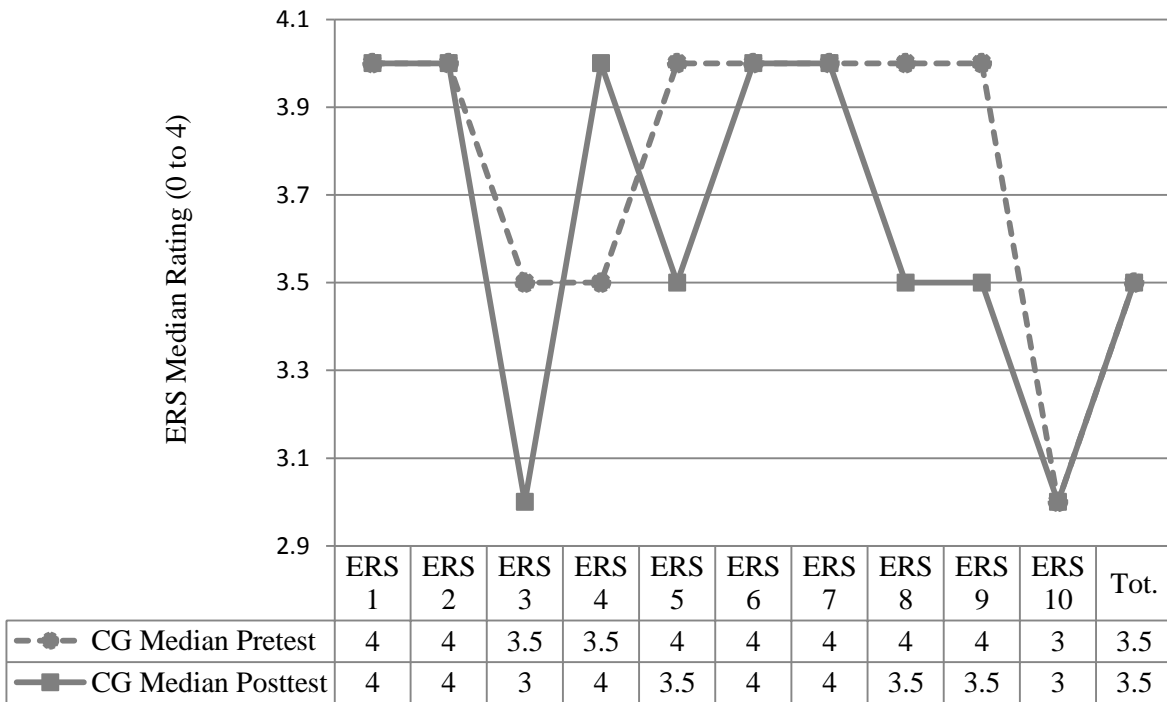
Caregivers' total median ERS score in the pre- and post-test conditions remained the same (pre-test median = 3.49; post-test mean = 3.5) (Table 4.13; Figure 4.7). The only ERS item that demonstrated a non-significant increased median rating was "I try to imagine being in their shoes" (i.e., ERS #4 in Figure 4.7) going from 3.50 to 4.0 units on the ERS. Four individual ERS items revealed a non-significant decrease in post-test median item caregiver rating of the caregiver's empathic responses toward the patient in comparison to the pre-test rating that include: "I try to experience what the patient was feeling", "I try to see things from the patient's point of view", "I try to help the patient by doing something for them", and "I try to figure out what will make the patient feel better". In addition, there were five ties in median pre- and post-test ERS ratings by caregivers.

Table 4.13
The Caregiver ERS Scores*

Caregiver ERS Items	CG Pretest (Post-test) Mean Score	CG Pretest (Post-test) Median Score	CG Pretest (Post-test) Range of Scores
1. I try to understand the patient's concerns	3.79 (3.71)	4.00 (4.00)	2-4 (2-4)
2. I try to understand how the patient felt	3.64 (3.50)	4.00 (4.00)	3-4 (3-4)
3. I try to experience what the patient was feeling	3.07 (3.07)	3.50 (3.00)	1-4 (2-4)
4. I try to imagine being in the patient's shoes	3.07 (3.29)	3.50 (4.00)	2-4 (2-4)
5. I try to see things from the patient's point of view	3.57 (3.36)	4.00 (3.50)	1-4 (2-4)
6. I try to accept the patient as they are now	3.64 (3.50)	4.00 (4.00)	2-4 (3-4)
7. I try to help the patient by listening to them	3.57 (3.50)	4.00 (4.00)	1-4 (2-4)
8. I try to help the patient by doing something for them	3.64 (3.43)	4.00 (3.50)	2-4 (2-4)
9. I try to figure out what will make the patient feel better	3.57 (3.36)	4.00 (3.50)	3-4 (3-4)
10. I try to provide comfort to the patient by telling them about my positive feelings for them	3.29 (3.14)	3.00 (3.00)	2-4 (3-4)
Total Score (mean on scale)	3.49 (3.39)	3.50 (3.50)	2.7-4.0 (2.4-4.0)

*Scale of 0 to 4 where "0" does not describe the caregiver very well and "4" describes the caregiver very well)

Figure 4.7. Caregiver ERS Ratings (n=14)



Abreviations: ERS=Empathic Responding Scale; CG=Caregiver; Tot.=Total

*Empathic Responding Scale of 0 to 4 where “0” does not describe the caregiver very well and “4” describes the caregiver very well

Potential ceiling effect in ERS responses. Of note, all median scores for individual ERS items were in the upper end of the scale at ratings of ‘3’ to ‘4’ units for patients and family caregivers. The range for each pre-test response item also indicated that there was a tendency by patients to rate caregivers at a level of ‘4’ (on a theoretical range of ‘0’ to ‘4’ units on the ERS scale) thus indicating a potential ceiling effect in patient perceptions of caregiver empathic responses at time of pre-test measurement (see Figures 4.8 to 4.10). Polit (2010) defined ceiling effect as “having scores at or near the highest possible value, which can constrain the amount of upward change possible and also tends to reduce variability in a variable” (p. 398). The four stacked column graphs in Figures 4.7 and 4.8 (patient pre- and post-test ratings) and Figures 4.10 and 4.11 (caregiver pre- and post-test ratings) visually demonstrated the high percentage of respective patient and family caregiver ERS ratings at ‘3’ and ‘4’ units out of a theoretical range of ‘0’ to ‘4’ units on the ERS.

For patient pre-test ERS ratings, eight out of 10 items had $\geq 50\%$ of the patients provide a response rating of ‘4’ on a scale of 0 to 4 units with the highest percentage of ‘4’ (or 85.7% of patients) occurring on ERS #7 (“my caregiver tries to help by listening to me”). Patients continued to rate ERS items as ‘3’ or ‘4’ at time of post-test measurement; e.g., for ERS#7 (“my caregiver tries to help by listening to me”) with 71.4% of patient response ratings at ‘4’. ERS items #6 (“my caregiver tries to accept me as I am now”) and #8 (“my caregiver tries to help me by doing something for me”) had the highest number of ‘4’ scores post-test, both at 78.6%). For further details see Figure 4.7 and 4.8.

Caregivers were less likely than patients to give a score of ‘4’ for their empathic responding toward the patient on both pre- and post-test (see Figure 4.9 and 4.10). Nonetheless, the majority of caregivers (> 70%) rated their empathic responding toward the patient as either

“3” or “4” on the ERS. The highest percentage of ‘4’ ratings by caregivers on both pre-test (78.6%) and post-test (71.4%) was for ERS item #1, “I try to understand the patient’s concerns”.

Summary of research question 2. Research question 2: Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to actively engage in a patient-oriented perspective-taking process, in the context of assessing and managing the patient's symptoms?

In summary, patient and caregiver responses on the ERS did not demonstrate a statistically significant improvement in family caregiver empathic responses toward the patient with HF two weeks after the caregiver received instruction to actively engage in a patient-oriented perspective taking process during day to day assessment and management of the patient's HF symptoms. Despite excellent ERS internal consistency reliability estimates (Cronbach's alpha = .86 to .91) in the current study, a ceiling effect was evident in pretest responses by both patients and caregivers that likely impacted their response variability and posed limited potential for upward changes in ERS ratings in the post-intervention condition (or enhanced empathic responding toward patients by family caregivers).

Research question 3. What are the perceptions of the HF patient and their family caregiver in response to the patient-oriented perspective-taking instruction, in the context of assessing and managing the patient's symptoms?

In order to answer Research Question 3, 12 patients and 12 caregivers completed a short audio recorded interview with the investigator based on separate semi-structured interview guides (Appendix J and K). All interviews were completed prior to verbatim transcription. Independent coding of two initial patient transcribed interviews was completed by Dr. Lobchuk, while the independent coding of two caregiver transcribed interviews was completed by Dr. McClement. The investigator met with each co-coder separately to compare and discuss the coding of themes and reach consensus by discussion when disagreements arose. A coding

template with definitions for each code was developed and employed for subsequent coding of remaining transcribed notes for 10 patient and caregiver interviews, respectively.

The patient experience. When asked to describe any change in their caregiver's behaviour when he or she was assessing their symptoms or trying to understand their experiences with symptoms over the prior two weeks, five out of 12 patients described their perceptions of a clear behavioural change in their family caregivers (Table 4.14). Patients had described an increase in observation, questioning, and helping behaviour. For example they would state that their family caregiver was, "watching me", "asked more how I feel...trying to give as best advice she can...", "makes sure she brings out the scale for me every morning", "more involved in um, trying to get me healthy...watching, help me watch the diet...trying to help me sleep...", "...lot more ah, attentive...always asking questions...how I'm feeling". One patient described that before his caregiver would "...listen but she wouldn't...um, respond...necessarily...I mean she'd...hear what you were saying but she wouldn't really respond to it" whereas now "if I wasn't feeling right or if, you know, feeling, feeling down or something, she'd ask me what's going on or talk about it. Which is a change from how it was before...". Increased symptom verification was also described in such statements by patients as: "she takes a guess at how I'm feeling and you know and then asks me, at, like actually asks me how I'm feeling". Commenting on the active process involved in the intervention, another patient noted of his spousal caregiver:

"this is basically the same thing with what you said, like do you think that she (the caregiver) is more alert, more susceptible to it and vice a versa. Yeah, most definitely, because you know what, (sigh) there's so many things that we do on a daily basis that we take for granted, that we don't even pay attention. We do them automatically and we don't think about it, until it's brought to your attention and you watch for it and then you realize that, yeah, it really does happen" (Pt 10, line 370).

Dyads Interviewed	Change Reported by Patient	Time Since Diagnosis	Relationship	Caregiver Healthcare Background
1	No	5 years ago or longer	Friend	Nurse
2	No	5 years ago or longer	Daughter	
3	No	6 months to < 5 years ago	Spouse	
4	No	5 years ago or longer	Spouse	
5	Yes	5 years ago or longer	Spouse	
6	Yes	6 months to < 5 years ago	Spouse	
7	No	5 years ago or longer	Spouse	Nurse
8	Yes	6 months to < 5 years ago	Spouse	
9	Yes	5 years ago or longer	Spouse	
10	No	6 months to < 5 years ago	Spouse	
11	No	5 years ago or longer	Spouse	Nurse
12	Yes	Less than 6 months ago	Spouse	

All five patients who noted a behaviour change in their family caregivers were in a spousal relationship with the family caregiver, and 60% of the patients had been diagnosed with HF less than five years prior (including one diagnosis less than six months prior).

The remaining seven out of 12 patients described that they had experienced a longstanding high level of supportive behaviour by their caregiver. For example, patients stated that, “she’s always very sympathetic”, “he watches me fairly closely...to see that everything’s okay”, “after almost forty years of married life she understands me...she’s always been there you know...”. Referring to his caregiver spouse who is also a nurse, one patient stated that given “...her background...wouldn’t have changed very much” indicating that a pre-existing high level of skill was already present in their caregiving relationship. Three out of 12 patients did not notice a change in caregivers with a nursing background and 71% of 12 patients had been diagnosed with HF five years or more prior to the intervention.

Several major themes emerged as patients described caregiver attempts to understand their symptoms and how that understanding was communicated to them by family caregivers as summarized in Table 4.15.

Table 4.15

Patient Experience: Major Themes and Subthemes.

<i>Patient Theme 1: Caregiver strategies for symptom monitoring.</i>	
Definition	Observable caregiver behaviour directed toward perceiving, understanding, assessing, or rating the presence of any symptom of HF experienced by the patient.
Subtheme 1.1	Direct observation
Subtheme 1.2	Open discussion, asking questions
<i>Patient Theme 2: Caregiver strategies for symptom management.</i>	
Definition	Caregiver activity (noted by the patient) to alter, ameliorate, alleviate, enhance the tolerance of, or change the course of a symptom experience with the aim of optimizing safe management of HF for and/or with the patient.
Subtheme 2.1	Attending appointments and record keeping
Subtheme 2.2	Taking a positive approach
Subtheme 2.3	Proactive care and blocking activities
<i>Patient Theme 3 – Consequences of being known.</i>	
Definition	Patients' descriptions of any impact on the patient or the caregiver as a result of the caregiver's attempts to perceive the patient's symptom experiences.
Subtheme 3.1	Cost and benefit of their knowing
Subtheme 3.2	Recognizing and mitigating caregiver burden
<i>Patient Theme 4 – Patient strategies for adaptation to HF symptoms.</i>	
Definition	Patient reported activity that patients engaged in to influence, ameliorate, tolerate, or demonstrate the occurrence of symptoms to others. Although this major theme does not directly address Research Question #3, this theme shed light on patient activities that may have impacted the caregiver's ability to know or perceive symptoms, according to the patient.
Subtheme 4.1	Acceptance: Not defined by the illness
Subtheme 4.2	Acceptance: Normalizing life
<i>Patient Theme 5 – Barriers and facilitators to understanding.</i>	
Definition	The patient's personal history and shared experiences with others, as well as characteristics of relationships they have had with family caregivers and friends that patients perceived as a directly influencing another person's ability to perceive or understand their symptom experiences.
Subtheme 5.1	The lens of their experience
Subtheme 5.2	Relationships and intimate knowledge
<i>Patient Theme 6 – Leveling out.</i>	
Definition	Patient or caregiver behaviour (identified by the patient) aimed at efforts to attain a joint understanding of patient symptoms and evolved since the time of HF diagnosis.

In addition, other themes arose that addressed the patient's overall experience in managing symptoms with their caregiver. In the post-intervention condition, patients most often reported an increase in current behaviour rather than new behaviour. Contributions of patients who did not report an increase in caregivers' empathy-related behaviour in relation to patients' symptoms will be included in the discussion of qualitative themes: these themes depicted empathy-related behaviors of caregivers as perceived by patients to be a high degree of caregiver involvement in managing HF that is germane to Research Question #3. Each theme is supported by direct patient quotations but where participant names have been altered to maintain the anonymity of study participants.

Patient theme 1: Caregiver strategies for symptom monitoring. Caregiver strategies for monitoring depicted any observable caregiver behaviour directed toward perceiving, understanding, assessing, or rating the presence of any symptom of HF experienced by the patient. There were two subthemes of 'Direct observation' and 'Open discussion, asking questions' included under Theme 1 as follows.

The sub-theme, 'Direct observation' depicted some form of observation that was employed by all caregivers to better comprehend patients' symptoms, regardless of whether or not family caregivers resided with the patient. One patient described the following as examples for this sub-theme:

"I might go sit in that chair and [my] face becomes different, hey. Like it seems that sometimes, just feel different, look different. You can almost see it on a person...she asks me if I'm feeling alright" (Pt 12, line 45).

"I think she can see the difference. But she's really noticeable person, like and she remembers things very well. You know, long term, so she knows different look, different colours, she remembers it you know, if you're greyish..." (Pt 12, line 147).

At times the patient described that their family caregiver observed things that the

patient was not aware of about themselves. Again, here are three exemplars:

“I think it’s good [having someone else watching] because sometimes I don’t recognize my symptoms, you know”. (Pt 2, line 79) “She’ll say ‘you know, you’re very short of breath today’, ‘Yeah, I am, yeah.’ And I, sometimes I don’t notice until she says it, you know” (Pt 2, line 94)

“She’s the one who noticed all the problems to begin with”
“Cause you, you think yourself that you know the answer but you don’t. You can’t measure yourself that well”. (Pt 12, line 264)

“...you need someone to say to you, ‘well you know you’re looking worse or you’re looking better’ or, you know, ‘things are picking up’ ...cause you, you think yourself that you know the answer but you don’t. You can’t measure yourself that well” (Pt 8, line 51)

The following exemplars under this sub-theme depict caregiver validation of what was observed and then followed-up by the caregiver with the patient. The caregiver would share his or her observation of the patient’s behaviors, cues, or symptoms with the patient to ensure that the caregiver’s observation or inference was accurate:

“...she takes a guess at how I’m feeling and you know and then asks me, at, like actually asks me how I’m feeling” (Pt 7, line 34).

“She’ll talk about it, you know that, she’ll say that ah ‘I noticed that you ah, you know you’re standing up, up straight now’, you know or, or ‘you’re, you’re bent over like an old man’ ” (Pt 8, line 80).

Patients also frequently described caregivers as closely watching them. One patient warm-heartedly described his wife by saying, “She’s probably like a cat, sleeping with one eye open”. This typifies the vigilance associated with many patients view of their caregiver’s observations.

The sub-theme, ‘Open discussion, asking questions’ described statements where patients would mention some degree or level of open discussion or conversation had occurred with their caregiver surrounding symptoms:

“We just discuss it, you know and I can tell by what she says that she knows that...you know, what’s happening” (Pt 2, line 43).

“...if something comes up or you know, well, we talk” (Pt 5, line 31).

“yeah, we’d sit there and discuss everything” (Pt 11, line 176).

As discussed above, validating one’s inferences by family caregivers was a common focus during patient and caregiver verbal exchanges about the patient’s symptoms. Patients also perceived that the caregiver’s questioning stance about their symptom experiences as equally engaged in by their caregivers. When asked how their caregiver understands their symptoms, several patients responded as follows:

“She asks, she asks me if I’m feeling alright” (Pt 12, line 60).

“Ah, she usually just asks or she can tell”. (Pt 7, line 105)

“Well, it’s lots of times when she phoning me and say “How you feel today? What you doing today? What you been today?...All the time.” (Pt 3, line 27).

On the other hand, one patient also indicated that he or she perceived his or her caregiver’s engagement in symptom assessment activities was not a formal activity but rather an activity that was quietly, subtly, or unobtrusively conducted by the family caregiver:

“You know, so, um, if something was noticed by [caregiver] she would, she’d be able to slip it into the, the conversation eh, you know, and get an answer” (Pt 5, line 88), “We haven’t got to a situation where okay you sit there, I’ll sit here and we’ll, we’ll find out how you feel” (Pt 5, line 93).

Patient Theme 2: Caregiver strategies for symptom management. The second major patient theme of, ‘Caregiver strategies for symptom management’ included any caregiver activity (noted by the patient) to alter, ameliorate, alleviate, enhance the tolerance of, or change the course of a symptom experience with the aim of optimizing safe management of HF for and/or with the patient. Under the second major patient theme, caregiver strategies for symptom

management, were three subthemes: ‘Attending appointments and record keeping’, ‘Taking a positive approach’, and ‘Proactive care and blocking activities’.

The first sub-theme was, ‘Attending appointments and record keeping’. Under this sub-theme, several patients described the benefits of having their caregiver accompany them to medical appointments to clarify symptom information and support their illness narrative:

“She always comes into appointments with me ...sometimes I’ll forget something...she doesn’t forget anything with a date on it, or a number attached to it...Oh, just confidence in what I’m saying in the doctor’s office.” (Pt 11, line 132).

“Even when I saw the doctor, he said well [patient name] I, there’s nothing really, you look fine...then I told him about certain problems that, [wife] was there with me, and then she told him and he’s ‘well I’ll send you to see the specialist’...” (Pt 12, line 266)

Patients spoke highly of their caregiver’s accuracy in describing their symptoms to health care professionals:

“More accurate than I would do it” (Pt 8, line 222).

“She is very accurate actually cause she’s, she’s very on the ball...she knows me so well” (Pt 12, line 72).

“She would be... fine if I couldn’t, if I was unable to ah speak, I think she’d be...more than capable of handling it.” (Pt 15, line 133).

The second subtheme, ‘Taking a positive approach’ described the patient’s account of their family caregivers who employed a positive manner in symptom monitoring and management. Here are comments that were shared by two spousal patients:

“When I tell her [how I’m feeling] you know she says, ‘Oh, well you know, we’ll take one day at a time’ and stuff like that and tries to make something, better out of it...make it look a little brighter and stuff but, just to be positive.” (Pt 7, line 39).

“She’ll say that ah you know, I go downstairs and come back up, I don’t tend to stop at the bottom of the stairs. So it, it’s positive things.” (Pt 8, line 88).

The third sub-theme, 'Proactive care and blocking activities' denoted patients who described that their caregivers routinely took action to ward off untoward consequences in relation to optimally managing the patient's safety and HF symptoms. Here are some exemplars for this sub-theme:

"Like, steadiness on a ladder or something like, she'll go and she'll help, if I have to put, change a light bulb...she comes right away and hold the ladder...she won't let me go up by myself cause she's worried that I might fall" (Pt 12, line 340).

"Like at night if I come out and if he's doing up some, some dishes and I come out he'll say 'Go back to your chair' or 'they're air drying' (Pt 4, line 33).

"...and she's supportive because she says 'Well if you don't feel like you're doing it, you know, you're up to it, don't do it. Cause you're just going to overdo it. You're going hurt yourself more than you're help yourself'" (Pt 10, line 134)

"[patient who lives alone speaking of visiting her friend down the street] I be go visit her but ah now I, I never go...I'm scared...last week [caregiver] yelling at me 'Don't go, don't go yourself, don't go yourself'. (Pt 3, line 137).

Other proactive behaviours of caregivers that were mentioned by patients involved the caregiver taking on new roles or adapting to limitations posed by the patient's symptoms in a supportive, empathic manner:

"I found that she was very involved with me and she was very caring and she would change herself to, to sort of fit with me. She wouldn't bully me." (Pt 8, line 31).

"And he, he had never cooked in his life before (chuckles) so, so he's doing well" (Pt 4, line 56)

"[We] go see her mother out in the country, well okay, I usually drive, so, I'm not up to it. Okay, so she drives." (Pt 13, line 74).

Patient Theme 3 – Consequences of being known. The third major theme, 'Consequences of being known' included patients' descriptions of any impact on the patient or the caregiver as a result of the caregiver's attempts to perceive the patient's symptom experiences. There were two

sub-themes under this major theme: ‘Cost and benefit of their knowing’, and ‘Recognizing and mitigating caregiver burden’.

The first sub-theme was, ‘Cost and benefit of their knowing’. This sub-theme captured statements offered by a majority of patients who described that they felt reassured their caregiver had a sound knowledge of their ongoing symptoms. However, at the same time, many patients also expressed their frustration with their caregiver’s constant monitoring and management of HF symptoms. The following are some exemplars that captured this subtheme for patients:

“[She] makes sure I have breakfast and lunch every morning, makes sure I take all my pills when I’m supposed to, which sometimes is good and sometimes can be a little frustrating.” (Pt 7, line 69).

“Oh yeah, yeah. No, I, it feels good that people, you know um are, are attentive um, but after you know, after a while, it’s kind of, it gets to be a little much” (Pt 15, line 90).

“I think if you have someone to talk to about it, makes a difference anyway. Cause if...you’re on your own it’s a...but not everybody has a caregiver, you know...I don’t know how you’d do it.” (Pt 8, line 467).

Several patients also indicated the benefits of their caregiver’s constant vigilance in comparison to the risks associated with poor symptom monitoring and management. When patients were asked if they found that it was comforting to know that someone else was aware of their symptoms, one patient responded:

“Oh God, yeah, oh yeah...yeah. Like I say, I don’t think you’d be doing all, that easily. I think you’d spend more time in a hospital.” (Pt 8, line 159).

On the other hand, at times patients described that they would conceal their symptoms and activities to lessen a perceived ‘over-response’ or attention by their family caregiver.

“I think I’m more careful how I present, present myself, then, so that, they’re always asking questions, I don’t like to let on that I’m not feeling well, it’s just that you know, me being stubborn.” (Pt 15, line 236).

The second sub-theme, 'Recognizing and mitigating caregiver burden' captures patients' comments that centered on their concern for the negative impact of strain, both emotional and physical, on their family caregiver which was associated with the management of HF and its associated symptoms.

"You know, [I] get worried about things a lot and then tell her and then she, I make her worry." (Pt 12, line 86).

"Sometimes I think maybe I'm pushing it too hard on her, you know, because she has her own health issues. But I, you never look at the other person. You look at yourself, you know. So that's kinda hard on her I think." (Pt 12, line 122)

"You know, even if she's tired she does it. It's not fair on her but she does it." (Pt 12, line 136).

"Yourself, that person with a family [referring to the caregiver]. Somebody's not feeling good, you're resting but you're not. You're sort of on, on the verge. Always on, on the lookout, you're on the listen" (Pt 10, line 318).

"it's going to upset her...or she worries about it" (Pt 10, line 493).

As part of their need to mitigate their family caregiver's strain, a number of patients described that they would withhold information from their caregiver until more was known about emergent symptoms and/or conceal symptoms and risky activities that could worsen their HF symptoms.

"...if I'm doing something in the garage or something, if I'm out there and I don't feel good I sit down out there. I won't come in and say 'hey, I don't feel good', cause I know it passes" (Pt 12, line 96).

"It's not that I try to keep it from her, ah, but I'll just say to her 'well you know what, I've been experiencing this over a period of time, ah, I did talk to the doctor about it' or 'I look up on the internet about it and it's, it's a side effect of some of the medication that I'm taking' or 'or it's to be expected'...That way once I'm informed on it, that I know that if I tell her that she accepts it in a more relaxed way..." (Pt 10, line 499).

Ultimately, the primary motivating factor for patients to conceal their ‘risky’ activities appeared to be their intention to lessen the burden on their caregivers.

Patient Theme 4 – Patient strategies for adaptation to HF symptoms. The fourth major patient theme, ‘Patient strategies for adaptation’ described any reported activity that patients engaged in to influence, ameliorate, tolerate, or demonstrate the occurrence of symptoms to others. Although this major theme does not directly address Research Question #3, this theme and two underlying sub-themes shed light on patient activities that may have impacted the caregiver’s ability to know or perceive symptoms, according to the patient: ‘Acceptance: Not defined by the illness’, and ‘Acceptance: Normalizing life’ .

The first sub-theme, ‘Acceptance: Not defined by the illness’ captured comments shared by several patients who passionately discussed the need to accept their new circumstances, often in the face of loss, unaccepting family and friends, personal distress, and inner conflict while still ‘holding on to’ their identity or the person that they were before diagnosis. Some patients indicated that their acceptance of daily life with HF may have influenced their willingness to share their symptom experiences with others (e.g., family caregiver, family members, or friends). One male patient frequently described his garage as a safe haven away from watchful eyes of his spousal caregiver. Within the garage were material objects that served as a remembrance of this patient’s former active life (e.g., power tools): he revealed his uncertainty about the future that was perhaps symbolic of his inner conflict and vulnerability in the face of loss:

“I’ve got a lot of stuff that I own and, and every time I feel terrible I’m thinking of selling it, like you know, I’ve got a lot of stuff, and I think, well, well should I sell it or should I keep on hanging on to it or what should I do with it? So that, that really bothers me, you know, and, so that’s my biggest concern.” (Pt 12, line 192).

His final comment, "...that's my biggest concern" lends gravity to his decision-making conflict in planning for his future that went beyond the value of his power tools.

Other patients described a need for their caregivers to acknowledge a degree of recovery along their HF trajectory that would allow them to perceive some degree of returning to a former active life. Some patients expressed that their caregiver's monitoring and management efforts could at times be perceived as oppressive or offensive:

"I'm being treated like a three year old, like listen, yeah okay, was the period in time when maybe I couldn't, but you've got to realize that I am beyond that point and I'm coming back now, that I can help myself, there are things that I can do..." (Pt 10, line 146).

"I understand but at the same time, I'm still the same person. I can't, you know, 'thank you for looking out for me but...', you know, I'm stubborn that way, kind of...I'm more of a, um, let's take care of it, let's get it done, I'll do it...I don't like to, you know, have other people do, do it for me." (Pt 15, line 98).

One patient went as far as to sabotage his spousal caregiver's efforts at organizing his daily medication, asserting control over his care that was demonstrated in this statement: "I'm not gonna spend my whole day taking pills. So I just you know, half the time (chuckle) take em all at once or whatever type thing..." (Pt 7, line 91). Another patient exerted control in decision making when he referred to his discussion of symptoms with his caregiver: "...probably more often than not that we discuss them [symptoms]. Ah, I'm the final decision maker because it pertains to me, like she tells me I'm stubborn" (Pt 10, line 555).

Some of the younger patients (< 65 years of age) struggled with others not acknowledging or not accepting their degree of limitation:

"I'm of the fifty plus or fifty five plus group so, ah, the fact that she [nurse caregiver] works in a care home maybe...like she'll sometimes say...more out of frustration...'well I look after seniors and they don't have that kind of problem'...I'll say 'I'm just tired' and, well, you know, [caregiver] 'well you just slept a whole night'. Yeah but I'm still tired. So what do we do now?" (Pt 13, line 51).

Another patient struggled with his co-workers' perceptions about his condition:

"They ask you questions so you tell them and then, three questions, answers, answers, they don't care anymore. So you, you might as well keep it to yourself. Unless they need to lift something, then you don't do it, then they understand." (Pt 12, line 407).

The same patient described deliberately not discussing his symptoms to avoid exhausting the interest of family and friends:

"I think I talk about it too much. I think sometimes she [caregiver] might get tired of hearing about the same thing, 'well you said that yesterday', you know, like, it's only normal, right?" (Pt 12, line 393).

The next patient sub-theme, 'Acceptance: Normalizing life' captured patients' statements where they described their initial struggle against accepting a new baseline of activity. This struggle with the diagnosis was eventually resolved as a peaceful contentment in 'letting go' of the old ways by patients who learned to not focus too much on the details of their symptoms. This sub-theme potentially served as a factor that impacted the patient's experience and reporting of symptoms to family caregivers where they embraced the diagnosis as a 'new' normal experience of daily life:

"...you have to be careful that you don't fixate on things...it's gonna to be what it's gonna to be, so I mean don't sit and worry about it. You worry about it and it's going to get worse. Yeah, you're gonna really panic (chuckle)." (Pt 8, line 142).

[avoiding a certain sleeping position] "cause you can't breathe. And you think whooo. So, you learn not to do that. You learn to sleep with your back against the, the chesterfield so you can't turn over." (Pt 8, line 350).

"But I appreciate the fact that I need to just sort of sit back and sometimes some people read it a little differently but, I've kind of learned to just say well, tough shit, you know, that's my life, not yours (chuckle) and hopefully, eventually people will either understand or at least respect the fact that you know" (Pt 13, 109).

“Death’s going to come whether I want it to or not, you know, it’s just whenever it happens, it’s going to happen and I’m sort of ready.” (Pt 13, line 122).

Patient Theme 5 – Barriers and facilitators to understanding. The fifth major patient theme, ‘Patient identified barriers and facilitators to understanding’ captured the patient’s personal history and shared experiences with others, as well as characteristics of relationships they have had with family caregivers and friends that patients perceived as a directly influencing another person’s ability to perceive or understand their symptom experiences. Under this major theme are two subthemes: ‘the lens of their experience’, and ‘relationships and intimate knowledge’.

The first sub-theme was, ‘The lens of their experience’ where patients described their belief that certain characteristics of a caregiver’s personal background can influence their ability to accurately perceive their symptoms. For two patients, a nursing background held by their caregivers was generally considered to be a benefit in enhancing the caregiver’s ability to accurately perceive symptoms:

“[referring to the caregivers HF symptom assessment ability] Pretty much as a nurse for, you know, twenty years. So she’s used to fixing it” (Pt 8, line 23).

“...because she’s a nurse when I tell her something I don’t have to explain it all to her, you know, she gets it right away” and “she certainly has a good academic understanding of all these things, even if she’s never really experienced them much herself” (Pt 2, line36).

Similar or varying personal experiences with illness by family caregivers was also seen by patients to enhance caregivers’ understanding of symptoms:

“I think it also helps he had bypass surgery himself, seven years ago so he has a little bit of an idea” (Pt 6, line 84).

“[patient’s mother] being in and out of the hospital and she, she’s diabetic , she’s bipolar, she suffers from depression, so, my, my dad from that, he’s very understanding cause he’s had to go through all that with her. So if I, you know, explain stuff to him, he knows...” (Pt 15, line192).

“...someone that’s a little older sometimes can maybe put themselves in your shoes a little bit because of certain situations that they lived through, you know, certain life changes and things like that.” (Pt 13, line 723).

The next sub-theme, ‘Relationship and intimate knowledge’ captured patients who were in a spousal relationship with a caregiver who held tacit knowledge about the patient’s symptom experiences that was based on the longstanding intimacy of their relationship. The intimacy of their relationship was often provided by patients as an explanation for the lack of change in their caregiver’s empathy-related responses toward them in the post- intervention condition:

“No...after almost forty years of married life she understands me you know” (Pt 5, line 25).

“I don’t think so. We usually think alike.” (Pt 4, line 18), and “lots of time when we’re sitting there and we’ll both come out with the same thought” (Pt 4, line 104).

On the other hand, the same patient saw this familiarity also as a barrier for the caregiver to perceive slow changes in his physical condition: i.e., due to a possible desensitization of the patient’s symptom experiences by the caregiver who had been caring for the patient over a protracted period of time:

“when you’re together like that you don’t notice things as, like someone coming in hadn’t seen you for a couple of weeks would probably notice a difference more so than being together day after day...for those slow changes” (Pt 4, line 109).

Even patients who described a definite post intervention change described their caregivers’ knowledge as being based on their intimate relationship and past shared experiences:

“...of course...being here all the time she has firsthand experience with what I’m going through” (Pt 11, line 51).

Other family and friends were seen by some patients as fulfilling roles other than assistance with symptoms:

“[friend], well she doesn’t like to come to hospitals...she’s a different type than [caregiver friend]’ (Pt 2, line 53).

“My brother, not so much. He’s more, if, if there, there’s a problem, he doesn’t understand it right away or, it’s not that he doesn’t understand, he just doesn’t want to make it his problem, you know, one of those, but...my parents can definitely understand what’s happening.” (Pt 15, line 208).

Another patient cited social awkwardness or fear of upsetting family members or friends as a barrier to sensitive understanding of his symptom experiences:

“It’s kind of like people suffering from cancer, you know...don’t talk to them about it because it’s, I mean, death is coming.” (Pt 13, line 116).

“[speaking of his adult children] they kind of, shy away from it...it’s very hard to understand when you’re young...they think that I, I might get upset and if I get upset well, that’s (imitating choking sound), you know, I’m going to die right away...don’t be afraid to, to ruffle feathers.” (Pt 13, line 165).

Patient Theme 6 – Levelling out. The sixth major patient theme, ‘Levelling out’ captured any patient or caregiver behaviour (identified by the patient) aimed at efforts to attain a joint understanding of patient symptoms and evolved since the time of HF diagnosis.

Just as patients described their attempts to adapt and accept HF symptoms in Patient Theme 4, they verbalized a need for their family caregivers to accept a certain degree of recovery for patients who desired a level of participation in activities of life. One patient described symptom monitoring as “something that you grow used to”. Another patient noted that his caregiver was once quite anxious but was now “more relaxed with it now though, because we know, we’ve gone through it, it’s been twenty months”. This patient continued to say that her caregiver no longer keeps notes on his symptoms, “it seems like every day’s a different day. What do you write? You know, ‘I feel lousy’, ‘feel good’, ‘I felt lousy this morning’.”

Another patient, who was diagnosed less than 6 months prior to this study's interview, had noted several experiences where he learned how to communicate with his spousal caregiver, and how they learned to function cooperatively:

"I'm more private, in that kind of way [sharing symptoms] where everything is okay um but I am learning through all this to, to communicate more effectively, so, um, in the last little while, yeah, it's gotten a lot better because I'm better at communicating to her if, if I'm having a problem, if not everything's okay, you know, 'this is what's happened' ...it's a learning experience for both of us, to change how, how we do things." (Pt 15, line 147).

"This whole thing has been a...learning process to change...how she reacts to me and...how I communicate with her to how...I'm doing, cause she also needs, needs to know if I'm having a problem, she needs to know how to handle it and what to do" (Pt 15, line 165).

"I like to take care of things and other than being taken care of or people asking me, you know, so I've, yeah, the, the more verbal is...I'm learning to change." (Pt 15, line 264).

This patient also expressed some initial "uncertainty" in the lengthy process of reaching the final diagnosis of HF but "as things progressed...it got a lot happier". Regarding his spousal caregiver, this patient noted that she has "been there with me through this whole thing so she can, she can also learn as well". A more experienced HF patient remarked of his spousal caregiver:

"before when it first all started she was really having a hard time sleeping and if I was away for too long she'd worry about it, right. But, it's now, it's to the point where if I disappear for a longer period somewhere she gets worried but basically it's, you know, leveled out" (Pt 12, line 24).

Summary of the patient experience. Six major themes emerged as patients described caregiver attempts to understand their symptoms, how that understanding was communicated by caregivers to patients, and how patients responded to being assessed and co-managed. Forty-two percent (n = 14) of patients were aware of a change in their caregiver's behaviour post-intervention. Patients were able to describe caregiver strategies for symptom monitoring and

symptom management, but also recognize barriers and facilitators to understanding their symptom experiences in a variety of relationships that included extended family, friends. Patients were mindful of the impact ongoing symptom assessment and management had on their own actions and wellbeing as well as that of their caregiver. In addition, patients offered a sense of transition where patients themselves adapted to their HF symptoms while at the same time their caregivers' behaviours, aimed at shared understanding, evolved and 'leveled out' after the initial diagnosis.

The caregiver experience. As with patients, caregivers were asked to describe their thoughts and feelings over the prior two weeks when employing the patient-oriented perspective taking technique to help them understand the patient's symptoms. Caregivers were also encouraged to describe whether they thought the patient-oriented perspective taking technique enhanced their ability to understand the patient's symptom experience. One caregiving daughter stated:

“That, that has helped. I feel I've always have done that. I might have right now in the last seven days listened a little bit more for the, and not asking my mom to repeat that she didn't sleep well again or anything like that, just taking a mental note that ah, if she said, you know, “I just didn't sleep all night”, listening to why she may be not have, maybe not really commented on it, but kind of hearing and registering how many times...” (Pt 3, line 22)

A spousal caregiver described using this sensitive, patient oriented approach to understand her husband's frustration over limited activity related to symptoms: “I tried to [perspective take] throughout, the days like, err, situations and I could see, all the time like how he feels. Like he gets frustrated...”.

Most caregivers described imagine-patient perspective taking as something they already do: “I think it's something I naturally do. It, yeah, I just think I just do that. It's part of me no matter who you are or where you're going.”, “Always, always doing it

[perspective taking], yeah”, “it’s a lot of times in a person’s character, but with this questionnaire it has made me, ah, a little bit more conscious of what I’m doing. Yeah as far as putting myself into her position”. It was apparent that many caregivers believed that perspective taking was already integral to their pre-intervention approach to symptom assessment. On the other hand, many of these caregivers indicated that the intervention may have heightened their awareness and increased their deliberate use of the technique: “I’m getting better at that [perspective taking]”.

Some caregivers shared examples where they had employed perspective-taking as a daily approach toward understanding the patient’s experiences with HF. For example, one spousal caregiver stated, “...and then he gets frustrated, so then I know ah, if it was me and if I couldn't do certain things, how upset I would be...”; but then she switched to the imagine-patient perspective adding: “So I could see his viewpoint when he gets tired or he gets moody or...ah, depressed”. In addition, this caregiver demonstrated consideration of the patient’s individual personality in interpreting their symptom experience:

“he's very outgoing um, outspoken, always on the move ah, doing things and, so now it's like, different. You know like if he does something he gets pooped out and, or he gets out of breath and, tiredness, [he's] flustered about all this, that he can't do”. (CG 12, line 54).

One spousal caregiver did not feel the technique enhanced her assessment ability but did acknowledge improved communication with the patient that was of benefit in symptom assessment:

“Well I tried consciously to ah not put myself in his shoes but try to think in terms of where he was coming from... I don't think it made me any more compassionate. I don't think it made me anymore efficient. But I did consciously try to see things from his point of view... what we did is had a discussion about some of the things that were making it impossible for me not to kill him (chuckle)... that openness made it a little easier to deal with some of the symptoms and, the times when he needs me.” (CG 11, line 19).

A daughter caregiver discussed a change in her caregiving motivation related to the intervention: “it wasn’t monotonous like ‘I’m doing, I’m doing’, you know, because I’m doing it for mom - now I’m a little more aware”.

The caregiver interviews revealed several themes with subthemes, summarized in Table 4.16, related to caregiver thoughts and feelings when employing the patient-oriented perspective taking technique.

Table 4.16

Caregiver Experience: Major Themes and Subthemes.

<i>Caregiver theme 1: Caregiver strategies for symptom monitoring.</i>	
Definition	Any self-reported caregiver behaviour directed toward perceiving, understanding, assessing, or rating the presence of any symptom of HF experienced by the patient.
Subtheme 1.1	Direct observation
Subtheme 1.2	Open discussion, asking questions
Subtheme 1.3	Morning report
<i>Caregiver theme 2: Caregiver strategies for symptom management.</i>	
Definition	Any self-reported caregiver activity directed at altering the course of a symptom, alleviating it, lessening it, or making it more tolerable or safe for the patient.
Subtheme 2.1	Attending appointments and record keeping
Subtheme 2.2	Blocking activities
Subtheme 2.3	Reassurance and a helping hand
<i>Caregiver theme 3 – Consequence of knowing.</i>	
Definition	Any impact on the patient or the caregiver as a result of the caregivers attempts to perceive the patients symptom experience.
<i>Caregiver theme 4 - Partnership in HF.</i>	
Definition	Caregiver thoughts and feeling on the impact of symptom assessment, management and long term prognosis on their day to day partnership in care and the outlook for their shared future.
Subtheme 4.1	Acceptance: We're in this together
Subtheme 4.2	Acceptance: Loss and uncertainty
Subtheme 4.3	Acceptance: Normalizing life
<i>Caregiver theme 5 – Barriers and facilitators to understanding.</i>	
Definition	Caregivers identified barriers and facilitators that influenced their ability to perceive or understand the patient's symptom experience including their capacity or willingness to imagine experiences they have not had, intimate knowledge of the patient, and the patient's willingness to be known.
Subtheme 5.1	Capacity to imagine
Subtheme 5.2	Willingness to be known
<i>Caregiver theme 6 – Levelling out</i>	
Definition	Patient and caregiver natural trajectory in developing a shared understanding of the patient's symptom experience. This theme includes any patient or caregiver behaviour (identified by the caregiver) aimed at a shared understanding of patient symptoms which have evolved since the time of their diagnosis.
Subtheme 6.1	Giving back control
Subtheme 6.2	Getting comfortable/learning to trust

Caregiver theme 1: Caregiver strategies for symptom monitoring. Caregiver strategies for symptom monitoring captured self-reported caregiver behaviour directed toward perceiving, understanding, assessing, or rating the presence of any symptom of HF experienced by the patient.

The first subtheme is ‘direct observation’ where caregivers who lived with the patient indicated that direct observation was a key component of their symptom assessment strategies:

“We watch her, the way she walks, and her dizzy spells, and her sleep, sleep, sleep, sleep” (CG 4, line 42).

“[likely to be] more observant”, (CG 8, line 40).

“I probably notice it [first]”, (CG 10, line 46).

“he's pretty good in that [relating symptoms] but I'm always watching”. (CG 12, 127).

One caregiver noted that observation alone was less upsetting to the patient:

“I found if I didn’t say anything, that he seemed to be a bit more relaxed, instead of ‘oh, you’re having a shitty day’ or ‘not breathing’, or ‘didn’t spend a very good night’ or whatever, he seemed more relaxed. As to, ‘no I didn’t have a very good night but whatever’. But if you said something he’d seem to get more worked up about it or something.” (CG 10, line 303).

In the second subtheme, “open discussion, asking questions”, the caregiver would seek new information or elaboration and verification of the patient’s observed symptom experience:

“I probably notice it, and I kind of note he didn’t have a very good night or whatever, and then he’ll respond more” (CG 10, line 46).

“[when concerned about a symptom] I ask, and it's more panic like (sigh). I think I drive him crazy” (CG 12, line 96).

“When I notice that he kind of makes a face or something, I’ll ask him ‘what’s wrong’ or something, he tells me...” (CG 15, line 22).

Listening to the patient describe their symptom experience was an important part of open discussion. One caregiver described having made an attempt to engage in improved listening post-intervention:

“I’ve been taking care of all her needs so I feel like I have [a deeper understanding of the symptoms], but I just kind of, it just tweaked my, you know, my own, ah sense of listening to, you know, what the symptoms are.” (CG 3, line 47).

When the caregiver lived outside the patient’s home, the discussion and questions are more likely to be over the telephone:

“I’m not with her often enough to observe... when she’s in her apartment I don’t know if she is lying on the sofa having trouble breathing until she phones me” (CG 2, line 110).

Family members who worked outside of the home also relied on regular telephone contact for symptom assessment:

“I still call about every 2 hours if not more.” (CG 8, line 88).

The third subtheme is, “morning report” – upon waking in the morning some caregivers described estimating the patient’s symptom level that could influence the patient’s activity and emotional state for the day.

“you can tell when she comes down in the morning, yeah, what kind of a day its gonna be” (CG 4, line 118).

“some days when he gets out of bed he knows it's not, as good as the day before” (CG 12, line 64).

Daily variability in patients’ symptom experiences appeared to inject uncertainty in long-term planning by caregivers:

“you never know, you can't really plan, cause you don't know, well what kind of day is he going to have today. Is it, can we go out today and even if we go out, well (chuckles), you know... is it going to be one of those days, or is he going to have a good day today?” (CG 13, line 500).

Caregiver theme 2: Caregiver strategies for symptom management. ‘Caregiver strategies for symptom management’ described any self-reported caregiver activity directed at altering the course of a symptom, alleviating it, lessening it, or making it more tolerable or safe for the patient.

In the first subtheme, “attending appointments and record keeping”, the most prominent tasks reported by caregivers involved recording the illness narrative, maintaining accurate medical information, and assisting in reporting accurate information to health care providers. Several caregivers recorded notes in the manner of a ‘home record’, engaged in note-taking during medical appointments to record new information, clarified historical information, and gently reminded the patient of new or ongoing problems with symptoms:

“...when we have the appointments it's like you know just the, the highlights or you know like whatever of the appointment and if they say you know ah BP's normal, his ejection fraction rate...this is the figure we're going to need. I write these things, so don't always have the paper copy of the report.” (CG 7, line 475).

“So whenever I do call back [to HCP], usually they'll have the same notes as me but if they don't remember and we go for the next appointment they'll say ‘Well how did you feel in the last little while?’...and he would go ‘not bad’ and I'm going ‘ahh...well you know what, you remember...’ and then we can go back [to the home record]...the last few months and say ‘not necessarily’.” (CG 7, line 492).

“I'm his living memory. And its not new. He's forgotten everything...you tend not to want to go in to see a doctor unless I'm there because they'll ask something like “when did you have your heart attack?” and its just, and I'll go “December 1997”, he just doesn't remember the dates, even if he writes them down.” (CG 11, line 116).

“I, like being in the room, and hearing what they have to say, and if I feel he's not ah, saying something, I sort of bring it up... and then he'll continue telling them...I have my list ah, my notes and I think they expect me to be there (chuckle).” (CG 12, line 174).

“I often do [report symptoms to the HCP] because I don't feel that he's forthright, with his symptoms... I just sometimes think that he doesn't think that they're important enough to tell them.” (CG 13, line 706).

Caregivers seemed quite confident that their role as a record keeper was appreciated by the patient even if at times it appeared to be undervalued by the patient. One caregiver reported that the patient eventually engaged in record-keeping activities:

“the blue book that we keep you know, we've kept for like the last six years...at one point I think it way bothering him that I was writing, it's like, ‘well go write in your book’. But now a lot of times we'll come back from appointments and if I go right back to work...I've come back before and I've looked and he's made notes in the book, so he realizes you know, how important it is.” (CG 7, line 445).

The second sub-theme, “blocking activities” encompassed self-reported caregiver behaviour which curbed patient activities that were considered unsafe related to the patient's HF symptoms. Several caregivers described gentle suggestions that they offered to the patient to keep him or her safe or avert symptom distress or occurrence:

“I tend to say it like “maybe we should have a bit of a break” or “time for a rest” or whatever” (CG 10, line 97).

“I'll suggest things that you know, ‘you could lay down’ or ‘go watch TV while I do my housework’ or something, but I always double check on him” (CG 12, line 106).

Some caregiver suggestions were more firm as the stakes became higher in relation to safety for patient and others:

“I looked at him and I says “but you're not driving are you”. He looked at me and I says “You know you cannot drive, you'd not be safe” So things like that, I will be pretty direct. But other things I'll just, let it go.” (CG 8, line 207).

The third sub-theme, “reassurance and a helping hand” included verbal supports offered by the caregiver that were aimed at bolstering the patient's confidence in their abilities and wellbeing: a ‘helping hand’ referred to caregivers who offered direct physical assistance to the patient in his or her management of HF symptoms.

One caregiver described his spouse awakening in the night that was a common occurrence for this HF patient:

“she wakes up very excited sometimes – she doesn’t know where she is... She just wants assurance, you just say “(patient)” and she’s awake” (CG 4, line 53).

Another caregiver felt they offered the reassurance of another person’s understanding:

“I think he is, needs that guidance or whatever, like, I’m certain it’s not easy to go through what they go through, anybody with his condition. But, ah, so I think it’s easier for anybody that’s faced with it. To have the next person understand what’s going on or if that was me, type of thing. Makes them feel better, and it makes you feel like ah, okay” (CG 10, line 202).

One caregiver described that remaining calm and in control can be a form of reassurance for the patient:

“if I show any signs of panic at all, it just gets him more upset. He sometimes says I’m cold but he’ll listen to my instructions and as he sees my instructions are making him feel better, he calms down quicker” (CG 11, line 81).

A sympathetic ear may be all that is required according to another caregiver:

“[I] will offer suggestions to you know, try and alleviate it [feet feeling cold], but, nothing usually helps, I think sometimes he just likes to complain, and so, that’s what he wants to do, then, that’s okay, I don’t mind listening.” (CG 5, line 39).

Another caregiver described that his or her offer of physical assistance must be willingly accepted by the patient. This caregiver also described that physical assistance can be offered subtly to the patient’s in his or her daily existence with symptoms:

“When, when I see her dizzy, turning round...trying to manipulate it and she knows that she can’t do, and you just put out your hand and it’s just given to ya, there’s no words spoken, and we just ah, a hand to hand thing, yeah, and she’s good at that though, she accepts it.” (CG 4, line 154).

“[I]try to trick her into things, but she knows, but she goes along with it. Yeah, she’s easy to get along with, very easy to get along with.” (CG 4, line 172).

Other caregivers talked about routines, such as meal preparation, that were a part of symptom alleviation and maintenance care:

“we were talking about food before and, and, things have changed a lot for him, they’ve changed for both of us in so far as what we do for um eating and drinking and you know, life is not the same. And I’m sure he does find that really hard and

one way that I try to help out there is that I try to prepare meals for him so he doesn't have to try and figure out what to do for himself." (CG 5, line 56).

One caregiver described that direct care can be very specific and related to medication routines and reminders:

"I am the one who prepares all his medication, and I take them out and I put them on the table and I have the insulin, I have everything so that it's a reminder for him and I do ask him, 'Did you take your pills?' ...I do remind him, every day." (CG 13, line 456).

Caregiver theme 3 – Consequence of knowing. "Consequence of knowing" included caregivers' descriptions of any impact on the patient or the caregiver as a result of the caregivers' attempts to perceive the patient's symptom experiences. The negative 'consequence of knowing' can drain the caregiver of personal resources and impact their ability to engage in effective symptom assessment.

Caregiver efforts that were required to perceive and understand the symptom experience of another individual impacted them in various ways. One burden most commonly cited by caregivers was their lack of sleep related to symptom monitoring. One caregiver described:

"I spent very sleepless nights when he was sitting at the kitchen table. Not being able to breathe" (CG 10, line 256).

For this caregiver and other caregivers, their loss of sleep related to symptom monitoring continued to occur throughout the trajectory of dealing with HF symptoms:

"I still get up during the night and say 'Ah, where are you?', 'Where are you sleeping?' you know 'How are you doing?' " (CG 8, line 135)

"He's always concerned that he's keeping you awake" (CG 10, line 312).

"...even when we're sleeping, if I hear something I right away wake up and, question it and if he gets out of bed and if it's too long or I could hear, something, I always question what he's up too." (CG 12, line 109).

One caregiver described that the patient who was concerned with his symptoms, would deliberately awaken her during the night:

“He would stand beside the bed and yell at me because I was asleep. I can’t stay awake 24 hours a day so I told him, you know, either you cut me some slack and I had to sleep here or you tell me what time of day I can sleep. So now he doesn’t yell. He will, if he’s in a lot of trouble, he will just tap me so. I then don’t wake up crazy.” (CG 11, line 33).

The caregiver’s need to assess symptoms and to be at-the-ready’ to assist the patient was, at times a continuous responsibility throughout the day:

“if she gets half way through a turtle neck I gotta come, (chuckle) so its twenty-four hours” (CG 4, line 162).

Leaving the patient on their own was reported as difficult for both the patient and the caregiver according to a number of caregivers:

“Leaving him alone would really bother me, and make sure somebody was around.” (CG 8, line 137).

“the hardest part is he’s frightened to be left alone. But he’s not physically capable sometimes of coming shopping with me. You know, so we need food, somebody’s got to buy food.” (CG 11, line 127).

At times this left the caregiver feeling isolated and overburdened. One caregiver described:

“on occasion I feel like I’m a prisoner. He’s not doing it maliciously or probably not even realizing it. But I do feel overwhelmed on occasion, and I have no siblings or parents left and he has no siblings here or parents so it’s just the two of us for the most part.” (CG 11, line 135).

Some caregivers described losing themselves in the ongoing process of symptom monitoring and management that meant being unable to meet their own self-care needs:

“I try to do more and then I'm thinking well what else I can do and then I forget about me.”(CG 12, line 189).

“...even going for a walk you know, it's, it's not a health walk, cause he can't keep up, so it's just, even just the little things.” (CG 13, line 333).

Role confusion for one nurse caregiver led to feelings of frustration:

“I don't want to be a nurse, I want to be a wife but I'm part nurse, part wife.” (CG 13, line 476).

Caregiver theme 4 - Partnership in HF. ‘Partnership in HF’ included caregiver thoughts and feelings about the impact of symptom assessment, management, and long term prognosis on their day-to-day partnership in care with the patient, and one’s outlook on their shared future. This theme was more prevalent in this study’s sub-sample of spousal caregivers.

In the first subtheme, “Acceptance: we’re in this together”, caregivers described their feelings of acceptance toward the patient’s change in functionality and their thoughts on the patient’s acceptance of their new circumstances. Caregivers described accepting the patient’s ever-changing activity tolerance:

“I’ll ask him if he feels like doing something or, not, or, if he doesn’t feel like it, that’s okay, we don’t have to go and do it. I don’t want him doing stuff just because I would like to” (CG 5, line 99).

“...if we’re out with the kids and it’s too much then it’s just time to call it quits. (pause) Not a big deal.” (CG 15, line 60).

A number of caregivers described that when they accurately perceived or understood the patient’s symptoms, they had greater potential to assist the patient in accepting his or her new circumstances:

“Then when they clear that [rule out additional lung problems] and they say that this is it... I think we need to sit down and say okay, your lungs are done, and you’re fine. It’s you congestive heart failure.” (CG 8, line 264).

“I don’t know if he’ll be able to do what he thinks he can do [return to work] you know...he doesn’t rest, ah he might have a nap or sit watching the news and fall asleep for 20 minutes, half-hour or whatever, but he doesn’t go lay down, type of

thing, unless he's not feeling well. But it's different when you're in the workplace and the stress..." (CG 10, line 406).

"I just, let him know...things have to change, whether it was now or ten years from now. It's, we have to deal with it now and you have to rest. You have to...plan your day." (CG 12, line 77).

One caregiver continued to struggle with acceptance leading to frustration and anger:

"I'm angry cause it happened, and I haven't accepted it...It's hard you know to, to see the person that he was, not, he's not the same person, and it's, it's, it's, it's hard." (CG 13, line 23).

In the second sub-theme, "acceptance: loss and uncertainty", when caregivers described their acceptance of new circumstances, particularly a reduction in the patient's functional ability due to symptoms and overall longevity this resulted in a sense of loss and uncertainty in caregivers. Caregivers described that their acceptance of loss and uncertainty reduced their perception of available resources for patients and caregivers (particularly spouses). Other caregivers described that unexpected retirements by patients contributed to the patient's and caregiver's financial strain and the patient's changing sense of purpose:

"...you have to retire anyways in your life...and because his job is very demanding and pressure of ah, heavy equipment and lifting and...I said you sort, just have to plan something different...you know, to pass your day away." (CG 12, line 85).

"He would love to stay working. He, he loved his work, but I guess it's frustrating for him I know because he can't work, and you know, being the major bread winner" (CG 13, line 953).

"he gets frustrated ah, you know about his job...extremes, you know from being very hard and working and on the go and active to have to stop, and sometimes it's not because he's doing it, it's his body..." (CG12, line 35).

Other caregivers described that delaying their own retirement strained their daily schedule and lead to feelings of guilt in the patient:

"I really want to retire (chuckle)...and I think that makes him feel bad too" (CG 13, line 945).

The loss of future promise and time together placed an emotional strain on caregivers:

“So...how long do we have of a window? Do we know? No.” (CG 8, line 293).

“..you know you get scared because you know well okay like I, I don't know how long his life expectancy will be and hey, it's just a fear of, fear of being alone, fear of not having you partner with you for, long time and then you know...you have a certain expectation of what your life would have been.” (CG 13, line 97).

“...you know, like it's just not being able to, you know to fully ah, enjoy you know ah, just the day to day things of life, like running around with your grandchildren.” (CG 13, line 404).

Caregiver theme 5 – Barriers and facilitators to understanding. Caregivers identified barriers and facilitators that influenced their ability to perceive or understand the patient’s symptom experiences, including their capacity or motivation to imagine experiences they have not had, intimate knowledge of the patient, and the patient’s willingness to be known.

“Capacity or motivation to imagine”, the first sub-theme, captured how some caregivers found it difficult at times to harness the imagine-other perspective of the patient:

“Well that was hard for me to separate it, you know...I mean it's hard to put yourself in somebody else’s shoes.” (CG 13, line 22).

“I can’t understand that, I don’t know how that feels” (CG 5, line 39).

“...you can’t imagine what it’s like if you can’t breathe” (CG 24, line 24).

One spousal caregiver indicated that she found trying to imagine the patient’s perspective on his symptom experiences to be a negative experience:

“...you know he complains about something and I try to listen to it, I can’t say that I’ve tried to feel what he’s feeling, cause who wants to?” (CG 5, line 24).

In the second subtheme, “Willingness to be known”, one spousal caregiver noted that her husband was uncooperative in her attempts to understand his symptoms in a discussion:

“something I’ll ask him ‘what’s wrong’ or something, he tells me, then I kinda try to understand it. But usually he tells me it’s nothing” (CG 15, line 23).

Another spousal caregiver felt her husband seemed hesitant to share a symptom concern to avoid worrying her:

“sometimes he might not because then I...get too upset about it but usually he's pretty good in saying” (CG 12, line 124).

Caregiver theme 6 – Levelling out. Levelling out described the patient's and the caregiver's natural trajectory in developing a shared understanding of the patient's symptom experiences. This theme included any patient or caregiver behaviour (identified by the caregiver) aimed at a shared understanding of patient symptoms which evolved since the time of diagnosis.

The first subtheme “Giving back control” captured how, after many months of symptom assessment and symptom management, caregivers begin to give back some of the control over care that they assumed during the patient's more acute illness. When describing her husband's increased activity, one caregiver proudly stated:

“And his medication – back in his hands.” (CG 8, line 50).

Other caregivers described that patients would take more personal responsibility for their own behaviours:

“I know when he's overdone it, or whatever, but he's supposed to know that too (laugh), he's supposed to back-off.” (CG 10, line 88).

A daughter caregiver described that her mother exhibited greater control over her health as her physical condition improved:

“Very alert and very in control. And still very bossy (laugh)” (CG 3, line 105).

In the second sub-theme, “Getting comfortable/learning to trust” captured how the patient and the caregiver grew more comfortable with symptom monitoring over time. One caregiver described a more relaxed approach to symptom monitoring:

“I always slept with one eye open, and for the previous five months, so, I’m far more relaxed with him, um, I encourage him to tell me if there’s some kind of problem” (CG 5, line 89).

“He’s very comfortable with the whole situation now so, and basically I am too.” (CG 10, line 87).

“it’s just everyday life now. But he seems to be a lot better than he was at first (laugh)” (CG 15, line 70).

“just kind of a learning thing, to um, been there, done that.” (CG 10, line 225).

Other caregivers shared examples of how the rules for certain types of behavior by patients and caregivers became more relaxed and normal activity resumed:

“I’m realizing the shift has to start changing now because there’s some improvement so there’s certain things that I’ll say ‘well you can empty the dishwasher’ when before I would just do, or I’d say ‘can you check this out for me?’, ‘can you call and do this?’ (CG 8, line 42).

“I’m always watching...it’s a habit and I’m trying to slowly, break away from over, I guess it’s like a mother with a child-like, letting them be able to do something, that he’s okay, and he, he’ll tell me if he’s not.” (CG 12, line 128).

Summary of the caregiver experience. As caregivers described their thoughts and feelings about their employment of the patient-oriented perspective-taking technique, they shared some subtle behavioural changes that included their: increased listening to the patient’s viewpoint on symptom experiences, increased attentiveness to the patient’s emotional state, enhanced communication with the patient about his or her symptom experiences, and heightened motivation to understand the patient’s viewpoint of his or her symptom experiences. The themes and sub-themes exhibited how caregivers’ strategies were similar to the patients’ strategies for symptom monitoring and management. Several caregivers described a natural inclination in the pre-test condition to employ perspective-taking. On the other hand, they also acknowledged that the intervention might have enhanced their continuous use of perspective taking to better comprehend the patient’s viewpoint on his or her symptom experiences. Although caregivers

described their experiences as being in a partnership with patients, they also felt at the same time some negative consequences as a result of having shared in symptom assessment and management activities with the patient. Caregivers openly discussed their awareness of barriers and facilitators in their understanding of patients' symptom experiences which included their capacity to imagine the patient's perspective and their awareness of the patient's willingness to be known. Finally, caregivers described a transition over time when they grew more comfortable with shared-care, developed an acceptable comfort level with the patient's new circumstances, and began to relinquish control and responsibility that they embraced during the acute phase of the HF diagnosis and stabilization.

Summary of research question 3. The investigator's analysis of perceptions of twelve patients with HF and their family caregivers in response to the patient-oriented perspective-taking intervention to enhance their assessment and management of the patient's symptoms resulted in six major themes for patients and caregivers. Of note, patient and caregiver participants tended to focus on the same or similar themes from their unique perspective on 'caregiver strategies for symptom monitoring', 'caregiver strategies for symptom management', 'consequences of being known/knowing', 'barriers and facilitators to understanding', and 'leveling out'. In addition, the patient interviews captured the unique theme of "patient strategies for adaptation to HF symptoms" while the caregiver interviews revealed the exclusive caregiver theme of "partnership in HF".

Summary of Results

The investigator's quantitative analysis of research question 1 revealed that the imagine-patient perspective-taking intervention resulted in statistically significant improvements in perceptual agreement between the patient and caregiver (using the HFSS) for two of 14 HF

symptoms on the dimension of frequency (full or bloated feeling in abdomen, chest pressure or heaviness in chest), three of 14 HF symptoms on the dimension of severity (Shortness of breath at rest, shortness of breath lying down, depressed or feeling down), two of 14 HF symptoms on the degree of interference with physical activity (full or bloated feeling in abdomen, depressed or feeling down), and two of 14 HF symptoms on the degree of interference with enjoyment of life (shortness of breath at rest, depressed or feeling down). In addition, the data showed an overall statistically significant increase in patient-caregiver perceptual agreement on the subscale totals for: frequency, severity, and interference with physical activity.

The investigator's quantitative analysis of research question 2 revealed that no significant increases in caregiver empathic responding as rated by both the patient and the caregiver. Of note, there were strong tendencies by patients and caregivers to provide pre-intervention ratings of '3' to '4' on a scale of 0 to 4 (ERS) that left limited opportunity for post-intervention improvement in ERS ratings.

The rich textual data obtained by the investigator from patient and caregiver semi-structured interviews on participants' perceptions of the caregiver's use of the patient-centred perspective-taking technique resulted in five common major themes between the patient and caregiver participant groups: 'caregiver strategies for symptom monitoring', 'caregiver strategies for symptom management', 'consequences of being known or knowing', 'barriers and facilitators to understanding', and 'leveling out'. In addition, the patients discussed 'patient strategies for adaptation to HF symptoms' while the caregivers discussed 'partnership in HF'.

Chapter Five – Discussion

Introduction

The main purpose of this pilot study was to examine the impact of a perspective-taking instructional prompt as a means to enhance family caregiver's ability to assess the symptom experience of patients with heart failure (HF). The study design was guided by Davis' (1996) organizational model of empathy and included quantitative and qualitative components. The feasibility of implementing the study design within the HF population was examined in addition to the reliability of all study instruments.

In this thesis chapter, the main findings of this study are interpreted and discussed in relation to recent literature, implications offered for practice and research, and conclusions are drawn as to the strength and contribution of this study's findings to caregiving literature in the context of HF. The results of this study's quantitative data demonstrated improvements in post-intervention caregiver-patient perceptual agreement for some HF symptoms. However, analysis was not able to demonstrate a significant increase in post-intervention levels of caregiver empathic responding according to the patient's or the caregiver's perceptual responses. The latter findings are discussed by the investigator in relation to this study's design and instrument delivery protocol. The qualitative portion of the study elicited six similar themes for patients and caregivers. Patient and caregiver participants were able to not only articulate their thoughts and feelings regarding the study intervention, but also shed light on some of the challenges, costs, barriers and facilitators that they encountered in daily symptom assessment and symptom management.

As part of the investigator's discussion of major findings are a discussion of study limitations, examination of participant recruitment, sample demographics, instrument delivery and reliability, and relevant findings for each research question in relation to existing literature.

Finally, clinical implications, suggestions for future research, and dissemination of results will be addressed.

Limitations

Although recruitment of patients and caregivers was approved at five sites within Winnipeg, all potential participants who were referred to the investigator and subsequently recruited into the study were from the St. Boniface General Hospital (SBGH) HF Clinic. An initial 6-month delay in obtaining access to SBGH site lead to the investigator's pursuit of access at Grace Hospital (GH) Adult Medical Clinic and an acute medical unit where recruitment procedures were established. Coincidentally, GH access approval was obtained just as approval to access SBGH became available. Overall, the investigator focused on recruiting eligible patients and caregivers at the SBGH HF Clinic that served a large population of patients who lived in Winnipeg and who come from diverse backgrounds.

During the time of recruitment in this study, the HF Clinic was also playing host to three other clinical studies targeting a similar population. The investigator was advised that an additional study was scheduled within two months' time at which point the focus of this clinic's recruitment efforts would shift away from the investigator's study. Therefore, the two month timeline for recruitment contributed to the small sample size of 14 dyads (14 dyads completed all quantitative study instruments) versus the recommended sample size of 20 dyads by the statistician (Mr. Brenden Dufault, Manitoba Centre for Nursing and Health Research, University of Manitoba) for a test of differences in the data. This small sample size diminished the statistical power of this study's data analyses to support convincing study findings.

As all participants were invited by clinicians during a two month period of clinic visits at SBGH HF Clinic, the potential pool of HF patients was limited to patients who had appointments

during the months of February and March in 2013. In addition, clinicians independently determined which patient-caregiver dyads to nominate for the study introducing further selection bias to this study. Of the 15 dyads that consented to participate in the study, only one dyad left the study due to the death of the patient shortly after the first visit. Six additional patients expressed an interest in the study but declined further contact with the investigator due to a lack of interest or inconvenience in participating in this study.

As each invited patient-caregiver dyad volunteered to participate or not participate in the study, the potential exists for this study's sample to possess unique characteristics (e.g., motivation to enhance perceptual understanding) that do not exist in the general population of HF patients and family caregivers. Clinic staff who engaged in recruitment cited their heavy work demand as the major reason for not recording data on eligible participants who were invited to participate in the study. The lack of acute record-keeping made it impossible to identify characteristics of eligible individuals who decided to participate or not participant in this study. Staff who assisted with the recruitment of eligible participants indicated that they limited their invitations to those patients who had a caregiver known to the staff and who the staff felt were most 'likely' to participate. It is plausible that this biased behavior of clinic staff excluded the participation of eligible patients who have caregivers who do not attend HF clinics with the patient, but who would have otherwise met the study inclusion and exclusion criteria. The investigator also speculates that patient-caregiver dyads that attended the HF clinic may have included a caregiver who is more informed and /or more engaged in symptom assessment and management in comparison to dyads where caregivers do not attend medical appointments with the patient. A high level of caregiver involvement in symptom assessment in the current study may have left caregivers with limited room for improved perceptual understanding or increased

empathic response. Selection of high functioning, cooperative, and engaged dyad members who were primarily in spousal relationships may have reduced the power of the investigator to detect a statistically significant pre-/post-test change in discrepancy scores for HF symptoms. To further scrutinize the potential for bias in this study's sample, patient and caregiver demographics were examined in the following section.

Ceiling effect and testing effects may have contributed to the limited significant results in this study (e.g., high ERS ratings for caregivers in the pre-test condition failed to see a significant increase in empathic responses by caregivers in the post-test condition). This is discussed in detail under 'Research Question 2' in this chapter.

Representativeness of the Study Sample

Of the 14 dyads, 12 (86%) consisted of married couples who resided together. This high proportion of co-residing spousal caregivers may not be representative of the general target population and may over-represent caregivers with greater intimate knowledge of the patient than caregivers who live apart from the patient. The study sample appeared to under-represent non-spousal caregivers. Therefore, it is plausible that non-spousal caregivers are in greater need of strategies to improve perceptual accuracy in symptom assessment and comparatively (with spousal caregivers) may benefit even more from interventions such as the empathic perspective-taking prompt.

All patients and caregivers self-identified their ethnic heritage as either Canadian or of European descent. First Nations, South American, Asian and African cultures were not represented in this study's sample thus limiting generalization to these Canadian sub-populations of patients with HF and their caregivers.

Patient demographics. The range for patient age in the current study was between 38 and 86 years with a mean age of 69 (SD, 12.9) years. Patients aged 76 ± 8 years of age ($n = 11$) were recruited by Quinn et al (2011) in their study of HF symptom assessment congruence between patients with HF and their family caregivers. In an earlier study, when asking if caregivers can serve as proxy for patients with HF, Quinn, Dunbar and Higgins' (2010) recruited 70 patients with HF who had a mean age of 71 (SD, 9.6) years. According to Arnold et al. (2012) the average age of first referral for patients to 27 HF clinics across Canada in 2010 was 66.2 ± 14.2 years suggesting that the current study's sample population was within the typical age for Canadian patients with HF.

Total household income for 43% of patient's was above \$80,000; 48% of Canadian "couple families" in the 2006 Canadian census reported a similar household income. Given that 86% of study patients lived with a spouse, the sample is relatively representative of couple families. Due to this study's small sample, there is insufficient data to evaluate the representativeness of the study patients living alone ($n=2$). Twenty-one percent of the study population had a household income below \$40,000, however it is not known if any of these patients fell below the poverty level. Based on the investigator's home visits to participants, all patient participants lived in comfortable, safe home environments. This study's convenience sample did not include patients in severely depressed socioeconomic areas of the city.

Caregiver demographics. The range for caregiver age in the current study was between 31 and 89 years with a mean age of 65 (SD, 13.6) years indicating that caregivers were younger than patients. Again, this was consistent with Quinn et al. (2011) who reported that caregivers in their study sample were younger than patients (i.e., caregiver's mean age was 55 ± 15 years while the patients' mean age 76 ± 8 years). Quinn, Dunbar and Higgins' (2010) also reported

younger caregivers in their study sample who had a mean age 57 (SD 15) years (the patients' mean age, 71 (SD, 9.6) years). Eight-six per cent (12 of 14) of the caregivers were married or living in a common-law relationship with the patients. This study's sample of cohabitating patients and family caregivers was notable in comparison to Quinn et al.'s (2011) study where caregiving dyads reported a spousal rate of nine percent. In contrast, Quinn, Dunbar and Higgins' (2010) in their study examining patient/caregiver congruence on symptom assessment, reported a spousal dyad rate of 43% (30 of 70 dyads).

In the current study 86% (12 of 14) of the caregivers were female (including both non-spousal and spousal caregivers) that suggests the reader should exercise caution in generalizing this study's findings to male caregivers - particularly those caregivers who are not in spousal relationships with patients.

Seventy-nine percent (11 of 14) of caregivers had attained either a high school or higher level of education, and all were able to speak and read English indicating a study sample who could comprehend patient care information well. Forty-three percent (6 of 14) of caregivers attended some formal HF teaching sessions. Caregivers reported significant contact with health care professionals within the year prior to the study that included cardiologists, family doctors, nurses, dieticians, and pharmacists.

The majority of caregivers had daily contact with the patient (93% ; 13 of 14), almost always assisted the patient with HF management (71%; 10 of 14), shared thoughts or feelings about HF with the patient (64% ; 9 of 14) and both the patient and caregiver reported that the caregiver knew the patient's thoughts and feelings about their symptoms at least somewhat well (of note, patients rated the caregivers higher than the caregivers rated themselves on this item). Overall, this study's sample of caregivers were knowledgeable and well engaged with the patient

in symptom assessment and management which likely contributed toward little change in caregivers' and patients' discrepancy scores of patients' symptom experiences in the post-test condition.

Reliability of Instruments and Fidelity to Intervention Delivery

The current study was strengthened by the investigator who was the sole individual who delivered and explained the study's instruments to participants in the pre- and post-test conditions, thus enhancing the internal validity (or procedural fidelity) of the study. Procedural fidelity was also maintained when the investigator was the sole individual who instructed caregivers on the imagine-other empathic intervention where she followed a script to deliver the instructions with consistency and complete explanation to family caregivers. Dr. Quinn, the investigator's external advisor also provided training to the investigator in administering the imagine-other empathic intervention according to the instructional script. Instrument reliability was supported by the investigator's choice of a reliable, known HF symptom tool (HFSS) that was followed-up by testing in this study's sample with the Cronbach's alpha reliability coefficient. The alpha coefficients for the HF with patients and caregivers indicated high internal consistency of use with this sample of patients and caregivers (i.e., $\alpha = .83$ to $.95$). Excellent internal consistency reliability estimates were also obtained on the Empathic Responding Scale (ERS) ($\alpha = .86$ to $.91$) when used with patients and caregivers in this study sample. The investigator took care to review returned questionnaires to ensure that there were no missing data and/or to obtain immediate clarification of any incomplete or illegible responses from patients and caregivers during the investigator's home visit to participants.

Although the ERS demonstrated excellent internal consistency, there was a notable ceiling effect displayed in responses by patients and caregivers: high responses ('4' out of '4'

units) on many ERS items in the pre-test condition that left little improvement in discrepancy scores in the post-test condition. To minimize a reactive effect, the investigator had reassured both patients and caregivers that their responses would not be shared with their caregiving partner. As well, the investigator placed a divider between the patient and the caregiver during instrument completion in a quiet area in the clinic setting? However, it remains plausible that patients and caregivers provided socially desirable responses in relation to presenting the caregiver in a positive light that lead to their high ERS ratings in the pre- and post-test conditions. This will be further discussed under Research Question 2.

It is also important to consider that completing the HFSS in the pre-test condition sensitized the caregiver to be more observant of subtle symptoms which resulted in a more accurate assessment (in relation to the patient's responses) in the post-test condition. Similarly, patients may have also been influenced by the pre-test HFSS scale (e.g., enhanced patients' awareness of the linkage of certain symptoms such as depression and abdominal bloating to their HF) thus enhancing their self-assessment during the intervention interval where they shared or discussed symptoms with their caregivers. Overall it is plausible that both the patient and the caregiver were subject to the testing effect of having completed the pre-test HFSS tool (i.e., by completing the pre-test HFSS measure prompted them to communicate more openly about certain symptoms that lead to less discrepancy in their respective HFSS ratings in the post-test condition).

Research Question 1

In regard to Research Question 1, 'Is there improved perceptual agreement between the family caregiver and the heart failure patient after family caregivers are instructed to actively engage in patient-oriented perspective-taking in the context of assessing the patient's

symptoms?', the study data demonstrated improved perceptual agreement for seven of the 14 HFSS symptoms along at least one of the four dimensions (frequency, severity, interference with physical activity, and interference with enjoyment of life; see Appendix M):

1. Shortness of breath at rest
2. Shortness of breath with activity
3. Shortness of breath when lying down
4. Full or bloated feeling in your abdomen
5. Chest pressure or heaviness in your chest
6. Worsening cough
7. Depressed or feeling down

Quinn et al (2011) employed a similar study design testing the same imagine-patient perspective-taking intervention over a two week study interval (originally developed by Lobchuk et al, 2007 a). Instead of measuring patient/caregiver discrepancy scores as in the current study, Quinn et al. (2001) employed correlational analysis and reported improved perceptual agreement between the patient and caregiver in the post-test condition for six of 14 HFSS symptoms:

1. Shortness of breath when lying down
2. Shortness of breath when you wake-up at night
3. Chest pressure or heaviness in your chest
4. Irregular heart beat or fluttering feeling in your chest
5. Difficulty sleeping
6. Forgetfulness or difficulty sleeping

Despite utilizing different measures (i.e., discrepancy scores and correlational analysis), the investigator's finding supported Quinn et al.'s (2011) conclusion that the imagine-patient

perspective taking intervention had a measurable and significant impact on improving perceptual agreement between the patient and caregiver in the context of assessing several HF symptoms in the community setting: in particular on the same symptoms of ‘shortness of breath when lying down’, and ‘chest pressure or heaviness in your chest’.

When Quinn et al.’s (2011) study sample characteristics were compared to this study’s sample characteristics, the investigator noted that Quinn et al.’s sample consisted of a larger proportion of female patients (82% or 9 of 11 patients, compared to 29% or 4 of 14 patients in the current study). Quinn et al.’s study sample also included patient and caregiver participants of African American heritage (45% or 5 of 11 caregivers) compared to no participants of African American heritage in the current study. As well, Quinn et al.’s study sample consisted of less spousal dyads (9% or 1 of 11 spousal dyads) compared to dyads who participated in the current study (86% or 12 of 14 spousal dyads). Regardless of the differences in socio-demographic characteristics between the two studies, this investigator’s study findings corroborated the impact of an imagine-patient perspective-taking intervention as found by Quinn et al. (2011). In other words, the imagine-patient perspective-taking intervention appeared to have a robust impact on improving patient-caregiver perceptual agreement on certain HF symptoms (i.e., shortness of breath when lying down, and chest pressure or heaviness in your chest) across diverse patient and caregiver populations dealing with HF.

More specific, the current study findings demonstrated a statistically significant improvement in perceptual agreement on symptom subscale totals for frequency ($p = .018$), severity ($p = .007$), and interference with physical activity ($p = .005$). These findings lend support for the positive impact that the imagine-patient caregiver perspective can have on enhancing overall patient-caregiver perceptual agreement on symptom dimensions (frequency,

severity, and interference with physical activity) across HFSS symptoms. This conclusion lends support to Lobchuk et al (2007 a). To clarify, while comparing the impact of multiple proxy perspectives in reducing the inter-rater gap among patients with cancer and their caregivers assessing symptom frequency and severity, Lobchuk et al (2007a) reported that when caregivers engaged in the imagine-patient perspective-taking stance this resulted in lower patient-caregiver mean discrepancy scores in comparison to the imagine-self perspective-taking stance for significant results related to symptoms of pain, weight loss, change in taste, worrying, and lack of appetite. Much like the current study, Lobchuk et al. (2007a) also examined the symptom dimension of ‘severity’ and found significantly lower mean discrepancy scores in four of six symptoms (i.e., worrying, lack of appetite, weight loss, and change in taste) among cancer patients and their caregivers. The current study also demonstrated significant improvement in perceptual agreement on the symptom ‘severity’ subscale total ($p = .007$) across 14 symptoms and lower mean patient-caregiver discrepancy scores in 13 of 14 symptoms (significantly lower mean discrepancy scores for the symptoms of short of breath with activity, short of breath lying down, and depressed or feeling down). Based on findings from Lobchuk et al.’s (2007a) study and the current study, caregivers seem to benefit the most in attaining decreased perceptual discrepancy on the symptom dimension of ‘severity’ (in comparison to this study’s other three symptom dimensions: frequency, interference with physical activity, and interference with enjoyment in life) when they engaged in imagine-patient perspective-taking stance. The imagine-patient perspective-taking intervention that was developed and employed by Lobchuk et al. (2007a) had served as the foundation for the perspective-taking intervention that was employed in both the investigator’s current study and Quinn et al.’s (2011) empirical work.

In 2010, Quinn, Dunbar, and Higgins examined 70 dyads (patients with HF and their family caregivers) and found that the highest degree of congruence between HF patients and their primary caregiver occurred on extremity edema, difficulty concentrating, and dizziness. The current study was unable to demonstrate a significant improvement in these symptoms that was likely due to high perceptual congruence between patient and caregiver in the pre-test condition. Further, Quinn, Dunbar, and Higgins (2010) reported that caregivers attained low perceptual agreement with patients on 'feeling depressed', 'SOB waking you up at night', and 'SOB when lying down', with the lowest congruence occurring on 'bloating and worsening cough'. On the other hand, the current study demonstrated the promising impact of the perspective-taking intervention on patient-caregiver agreement for three of four dimensions (severity, interference with physical activity, interference with enjoyment of life) for the symptom 'depressed or feeling down', 'full or bloated feeling in your abdomen', 'worsening cough', and 'shortness of breath when lying down' caregivers demonstrated significant improvement in their perceptual agreement in the post-test condition. These findings suggested that the HFSS symptoms 'depressed or feeling down', 'full or bloated feeling in our stomach', 'worsening cough', and 'shortness of breath when lying down', patients appeared to benefit most from the caregiver's imagine-patient perspective-taking intervention that fostered the caregiver's enhanced understanding of these specific symptoms from the patient's perspective.

Of note, the symptom subscale of interference with enjoyment of life approached statistical significance ($p = .058$). Thirteen of 14 symptoms demonstrated a decrease in mean discrepancy scores on post-test, however, only two symptoms demonstrated a significant decrease in mean discrepancy scores on post-test (i.e., shortness of breath at rest, and depressed or feeling down). When the investigator provided instructions on how to respond to items on the

HFSS, many participants requested clarification on the meaning of ‘interference with enjoyment of life’ and how to apply the Likert-type scale of 0 to 10 (where “0” refers to no interference and “10” refers to a great deal of interference) when providing their responses to the respective sub-scale items. It is possible that this dimension of symptom assessment was more difficult to interpret and led to wider perceptual discrepancies between patient and caregiver raters on this HFSS symptom dimension.

Research Question 2

In regard to Research Question 2, “Do empathic responses of family caregivers toward patients with HF improve after family caregivers are instructed to actively engage in a patient-oriented perspective-taking process, in the context of assessing and managing the patient's symptoms?” the study data did not measure increased empathic responding in the post-test condition using the ERS.

Across all ERS items, there were no statistically significant increases in how patients and family caregivers respectively perceived the empathic responses of family caregivers toward the patient in pre- and post-test conditions. As well, there were no significant differences in patient and caregiver total ERS scores in the pre- and post-test conditions. Furthermore, there was no increase in median or mean caregiver empathic responses as reported by patients and caregivers in the post-test condition. It is very likely that there was a combined ceiling and testing effect that contributed toward these non-significant findings.

As described earlier under “Instrument Delivery and Reliability” in this chapter, there was a notable ceiling effect (i.e., pre-test responses by patients and caregivers that were in the ‘3’ to ‘4’ range of response items on the ERS of 0 to 4 where “0” does not describe the caregiver well and “4” does describe the caregiver well) that resulted in limited opportunity to

find a significant improvement in caregiver ERS ratings in the post-test condition. In comparison, Lobchuk and Bokhari (2008) reported that ovarian cancer patients rated their caregivers' mean total ERS score to be 2.86 (out of 4) on the ERS tool thus indicating a moderate rating of caregiver empathic responding toward ovarian cancer patients. In comparison, the current study found that both patient and caregiver pre- and post-test mean total ERS scores for caregivers were distinctly higher (ranging from 3.39 to 3.50). This inconsistency between studies may be related to differences in sample characteristics such as gender mixes of patients and caregivers, the nature of the caregiving relationship, or the delivery of the ERS instrument. To the best of the investigator's knowledge, there are no previous studies that employed the ERS in a pre- and post-test intervention design study to compare ERS results.

In addition, the investigator was surprised with results that indicated many of the mean ERS item ratings by patients and caregivers had decreased in the post-test condition. It is plausible that, in the pre-test condition, both patients and caregivers had offered an initial emotional or socially desirable response to the question about caregiver empathic behaviours toward the patient. During the post-test interview, most dyads had described themselves as being well engaged, cooperative, and open to jointly sharing in many aspects of HF symptom assessment and management. The majority of patient-caregiver dyads in the current study were in supportive spousal relationships where caregivers had often accompanied patients to medical appointments and assisted patients in their care on a regular basis. These high functioning dyads may have initially felt inclined or conscientious in acknowledging the caregiver's efforts and provided high ERS ratings (i.e., "3" or "4" units) on such items as, "My caregiver tries to understand my concerns" and "My caregiver tries to help me by doing something for me". On the other hand, in having been exposed to ERS items in the pre-test condition (or sensitized to

the meaning of empathic behaviors by caregivers) and during the two-week intervention interval, the patient and caregiver may have appraised caregiver behaviour through a more critical or educated stance that resulted in their lower ERS ratings due to their enhanced understanding of what to anticipate in empathic responses from caregivers.

Research Question 3

The investigator's qualitative analyses of post-test interview transcripts for patients and caregivers addressed the third research question: "What are the perceptions of HF patients and their family caregivers in response to the patient-oriented perspective-taking intervention in the context of assessing and managing the patient's symptoms?"

Six patient and six caregiver themes emerged from the interview data with 13 patients and 13 caregivers. Based on the respective patient and caregiver responses to interview questions, five of the six themes (caregiver strategies for symptom monitoring, caregiver strategies for symptom management, consequences of knowing/being known, barriers and facilitators to understanding, and leveling out) were the same in the patient and caregiver sub-groups. As well, caregivers described 'partnership in HF' and patients described 'patient strategies for adaptation to HF symptoms' as added themes. During the interview process, patients and caregivers not only shared their experiences related to the perspective-taking intervention, but also offered rich personal insights into the nature of joint patient-caregiver symptom assessment and management at home. For the purpose of this thesis topic, the following discussion will focus on themes directly related to participants' experiences or responses to the perspective-taking intervention (research question 3).

Caregiver strategies for symptom monitoring (Patient and Caregiver Theme 1).

Literature describes that HF symptoms primarily exist within the sensory and emotional

experience of the patient (Potter & Perry, 2006) and are not easily identified by observers, such as family caregivers. Notably, however, five of the 12 patients described an observable change in their caregiver's behaviour in the post-test condition. More specific, patients observed an increase in their caregiver's direct observation and symptom discussion that included the caregiver's increased practice of verifying his or her inference of patients' symptom experiences.

The following describes the likely impact of the perspective-taking intervention on patients' awareness of a change in their caregiver's symptom monitoring and assessment behaviour. When caregivers were instructed on how to engage in a patient-sensitive empathic perspective-taking stance, they were also encouraged to dialogue and validate with the patient subtle signs that appeared to reflect the patient's inner symptom experience. The investigator had hypothesized that when the caregiver detected subtle signs about the patient's symptom experiences, this would trigger an increased motivation in the caregiver to discuss symptom occurrence more frequently and to seek validation of his or her 'hunch' regarding the patient's internal symptom experience. In turn, the caregiver's validation of his or her inference with the patient would lead to improved perceptual understanding by the caregiver.

Interestingly, the investigator did not find significant quantitative changes in caregivers' empathic responses toward the patient in the post-intervention condition (i.e., ratings by patients and caregivers remained in the '3' and '4' range of responses on the ERS). On the other hand, qualitative responses from five patients indicated their awareness of an increase in their caregiver's direct observation and discussion of symptoms that included the caregiver's validation of their symptom inferences with them. Of note, these patients tended to be in caring relationships for more than 6 months but less than 5 years suggesting that this sub-group of

caregivers were less experienced in symptom assessment and benefited to some degree from the perspective-taking intervention.

The remaining seven patients and all caregivers indicated that they had already engaged in patient-oriented perspective taking which was corroborated in their quantitative ratings (high ratings of '3' and '4' of 4 units) on the ERS. Regardless, patients and caregivers indicated in their qualitative responses that the perspective-taking intervention may have heightened the caregiver's awareness of patient's symptoms and increased the caregiver's deliberate use of perspective-taking as part of optimizing his or her communication with the patient about symptom experiences. For instance, one caregiver described an "openness" in communication with the patient that "made it easier to deal with some of the symptoms". In related literature, Redmond (1985) found in a sample of university students ($n = 173$) a high correlation between competent communication and empathy (Pearson correlation $r = .98$). It is possible this caregiver's qualitative response of improved or more 'competent' communication with the patient was the result of his or her increased empathic responses toward the patient during the two-week intervention interval.

Although the investigator did not capture the frequency of caregivers' engagement in imagine-patient perspective-taking over the intervention interval, it is plausible that being exposed to the intervention triggered in the caregiver an increased sensitivity to observe and make inferences about subtle signs of the patient's internal symptom experience which, in turn, led to the caregiver's increased motivation to dialogue and validate his or her inferences with the patient. It is important to note that there were no significant changes in caregivers' post-test ERS ratings (by patients and caregivers), as well as mainly no significant changes in their post-test discrepancy scores (i.e., likely due to elevated ratings of "3" or "4" on the ERS in the pre- and

post-test conditions). On the other hand, the investigator detected a non-significant pattern of reduced median discrepancy scores in the post-test condition (as hypothesized) for a number of symptoms and symptom dimensions that were greater than 1 unit of difference (e.g., for frequency, short of breath at rest, short of breath lying down, short of breath waking up at night, full or bloating feeling, fatigue, chest pressure, and depressed/feeling down; on severity: short of breath with activity, short of breath lying down, short of breath waking up at night, bloating, and depressed; interference with physical activity: short of breath at rest, short of breath with activity, short of breath lying down, short of breath waking up at night; and, interference with enjoyment of life: depression. It is possible that a larger study sample would have revealed statistically significant differences in pre- and post-test discrepancy scores for the noted symptoms.

Overall, further research is required to test the impact of the perspective-taking intervention in a larger sample of patients with HF and their caregivers, plus target caregivers who are challenged in their empathic understanding of patients' symptom experiences or caregivers with low ERS ratings. The investigator also recommends that future studies incorporate a method of record or diary-keeping by family caregivers where they describe their perspective-taking activities or 'triggers' in response to patient symptom experiences over the intervention interval.

Caregiver strategies for symptom management (Patient and Caregiver Theme 2).

This study's participants (both patients and family caregivers) described how caregivers attended medical appointments with the patient, provided clear historical information to the patient's physician, provided information regarding current symptom occurrence, and/or prompted the patient to share their experiences with symptom occurrence with their health care providers. This

reporting and record-keeping role was seen as a critical perspective-taking related caregiver activity as reflected in the descriptions of a majority of patients and caregivers. Patients appreciated and valued the caregiver's accuracy or the caregiver's patient-oriented approach that served as the basis of their symptom monitoring and reporting activities even though the patient felt these behaviours were overbearing or intrusive at times. Some patient participants pondered how other patients managed their HF experiences on their own. Although this small sample of caregivers did not seem to be significantly influenced by the perspective-taking intervention (i.e., patient and caregiver ERS ratings remained unchanged at '3' or '4' of 4 units on the ERS in both pre- and post-test conditions), their qualitative responses indicated that their role in symptom management was enhanced by the intervention that prompted them to engage in: more conscious patient-oriented observations, joint discussions, and validations with the patient of their inferences on symptom experiences, as well as experience an increased motivation to engage in patient-oriented perspective-taking to better understand the patient's symptom experiences.

The investigator feels that it is also important to highlight several sub-themes under the theme, 'Caregiver strategies for symptom management' which suggest several interpersonal or helping-behaviour outcomes in ongoing testing of the perspective-taking intervention, as guided by Davis' (1996) organizational model of empathy. For instance, according to Davis's empathy model, when caregivers strive toward a reasonable patient-oriented understanding of HF symptom experiences, needs, goals, or preferences for care (i.e., an intrapersonal outcome in Davis's model) this could lead to observable patient-oriented care behaviors (i.e., interpersonal outcomes in Davis's model) such as blocking behavior by caregivers to avert potentially harmful patient activities or extending a helping hand with daily activities and proactive care that warrant further testing in future intervention studies.

Consequence of knowing/being known (Patient and Caregiver Theme 3). The third shared theme offers a cautionary note about the negative consequences of the perspective-taking intervention as experienced by some patients and caregivers when caregivers attempted to access the patient's inner or subjective experiences with symptoms. For instance, some patients reported feeling frustrated when they were constantly monitored by their caregiver. For some patients, the constant caregiver surveillance lead to the patient concealing his or her symptom experiences from the caregiver that inevitably thwarted the caregiver's efforts in symptom management. A plausible scenario is that, in their frustration and personal distress, some patients exerted their need for self-directed control in decision-making and management of symptoms by concealing one's experiences from the caregiver that, in turn, posed a threat to optimal symptom management.

In his seminal findings on perspective-taking outcomes, Batson (1997) described individuals who engaged in perspective-taking activities as being at some degree of risk for experiencing personal distress in understanding the other person's suffering. The qualitative accounts by caregivers in this study revealed some degree of personal distress as a result of the caregiver's efforts to access the patient's inner or subjective world of symptom experiences. In other words, for caregivers the realization of understanding the nature of the patient's experiences with symptoms was disturbing and seemed dependent on the caregiver's own psychological state or sense of self-efficacy in the caregiver role which were not captured in this study. Davis (1996) also stated that it is possible for negative intrapersonal outcomes to result from the caregiver's perspective-taking behaviour. For instance, when improved interpersonal accuracy or understanding of the patient's suffering is desired, it is possible the caregivers may theoretically endure more negative responses, such as stressful empathic concern, personal

distress, and even anger. In the current study, some patients had linked their caregiver's lack of sleep to 'around-the-clock' symptom monitoring (or "sleeping with one eye open") and potentially the caregiver's excessive empathic concern about the patient at night-time. Both patients and caregivers reported their concern about an emotional burden that is placed on the caregiver due to his or her continual involvement in symptom monitoring. In keeping with the work of Batson (1997), encouraging caregivers to assume a perspective-taking stance may contribute to an increase in the caregiver's personal distress that cannot be ignored as a hazard to the caregiver's well-being. Therefore, the investigator recommends that clinicians assess the caregiver's emotional or psychological state before offering the imagine-patient perspective-taking intervention so as to avert unwarranted distress in caregivers.

Future studies need to identify profiles of patients and caregivers to help clinicians identify appropriate dyads to target in perspective-taking interventions as influenced by caregiving partners' need for control, personality type, psychological or mental state, relationship quality, and willingness or desire for open dialogue surrounding health-related issues and symptoms. However, despite the small number of patients and caregivers who described negative experiences with caregiver perspective-taking, patients overwhelmingly shared their preference for the comfort and reassurance of knowing that another person was continually aware of their condition and on hand to help in daily care despite the accompanying frustration that can arise with constant surveillance by their caregiver.

Patient strategies for adaptation to HF symptoms (Patient Theme 4). This theme provided further evidence for negative consequences or patient backlash that can occur when caregivers engage in perspective-taking behaviors that warrants close attention. In this study, patients simultaneously described not wanting to be defined by their illness (the inner conflict of

‘holding on’ to the person that they were before diagnosis in the face of personal loss and irrevocable change) and yet striving to normalize to their ‘new’ life that required adjustments to their activities of daily living. This theme captured how some patients escaped the watchful eyes of their caregiver, felt resentment towards their caregiver’s close management, and experienced frustration with unaccepting family or friends. Other patients described having progressed toward a peaceful contentment in ‘letting go’ in having learned not to focus too much on the details of their symptoms. In both sets of scenarios, there appeared to be a patient preference for less discussion of the ‘minute’ details of their condition with the assumption that the caregiver could skillfully infer their inner symptom experience as corroborated by patient’s high ratings on their caregiver’s empathic responses toward them in the pre- and post-test conditions. These findings suggested that caregivers need to appreciate a perspective-taking stance that takes into consideration the patient’s preference for degree of open dialogue and surveillance about his or her symptoms.

Partnership in HF (Caregiver Theme 4). Qualitative responses in this thematic finding assisted the investigator in comprehending what appeared to be a ‘natural’ inclination of caregivers, mainly spouses, in this study to engage in empathic responses or perspective-taking behaviors toward the patient (i.e., as reflected in the patient’s and caregiver’s high ERS ratings in the pre-test condition). Caregivers in this study viewed symptom assessment and management as a cooperative or shared process where both members of the caregiving dyad jointly accepted the change in patient lifestyle and the impact on the trajectory of their lives together. Improved perceptual understanding of the patient’s inner emotional struggle with their new way of life was important to caregivers so as to help them to provide safe and effective supportive, patient-oriented care. In particular, the qualitative responses of patients and

caregivers suggested that sensitive patient-oriented perspective-taking by caregivers was particularly beneficial in improving the caregiver's perceptual understanding of the patient's emotional state of feeling 'depressed or feeling down' with significant improvement in estimating severity, interference with physical activity, and interference in enjoyment of life. These qualitative findings were corroborated by reduced discrepancy scores for various symptoms and symptom dimensions (e.g., list them here for the reader).

Barriers and facilitators to understanding (Patient and Caregiver Theme 5).

Interestingly this theme revealed that patients focused more on expressing their appreciation and placing value on the caregiver's actual life experiences when describing their caregiver's ability to assess the patient's symptoms. On the other hand, in this same theme, caregivers tended to focus on their ability to "imagine" what was happening to the patient. This may be a function of having explicitly instructed caregivers to engage in the exercise of "imagining" the patient's perspective during the study interval; patients were not included in the instructional session where caregivers learned how to engage in perspective-taking behaviours over the course of the intervention interval. Of note, however, the investigator found it significant that most caregivers reported that engaging in the imaginative process of attempting to step inside the patient's shoes as difficult, and for one caregiver the perspective-taking activity was particularly unpleasant. Such struggles and negative feelings may have hindered caregivers from fully engaging in patient-oriented perspective-taking thereby diminishing the impact of the intervention on perceptual agreement.

Regardless of caregivers' reported challenges with patient-oriented perspective-taking, the majority of patients felt that their close relationship with their caregivers and their caregivers' intimate knowledge of them played a key role in the caregiver's ability to understand the

patient's inner world of thoughts and emotions. It is possible that these couples have already developed relationships based on an acceptance that engaging in high levels of empathy requires a certain level of mental effort to understand each other's perspectives on experiences, beliefs, values, goals, and decision-making regarding care preferences. This is supported by the high ratings provided on the ERS by both patients and caregivers. Again this high level of empathy among sample dyads may make the sample less typical of the target population. However, it is reasonable to speculate that the impact of the imagine-patient perspective-taking intervention may be greater in caregiving dyads with less highly developed empathic relationships.

Leveling out (Patient and Caregiver Theme 6). In this theme, both patients and caregivers described a gradual transition where the caregiving dyad became less actively focused on regimented symptom assessment and eased into the routine of a 'new' life together as defined by the patient's HF and its limitations on activities of daily living and old routines. It is plausible that as caregivers adjusted to the patient's health state, they were able to grow in appreciation of the patient's need for control and adjustment as influenced by their understanding of the patient's changing beliefs, preferences, and life goals. In their qualitative responses, a number of caregivers described their acts of giving back control and responsibility to the patient for monitoring and control over various activities that the caregiver had assumed during the more acute phase of patient illness (e.g., medication regimes, and division of labour or roles in the household). During the acquiescent stage of the HF trajectory, vigilance on the part of the caregiver may have become more significant in preventing recurrent exacerbations and repeat hospitalizations. However, given that patients described their frustration with being overly monitored, caregivers may benefit from a less obtrusive method of symptom monitoring that is based on their perspective-taking activities to sensitively elicit the patient's preference for

symptom surveillance and management methods. As well, in the acquiescent stage of HF, caregivers could learn the importance of engaging in perspective-taking to help them detect and validate subtle signs or clues of symptoms that are key indicators of deterioration so as to lessen the frustration for the patient that is associated with ‘obtrusive’ monitoring by their care caregiver. A significant factor in the early treatment of HF exacerbations is the patient's hesitation in disturbing or bothering their family caregiver with changes in symptom severity or frequency that often leads to a delay in treatment (Dunbar et al., 2008). This finding suggests that poor or dysfunctional communication between patients and family caregivers is a key risk factor for poor symptom management in HF. Thus, this study focused on a promising technique to enhance empathic communication and understanding by the caregiver on patient symptom experiences to avert unwarranted and costly medical attention or hospitalization when symptoms are not dealt with in a timely, open, and patient-oriented manner. More specific, the findings in the current study indicated that perspective-taking is a promising technique that can improve the caregiver's sensitive, early detection of subtle symptom changes that is followed up with verification and clarification with the patient. Consequently, a sensitive, patient-oriented approach by caregivers in detecting and managing symptoms can lead to appropriate care that averts full blown exacerbation of the patient's condition.

Implications for Clinical Practice

Although it is difficult to change educational and/or clinical practice based on small-scale study findings, , the current study's results lend support for prior research conducted by Lobchuk and Vorauer (2003), Lobchuk et al. (2006), and Lobchuk et al. (2007 a, b) and Quinn et al. (2011) on the impact of a patient-oriented perspective-taking on patient-family caregiver perceptual agreement on patient symptom experiences . In particular, findings Quinn et al.

(2011) also demonstrated improved perceptual agreement on patient symptoms between patients and caregivers who were dealing with HF through the use of a simple, non-invasive perspective-taking instructional set that was similar to the perspective-taking prompt employed by the investigator in the current study.

The current study's findings suggested that teaching caregivers to take the perspective of the patient appeared to enhance patient-caregiver perceptual agreement on specific HF symptoms (e.g., shortness of breath at rest, shortness of breath with activity, shortness of breath when lying down, full or bloated feeling in your abdomen, chest pressure or heaviness in your chest, worsening cough, and depressed or feeling down). In HF management, enhanced caregiver-patient perceptual agreement is highly relevant in helping the caregiver to respond sensitively to the needs of the patient and to make sensitive care decisions jointly with the patient to manage the daily occurrence or exacerbation of symptoms. Furthermore, and perhaps most important, sensitive caregiver perception of the patient's subjective symptom experiences can boost the caregiver's confidence in his or her symptom assessment role where he or she is motivated to initiate a discussion of symptoms and not be solely reliant on the patient to initiate discussions about symptom experiences. Instead, findings from the current and extant studies provided promising evidence for perspective-taking as a valuable skill for caregivers: one that boosts their sensitivity to early perception and accurate, patient-oriented responses to avert unwarranted development of symptoms or symptom exacerbations, as well as costly hospitalizations and medical attention.

This study's participants described that they had engaged in a significant number of contacts with a variety of health care providers (HCPs), including physicians, nurses, physiotherapists, dieticians, and pharmacists. In best practice for the management of HF, it has

been long accepted that family caregivers are a critical source of patient health information – especially the patient’s experiences with symptoms. Given the current study’s findings, when HCPs care for ambulatory patients with HF they need to also carefully consider what perspective or viewpoint family caregivers assume when asked to provide information about the patient’s symptoms (Lobchuk, McClement, Daeninck, Elands, 2007a) and whether the caregiver is reliable in their accurate reporting of the patient’s experiences with symptoms. . The current study’s patient-oriented perspective-taking intervention could be easily incorporated into current clinical education strategies with minimal disruption or additional time by HCPs to improve the quality of caregiver reporting on patient-oriented symptom experiences. An inter-disciplinary approach could involve the many HCPs in contact with the caregiver (e.g., primary care physicians, nurses, physiotherapists, dieticians, pharmacists, etc.) teaching and reinforcing patient-sensitive perspective taking in symptom assessment as a team during multiple points of contact.

Suggestions for Future Research

Future systematic examination of caregiver subgroup differences in response to the perspective-taking intervention could benefit clinicians in their decision to offer the intervention to specific cohorts of caregivers and patients who could garner great benefit than harm from the intervention. For instance, investigators can examine the impact of the perspective-taking intervention on members of caregiving dyads who: live together versus those who live apart; patients in a spousal relationship versus alternate relationships with caregiver individuals (spouses versus siblings); short-versus long-term caregivers; caregivers from diverse ethnic or cultural backgrounds; and, male versus female caregivers. Researchers need to identify susceptible subgroups for poor symptom assessment and empathic responding to maximize the

impact of the perspective-taking intervention on caregiver skill in symptom monitoring and assessment.

The investigator's review of the literature indicated that this is the first time the ERS tool has been employed in a pre- and post-test study. However, given the ceiling effect and testing effect encountered in this study, further testing of the tool's use in a larger pre/post-test design study with a sample of caregivers with low ERS ratings needs to capture the ERS's reliability in detecting a change in caregiver empathic behaviors in response to the perspective-taking intervention. Researchers can consider alternate delivery methods and instruction to enhance the ability of the ERS tool to detect pre-/post-test changes in outcome scores (e.g., completing the ERS in separate rooms, presenting the ERS to participants at the initial visit to foster their familiarity with the response items prior to initial testing, and expanding the Likert-type scale beyond five options to allow for finer discernment in scoring).

Overall, caregivers in this study demonstrated an interest in learning about and applying the intervention in their symptom management role. Of note, most caregivers were in longstanding spousal relationships with patients; most felt that they already practiced patient-oriented perspective-taking to some degree in the pre-test condition. Therefore, to further develop the perspective-taking intervention for applicability across diverse caregiver populations, it will be important to target caregivers and identify profiles of caregivers who are challenged in their empathic responding skills toward the patient. In addition, it will be important for ongoing research to examine whether and how nurses or allied health care professionals would be willing to incorporate a patient-oriented perspective taking intervention into their educational strategies for caregivers of patients with HF.

The current study focused on a one-time instructional session with caregivers to engage in a patient-oriented perspective-taking stance to better comprehend patient's symptoms over a two-week interval at home. It is possible that caregivers could benefit from follow-up reminders or coaching by clinicians about the perspective-taking technique at three-months, six-months or annual intervals. This may include a detailed instructional set, or an abbreviated version of the instructional set (see Appendix L) as a follow-up resource for family caregivers. Future studies may be aimed at measuring caregivers' retention of the perspective-taking intervention, or comparing the retention of the perspective-taking intervention by a caregiver group that received reinforcement of the technique at intervals with caregiver groups that did not receive reinforcement of the technique.

Finally, the benefits of the perspective-taking intervention can be tested in alternate chronic illness populations where caregivers engage in ongoing symptom assessment and monitoring at home within the context of dealing with diabetes, chronic lung conditions, chronic gastrointestinal disorders, rheumatoid disease, and renal failure.

Dissemination of Results

Education on symptom assessment and management for patients with HF and family caregivers is generally accomplished through the efforts of an inter-disciplinary team of health care professionals across health care settings (i.e., acute and community-based care). In the acute care setting, the investigator plans to disseminate this study's findings at 'grand rounds' at the SBGH HF Clinic. This clinic is comprised of an inter-disciplinary team at the largest setting in Winnipeg that provides direct education and care for patients and caregivers dealing with HF.

The investigator also plans to present the results of this thesis project at one of the noon-hour sessions held by the Manitoba Centre for Nursing and Health Research in Winnipeg that is

open to the general public, clinic staff, and academic staff in Winnipeg, and to the public or clinic staff located in rural or remote areas in Manitoba via Manitoba Telehealth video-linkage.

A presentation has also been promised to the current study's sponsor, the Fort Garry Legion Poppy Fund. The audience will be comprised of veterans living in the community, their family members, and associated Fort Garry Legion community organizers.

This study's findings will also be submitted for publication in a peer-reviewed journal, such as *The Canadian Journal of Cardiovascular Nursing*. An abstract of this study's results will be provided to each recruitment site (i.e., SBGH inpatient medical units and the HF Clinic; the Grace Hospital inpatient medical unit and Adult Medical Clinic). In addition, a simplified written report will be mailed to study participants who requested a copy of the final study results.

Summary

Family caregivers play a vital and intricate role in the symptom assessment and management of chronic illness with patients living in the community. In particular, family caregivers' efforts in effective symptom assessment and management are a critical factor in preventing or mitigating exacerbations and frequent costly hospitalizations of patients with HF. This study builds on previous work by Lobchuk et al. (2003, 2006, 2007a,b) and Quinn et al. (2011): their similar hypothesis was that family caregivers would achieve a closer perceptual understanding of the patient's symptom experiences from the patient's viewpoint when they engaged in imagine-patient perspective-taking. This investigator's study findings confirmed that hypothesis or in other words, when caregivers followed a simple, non-invasive instructional prompt to engage in imagine-patient perspective-taking, they were able to significantly improve their approximation of the patient's experiences on specific symptoms (i.e., shortness of breath at rest, shortness of breath with activity, shortness of breath when lying down, full or bloated

feeling in your abdomen, chest pressure or heaviness in your chest, worsening cough , and depressed or feeling down). When examining the current study's findings within the context of related symptom and perspective-taking literature, it is possible that those symptoms caregivers struggle to accurately assess, see the greatest improvement in patient-caregiver perceptual agreement (e.g., psychological symptoms like depression and physical symptoms like shortness of breath when lying down) when caregivers engage in patient-oriented perspective-taking activities. Furthermore, this study's qualitative interviews suggested that dyad members who were in a caregiving relationship for a shorter length of time may experience the greatest benefit in achieving a shared understanding of patient symptoms when caregivers adopt a patient-oriented perspective in patient symptom assessment.

In summary, this investigator's study findings provided evidence in support of a caregiver perspective-taking intervention that has demonstrated a promising effect on helping caregivers to sensitively understand the symptom experiences of patients dealing with HF. This simple, non-invasive technique is worthy of further study, development, and implementation to promote early, patient-oriented attention to patient's HF symptoms by caregivers to avert well-known exacerbations of HF symptoms that impact the welling of patients, family caregivers, and the health care system.

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Appendix A

(University of Manitoba, Faculty of Nursing letterhead)

Invitation to Individuals with Symptomatic Heart Failure and their Family Caregiver

(A study by Christine Scoville RN, Faculty of Nursing, University of Manitoba, Graduate Studies)

Hello,

My name is Christine Scoville. I am a registered nurse and a Graduate Studies Student at the Faculty of Nursing, University of Manitoba, Winnipeg. I am doing thesis research at St. Boniface Hospital about heart failure patients and how their family caregivers help assess their symptoms. I am interested in testing how empathy (or the ability to understand another person's viewpoint) helps family caregivers to understand how symptoms are experienced by the individual with heart failure. This information will help health care professionals to help patients with heart failure and their family caregivers communicate better about heart failure symptoms and more effectively manage the patient's heart failure symptoms. This thesis research is financially supported by the Fort Garry Branch, Royal Canadian Legion Poppy Trust Fund.

You are invited to participate because you are a person with heart failure or the caregiver of a person with heart failure. The information that you and your family caregiver give will be kept strictly confidential. In the event that you cannot provide accurate medical information about your heart failure issues, I will be requesting your permission to verbally obtain this information from your health care provider at the St. Boniface Hospital. If that occurs, your health care provider will become aware that you are a participant in the study. Your participation is voluntary and is expected to not affect the care you receive.

I am recruiting both patient's experiencing heart failure symptoms and their family caregiver into the study. Some of my questions for this study involve interviewing a family caregiver who will be identified by you as an individual who plays a key role in helping you to manage your heart failure symptoms. Therefore, I am seeking your willingness to assist in identifying your family caregiver and providing them with this invitation to speak with me further about the study. If either you or your family caregiver do not want to participate then

neither individual will be recruited into the study. Both you and your family caregiver must be willing to participate in this study.

I would like to talk to you and your family caregiver about this thesis study to further explain the nature of the questions being asked and what would be required of you. It is my intention to conduct two visits to complete questionnaires, provide instruction in a novel approach to symptom assessment, and conduct a face-to-face interview at a place and time of your convenience. At the first visit, you and your family caregiver will be asked to complete a socio-demographic data form, a heart failure symptom assessment form, and an empathy questionnaire. Your family caregiver will receive instruction in an approach to heart failure symptom assessment. I expect that it will take 15 to 20 minutes to complete the questionnaires and 10 minutes for the instruction. Two weeks later, I will visit you a second time. After re-completing the heart failure symptom assessment form and the empathy questionnaire, you will each be interviewed about your response to the new symptom assessment approach. This interview will be audio-recorded and will last approximately 15 to 20 minutes. If over the course of the interview you and/or your family caregiver become fatigued or feel too unwell to continue the interview we can stop the interview at any time. I will invite you and/or your family caregiver to continue the interview at another time or date that is convenient to you.

If you and your family caregiver are interested in participating in the study, please sign the attached reply form that indicates you and your family caregiver are willing to speak with me (Christine Scoville, research nurse) so that I can explain the study to you and your family caregiver. You and your family caregiver's participation are completely voluntary and non-participation does not lead to any penalty to you. A \$10 grocery gift certificate will be offered to each of you to thank you for participating.

PRINT NAME: _____ DATE: _____

Signature: _____

_____ Yes, I agree to speak with Christine Scoville, the research nurse

Home Phone # _____

Other _____

Best time to call:

_____ No, I do not agree to speak with Christine Scoville, the research nurse

PLEASE RETURN THIS PAGE TO YOUR NURSE OR CLERK

Appendix B

Patient Consent Form

(University of Manitoba Letterhead)

Thesis Project Title: A perspective taking intervention to enhance family caregiver symptom assessment and improve symptom management for the heart failure patient

Researcher: Christine Scoville, Graduate Student, University of Manitoba, Faculty of Nursing

Thesis Advisory Committee: Dr. Michelle Lobchuk (chair), University of Manitoba, Faculty of Nursing; Dr. Susan McClement, University of Manitoba, Faculty of Nursing; Dr. Christina Quinn, Gordon College, Barnesville, Georgia.

Sponsor: (disclose any funding if obtained).

What is the nature and purpose of the study?

You are invited to take part in a study regarding symptoms experienced with heart failure and how patients and family caregivers recognize these symptoms. The purpose of the study is to explore ways of assisting heart failure patients and their family caregivers in assessing heart failure symptoms.

What am I being asked to consent to? What is the nature of my participation in the study?

If you and your family caregiver consent to take part in the study this means that you and your family caregiver agree to meet with the researcher on two occasions in your home or your caregiver's home. If either you or your family caregiver do not want to participate in the study, then neither you or your family caregiver will be enrolled in the study. This is a study that involves the participation of both the patient and the family caregiver.

During the first visit you will be asked to complete three questionnaires and answer some general questions. The first questionnaire will ask you general questions about your age and how long you have had heart failure. The second questionnaire will ask about your current heart failure symptoms, and the third questionnaire will be asked about how your family caregiver behaves and acts towards you when trying to understand how you are feeling. These questionnaires will take about 15 minutes to complete.

Following the first questionnaire, you and your family caregiver will be asked to go to separate areas within the home. After you and your family caregiver independently complete the second and third questionnaires, your family caregiver will have a short discussion with the researcher regarding an approach to symptom assessment. After two weeks, there will be a second visit with the researcher. You will be asked to complete two questionnaires (the same as the original

second and third questionnaires) and participate in a short informal audio-recorded interview about your thoughts and feelings regarding symptom assessment during the two weeks. The second visit with you should take about 45 minutes for you to complete the questionnaires and conduct an audio-recorded interview with the researcher. If you require assistance in reading or filling out any of the forms, the researcher will be pleased to assist you. Once the questionnaires are completed, the researcher will be willing to spend additional time with you to answer any questions that you may have about your responses.

If you consent to take part in this study, you are also giving the researcher permission to speak with your healthcare providers at St. Boniface General Hospital for medical information. The medical information that will be sought includes: when and how you were first diagnosed with heart failure, the stage of your heart failure, and the types of treatment you are receiving or have received in the past. The researcher will access this information under the direction of the clinical nurse specialist either on your in hospital unit (E5 or E6), or in the Heart Failure Clinic who will be provided with a copy of your signed consent form. All information obtained from your healthcare providers will be kept confidential, and will be handled in accordance with the Personal Health Information Act (PHIA) guidelines. You may choose not to have the researcher access your healthcare providers and still participate in the study.

How will the information be handled during and after the study?

Any information that you provide to the researcher will be kept confidential. The only exception would be if the researcher discovered abuse in the course of the study, in which case there is a legal obligation to report this to the appropriate authorities. Your usual health care providers will not know your responses to the study questions. Your identity will be protected by assigning you a code number that is known only to the researcher. No personal identifying information will be recorded on any of the data collection forms used in this study. The researcher, the thesis committee members, and the data analyst will have access to the questionnaires that you complete on which only your code number will appear (not your name). During and after the study, all consents and questionnaires will be securely locked up in the researcher's home office. Study data will be kept for seven to ten years and then destroyed as confidential waste. In reporting the results of the study, under no circumstances would your identity be revealed. Information will be reported in aggregate or group form in the quantitative analysis. Any direct supportive quotes in the qualitative analysis will have any identifying information removed. Any publications or presentations that are produced as a result of this study will not provide specific names of the clinic or unit that you were recruited from: instead publications will report that patients and caregivers were invited to participate from three treatment sites in the City of Winnipeg, Manitoba.

What are the benefits and burdens associated with participating in the study?

This study is designed to learn about how you and your family caregiver interact to understand and respond to your heart failure symptoms. Some of the questions may cause you to reflect on your behavior and feelings and cause you some concern. If you become uncomfortable answering these questions, you can stop at any time. A referral for psychological counselling may be made if appropriate. Any questions related to your medical treatment will be referred to your health care provider. There may be risks, discomforts, or side effects that are not yet known.

This study may not benefit you directly. However, the information may be beneficial to researchers and healthcare providers to learn more about how heart failure patients and their families recognize common symptoms of heart failure. This study hopes to find ways to help patients and their family caregivers better assess and respond to heart failure symptoms to enhance wellbeing and reduce the need for urgent care.

What if I want to withdraw from participating from the study?

Your participation is completely voluntary and you have the right to refuse to be in this study. You can stop participating at any time after giving your consent. If either you or your family caregiver decide to withdraw from the study, any completed questionnaires and audio-recorded interviews held with you or your family caregiver will not be included in the results, and confidentially destroyed. This decision will not affect in any way your current or future medical care or any other benefits to which you are otherwise entitled. We may learn new things during the study that you may need to know. We can also learn about things that might make you want to stop participating in the study. If so, you will be notified about any new information. The study researcher may stop you from taking part in this study at any time if they decide it is in your best interest, or if you do not follow study instructions. You will be given a copy of this consent form to keep.

Can I get a copy of the results of the study?

A summary of the results of the study will be made available to you if you would like to receive them once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the form at the end of the consent.

Cost and Compensation

There will be no costs to you for taking part in this study. You and your caregiver will each receive one grocery store gift card in the amount of \$10.00 for your time and effort in completing the questionnaires and interview.

Contact Persons

If you have any questions about this study call Christine Scoville, study researcher. You may obtain information and clarification from Christine Scoville's thesis advisor, Dr. Michelle Lobchuk.

Their telephone numbers are:

Christine Scoville: (204)801-3071

Dr. Michelle Lobchuk: (204)474-7135

This study has been approved by the Education and Nursing Research Ethics Board of the University of Manitoba, the Research Access Board of the Winnipeg Regional Health Authority and the Office of Clinical Research Impact of St. Boniface General Hospital. If you have any concerns or complaints about this project, you may contact the Human Ethics Secretariat at (telephone #) or email (email).

Prior to signing this consent form, please put a check mark in the box below if you agree to permit access to your St. Boniface Hospital healthcare providers.

- Permission for Christine Scoville, Masters of Nursing Student to speak with my healthcare providers at the St. Boniface General Hospital to collect information for the study as outlined in this consent.

If you are willing to volunteer for this research study, please sign below:

Participant's Name (please print) _____
Participant's Signature _____
Date

Researcher's Name (please print) _____
Researcher's Signature _____
Date

If you would like to receive a summary of the results of this study, please fill out the form below:

Name of person to whom the study results should be sent:

Mailing Address:

Postal Code:

Appendix C

Family Caregiver Consent Form (University of Manitoba Letterhead)

Thesis Project Title: A perspective taking intervention to enhance family caregiver symptom assessment and improve symptom management for the heart failure patient

Researcher: Christine Scoville, Graduate Student, University of Manitoba, Faculty of Nursing

Thesis Advisory Committee: Dr. Michelle Lobchuk (chair), University of Manitoba, Faculty of Nursing; Dr. Susan McClement, University of Manitoba, Faculty of Nursing; Dr. Christina Quinn, Gordon College, Barnesville, Georgia.

Sponsor: Fort Garry Branch of the Royal Canadian Legion Poppy Trust Fund .

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

What is the nature and purpose of the study?

You are invited to take part in a study regarding symptoms experienced with heart failure and how patients and family caregivers recognize these symptoms. The purpose of the study is to explore ways of assisting heart failure patients and their family caregivers in assessing heart failure symptoms.

What am I being asked to consent to? What is the nature of my participation in the study?

If you and the patient consent to take part in the study this means that you and the patient agree to meet with the researcher on two occasions in your home or the patient's home. If either you or the patient do not want to participate in the study, then neither you or the patient will be enrolled in the study. This is a study that involves the participation of both the patient and the family caregiver.

During the first visit you will be asked to complete three questionnaires and answer some general questions. The first questionnaire will ask you general questions about your age and how long the patient has had heart failure. The second questionnaire will ask about the patient's current heart failure symptoms and the third questionnaire will be asked about how you behave and act

towards the patient when you are trying to understand how the patient is feeling about their heart failure symptoms. These questionnaires will take about 15 minutes to complete.

Following the first questionnaire, you and the patient will be asked to go to separate areas within the home. After you and the patient independently complete the second and third questionnaires, you will have a short discussion with the researcher regarding an approach to symptom assessment. After two weeks, there will be a second visit with the researcher. You will be asked to complete two questionnaires (the same as the original second and third questionnaires) and participate in a short informal audio-recorded interview about your thoughts and feelings regarding symptom assessment during the two weeks. The second visit with you should take about 45 minutes for you to complete the questionnaires and conduct an audio-recorded interview with the researcher. If you require assistance in reading or filling out any of the forms, the researcher will be pleased to assist you. Once the questionnaires and interviews are completed, the researcher will be willing to spend additional time with you to answer any questions that you may have about your responses.

How will the information be handled during and after the study?

Any information that you provide to the researcher will be kept confidential. The only exception would be if the researcher discovered abuse in the course of the study, in which case there is a legal obligation to report this to the appropriate authorities. Your identity will be protected by assigning you a code number that is known only to the researcher. No personal identifying information will be recorded on any of the data collection forms used in this study. The researcher, the thesis committee members, and the data analyst will have access to the questionnaires that you complete on which only your code number will appear (not your name). During and after the study, all consents and questionnaires will be securely locked up in the researcher's home office. Study data will be kept for seven to ten years, then destroyed as confidential waste. In reporting the results of the study, under no circumstances would your identity be revealed. Information will be reported in aggregate or group form. Any direct supportive quotes in the qualitative analysis will have all identifying information removed. Any publications or presentations that are produced as a result of this study will not provide specific names of the clinic or unit that you were recruited from but instead will report that patients and caregivers were invited to participate from three treatment sites in the City of Winnipeg, Manitoba.

What are the benefits and burdens associated with participating in the study?

This study is designed to learn about how you and the patient interact together to understand and respond to the patient's heart failure symptoms. Some of the questions may cause you to reflect on your behavior and feelings, causing you some concern. If you become uncomfortable answering these questions, you can stop at any time. A referral for psychological counselling may be made if appropriate. Any questions related to the patient's medical treatment will be

referred to the patient's health care provider. There may be risks, discomforts, or side effects that are not yet known.

This study may not benefit you directly. However, the information may be beneficial to researchers and healthcare providers to learn more about how heart failure patients and their families recognize common symptoms of heart failure. This study hopes to find ways to help patients and their family caregivers better assess and respond to heart failure symptoms to enhance wellbeing and reduce the need for urgent care.

What if I want to withdraw from participating from the study?

Your participation is completely voluntary and you have the right to refuse to be in this study. You can stop participating at any time after giving your consent. If either you or the patient decides to withdraw from the study, any completed questionnaires of both of you will not be included in the results, and confidentially destroyed. This decision will not affect in any way the patient's current or future medical care or any other benefits to which you or the patient are otherwise entitled.

We may learn new things during the study that you may need to know. We can also learn about things that might make you want to stop participating in the study. If so, you will be notified about any new information. The study researcher may stop you from taking part in this study at any time if they decide it is in your best interest, or if you do not follow study instructions. You will be given a copy of this consent form to keep.

Can I get a copy of the results of the study?

A summary of the results of the study will be make available to you if you would like to receive them once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the form at the end of the consent.

Cost and Compensation

There will be no costs to you for taking part in this study. You will each be given a grocery store gift card in the amount of \$10.00 for your time and effort in completing the questionnaires and interview.

Contact Persons

If you have any questions about this study call Christine Scoville, study researcher. You may obtain information and clarification from Christine Scoville's thesis advisor, Dr. Michelle Lobchuk.

Their telephone numbers are:

Christine Scoville: (204)801-3071

Dr. Michelle Lobchuk: (204)474-7135

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

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Research Ethics Board of the University of Manitoba, the Research Access Board of the Winnipeg Regional Health Authority and the Office of Clinical Research Impact of St. Boniface General Hospital

This study has been approved by the Research Ethics Board of the University of Manitoba, the Research Access Board of the Winnipeg Regional Health Authority and the Office of Clinical Research Impact of St. Boniface General Hospital. If you have any concerns or complaints about this project, you may contact the Human Ethics Secretariat at (telephone #) or email (email).

If you are willing to volunteer for this research study, please sign below:

_____	_____	_____
Participant's Name (please print)	Participant's Signature	Date
_____	_____	_____
Researcher's Name (please print)	Researcher's Signature	Date

If you would like to receive a summary of the results of this study, please fill out the form below:

Name of person to whom the study results should be sent:

Mailing Address:

Postal Code:

Appendix D

Subject ID

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Heart Failure Patient - Demographic Survey

The following survey asks questions regarding your background and medical history. This information will allow us to describe the characteristics of the group participating in this study.

All responses will remain anonymous and are voluntary.

1.	What do you identify as your cultural or ethnic heritage?	Specify: _____ <input type="checkbox"/> I prefer not to answer
2.	What is your highest level of education?	<input type="checkbox"/> Less than High School <input type="checkbox"/> High School graduate <input type="checkbox"/> At Least one year College or University <input type="checkbox"/> College or University Graduate <input type="checkbox"/> Graduate/Professional Training <input type="checkbox"/> I prefer not to answer
3.	What is your marital status?	<input type="checkbox"/> Married <input type="checkbox"/> Common-law <input type="checkbox"/> Never married <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> I prefer not to answer

Adapted with permission from Dr. M. Lobchuk et al.

4.	What is your age?	<input type="text"/> State age in years <input type="checkbox"/> I prefer not to answer
5.	What is your gender?	<input type="checkbox"/> Female <input type="checkbox"/> Male
6.	What is your occupational status?	<input type="checkbox"/> Full-time <input type="checkbox"/> Part-time <input type="checkbox"/> Casual <input type="checkbox"/> Student <input type="checkbox"/> Medical leave <input type="checkbox"/> Unemployed <input type="checkbox"/> Retired <input type="checkbox"/> I prefer not to answer
7.	What is your current (or previous) type of employment?	<input type="checkbox"/> Clerical <input type="checkbox"/> Labourer <input type="checkbox"/> Homemaker <input type="checkbox"/> Professional/Management <input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> I prefer not to answer
8.	What is your total annual gross household income?	<input type="checkbox"/> Below \$40,000 <input type="checkbox"/> \$40,000 - \$79,999 <input type="checkbox"/> Over \$80,000 <input type="checkbox"/> I prefer not to answer

9.	How many individuals do you live with?	<input type="text"/> number of people <input type="checkbox"/> I prefer not to answer
10.	Approximately how long ago were you diagnosed with heart failure?	<input type="checkbox"/> Less than 6 months ago <input type="checkbox"/> 6 months to < 5 year ago <input type="checkbox"/> 5 years ago or longer <input type="checkbox"/> I do not know when I was diagnoses
11.	In the past 6 months, approximately how many times have you visited your <u>family doctor, heart specialist or heart failure clinic</u> due to heart failure symptoms?	<input type="checkbox"/> None <input type="checkbox"/> 1 to 2 times <input type="checkbox"/> 3 or more times
12.	In the past 6 months, approximately how many times have you visited an <u>emergency room</u> due to heart failure symptoms?	<input type="checkbox"/> None <input type="checkbox"/> 1 time <input type="checkbox"/> 2 or more times
13.	In the past 6 months, approximately how many times have you been <u>admitted to a hospital</u> due to heart failure symptoms?	<input type="checkbox"/> None <input type="checkbox"/> 1 time <input type="checkbox"/> 2 or more times

14.	<p>Have you ever attended a formal teaching session about heart failure?</p> <p>If you answered "yes", approximately how many hours was the teaching session(s)?</p>	<table style="width: 100%; border: none;"> <tr> <td style="width: 20px; text-align: center;"><input type="checkbox"/></td> <td>Yes</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>No</td> </tr> <tr> <td colspan="2"> </td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Less than 2 hours</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>2 hours to 8 hours</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>More than 8 hours</td> </tr> </table>	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No			<input type="checkbox"/>	Less than 2 hours	<input type="checkbox"/>	2 hours to 8 hours	<input type="checkbox"/>	More than 8 hours
<input type="checkbox"/>	Yes													
<input type="checkbox"/>	No													
<input type="checkbox"/>	Less than 2 hours													
<input type="checkbox"/>	2 hours to 8 hours													
<input type="checkbox"/>	More than 8 hours													

15.	<p>In the past year, have you discussed your heart failure symptoms or management with <u>any</u> of these health care professionals?</p>	<table style="width: 100%; border: none;"> <tr> <td style="width: 20px; text-align: center;"><input type="checkbox"/></td> <td>Cardiologist</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Family Doctor</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Nurse</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Physiotherapist</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Dietician</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>Pharmacist</td> </tr> </table>	<input type="checkbox"/>	Cardiologist	<input type="checkbox"/>	Family Doctor	<input type="checkbox"/>	Nurse	<input type="checkbox"/>	Physiotherapist	<input type="checkbox"/>	Dietician	<input type="checkbox"/>	Pharmacist
<input type="checkbox"/>	Cardiologist													
<input type="checkbox"/>	Family Doctor													
<input type="checkbox"/>	Nurse													
<input type="checkbox"/>	Physiotherapist													
<input type="checkbox"/>	Dietician													
<input type="checkbox"/>	Pharmacist													

16.	<p>How often do you weigh yourself?</p>	<table style="width: 100%; border: none;"> <tr> <td style="width: 20px; text-align: center;"><input type="checkbox"/></td> <td>I do not weigh myself</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>once a day</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>once every 2-3 days</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>once every week</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>once every month</td> </tr> </table>	<input type="checkbox"/>	I do not weigh myself	<input type="checkbox"/>	once a day	<input type="checkbox"/>	once every 2-3 days	<input type="checkbox"/>	once every week	<input type="checkbox"/>	once every month
<input type="checkbox"/>	I do not weigh myself											
<input type="checkbox"/>	once a day											
<input type="checkbox"/>	once every 2-3 days											
<input type="checkbox"/>	once every week											
<input type="checkbox"/>	once every month											

17.	<p>Do you take a diuretic or "water pill"?</p>	<table style="width: 100%; border: none;"> <tr> <td style="width: 20px; text-align: center;"><input type="checkbox"/></td> <td>Yes</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>No</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td>I do not know</td> </tr> </table>	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	I do not know
<input type="checkbox"/>	Yes							
<input type="checkbox"/>	No							
<input type="checkbox"/>	I do not know							

18.	<p>Have you been perscribed daily medications?</p> <p>Are your medications pre-packaged or "bubble packed" by your pharmacy?</p> <p>How regularly do you take your medications as prescribed?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Always
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19.	<p>How long has your caregiver been involved in your daily care and routines?</p>	<input type="checkbox"/> Less than 6 months <input type="checkbox"/> 6 months to < 5 year ago <input type="checkbox"/> 5 years or longer
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20.	<p>What is the extent to which your caregiver assists you in coping with your medical condition and symptoms?</p>	<input type="checkbox"/> Never assists me <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Always
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21.	<p>Do you and your caregiver talk openly about what your thoughts and feelings are in regard to your health symptoms?</p>	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Always
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22.	Do you and your caregiver talk openly about what your thoughts and feelings are in regard to your symptoms?	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Always
23.	How well do you think your caregiver knows how you think and feel about your symptoms?	<input type="checkbox"/> Not at all <input type="checkbox"/> Not very well <input type="checkbox"/> Has some knowledge <input type="checkbox"/> Somewhat well <input type="checkbox"/> Very well
24.	How much contact does your caregiver have with you?	<input type="checkbox"/> Daily, my carer lives with me <input type="checkbox"/> Daily, but my carer does not live with me <input type="checkbox"/> More than weekly, I do not live with my carer <input type="checkbox"/> Weekly, I do not live with my carer <input type="checkbox"/> Less than weekly, I do not live with my carer
25.	Does your caregiver have a chronic medical condition that you assist he or she with on a regular basis?	<input type="checkbox"/> Yes <input type="checkbox"/> No

Appendix E

Subject ID

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Family Caregiver - Demographic Survey

The following survey asks questions regarding your background and history. This information will allow us to describe the characteristics of the group participating in this study.

All responses will remain anonymous and are voluntary.

1.	What do you identify as your cultural or ethnic heritage?	Specify: _____ <input type="checkbox"/> I prefer not to answer
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2.	What is your highest level of education?	<input type="checkbox"/> Less than High School <input type="checkbox"/> High School graduate <input type="checkbox"/> At Least one year College or University <input type="checkbox"/> College or University Graduate <input type="checkbox"/> Graduate/Professional Training <input type="checkbox"/> I prefer not to answer
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3.	What is your marital status?	<input type="checkbox"/> Married <input type="checkbox"/> Common-law <input type="checkbox"/> Never married <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> I prefer not to answer
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Adapted with permission from Dr. M. Lobchuk et al.

4.	What is your age?	<input type="text"/> State age in years <input type="checkbox"/> I prefer not to answer
5.	What is your gender?	<input type="checkbox"/> Female <input type="checkbox"/> Male
6.	What is your occupational status?	<input type="checkbox"/> Full-time <input type="checkbox"/> Part-time <input type="checkbox"/> Casual <input type="checkbox"/> Student <input type="checkbox"/> Medical leave <input type="checkbox"/> Unemployed <input type="checkbox"/> Retired <input type="checkbox"/> I prefer not to answer
7.	What is your current (or previous) type of employment?	<input type="checkbox"/> Clerical <input type="checkbox"/> Labourer <input type="checkbox"/> Homemaker <input type="checkbox"/> Professional/Management <input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> I prefer not to answer
8.	How many individuals do you live with?	<input type="text"/> number of people <input type="checkbox"/> I prefer not to answer

9.	<p>What is your relationship to the patient?</p>	<table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 20px; text-align: center;"><input type="checkbox"/></td><td>Wife</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Husband</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Parent</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Daughter</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Son</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Sister</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Brother</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Friend</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Other (Specify)</td></tr> <tr><td></td><td>_____</td></tr> </table>	<input type="checkbox"/>	Wife	<input type="checkbox"/>	Husband	<input type="checkbox"/>	Parent	<input type="checkbox"/>	Daughter	<input type="checkbox"/>	Son	<input type="checkbox"/>	Sister	<input type="checkbox"/>	Brother	<input type="checkbox"/>	Friend	<input type="checkbox"/>	Other (Specify)		_____
<input type="checkbox"/>	Wife																					
<input type="checkbox"/>	Husband																					
<input type="checkbox"/>	Parent																					
<input type="checkbox"/>	Daughter																					
<input type="checkbox"/>	Son																					
<input type="checkbox"/>	Sister																					
<input type="checkbox"/>	Brother																					
<input type="checkbox"/>	Friend																					
<input type="checkbox"/>	Other (Specify)																					

11.	<p>Have you ever attended a formal teaching session about heart failure?</p> <p>If you answered "yes", approximately how many hours was the teaching session(s)?</p>	<table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 20px; text-align: center;"><input type="checkbox"/></td><td>Yes</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>No</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Less than 2 hours</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>2 hours to 8 hours</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>More than 8 hours</td></tr> </table>	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Less than 2 hours	<input type="checkbox"/>	2 hours to 8 hours	<input type="checkbox"/>	More than 8 hours
<input type="checkbox"/>	Yes											
<input type="checkbox"/>	No											
<input type="checkbox"/>	Less than 2 hours											
<input type="checkbox"/>	2 hours to 8 hours											
<input type="checkbox"/>	More than 8 hours											

12.	<p>In the past year, have you discussed the patient's heart failure symptoms or management with <u>any</u> of these health care professionals?</p>	<table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 20px; text-align: center;"><input type="checkbox"/></td><td>Cardiologist</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Family Doctor</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Nurse</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Physiotherapist</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Dietician</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Pharmacist</td></tr> </table>	<input type="checkbox"/>	Cardiologist	<input type="checkbox"/>	Family Doctor	<input type="checkbox"/>	Nurse	<input type="checkbox"/>	Physiotherapist	<input type="checkbox"/>	Dietician	<input type="checkbox"/>	Pharmacist
<input type="checkbox"/>	Cardiologist													
<input type="checkbox"/>	Family Doctor													
<input type="checkbox"/>	Nurse													
<input type="checkbox"/>	Physiotherapist													
<input type="checkbox"/>	Dietician													
<input type="checkbox"/>	Pharmacist													

13.	<p>What is the extent to which you assist the patient in coping with his or her medical condition and symptoms?</p>	<table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 20px; text-align: center;"><input type="checkbox"/></td><td>Never</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Rarely</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Sometimes</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Frequently</td></tr> <tr><td style="text-align: center;"><input type="checkbox"/></td><td>Always</td></tr> </table>	<input type="checkbox"/>	Never	<input type="checkbox"/>	Rarely	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Frequently	<input type="checkbox"/>	Always
<input type="checkbox"/>	Never											
<input type="checkbox"/>	Rarely											
<input type="checkbox"/>	Sometimes											
<input type="checkbox"/>	Frequently											
<input type="checkbox"/>	Always											

Adapted with permission from Dr. M. Lobchuk et al.

14.	Do you and the patient talk openly about what the patient's thoughts and feelings are in regard to the patient's symptoms?	<input type="checkbox"/> Never <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Always
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15.	How well do you think you know how the patient thinks and feel about his or her symptoms?	<input type="checkbox"/> Not at all <input type="checkbox"/> Not very well <input type="checkbox"/> Has some knowledge <input type="checkbox"/> Somewhat well <input type="checkbox"/> Very well
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16.	How much contact do you have with the patient?	<input type="checkbox"/> Daily, the patient lives with me <input type="checkbox"/> Daily, but the patient does not live with me <input type="checkbox"/> More than weekly, I do not live with the patient <input type="checkbox"/> Weekly, I do not live with the patient <input type="checkbox"/> Less than weekly, I do not live with the patient
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Appendix F

Heart Failure Symptom Survey – Patient Version

Subject ID

Dyad ID

HEART FAILURE SYMPTOM SURVEY - Patient Version

Please think about how you perceive the heart failure or cardiac symptoms you have experienced over the last 7 days. Please read the following questions carefully. If the answer is **yes** to any of the questions, rate that question as to **frequency**, **severity**, interference with **physical activity**, and interference with your **enjoyment of life**. If the answer is **no**, put "0" for frequency and skip to the next question.

FREQUENCY SCALE = 0 - 10

0 = Never
10 = Very Frequently

SEVERITY SCALE = 0 - 10

0 = No Severity
10 = Very Severe

PHYSICAL ACTIVITY / ENJOYMENT OF LIFE SCALE = 0 - 10

0 = No Interference
10 = Great Deal of Interference

Symptom

Frequency

Severity

Interference with Physical Activity

Interference with Enjoyment of Life

What things have you done to lessen or manage this symptoms?

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Write your responses in the box below

1. In the last 7 days, have you had shortness of breath at rest?

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2. In the last 7 days, have you had shortness of breath with activity?

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HEART FAILURE SYMPTOM SURVEY - Patient Version

Subject ID

Adapted with the permission of Dr. Anita DeLongis

HEART FAILURE SYMPTOM SURVEY - Patient Version

Subject ID				
Dyad ID				

Please think about how you perceive the heart failure or cardiac symptoms you have experienced over the last **7 days**. Please read the following questions carefully. If the answer is **yes** to any of the questions, rate that question as to **frequency**, **severity**, interference with **physical activity**, and interference with your **enjoyment of life**. If the answer is **no**, put "0" for frequency and skip to the next question.

<u>FREQUENCY SCALE = 0 - 10</u>	<u>SEVERITY SCALE = 0 - 10</u>	<u>PHYSICAL ACTIVITY / ENJOYMENT OF LIFE SCALE = 0 - 10</u>
0 = Never	0 = No Severity	0 = No Interference
10 = Very Frequently	10 = Very Severe	10 = Great Deal of Interference

<u>Symptom</u>	<u>Frequency</u>	<u>Severity</u>	<u>Interference with Physical Activity</u>	<u>Interference with Enjoyment of Life</u>	<u>What things have you done to lessen or manage this symptoms?</u>
1. In the last 7 days, have you had shortness of breath at rest?	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	Write your responses in the box below <input type="text"/>
2. In the last 7 days, have you had shortness of breath with activity?	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	Rate from: 0-10 <input type="text"/>	<input type="text"/>

Subject ID

HEART FAILURE SYMPTOM SURVEY - Patient Version

Adapted with the permission of Dr. Anita DeLongis

<u>Symptom</u>	<u>Frequency</u>	<u>Severity</u>	<u>Interference with Physical Activity</u>	<u>Interference with Enjoyment of Life</u>	Write your responses in the box below
	Rate from: 0-10	Rate from: 0-10	Rate from: 0-10	Rate from: 0-10	
8. In the last 7 days, have you had chest pressure or heaviness in your chest?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
9. In the last 7 days, have you had an irregular heart beat or fluttering feeling in your chest?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
10. In the last 7 days, have you had a worsening cough?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
11. In the last 7 days, have you had dizziness or lightheadedness?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
12. In the last 7 days, have you had difficulty sleeping?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	

Dyad ID

What things have you done to lessen or manage this symptoms?

Subject ID

HEART FAILURE SYMPTOM SURVEY - Patient Version

Adapted with the permission of Dr. Anita DeLongis

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Dyad ID

Symptom **Frequency** **Severity** **Interference with Physical Activity** **Interference with Enjoyment of Life** **What things have you done to lessen or manage this symptoms?**

Rate from: 0-10 Rate from: 0-10 Rate from: 0-10 Rate from: 0-10 Write your responses in the box below

13. In the last 7 days, have you had forgetfulness or difficulty concentrating?

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14. In the last 7 days, have you been depressed or feeling down?

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15. Are there any other symptoms you have had over the last 7 days?

Yes

No

If yes, describe the symptom(s)?

Appendix G

Heart Failure Symptom Survey – Family Version

HEART FAILURE SYMPTOM SURVEY - Family Version

Subject ID

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Please think about how you perceive the heart failure or cardiac symptoms your family member has experienced over the last **7 days**. Please read the following questions carefully. If the answer is **yes** to any of the questions, rate that question as to **frequency**, **severity**, interference with **physical activity**, and interference with **their enjoyment of life**. If the answer is **no**, put "0" for frequency and skip to the next question.

USE THE FOLLOWING RATING SCALES FOR YOUR RESPONSES:

FREQUENCY SCALE = 0 - 10

SEVERITY SCALE = 0 - 10

PHYSICAL ACTIVITY / ENJOYMENT OF LIFE SCALE = 0 - 10

0 = Never

0 = No Severity

0 = No Interference

10 = Very Frequently

10 = Very Severe

10 = Great Deal of Interference

Symptom	Frequency	Severity	Interference with Physical Activity	Interference with Enjoyment of Life	What things have they done to lessen or manage this symptom?
1. In the last 7 days, has he or she had shortness of breath at rest?	Rate from: 0-10 <input style="width: 30px; height: 20px;" type="text"/>	Rate from: 0-10 <input style="width: 30px; height: 20px;" type="text"/>	Rate from: 0-10 <input style="width: 30px; height: 20px;" type="text"/>	Rate from: 0-10 <input style="width: 30px; height: 20px;" type="text"/>	Write your responses in the box below <div style="border: 1px solid black; height: 40px; width: 100%;"></div>
2. In the last 7 days, has he or she had shortness of breath with activity?	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<input style="width: 30px; height: 20px;" type="text"/>	<div style="border: 1px solid black; height: 40px; width: 100%;"></div>

Adapted with the permission of Dr. Anita DeLongis

Subject ID

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HEART FAILURE SYMPTOM SURVEY - Family Version

What things have they done to lessen or manage this symptom?

Interference with Enjoyment of Life

Interference with Physical Activity

Severity

Frequency

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

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3. In the last 7 days, has he or she had shortness of breath when lying down in bed?

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4. In the last 7 days, has he or she had shortness of breath when they wake up during the night?

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5. In the last 7 days, has he or she had swelling in their feet, ankles or legs?

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6. In the last 7 days, has he or she had a full or bloated feeling in their abdomen?

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7. In the last 7 days, has he or she had fatigue, tiredness or lack of energy?

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Subject ID

HEART FAILURE SYMPTOM SURVEY - Family Version

What things have they done to lessen or manage this symptom?

Interference with Enjoyment of Life

Interference with Physical Activity

Severity

Frequency

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

Rate from: 0-10

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8. In the last 7 days, has he or she had chest pressure or heaviness in their chest?

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9. In the last 7 days, has he or she had an irregular heart beat or fluttering feeling in their chest?

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10. In the last 7 days, has he or she had a worsening cough?

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11. In the last 7 days, has he or she had dizziness or lightheadedness?

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12. In the last 7 days, has he or she had difficulty sleeping?

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Subject ID

HEART FAILURE SYMPTOM SURVEY - Family Version

What things have they done to lessen or manage this symptom?

Interference with Enjoyment of Life
Rate from: 0-10

Interference with Physical Activity
Rate from: 0-10

Severity
Rate from: 0-10

Frequency
Rate from: 0-10

Symptom

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13. In the last 7 days, has he or she had forgetfulness or difficulty concentrating?

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14. In the last 7 days, has he or she been depressed or feeling down?

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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15. Are there any other symptoms he or she has had over the last 7 days?

If yes, describe the symptom(s)?

Appendix H
Empathic Responding Scale – Patient Version

Subject ID				
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How well do the following statements describe your caregiver’s behaviour and actions toward you on a scale of 0 to 4, where 0 <u>does not</u> describe him or her very well and 4 describes him or her very well.						
For each question, <u>circle</u> the number that best describes your caregiver's behavior and actions toward you over the last 7 days.		Does not describe them very well				Describes them very well
1.	My caregiver tries to understand my concerns.	0	1	2	3	4
2.	My caregiver tries to understand how I felt.	0	1	2	3	4
3.	My caregiver tries to experience what I was feeling.	0	1	2	3	4
4.	My caregiver tries to imagine being in my shoes.	0	1	2	3	4
5.	My caregiver tries to see things from my point of view.	0	1	2	3	4
6.	My caregiver tries to accept me as I am now.	0	1	2	3	4
7.	My caregiver tries to help me by listening to me.	0	1	2	3	4
8.	My caregiver tries to help me by doing something for me.	0	1	2	3	4
9.	My caregiver tries to figure out what would make me feel better.	0	1	2	3	4
10	My caregiver tries to provide comfort to me by telling me about their positive feelings for me?	0	1	2	3	4

Appendix I
Empathic Responding Scale – Family Version

Subject ID				
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How well do the following statements describe your own behaviour and actions toward the patient on a scale of 0 to 4, where 0 does not describe you very well and 4 describes you very well.						
For each question, <u>circle</u> the number that best describes your behavior and actions toward the patient.		Does not describe you very well				Describes you very well
1.	I try to understand the patient's concerns.	0	1	2	3	4
2.	I try to understand how the patient felt.	0	1	2	3	4
3.	I try to experience what the patient was feeling.	0	1	2	3	4
4.	I try to imagine being in the patient's shoes.	0	1	2	3	4
5.	I try to see things from the patient's point of view.	0	1	2	3	4
6.	I try to accept the patient as they are now.	0	1	2	3	4
7.	I try to help the patient by listening to them.	0	1	2	3	4
8.	I try to help them by doing something for them.	0	1	2	3	4
9.	I try to figure out what would make the patient feel better.	0	1	2	3	4
10.	I try to provide comfort to them by telling them about my positive feelings for them.	0	1	2	3	4

Appendix J

Semi-Structured Interview Questions – Patient Version

Ask the patient to consider their interaction with their family caregiver over the past two weeks with respect to symptom assessment and symptom management.

1. Can you describe any change in your caregiver's behaviour when he or she was assessing your symptoms or trying to understand your experiences with symptoms over the past two weeks?
 2. In what ways did your caregiver show or communicate to you that they understood your heart failure symptoms over the past two weeks?
 3. What things was your caregiver doing to help him or her understanding your heart failure symptom experience over the past two weeks?
-

Appendix K

Semi-Structured Interview Questions – Family Caregiver Version

Ask the family caregiver to consider their interaction with the patient over the past two weeks with respect to the perspective taking intervention, symptom assessment, and symptom management.

1. Can you describe your thoughts and feelings about the perspective taking technique when you applied it over the past two weeks to help you understand the patient's symptom experiences?
2. Can you tell me whether you think that the perspective-taking intervention helped you to understand better the patient's symptom experience over the past two weeks?

Prompt: If yes – I would be interested in knowing 'how' the intervention helped you?

Prompt: Did the intervention change how you felt about the patient?

Prompt: Did the intervention change your behavior toward the patient? Can you describe whether your approach in trying to understand the patient's symptoms is different now since you learned this new technique?

Prompt: Can you tell me whether you plan to continue using this technique to help you understand the patient's symptoms better? If no, why not? If yes, why?

Prompt: I am also interested in knowing if the technique caused you to learn something different about yourself and how you view the patient's illness?

3. As a last question, is there anything else you would like to add to help health care professionals help you and your family caregiver assess or manage your symptoms?
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Appendix L
Empathic Perspective-Taking Intervention
Intervention Script for Family Member at Initial Visit

Introduction:

This intervention will take place after all questionnaires have been completed by both patient and family member during an initial home visit.

The family member will be asked to sit in another area to discuss the idea of an empathic perspective-taking prompt and its use over the next two weeks.

Step One (introduction)

Researcher:

The purpose of my visit with you is to teach you a different way to look at (insert the patient's name) symptom experiences arising from heart failure. Most importantly, this technique I will be teaching you should help you and (insert the patient's name) to come to a closer understanding of how symptoms are being experienced.

Step 2 (realizing patient and family have different ways of looking at things)

There are several ways that people look at the same thing. For example, think of a situation when you were anxious. Did others around you feel the same anxiety? Did you wish that they could understand how you were feeling?

Now, can you think of a symptom that you have had trouble recognizing or assessing related to (insert the patient's name)'s heart failure?

We can look at the list of symptoms from the questionnaire that you just filled out.

Family:

Tells researcher which symptom they have trouble recognizing.

Researcher:

What I am going to teach you today is a technique I would like you to practice over the next two weeks that can help you recognize or assess symptoms like (the one they just identified in the above step). This technique is called perspective taking. This approach can be viewed using two different approaches.

One way perspective taking is viewed is by thinking about how *you* would feel if *you had a disease* with symptoms that occur such as in heart failure; and the other is to think about *how (insert the patient's name) feels* when he/she has certain symptoms such as those that occur with heart failure.

The perspective that I am going to ask you to practice over the next two weeks is to focus on and imagine how (insert the patient's name) is feeling not from your point of view, but *from (insert the patient's name)'s point of view*. Another way to think of this is consciously putting yourself “in the other person’s shoes” each time you are assessing or interpreting your loved one’s symptoms.

This may or may not be a new way of thinking about (insert the patient's name)’s symptoms, however, I’d like for you to consciously try this approach until the next time we talk in two weeks.

Step 3 (practice)

Let’s practice by looking at the symptom that you mentioned above that you had trouble recognizing.

With that symptom, what kind of cues do you usually rely on to tell you something has changed? Is it usually a verbal cue such as your loved one saying something aloud? Or is it usually a non-verbal cue such as a grimace or a change in their movement or change in their daily routine?

Family:

(Allow family to think about how this particular symptom is recognized)

Step 4 (instructions for practice over next two weeks)

Researcher:

During the next two weeks, I’d like you to notice how you interpret various symptoms that your loved one is having. You can also validate or ask them if what you are noticing is close to what they are feeling. This step in validation is another part of learning perspective taking.

Researcher:

When I return in two weeks, I will ask you to fill out the same questionnaire regarding symptoms that persons with heart failure usually have (like the one we filled out today that listed 10

possible symptoms). When you answer these questions next time, I will ask you to think back over the past week and use this technique we discussed today.

I will ask you to forget yourself and put yourself in your loved one's shoes. What I mean by that is to try to picture how each symptom feels to (insert patient's name). Then, I will ask you to answer the questions as you believe they would.

Step 5 (scheduling)

As planned, I will return in two weeks to speak with you again. Let's set up a time and day now.

Remind them that they will receive two \$10.00 grocery store gift cards when you return for the second visit. Ask them if they have a grocery store they prefer.

Step 6 (summarize)

Researcher:

Just as a reminder, over the next two weeks, I want you to practice noticing your loved one's symptoms and thinking about how he or she would rate the symptom. A good time to practice is when you notice a change in something about your loved one such as he or she seems more/less tired or more/less short of breath or has more/less fatigue (key symptoms associated with the condition). Try to focus on how your loved one feels and you can validate your rating with him or her as you practice. I would encourage you to keep some notes about your thoughts and feelings when you attempted to picture how symptoms felt to (insert patient's name) over the next two weeks.

Appendix M

Wilcoxon Sign-Rank p-values from a comparison of Pre-test and Post-test discrepancy scores:

- i. Patient-Caregiver HF Symptom Discrepancy Scores (total HFSS tool)
- ii. Patient-Caregiver HFSS Subscale Median Discrepancy Scores (Frequency, Severity, Interference with Activity, and Interference with Enjoyment of Life)

HFSS Symptom	Frequency (p-value)	Severity (p-value)	Interference with Physical Activity (p-value)	Interference with Enjoyment of Life (p-value)
1.Shortness of breath at rest	.235	.050	.304	.048*
2.Shortness of breath with activity	.325	.036*	.059	.164
3.Shortness of breath when lying down	.137	.017*	.671	.932
4.Shortness of breath when you wake-up at night	.129	.083	.051	.114
5.Swelling in your feet, ankles or legs	.811	.418	.646	.682
6.Full or bloated feeling in your abdomen	.009*	.056	.048*	.270
7.Fatigue, tiredness or lack of energy	.218	.583	.472	.244
8.Chest pressure or heaviness in your chest	.041*	.084	.088	.093
9.Irregular heart beat or fluttering feeling in your chest	.752	.078	.104	.147
10.Worsening cough	.168	.046*	.394	.609
11.Dizziness or lightheadedness	.210	.084	.262	.167
12.Difficulty sleeping	.442	.397	.291	.201
13.Forgetfulness or difficulty concentrating	.408	.503	.608	.478
14.Depressed or feeling down	.058	.011*	.032*	.022*
Subscale Median Score	.018*	.007*	.005*	.058

Note: *indicates significant results at a p-value < .05

Appendix N

HFSS: Mean, Median, and Range for Pretest and Posttest Absolute Discrepancies between Caregiver Scores and Patient Scores for Frequency, Severity, Interference with Physical Activity, and Interference with Enjoyment or Life

HFSS Item	Mean Pre (Post)	Minimum Pre (Post)	Maximum Pre (Post)	Median Pre (Post)
Frequency:				
Short of breath at rest	3.29 (2.21)	0 (0)	10 (7)	2.50 (1.00)
Short of breath with activity	3.14 (2.43)	0 (0)	10 (5)	2.00 (2.50)
Short of breath lying down	3.21 (1.71)	0 (0)	9 (8)	3.00 (0.50)
Short of breath waking up at night	3.86 (2.14)	0 (0)	10 (6)	4.00 (2.00)
Swelling in your feet, ankles or legs	2.50 (2.57)	0 (0)	10 (8)	0.50 (1.50)
Full or bloating feeling in your abdomen	3.50 (2.00)	0 (0)	10 (7)	3.00 (1.00)
Fatigue, tiredness or lack of energy	3.29 (2.50)	0 (0)	6 (7)	4.00 (2.00)
Chest pressure / heaviness	2.36 (1.07)	0 (0)	10 (8)	1.50 (0.50)
Irregular heart beat / fluttering in chest	1.50 (1.43)	0 (0)	10 (8)	0.00 (0.00)
Worsening cough	0.79 (1.43)	0 (0)	5 (5)	0.00 (0.50)
Dizziness / lightheadedness	2.71 (1.79)	0 (0)	10 (6)	2.00 (1.00)
Difficulty sleeping	3.07 (2.86)	0 (0)	10 (8)	2.00 (2.00)
Forgetfulness / difficulty concentrating	1.93 (1.71)	0 (0)	6 (6)	1.50 (1.00)
Depressed / feeling down	3.64 (2.57)	0 (0)	8 (8)	3.00 (1.50)
Median Frequency Subscale Score	2.07 (1.21)	0 (0)	4.00 (2.50)	2.00 (1.00)
Severity:				
Short of breath at rest	3.36 (1.86)	0 (0)	10 (6)	2.50 (2.00)
Short of breath with activity	4.07 (2.14)	0 (0)	10 (6)	3.50 (2.00)
Short of breath lying down	3.86 (1.79)	0 (0)	9 (7)	4.50 (1.00)
Short of breath waking up at night	4.21 (2.29)	0 (0)	10 (7)	4.50 (2.50)
Swelling in your feet, ankles or legs	2.14 (1.64)	0 (0)	7 (7)	2.00 (1.00)
Full or bloating feeling in your abdomen	3.07 (2.00)	0 (0)	10 (7)	2.50 (1.00)
Fatigue, tiredness or lack of energy	3.29 (3.00)	0 (0)	7 (6)	3.50 (3.00)
Chest pressure / heaviness	2.43 (1.29)	0 (0)	10 (8)	0.50 (0.00)
Irregular heart beat / fluttering in chest	2.14 (1.36)	0 (0)	10 (7)	0.50 (0.00)
Worsening cough	0.64 (1.64)	0 (0)	3 (7)	0.00 (1.50)
Dizziness / lightheadedness	3.00 (1.50)	0 (0)	10 (8)	1.00 (0.50)
Difficulty sleeping	2.64 (2.36)	0 (0)	9 (8)	2.00 (1.50)
Forgetfulness / difficulty concentrating	2.14 (1.86)	0 (0)	9 (6)	1.50 (0.50)
Depressed / feeling down	3.79 (2.07)	0 (0)	10 (7)	3.00 (1.00)
Median Severity Subscale Score	2.25 (1.25)	0 (0)	4.50 (3.00)	2.25 (1.00)
Interference with Physical Activity:				
Short of breath at rest	2.93 (2.00)	0 (0)	10 (8)	1.50 (0.00)
Short of breath with activity	4.07 (2.57)	0 (0)	10 (10)	3.50 (1.50)
Short of breath lying down	2.07 (1.64)	0 (0)	7 (8)	1.50 (0.00)
Short of breath waking up at night	3.79 (1.93)	0 (0)	10 (8)	1.50 (0.00)
Swelling in your feet, ankles or legs	2.21 (1.64)	0 (0)	8 (8)	0.50 (0.50)

Full or bloating feeling in your abdomen	3.00 (1.93)	0 (0)	10 8()	2.00 (1.00)
Fatigue, tiredness or lack of energy	3.29 (2.64)	0 (0)	7 (8)	2.50 (2.00)
Chest pressure / heaviness	2.86 (1.57)	0 (0)	10 8()	1.00 (0.50)
Irregular heart beat / fluttering in chest	2.14 (1.21)	0 (0)	10 5()	0.50 (0.00)
Worsening cough	0.64 (1.21)	0 (0)	5 (5)	0.00 (0.00)
Dizziness / lightheadedness	2.79 (1.64)	0 (0)	10 (9)	1.00 (1.00)
Difficulty sleeping	3.36 (1.93)	0 (0)	10 (10)	2.00 (1.50)
Forgetfulness / difficulty concentrating	2.71 (1.64)	0 (0)	10 (8)	0.00 (0.00)
Depressed / feeling down	4.07 (2.21)	0 (0)	10 (7)	5.00 (2.00)
Median Interfere with Physical Activity Score	1.61 (0.71)	0 (0)	5.00 (2.00)	1.50 (0.50)
Interference with Enjoyment of Life:				
Short of breath at rest	3.64 (2.07)	0 (0)	10 (7)	2.00 (2.00)
Short of breath with activity	4.36 (3.64)	0 (0)	10 (10)	3.50 (4.00)
Short of breath lying down	2.21 (2.07)	0 (0)	8 (9)	0.50 (0.00)
Short of breath waking up at night	3.29 (1.93)	0 (0)	10 (8)	0.00 (0.00)
Swelling in your feet, ankles or legs	2.29 (1.64)	0 (0)	10 (8)	0.50 (0.00)
Full or bloating feeling in your abdomen	2.71 (2.07)	0 (0)	10 (7)	0.50 (0.00)
Fatigue, tiredness or lack of energy	3.86 (2.79)	0 (0)	10 (8)	3.00 (2.50)
Chest pressure / heaviness	3.14 (1.79)	0 (0)	10 (9)	1.00 (0.00)
Irregular heart beat / fluttering in chest	1.93 (0.57)	0 (0)	10 (3)	0.00 (0.00)
Worsening cough	1.07 (1.14)	0 (0)	10 (5)	0.00 (0.00)
Dizziness / lightheadedness	3.00 (1.64)	0 (0)	10 (9)	0.50 (1.00)
Difficulty sleeping	4.00 (2.07)	0 (0)	10 (10)	2.50 (1.50)
Forgetfulness / difficulty concentrating	2.86 (2.00)	0 (0)	10 (8)	0.50 (0.50)
Depressed / feeling down	3.93 (2.43)	0 (0)	10 (7)	4.50 (2.00)
Median Interfere with Enjoyment of Life Score	1.36 (0.96)	0 (0)	4.50 (4.00)	0.50 (0.25)