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# Exploring Personal Growth in Individuals Living with Heart Failure

Kristen Jayne Overbaugh

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**EXPLORING PERSONAL GROWTH IN  
INDIVIDUALS LIVING WITH HEART FAILURE**

**BY**

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DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of  
**Doctor of Philosophy**

**Nursing**

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Albuquerque, New Mexico

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## **DEDICATION**

This research is dedicated to all individuals living with chronic illness who struggle day to day to find a silver lining in the face of their illness and to their family members, support systems, and health care providers who work with compassion and commitment to improve their illness experience.

## ACKNOWLEDGMENTS

*Courage does not always roar. Sometimes courage is the quiet voice at the end of the day, saying, "I will try again tomorrow."* Mary Anne Radmacher

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**ABSTRACT**

This exploratory study described levels of personal growth and examined relationships among personal growth, demographic, clinical, and cognitive factors in a convenience sample ( $N = 103$ ) of community-residing adults with New York Heart Association (NYHA) functional class II-IV heart failure (HF). The study was guided by Mishel's reconceptualized uncertainty in illness theory and Tedeschi and Calhoun's post-traumatic growth model. The following research questions were addressed: (1) Do adults living with NYHA class II-IV HF report personal growth following their diagnosis of HF? (2) To what extent are age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels associated with personal growth in individuals with HF? and (3) Which variables (age, sex, ethnicity, disease severity, time since diagnosis, symptom status, or uncertainty levels) make independent contributions to personal growth in individuals living with NYHA class II-IV HF? Participants completed a demographic and clinical survey, the Posttraumatic Growth Inventory (PTGI), the Mishel Uncertainty in Illness Scale-Community Version, and the Memorial Symptom Assessment Scale-Heart Failure. Participants reported moderate levels of personal growth ( $M = 48.6$ ,  $SD = 28.6$ ). There were no significant differences in personal growth

by sex, ethnicity, or disease severity. Personal growth had a weak, negative correlation with age ( $r = -.20, p < .05$ ) and a weak, positive correlation with symptom burden ( $r = .20, p < .05$ ). Uncertainty was positively correlated with symptom burden ( $r = .49, p < .01$ ) and disease severity ( $r = .28, p < .01$ ), but was not significantly correlated with PTGI scores. A hierarchical regression model that included age, sex, ethnicity, NYHA classification, years since diagnosis, uncertainty, and symptom burden did not account for significant variance in PTGI scores. Findings provide foundational knowledge to guide future study of personal growth in HF and add to the overall literature on personal growth in relation to uncertainty and symptoms within chronic illness.



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## CHAPTER 1

### INTRODUCTION

Currently, more than 5 million Americans are living with a diagnosis of heart failure (HF), and by 2030, this population is expected to increase by 3 million (Go et al., 2013). HF is a chronic, progressive disease that is associated with an unpredictable disease trajectory, significant symptom burden, increased rates of anxiety and depression, poor quality of life, decreased life expectancy, and increased health-care costs (Adler, Goldfinger, Kalman, Park, & Meier, 2009). National guidelines that address the diagnosis and treatment of HF largely focus on disease-modifying interventions based on a biomedical model of care (Heart Failure Society of America, 2010a, 2010b; Jessup et al., 2009). To date, the majority of research conducted with this population has focused on the adverse physical and psychosocial effects of living with a diagnosis of HF. A growing body of research suggests that people living with serious illness may also report personal growth and positive outcomes (Barskova & Oesterreich, 2009). Major gaps in the literature exploring personal growth in patients with HF exist. A better understanding of personal growth and factors that contribute to it may help to supplement traditional HF management programs and inform models, such as palliative approaches, that are being investigated to provide more holistic, supportive care to this population (Bekelman, Nowels, Allen et al., 2011; Bekelman, Nowels, Retrum et al., 2011; Goodlin, 2009; Hupcey, Penrod, & Fenstermacher, 2009). The purpose of this exploratory study was to describe levels of personal growth in HF and to examine the relationship between relevant demographic, clinical, and cognitive variables and personal growth.



## **HF: Epidemiology, Pathophysiology, and Demographics**

HF is a complex condition resulting from structural cardiac changes that impact the ability of the heart to pump or fill, limiting its ability to provide adequate cardiac output and/or to support venous return, ultimately reducing the heart's ability to meet the basic metabolic demands of the body (Kemp & Conte, 2012). An insult to the myocardium arising from any of the following cardiac pathologies can lead to the loss of functioning myocardial cells and trigger the development of HF: coronary artery disease (CAD), myocardial infarction (MI) or chronic ischemia, hypertension (HTN), valvular heart disease, cardiomyopathies, or, less commonly, myocardial injury due to infection, toxins, or sustained dysrhythmias (Kemp & Conte, 2012; Ramani, Uber, & Mehra, 2010). Modifiable risk factors for HF include those that are associated with the development of CAD, HTN, and/or cardiomyopathies and include factors such as diabetes, dyslipidemia, obesity, smoking, and alcohol or drug abuse. Advancing age is the primary nonmodifiable risk factor for HF (Jessup et al., 2009).

By age 40, both men and women have a 20% lifetime risk of developing HF (Go et al., 2013). The incidence of HF increases for both sexes after the age of 65 (Go et al., 2013). According to the U.S. Department of Health and Human Services (2014), the number of people aged 65 years and older is expected to reach 72.1 million by the year 2030, contributing to a growing prevalence of HF. With advances in cardiac care, such as the use of better drugs, stents, and cardiac devices, people who might have died from an MI in the past are now living longer and may eventually be diagnosed with HF. Thus, increases in life expectancy generally, as well as improvements in cardiac care and improvements in diagnostic capabilities, have all contributed to increasing the number of

people living with HF. Despite improvements in survival after an HF diagnosis, 50% of people diagnosed with this disease die within 5 years (Go et al., 2013). Over time, many with the diagnosis will progress to advanced stages of HF (Jessup et al., 2009; Stuart, 2007). In the United States, the risk of developing HF is highest in African Americans, followed by Hispanics, non-Hispanic Whites, and persons of Chinese heritage; in general, HF events are higher in men than in women until age 65 (Go et al., 2013).

Providers diagnose HF as systolic, diastolic, or mixed systolic and diastolic, according to the primary pathology of the left ventricle underlying the development of HF. *Systolic dysfunction* describes the inability of the left ventricle to effectively contract or pump and is present when the left ventricular ejection fraction (the percentage of blood volume ejected from the left ventricle per heartbeat) is less than 40%; *diastolic dysfunction* describes the inability of the ventricles to relax or fill adequately during diastole (Kemp & Conte, 2012). Changes in myocardial fiber function lead to dilation or hypertrophy of the cardiac chambers and stimulate a neurohormonal reaction involving the release of catecholamines (norepinephrine and epinephrine) and vasopressin, as well as activation of the renin-angiotensin-aldosterone axis. This response initially serves as a compensatory mechanism to support cardiac output and perfusion, but over time, results in cardiac cell death and further hypertrophy, leading to ventricular remodeling (a change in the size, shape, composition, or function of the ventricle) and worsening contractile dysfunction (Ramani et al., 2010). Other neurohormones that are elevated in HF include the natriuretic peptides and endothelium-derived vasoactive agents (which promote compensatory vasodilation), and various cytokines (Kemp & Conte, 2012).

Left ventricular HF is primarily associated with pulmonary signs and symptoms. Worsening left ventricular HF can lead to right ventricular HF, resulting in venous congestion in the systemic circulation and corresponding signs and symptoms, which include peripheral edema and jugular venous distention, and abdominal pain and nausea (Kemp & Conte, 2012). As a result of ventricular dysfunction, individuals living with HF experience a significant symptom burden. Studies indicate that dyspnea and fatigue are the two most common and distressful symptoms, but also report that patients experience insomnia, pain, depression, anxiety, cough, anorexia, dry mouth, nausea, palpitations, dizziness, and difficulty concentrating, among others (Janssen, Spruit, Wouters, & Schols, 2008; Zambroski, Moser, Bhat, & Ziegler, 2005).

### **HF Classification Systems and Models of Care**

The NYHA classification system for HF is based on the occurrence of fatigue, palpitations, dyspnea, and angina with various degrees of activity. Clinicians use this system to assess functional abilities and mortality risk in the context of HF (Kemp & Conte, 2012). Class I patients are asymptomatic with usual activity; class II patients are asymptomatic at rest, but have slight limitations with usual activity due to symptoms; class III patients have more moderate limitations that occur with less than usual activity; and class IV patients have significant symptoms even at rest, limiting their ability to participate in any activity (Hunt et al., 2009).

The American College of Cardiology/American Heart Association (ACC/AHA; Hunt et al., 2001) developed a second classification system to supplement the NYHA system. The ACC/AHA classification incorporates markers of the development and progression of HF and outlines goals of therapy based on disease staging. This staging

system highlights disease prevention strategies for patients at high risk for HF and recommends a continuum of treatment options for individuals with structural heart disease based on their symptom burden, functional limitations, and response to current therapies. Lifestyle modifications, such as diet and exercise, largely constitute risk reduction strategies for individuals at high risk for HF, whereas pharmacologic, device therapy (such as biventricular pacemakers and implantable defibrillators), and surgical options are accepted interventions for advancing HF. These guidelines recommend end-of-life care when individuals meet criteria for stage D, class IV HF and are no longer responsive to evidence-based medical or surgical therapies.

Advocates for palliative care have suggested that practitioners initiate palliative care earlier in the trajectory of HF rather than at the end stage (Adler et al., 2009; Bekelman, Nowels, Allen et al., 2011; Bekelman, Nowels, Retrum et al., 2011; Goodlin, 2009; Hupcey et al., 2009). More contemporary conceptualizations of palliative care characterize it as a supportive approach that should be initiated for individuals impacted by chronic or life-limiting illnesses, such as HF, at the time of diagnosis to improve symptom management, quality of life, communication, decision making, and psychosocial support for the patient and family (Adler et al., 2009; Goodlin, 2009; Hupcey et al., 2009). Unlike traditional disease management programs, models integrating palliative care incorporate goals of psychosocial and spiritual well-being and aim to facilitate personal growth (National Consensus Project for Quality Palliative Care, 2009). Research examining whether individuals with HF report positive psychosocial consequences or personal growth as a result of their illness experience is needed to support the development of these supportive care models.

## Personal Growth

Over the last 20 years, researchers in the behavioral, psychological, social, and health sciences have examined the concept of personal growth more extensively. Researchers have conceptualized personal growth as positive psychosocial adjustment or adaptation to some form of adversity, such as a serious illness. This kind of growth has been referred to in the literature as post-traumatic growth (PTG), stress-related growth, thriving, adversarial growth, benefit finding, and positive disease adjustment (Barskova & Oesterreich, 2009). Corresponding assessment tools measure growth as an individual's ability to achieve a positive change in relationships, a greater appreciation for life, a change in life priorities, personal strength, new opportunities, and enhanced spirituality (Calhoun & Tedeschi, 2006; Pakenham, 2007). The literature on personal growth suggests that growth is dependent on coping with a difficult experience (Barskova & Oesterreich, 2009). Similarly, Tedeschi and Calhoun (2004) assert within their work on PTG that the adverse event or stimulus should be serious enough to incite stress that is sufficient to challenge or threaten existing personal worldviews and to provoke reframing of life goals and priorities.

Medical researchers have most frequently studied growth in cancer (Stanton, Bower, & Low, 2006) and HIV (Milam, 2006a) populations; other research has been conducted with individuals living with multiple sclerosis, arthritis, lupus erythematosus, neurological disorders, and heart disease (Barskova & Oesterreich, 2009). In a review of studies exploring growth in individuals living with a variety of medical illnesses, Barskova and Oesterreich (2009) concluded that demographic factors (e.g., age, gender, and ethnicity), as well as social support, coping styles, and mental and physical health,

correlated with measures of growth. They suggested that growth may be an important and relevant indicator of positive disease outcomes. Subsequent positive outcomes significantly associated with growth included improved morbidity and mortality, higher CD4 T-lymphocyte levels, better health-related quality of life (HRQOL), and decreased levels of cortisol, pain, fatigue, disability, depression, and anxiety (Barskova & Oesterreich, 2009).

Another approach to growth in response to serious health conditions has been to consider it an adaptive response to uncertainty (Mishel, 1990). Growth through uncertainty has been studied less frequently than has PTG and mostly in cancer populations (Mishel & Clayton, 2008). Mishel (1990) describes growth through uncertainty, experienced by individuals living with ongoing uncertainty due to persistent illness, as a potential outcome within her reconceptualized uncertainty in illness theory (RUIT). In the RUIT, growth is defined as a new life perspective, that is, “a new ability to focus on multiple alternatives, choices and possibilities; re-evaluate what is important in life; consider variations in personal investment; and appreciate the impermanence and fragility of life” (Mishel & Clayton, 2008, p. 60). The RUIT proposes that individuals who achieve growth through uncertainty move beyond basic adaptation and experience a process of favorable psychological adjustment (Mishel, 1990).

In general, studies explicitly examining either PTG or growth through uncertainty in an HF population are lacking. The following well-documented factors characterize HF as a challenging illness to live with: (a) an unpredictable illness course, (b) uncertainty in prognosis, (c) significant symptom burden, and (d) impact on psychosocial well-being.

Efforts to improve the holistic management of HF would also benefit from a greater understanding of how these factors relate to personal growth.

### **Uncertainty in HF**

Individuals living with HF, their caregivers, and their health care providers frequently experience uncertainty related to knowledge deficits, an unpredictable disease trajectory, inadequate social support, and varying frequency, duration, and severity of symptoms and distress over time (Brännström, Forssell, & Pettersson, 2011; Falk, Swedberg, Gaston-Johansson, & Ekman, 2007; Hopp, Thornton, & Martin, 2010; Hupcey, Fenstermacher, Kitko, & Penrod, 2010; Jurgens, 2006). In a qualitative review of individuals' experiences of living with HF, Yu, Lee, Kwong, Thompson, and Woo (2007) reported that

patients used the terms “a roller coaster life” and “knocking on death’s door” to describe their meanings of living with CHF [congestive heart failure]. The former, a symbolic representation of the life situation characterized by the ongoing oscillations between ups and downs, the latter of being threatened by the unpredictable condition and uncertain future. (p. 478)

Thus, uncertainty contributes to the challenges of coping with HF. Overcoming or adapting to uncertainty is likely to be a prerequisite for growth following a diagnosis of HF. Therefore, in this study, the RUIT served as an overall conceptual framework for the exploration of personal growth in individuals living with HF.

## **Conceptual Frameworks**

Mishel's (1990) RUIT served as the primary guiding framework for this study. In addition to the RUIT, Tedeschi and Calhoun's (2004) conceptualization of PTG and assumptions related to PTG also informed the development of this study.

### **Reconceptualized Uncertainty in Illness Theory**

The RUIT describes how individuals living with chronic illness or disease reoccurrence can reappraise ongoing uncertainty and move beyond adaptation to achieve growth through the discovery of new life meaning and the acceptance of change (Mishel, 1990; see Appendix A). Uncertainty is among the challenges experienced by individuals living with HF. The RUIT provides a broad lens to examine whether individuals can potentially achieve growth through attempts to cope with this type of adversity. It was developed in response to clinical cases and qualitative studies of uncertainty in chronic illness in which Mishel's (1988) original uncertainty in illness theory (UIT) did not account adequately for the experiences of some individuals living with enduring uncertainty.

Mishel's (1990) reconceptualization of the UIT was influenced by critical social theory and a desire to situate uncertainty in the context of culture. Critical social theory illuminated Western biases that tend to value order, balance, and predictability over uncertainty and disequilibrium, potentially limiting growth and change (Mishel, 1990). Furthermore, UIT was mechanistic in nature, focusing more on uncertainty as a state than as a process. In addition, the UIT did not address how time and culture could influence one's experience of uncertainty over the course of chronic illness (Mishel, 1990). The RUIT has the following new assumptions (Mishel, 1990):



- Uncertainty in chronic illness is an ongoing experience.
- Appraisal of uncertainty evolves over time.
- Embracing complexity and change alters existing personal realities and may help individuals to adapt and grow in the face of uncertainty.

Mishel (1990) retained the original antecedents of UIT (stimuli frame, cognitive capacity, and structure providers), which classify the factors that can contribute to uncertainty (see Appendix B). Stimuli frame includes symptom pattern, event familiarity, and event congruence. The stimuli frame can, in turn, be influenced by the other two antecedents, cognitive capacity and structure providers. Structure providers consist of credible authority, social support, and education.

The RUIT builds upon uncertainty, originally defined as “the inability to determine the meaning of illness-related events occurring when the decision maker is unable to assign definite value to objects or events and/or is unable to accurately predict outcomes” (Mishel & Clayton, 2008, p. 59), by suggesting that individuals can integrate ongoing uncertainty into a novel worldview not characterized by predictability and control and, as a result, achieve growth. Reframing one’s view of uncertainty begins at the appraisal stage and is influenced by two new concepts, self-organization and probabilistic thinking (Mishel & Clayton, 2008).

Self-organization is defined as the ability of an individual to recreate a new version of order from enduring uncertainty that is built on probabilistic or conditional thinking (Mishel, 1990). Probabilistic thinking implies that uncertainty becomes an accepted part of one’s reality, generating new possibilities and is conceptualized in the RUIT as an opportunity for growth (Mishel, 1990). Additionally, prior life experiences,

physiologic status, social resources, and interactions with health care providers can influence this process. Social support and health care providers that promote probabilistic thinking can help facilitate growth (Mishel, 1990). Therefore, appraisal of uncertainty in the RUIT is based on one's ability to cognitively reframe an event in a positive yet realistic way.

### **Post-Traumatic Growth**

Tedeschi and Calhoun (2004) conceptualize PTG as a process and/or an outcome that results from grappling with a life-altering event, commonly characterized as a trauma, major crisis, threat, or significant challenge. The following assumptions guide Tedeschi and Calhoun's (2004) work on PTG:

- PTG occurs in circumstances in which an individual's fundamental worldviews are substantially disrupted as a result of an extremely adverse event that may be discrete or ongoing.
- Growth occurs concurrently with serious psychological distress and does not necessarily minimize the suffering associated with a traumatic event or imply that an individual, if given the option, would choose to experience the challenging circumstances.
- Growth does not simply reflect a coping mechanism, but rather, an outcome or process that enables an individual to move beyond pre-trauma levels of adaptation, which is characterized by some degree of personal transformation.
- Growth is dependent on an individual's struggle to come to terms with a reality that has been significantly altered by the challenging circumstances.

- The struggle primarily represents a process of cognitive restructuring, but it also encompasses an affective component.

### **Specific Aims**

The specific aims of this study were:

1. To describe the levels of personal growth in adults living with NYHA class II-IV HF and explore the relationship of personal growth with age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels.
2. To determine the extent to which variance in personal growth in individuals living with NYHA class II-IV is accounted for by age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty.

The following research questions address these specific aims:

1. Do adults living with NYHA class II-IV HF report personal growth following their diagnosis of HF?
2. To what extent are age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels associated with personal growth in individuals with HF?
3. Which variables (age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels) make independent contributions to personal growth in individuals living with NYHA class II-IV HF?

### **Limitations**

The following limitations of this study were anticipated:

1. Convenience sampling was used to recruit participants, reducing the external validity of findings and decreasing generalizability.
2. Participants living near San Antonio, TX, were recruited, limiting the generalizability of findings to individuals with HF with similar socioeconomic and demographic characteristics.
3. Participants were limited to those who could speak and understand English, most likely limiting conclusions related to ethnic differences in personal growth.
4. The descriptive, exploratory nature of the study design did not allow for the testing of causal hypotheses between select variables and personal growth.
5. Cross-sectional data did not support inferences related to growth as an evolving temporal process.

### **Significance of the Study**

Results from this study addressed significant gaps in the literature by first revealing the extent to which personal growth is present in persons with HF and by identifying factors that are associated with growth. Findings add to the body of literature exploring growth in chronic illness and enhance the theoretical understanding of growth through uncertainty. Findings may also help inform the supportive care models being developed to supplement traditional medical management of HF.

## **CHAPTER 2**

### **REVIEW OF THE LITERATURE**

In this chapter, a summary of the literature on personal and post-traumatic growth in cardiac populations and how these findings compare with findings of personal and post-traumatic growth in other illnesses is provided. Next, uncertainty in HF, which is postulated under the RUIT as a stimulus for growth, is presented, and the literature that explores the concept of growth through uncertainty is described. The chapter concludes with a summary of symptom status and burden in HF.

#### **Personal Growth: An Overview**

In recent years, there has been increasing interest in the potential positive psychosocial consequences of illness rather than focusing exclusively on negative outcomes (Barskova & Oesterreich, 2009). This trend has been particularly evident in health psychology (Affleck, Tennen, Croog, & Levine, 1987; Barskova & Oesterreich, 2009; Chan, Lai, & Wong, 2006; Leung et al., 2010; Luszczynska, Sarkar, & Knoll, 2007; Petrie, Buick, Weinman, & Booth, 1999; Senol-Durak & Ayvasik, 2010a, 2010b; Sheikh, 2004) and nursing (Benetato, 2011; Black & Sandelowski, 2010; Chiba, Kawakami, & Miyamoto, 2011; Kahana, Kahana, Deimling, Sterns, & VanGunten, 2011; Kamibeppu et al., 2010; Mosher, Danoff-Burg, & Brunner, 2006; Panagopoulou, Triantafyllou, Mitziori, & Benos, 2009; Rahmani et al., 2012; Sato, Yamazaki, & Sakita, & Bryce, 2008; Steel, Gamblin, & Carr, 2008; Turner & Cox, 2004; Turner-Sack, Menna, & Setchell, 2012).

Researchers focusing on personal growth have attempted to identify its antecedents, understand relationships among factors that contribute to or impede growth, and evaluate the influence of growth on other clinically important outcomes, such as mortality, depression, and health behaviors, in a variety of populations with chronic or acute health problems. Personal growth has been most extensively studied in cancer populations. Researchers have also studied personal growth in individuals living with HIV, multiple sclerosis, arthritis, lupus, neurological disorders, and heart disease (Barskova & Oesterreich, 2009). In addition to illness, researchers have studied growth in a variety of traumatic contexts, including grief, infertility, sexual abuse, domestic violence, traumatic injuries, homicides, war, natural disasters, and airline crashes (Antoni et al., 2001; Tedeschi & Calhoun, 2004).

The growth literature encompasses seminal research in psychology that explored individuals' abilities to successfully adapt, positively perceive difficult circumstances, or find meaning during times of significant stress, loss, or suffering. It has been largely influenced by well-known scholars, such as Maslow, Caplan, Dohrenwend, Frankl, and Yalom, who have generated foundational research and theory pertaining to stress, coping, and positive psychology (Tedeschi & Calhoun, 2004). Beginning in the 1980s, researchers began studying growth as a distinct phenomenon that was conceptualized as a process or outcome characterized by positive changes in psychosocial perceptions resulting from significant adversity (Tedeschi & Calhoun, 2004). To support this inquiry, researchers have used a variety of psychometric instruments to measure personal or post-traumatic growth, including the Stress-Related Growth Scale (SRGS; Park, Cohen, & Murch, 1996), the Benefit Finding Scale (BFS; Mohr et al., 1999), the Posttraumatic

Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), and the Growth Through Uncertainty Scale (GTUS; Mishel & Fleury, 1994).

Tedeschi and Calhoun's (2004) work on PTG and studies using the PTGI have informed much of the research on personal growth. Tedeschi and Calhoun (2004) define trauma as more or less synonymous with highly stressful life events or crisis, including but not restricted to physical or psychological injury. They suggest that PTG can occur with "circumstances that represent significant challenges to the adaptive resources of the individual, and that represent significant challenges to individuals' ways of understanding the world and their place in it" (Janoff-Bulman, as cited in Tedeschi & Calhoun, 2004, p. 1). Tedeschi and Calhoun (2004) conceptualize PTG as encompassing processes of cognitive reappraisal as well as cognitive and behavioral outcomes of those processes.

### **Personal or Post-Traumatic Growth in Cardiac Populations**

Relatively few studies explore personal growth in cardiac conditions. Most studies were exploratory. For purposes of this review, they are presented chronologically. Affleck et al. (1987) conducted a secondary analysis of data from the Boston Heart Patient Study, a longitudinal investigation of health, psychological outcomes, and social outcomes in healthy men who had experienced a first-time MI. They found that individuals who reported benefits 7 weeks after experiencing their first MI were less likely to have a subsequent MI and had experienced less morbidity over the following 8 years than those who reported no benefits. Both 7 weeks and 8 years following the initial MI, a majority (58% and 59%, respectively) reported benefits or gains that they attributed to the event. Gains or benefits included learning the value of healthier behaviors and positive changes in life, values, overall outlook, or relationships.

Participants in the original study ( $N = 345$ ) were recruited from 26 hospitals in Massachusetts. Interviews were conducted after discharge home, 7 weeks following a first MI. Approximately 60% ( $n = 205$ ) were reinterviewed 8 years later. In the original and follow-up interviews, causal attributions (categorized as personal behavior, stress responses, other people, bad luck, and hereditary) and perceived benefits (in response to open-ended questioning) were among the topics assessed. The most frequently reported benefits involved changes in (a) life philosophy/values/religion, (b) family life and relationships, (c) stress and conflict reduction, (d) life enjoyment, (e) health behaviors, and (f) longevity expectations.

The secondary analysis ( $N = 287$ ) included a sample of 82 participants who died before the 8-year follow-up plus all 205 who were interviewed again at 8 years. Among those interviewed for the 8-year follow-up, 111 had suffered at least one additional MI (Affleck et al., 1987). After controlling for age, prognostic severity of the initial MI, and socioeconomic status, the inability to identify benefits and blaming others (e.g., family problems) 7 weeks after the initial MI were independent predictors of a second MI over the subsequent 8 years. Among the 205 survivors interviewed 8 years after the initial MI, after controlling for age, statistically significant independent predictors of greater morbidity 8 years later included the prognostic severity of the initial MI, socioeconomic status, inability to identify benefits and causal attributions of stress 7 weeks after the initial MI. Affleck et al. (1987) also found that participants who experienced a second MI prior to the 8-year follow-up reported greater benefit at 8 years than did those who had not. Affleck et al. (1987) acknowledged that the identification of benefits by the sample studied may not generalize to sicker populations for which clinical outcomes may not be



as responsive to lifestyle changes or emotional reframing. This study was the first to explore associations between perceiving benefits, a key component within the personal growth literature, and health outcomes in a cardiac population. A major limitation was the all-male sample.

Petrie et al. (1999) examined the positive changes reported by individuals 3 months after either their first MI or a diagnosis of breast cancer. The MI sample consisted of 143 participants (87% men), aged 65 years or younger (mean age  $\approx$  53 years). The breast cancer sample consisted of 52 women with primary breast cancer (and no prior breast cancer diagnosis), who were scheduled to begin radiation therapy (mean age  $\approx$  54 years). Both samples were recruited from university hospitals in New Zealand. At 3 months, 58% of both samples completed a questionnaire that asked “What positive effects do you feel may have occurred in your life due to your heart attack/cancer?” (Petrie et al., 1999, p. 539) There were no significant differences in illness severity between participants who reported positive changes from their illness and those who did not in either the MI or breast cancer group. However, patients who experienced an MI were significantly more likely to report positive outcomes than were participants in the breast cancer group.

Three independent researchers reviewed and categorized the written responses detailing the participants’ positive effects of illness. Positive outcomes reported by the MI participants included (a) healthy lifestyle changes (68%), (b) greater appreciation of health and life (28%), (c) improved close relationships (23%), and (d) changes in personal life priorities (17%); followed by smaller percentages of participants reporting perceiving second chances, greater knowledge about health, and improved empathy.

Breast cancer participants reported improved close relationships (33%), greater appreciation of life (27%), changes in personal priorities (20%), and improved empathy (20%). No significant differences related to gender were shown in the MI group, and no significant relationships among positive outcomes and age, education, self-rated health, and life satisfaction were shown in either group (Petrie et al., 1999).

Sheikh (2004) examined the degree to which personality traits, coping styles, and social support contributed to positive outcomes in survivors of cardiac arrest. The sample consisted of 28 participants recruited from a cardiac rehabilitation program in the United States and 82 participants recruited from a cardiac support group in the United Kingdom. Positive outcomes were measured using the PTGI total score. In addition to assessing demographics, time since diagnosis, treatments, and perception of control, participants completed measures of personality traits, social support, stressful life events, and coping.

No significant differences between the samples were shown in any of the main study variables. PTG was positively correlated with measures of problem-focused and emotion-focused coping to a moderate degree and more weakly with extraversion and satisfaction with social support. No significant association was found between time since diagnosis and PTG, suggesting that time alone is not a sufficient condition for growth. There was a significant association between PTG and perceived control. Extraversion was the only personality trait independently predicting PTG. Controlling for previous traumatic experiences and perceived control, extraversion was the strongest predictor of PTG; problem-focused coping partially mediated that association (Sheikh, 2004). Social support satisfaction was not found to be a significant independent predictor of PTG. Sheikh (2004) hypothesized that resources that facilitate the cognitive processing of an

event may be more important to achieving growth than the overall satisfaction with social support or the number of people available to help.

Chan et al. (2006) studied the effects of personal resilience and cardiac rehabilitation on PTG in 67 Chinese patients with single-vessel CAD following percutaneous transluminal coronary angioplasty (PTCA). They found that resilience and attributions of growth to the rehabilitation program were significant predictors of PTG. A path model showed strong direct effects of both resilience and attributions of growth to participation in cardiac rehabilitation. In addition, there was a weaker, although still significant, indirect path whereby the attributions of growth to participation in rehabilitation partially mediated the relationship between resilience and PTG.

Resilience in this study was evaluated using a composite score from measures of optimism, perceived control, and self-esteem. PTG was measured using a composite of items from the SRGS and the PTGI. Most of the participants reported not having a religion. Participants reported higher levels of PTG in the area of family appreciation and lower levels of PTG related to spirituality. The authors suggested that study findings imply that certain personal attributes, such as resilience, may help facilitate an individual's ability to perceive gain in other areas of his or her life, in the face of serious stress or suffering that result from illness.

Panagopoulou et al. (2009) conducted semistructured interviews with 11 married couples in Greece to explore dyadic benefit finding. One partner in each couple had experienced an MI. Interview questions focused on general concerns and the consequences and positive outcomes of experiencing an MI. Specifically, participants were asked the following question, which has been utilized in other studies exploring

benefit finding: “Sometimes people who are faced with a sudden health threat find some positive aspect in the experience. For example, some people feel they learn something about themselves or others. Have you found anything positive in this experience?” (Panagopoulou et al., 2009, p. 293)? Three researchers analyzed the interview transcripts using an interpretative phenomenologic approach. Participants perceived the MI as a stimulus for change, particularly in terms of health behaviors and as a chance to help others. Spouses were more purposeful in their efforts to recognize benefits, but had a more difficult time perceiving positive consequences from their partners’ MI. In most cases, spouses acknowledged benefits only in terms of having avoided more serious outcomes. Patients and spouses reported that benefit finding was generally a deliberate effort.

Leung et al. (2010) investigated PTG in patients with CAD ( $N = 1,237$ ) enrolled in outpatient rehabilitation in Canada. This study was the only one found that included participants with a diagnosis of HF ( $N = 178$ ). This secondary analysis of data from a prospective cohort study (Grace et al., 2008) explored the relationships among sociodemographic, clinical, and behavioral factors and PTGI scores. Leung et al. examined which factors contributed most significantly to PTG and they compared scores of PTG from their cardiac sample with PTGI scores reported in the literature for other chronic illnesses.

Significant correlates of PTG included younger age, non-White race, less income, reduced functional abilities, less depression, and better social support. In addition, participants who perceived their CAD as an acute illness associated with serious outcomes and as a condition that was responsive to treatment, rather than a chronic

cyclical disease in which they had less control over outcomes, reported higher levels of PTG. In general, compared with results of earlier studies in patients with various diagnoses, PTG scores in this large heterogeneous sample of cardiology outpatients were equivalent to previously reported scores in patients with MI or CABG, HIV/AIDS, and colorectal or prostate cancers, but substantially lower than previously reported in patients with multiple sclerosis, breast cancer, stage IV liver cancer, or bone marrow transplant.

Senol-Durak and Ayvasik (2010a, 2010b) explored factors associated with PTG among patients with MI and spouses of patients with MI. The MI sample consisted of 148 individuals (mean age = 56 years; 87% male) following an MI, recruited from four different Turkish hospitals (Senol-Durak & Ayvasik, 2010a). Senol-Durak and Ayvasik (2010a) investigated the influence of perceived social support, event perception, and coping on PTG in this sample. Turkish translations of the PTGI and measures of coping and social support were used. Overall, women had significantly higher PTG scores than did men. PTG scores were significantly and positively correlated with measures of social support, emotion-focused coping, and problem-focused coping.

In a structural equation model, perceived social support was significantly and directly associated with event perception and coping. Coping (problem-focused, emotion-focused, and indirect) was significantly related to PTG; perceived social support showed significant indirect effects via coping on PTG (Senol-Durak & Ayvasik, 2010a). However, event perception was not significantly related to PTG. The authors suggested that variations in the nature of an illness (disease stage, symptom burden, illness duration, and probability of reoccurrence) may impact results related to event perception and therefore its impact on PTG.

## **Synthesis of Findings**

In summary, researchers examining personal growth in cardiac populations have included individuals who experienced an MI (Affleck et al., 1987; Leung et al., 2010; Panagopoulou et al., 2009; Petrie et al., 1999; Senol-Durak & Ayvasik, 2010a), with a history of heart disease, specifically cardiac arrest (Sheikh, 2004), with single-vessel CAD undergoing PTCA (Chan et al., 2006), and with either a diagnosis of HF or history of CABG (Leung et al., 2010). Variations in population characteristics and measurement approaches limit the ability to draw solid conclusions related to personal growth in cardiac populations.

All of the quantitative studies were observational; only two included participants from the United States (Affleck et al., 1987; Sheikh, 2004). Only one study included patients with a diagnosis of HF (Leung et al., 2010). Most studies involved cross-sectional data collection; only two studies evaluated the trajectory of growth over time, but with samples that were exclusively (Affleck et al., 1987) or predominantly (Petrie et al., 1999) male.

Growth was explored in relation to MI reoccurrence and morbidity (Affleck, et al., 1987); disease severity (Petrie et al., 1999); time since diagnosis (Sheikh, 2004); gender, age, and other illness populations (Leung et al., 2010; Petrie et al., 1999); ethnicity, income, functional abilities, and depression (Leung et al., 2010); personality traits (Sheikh, 2004); event perceptions (Leung et al., 2010; Senol-Durak & Ayvasik, 2010a; Sheikh, 2004); social support (Leung et al., 2010; Sheikh, 2004); coping (Senol-Durak & Ayvasik, 2010a; Sheikh, 2004); resilience (Chan et al., 2006); and causal

attributions or perceived benefits (Affleck et al., 1987; Chan et al., 2006; Panagopoulou et al., 2009; Petrie et al., 1999).

In general, benefits or positive outcomes reported by the participants fit into the following categories: (a) health promotion knowledge/strategies (Affleck et al., 1987; Panagopoulou et al., 2009; Petrie et al., 1999); (b) reevaluation of values, priorities, and interpersonal relationships (Affleck et al., 1987; Chan et al., 2006; Panagopoulou et al., 2009; Petrie et al., 1999); (c) greater appreciation for life (Affleck et al., 1987; Petrie et al., 1999); and enhanced religious or spiritual views (Affleck et al., 1987; Chan et al., 2006; Panagopoulou et al., 2009).

### **Personal or Post-Traumatic Growth in Other Illness Populations**

Barskova and Oesterreich (2009) conducted a systematic review of 68 studies published between 1985 and 2009 that focused on growth in patients with or survivors of a variety of medical illnesses, including cancer (36 studies), HIV/AIDS (eight studies); brain and spinal cord injuries (six studies); heart disease (five studies); multiple sclerosis (four studies); rheumatoid arthritis (four studies); multiple chronic conditions or disabilities (two studies); burns (one study); orthopedic injuries (one study); and lupus erythematosus (one study). A majority of these studies measured personal growth using either the PTGI or the Benefit Finding Scale (BFS).

In two studies that used the PTGI, higher levels of growth were found in participants who were younger in age or female (Bellizzi, 2004; Morris, Shakespeare-Finch, & Scott, 2007). In contrast, studies using the BFS either did not detect relationships with age or sex (Katz, Flasher, Cacciapaglia, & Nelson, 2001; Schulz & Mohamed, 2004; Siegel & Schrimshaw, 2007) or found greater growth in older compared

with younger participants (Carver & Antoni, 2004; Luszczynska et al., 2007).

Correlations between growth and education or income level examined in studies included in Barskova and Oesterreich's (2009) review were predominantly nonsignificant. Five studies that examined growth in relation to ethnicity demonstrated that compared with non-Hispanic White participants, minority groups, specifically African Americans and Hispanics, reported more personal growth (Milam, 2004, 2006b; Siegel, Schrimshaw, & Pretter, 2005; Tomich & Helgeson, 2004; Urcuyo, Boyers, Carver, & Antonio, 2005). Two studies that did not show a significant association between growth and ethnicity (Thornton & Perez, 2006; Widows, Jacobsen, Booth-Jones, & Fields, 2005) included a small number of ethnically diverse participants, possibly diminishing the statistical power to detect significant relationships.

Six studies cited by Barskova and Oesterreich (2009) showed that growth was significantly higher in individuals who had lived longer with their diagnosis (Cordova, Cunningham, Carlson, & Andrykowsky, 2001; Evers et al., 2001; McGrath & Linley, 2006; Pakenham, 2005; Powell, Ekin-Wood, & Collin, 2007; Sears, Stanton, & Danoff-Burg, 2003), whereas only one (Milam, 2004) found a negative association between time since diagnosis and PTG in individuals living with HIV. Nine studies cited by Barskova and Oesterreich did not detect a significant relationship between time and growth.

Illness severity (based on established criteria for specific diseases) was related to growth in some studies cited by Barskova and Oesterreich (2009), but not others. In three studies of cancer, greater personal growth was found in individuals with more advanced disease (Carver & Antoni, 2004; Tomich & Hegelson, 2004; Urcuyo et al., 2005), but Lechner et al. (2003) found higher levels of PTG in people with stage II cancer compared



with either stage I or stage IV. One study of multiple sclerosis showed higher growth in participants in a relapse-remitting phase than among those living with a chronic, progressive form of the disease (Pakenham, 2005). Six studies cited by Barskova and Oesterreich did not demonstrate significant associations between growth and illness severity.

### **Uncertainty in HF**

Uncertainty is a common challenge for persons living with HF (Hopp et al., 2010; Jurgens, 2006; Waterworth & Jorgensen, 2010; Winters, 1999; Yu et al., 2007). Winters (1999) conducted one of the first studies to examine uncertainty in community-residing patients with HF. The sample in this mixed-methods study included 15 men and 7 women classified as NYHA class I to IV who were recruited from outpatient cardiology clinics. The mean number of years that participants had been living with HF was 7 (range, 1 to 21 years). Participants most frequently described uncertainty related to (a) changing symptoms and therapies, (b) insufficient patient education, (c) decreased perceived control, (e) thoughts of the future, and (f) the impact of aging. In addition, participants reported higher uncertainty at the time of initial diagnosis and during diagnostic testing and treatment adjustments. Themes characterizing uncertainty in the qualitative portion of this study included *recognition and response to symptoms and treatment, trying to stay well: a shared responsibility*, and *looking forward: quality of life and death* (Winters, 1999). Participants' perceptions of uncertainty changed over time and were influenced by the adequacy of information, communication, trusting relationships with providers, spirituality, hope, social support, and self-care capabilities. Uncertainty scores (possible range, 23-115) were moderate (mean score = 54.9,  $SD = 7.7$ ). Scores were highest for the

items that addressed uncertainty related to the progression of symptoms, expectations related to the future, and the likelihood of additional health problems (Winters, 1999).

### **Qualitative Studies**

Several exclusively qualitative studies have identified uncertainty as a common theme among individuals living with HF (Aldred, Gott, & Gariballa, 2005; Brännström, Ekman, Boman, & Strandberg, 2007; Brännström, Ekman, Norberg, Boman, & Strandberg, 2006; Dougherty, Pyper, Au, Levy, & Sullivan, 2007; Nordgren, Asp, & Fagerberg, 2007; Russell, Geraci, Hooper, Shull, & Gregroy, 1998; Waterworth & Jorgensen, 2010).

Russell et al. (1998) explored how individuals living with HF or chronic obstructive pulmonary disease (COPD) understood or explained the etiology, cause, effects, and treatments of an acute exacerbation. Participants were recruited from a Veterans Affairs Medical Center. The HF subsample consisted of 30 adult men (mean age = 69 years; mean ejection fraction = 35%) admitted to noncritical care units. The participants' mean subjective disease severity was 3.2 on a 1-to-4 scale, with 4 indicating more severe disease. Participants reported uncertainty related to the cause of their hospitalization. In particular, one third of the HF participants could not describe the factors that had triggered an acute change in their HF stability, precipitating the need for hospitalization.

Brännström et al. (2006) conducted a phenomenological study to better understand the experience of living with severe HF. Participants included 1 woman (NYHA class III) and 3 men (NYHA class IV) receiving palliative advanced home care in Sweden, with a median age of 79 years. One-time interviews were conducted in the

individuals' homes. Using a hermeneutic interpretative approach to analysis, Brännström et al. identified four major themes, two of which were related to uncertainty: "being aware that one's life hangs by a fine thread" and "struggling to cope with one's unpredictable deteriorated body" (Brännström et al., 2006, p. 297). Uncertainty was described in relation to symptoms, periods of instability, and expected death. Two other themes pertained to isolation and the reactions to receiving HF care at home. Brännström et al. (2006) characterized the overall experience of living with severe HF as "being forced to ride a 'roller coaster' with an ongoing oscillation between ups and downs" (p. 301). To further elucidate the meaning of living with the ups and downs, Brännström et al. (2007) subsequently recruited 1 of those participants with severe HF (NYHA class IV) and his wife, who were living at home, to participate in longitudinal interviews every 3 to 5 months over a 4.5-year period, for a total of 26 interviews. Using a phenomenological–hermeneutic approach, Brännström et al. (2007) characterized the participants' overall experience of ups and downs as "integrating the unpredictable illness into life, enduring suffering, and enjoying life." Subthemes included "Living life as it has become; Adapting to versus struggling against fatigue; Learning to take the good with the bad—striving to keep a check on the failing heart; [and] Finding meaning in togetherness with the spouse, others and God" (Brännström et al. 2007, p. 14). These themes characterized the couple's daily attempts to balance the uncertainty associated with living with a diagnosis of HF, while embracing opportunities to live more fully.

Aldred et al. (2005) studied the impact of advanced HF on 7 men and 3 women, recruited from a U.K. hospital, aged 60 years or older, categorized as NYHA class II to IV, and their primary informal caregivers. Interviews addressed the participants'

understanding of HF, its impact of their daily lives, their educational needs, their feelings on available support services, and their general concerns. The patients and their respective caregivers were interviewed together in their homes. They identified four major themes: *impact of HF on daily life*, *impact of HF on relationships*, *professional support*, and *future concerns*. Uncertainty per se was not identified as a theme in this study, but participants expressed concerns about the unpredictability of symptoms making it difficult to plan daily activities. Participants also had concerns about prognosis, changes in condition, and availability of support services.

Dougherty et al. (2007) conducted semistructured interviews with 24 participants (21 male) meeting criteria for stage C or D HF (Heart Failure Society of America, 2010a, 2010b) to explore how individuals living with advanced HF perceive and plan for their future. This qualitative study was part of a larger study that aimed to explore end-of-life decision making in people living with advanced HF or COPD. Using grounded theory content analysis procedures, the authors identified *Living with HF* as the central theme and the following subthemes: *my experience of HF*, *help with HF*, and *my future with HF*. Uncertainty was implicit in the participants' characterizations of daily life, their ability to make plans, end-of-life discussions with family, and life expectancy: "people with HF described their future in terms of an uncertain *shortened life*" (Dougherty et al., 2007, p. 483, emphasis original).

Nordgren et al. (2007) conducted a phenomenological study with 4 men and 3 women, 38 to 66 years of age, to explore their experiences of living with HF. Participants were recruited from a hospital in Sweden. All reported at least one hospital admission for HF within the past year and met criteria for NYHA class III or IV. The major themes

included *ambiguity of the body*, *losing track of life*, and *balancing life*. Uncertainty was implicit in these themes; overall, Nordgren et al. concluded that living with HF was experienced “as living with an unpredictable and failing body, an altered self-image, a rapidly changing health condition, and a life under constant and immediate threat” (p. 6). However, over time, individuals adjusted to living within their limitations, participated in activities that were meaningful to them, and achieved a sense of balance and contentment in their lives.

Waterworth and Jorgensen (2010) conducted a longitudinal, qualitative study of 25 older individuals (70 to 90 years of age) living in New Zealand who were transitioning toward greater dependence due to their HF diagnosis. Interviews were conducted every 3 months for up to 1 year; 19 participants completed all interviews. Uncertainty emerged as a major theme in this study. Participants expressed uncertainty about daily happenings, future expectations, their ability to recognize changes in their health status, and death. Information-seeking, relying on religious and community support services, following medical instructions (e.g., regarding diet, activity, and stress management), and participating in advanced care planning discussions with family were among the ways participants managed uncertainty.

Bekelman, Nowels, Retrum et al. (2011) conducted interviews with 33 individuals diagnosed with NYHA class II-IV HF and 20 informal caregivers to gain a better understanding of palliative care needs. Participants were recruited through providers at a university hospital in Colorado. They found that the patients’ daily and longer-term experiences were characterized by uncertainty related to symptoms, functioning, acute

exacerbations, and impending death. They concluded that research exploring palliative models for this population should address the management of illness uncertainty.

### **Quantitative Studies**

As part of a larger Swedish study, Ekman, Norberg, and Lundman (2000) conducted an intervention study that consisted of scheduled visits to a nurse-managed outpatient HF clinic and regular follow-up phone consultations with a group of 158 individuals diagnosed with moderate to severe HF (NYHA class III-IV). The intervention aimed to educate participants and, when present, their caregivers on identifying and managing HF signs, symptoms, and treatments and to provide them with tools to achieve these goals. The nurses individualized care based on each patient's unique illness experience and cultural preferences. Seventy-nine participants were randomly assigned to either the control group (conventional care) or the intervention group. A validated Swedish version of the Cardiac Population Scale (CPS; Mishel, 1983), a modified version of the Mishel Uncertainty in Illness Scale (MUIS), also developed by Mishel to assess perceptions related specifically to illness ambiguity and complexity of treatments in people with heart disease, was used to measure uncertainty. Data were collected at baseline (during hospitalization) and 6 months later. At the 6-month follow-up, 21 participants had died, leaving 58 participants in the intervention group and 62 in the control group. Follow-up questionnaires assessing uncertainty were completed by 45 participants in the intervention group and 47 participants in the control group.

There were no significant differences in uncertainty scores between the groups at baseline or at follow-up. Uncertainty scores at follow-up were significantly lower for both groups compared with baseline scores. In particular, no differences in participants'

abilities to identify signs or symptoms of worsening HF were detected between groups at 6 months. Ekman et al. (2000) offered two possible explanations for these findings: the CPS may not be sensitive enough to capture changes in uncertainty scores and/or the uncertainty associated with a life-threatening illness, such as HF, might not be responsive to cognitive strategies alone. They also suggested that measuring the participants' knowledge post-intervention may have been a more suitable outcome for assessing the effectiveness of the intervention (Ekman et al., 2000).

Thompson (2006) tested a model of self-care in 100 men and women with class I or II HF to better understand the relationships among social support, spiritual well-being, uncertainty, and self-care in this population. Path analyses were conducted to examine social support and spiritual well-being as predictors of self-care and uncertainty, and social support, spiritual well-being, and uncertainty as predictors of self-care, while controlling for comorbidities. In addition, Thompson examined whether uncertainty mediated relationships between social support and self-care and between spiritual well-being and self-care. Spiritual well-being was found to be the main predictor of self-care. Thompson found strong relationships between spirituality and self-care and between spirituality and uncertainty. Although spirituality accounted for 22% of the variance in uncertainty, uncertainty did not significantly contribute to self-care and it weakened the relationship between social support and self-care.

Jurgens (2006) investigated relationships among uncertainty, somatic awareness, symptom severity, symptom pattern (sudden vs. gradual onset), age, sex, HF history, and delay in care-seeking patterns in a sample of 201 adult patients admitted with a diagnosis of acute HF to either an urban or suburban tertiary or community hospital in the eastern

United States. The majority of the participants were White (95%) and male (56%), and the mean age of the sample was 70 years. Uncertainty was measured using the MUIS–Community Version (MUIS-C). The Heart Failure Somatic Awareness Scale (HFSAS) was used to measure somatic awareness and symptom severity. Symptom duration was used to measure delay in care-seeking and was assessed during a researcher interview. Uncertainty scores (possible range, 23-115) were moderate (mean score = 71.4,  $SD = 9.6$ ). Jurgens reported that the majority of the participants indicated that they still had many questions and were not sure what was wrong with them (cf. Winters, 1999). Uncertainty scores did not differ based on symptom onset (gradual or acute), age, sex, or prior HF admissions. Uncertainty scores were not related to age, symptom pattern or duration, or delay in care seeking. Uncertainty scores were positively associated HFSAS scores ( $r = .36, p < .01$ ), suggesting that greater somatic awareness and symptom severity were associated with greater uncertainty.

Falk et al. (2007) examined the impact of uncertainty and sense of coherence on fatigue in 93 individuals with HF (52% male; mean age = 74 years; NYHA class I-IV HF) admitted to a university hospital in Sweden for worsening HF. To measure uncertainty, they used a Swedish version of the CPS. To measure fatigue, they used a Swedish version of the Multidimensional Fatigue Inventory, which measures general fatigue, physical fatigue/tiredness, functional/activity status, motivation, and mental fatigue. Uncertainty was positively associated with tiredness and reduced functional/activity status. When modeled with sense of coherence and NYHA class, uncertainty made a significant, but small (4%), independent contribution to physical



fatigue, but did not account for significant variance in any of the other domains of fatigue.

### **Synthesis of Findings**

In summary, qualitative investigations have highlighted uncertainty as a highly challenging but common component of the HF illness experience. Consistent with the aims of qualitative research, these studies used convenience, purposive, or theoretical sampling procedures and included small sample sizes (2 to 33 participants). Two studies (Bekelman, Nowels, Retrum et al., 2011; Brännström et al., 2007) included caregivers in addition to individuals living with HF. Quantitative studies used larger sample sizes (93 to 201 participants), but also used convenience sampling. The majority of samples included a greater percentage of men, individuals older than age 65, and participants with NYHA class II-IV HF. Nordgren et al.'s (2007) study was the only one to specifically examine the HF experience in a middle-aged population, but their sample only included 7 people. Only one study included African American participants (Russell et al., 1998). Studies addressing uncertainty in HF were conducted in the United States (Bekelman, Nowels, Retrum et al., 2011; Dougherty et al., 2007; Jurgens, 2006; Russell et al., 1998, Thompson, 2006; Winters, 1999), the United Kingdom (Aldred et al., 2005), New Zealand (Waterworth & Jorgensen, 2010) and Sweden (Brännström et al., 2006; Brännström et al., 2007; Ekman et al., 2000; Falk et al., 2007; Nordgren et al., 2007).

Uncertainty was described in relation to symptoms (Aldred et al., 2005; Bekelman, Nowels, Retrum et al., 2011; Brännström et al., 2006; Brännström et al., 2007; Falk et al., 2007; Jurgens, 2006; Russell et al., 1998; Winters, 1999) and planning for the future or anticipation of death (Aldred et al., 2005; Bekelman, Nowels, Retrum et al.,

2011; Brännström et al., 2006; Brännström et al., 2007; Nordgren et al., 2007, Waterworth & Jorgensen, 2010; Winters, 1999). Participants suggested that information, supportive communication, trusting relationships, health care provider support, religion or spirituality, and self-care behaviors helped them to deal with uncertainty (Brännström et al., 2006; Brännström et al., 2007; Waterworth & Jorgensen, 2010; Winters, 1999). Participants in a few studies expressed the ability to perceive positive outcomes from their HF diagnosis, such as reframing their expectations, finding joy and meaning in their lives, and focusing on new possibilities (Brännström et al., 2006, Nordgren et al., 2007, Winters, 1999).

Quantitative assessments of uncertainty levels were obtained via the MUIS-C or a Swedish-translated version of the CPS. For the most part, moderate levels of uncertainty were reported (Ekman et al., 2000; Jurgens, 2006; Winters, 1999) Positive associations were reported between uncertainty and spirituality (Thompson, 2006), HF-specific somatic awareness (symptom severity; Jurgens, 2006), and tiredness and reduced functional abilities (Falk et al., 2007). One nurse-directed education interventional, which randomly assigned participants to groups, did not demonstrate significant differences in uncertainty scores between the intervention and control groups (Ekman et al., 2000).

### **Growth Through Uncertainty**

Results of both qualitative and quantitative studies indicate that uncertainty is common in HF. As proposed within the RUIT, positive reappraisal of uncertainty may be a stimulus for growth.

## Qualitative Studies

The Winters (1999) study reviewed above was the only investigation to provide some qualitative support for the RUIT within an HF population. Winters suggested that “In response to uncertainty, participants looked to the future, maintained a positive outlook, and identified a positive outcome resulting from their illness” (p. 89). Mishel and Murdaugh’s (1987) study of family adjustment to heart transplantation provided preliminary qualitative support for how family members of patients with major cardiac conditions process unpredictability and adopt a new life perspective in relation to three phases of transplantation: (a) waiting for a heart, (b) hospitalization (transplant surgery and the post-operative period), and (c) recovery and life after the transplant. Participants were 20 family members (14 wives, 5 mothers, and 1 sister) of heart transplant recipients or of individuals awaiting transplant who were willing to participate in support groups focused broadly on their experiences. Support sessions were conducted over 12 weeks. Data collection and analysis were concurrent using a grounded theory approach.

The major theme was *redesigning the dream*, which summarized the cognitive and behavioral changes experienced by the family members through the phases of waiting, hospitalization, and recovery. Those phases were characterized by the subthemes of *immersion*, *passage*, and *negotiation*, respectively. Immersion and passage described the cognitive and psychosocial changes experienced almost exclusively by the family members, whereas the negotiation phase described how the family member and patient integrated ongoing uncertainty into their future together. Throughout this process, the family members restructured their views of reality to create a *new normal*. Mishel and Murdaugh (1987) described how living with ongoing uncertainty resulted in a new view

of reality in which family members redefined their expectations and integrated uncertainty in their worldview. They did not, however, provide substantial support that this process resulted in the positive appraisal of uncertainty or growth.

Fleury, Kimbrell, and Kruszewski (1995) explored the experiences of women after an acute coronary event to better understand the psychosocial processes that support their recovery. The sample consisted of 13 women in the United States: 4 had been diagnosed with an acute MI, 5 had undergone CABG surgery, 2 had undergone PTCA, and 2 had been diagnosed with myocardial ischemia. Data were collected from weekly support group meetings over 9 months. Sessions were initiated with open-ended questions about how participants were doing in general. Sessions were not recorded; rather, the researchers took detailed notes after each session describing the content discussed, observations, and group interactions.

The major theme that evolved from this study was *healing*, which was defined as “an individual patterning that evolved over time and incorporated a struggle through the uncertainty that surrounded the cardiac event to a way of creating a new and positive health behavior change” (Fleury et al., 1995, p. 477). Fleury et al. (1995) characterized this process as involving three nonsequential stages, *surviving*, *originating*, and *patterning balance*. *Surviving* was characterized by instability that initiated changes in personal worldviews. *Originating* involved developing new ways of living to reduce cardiac risk in the face of uncertainties. *Patterning balance* was characterized by reprioritizing life goals and values and redefining personal worldviews to effect positive lifestyle changes. The authors argued that the process was congruent with the RUIT.

Baier (1995) conducted a qualitative study exploring how individuals living with schizophrenia and their family members experienced uncertainty to specifically assess the applicability of Mishel's (1990) RUIT to this population. She interviewed 6 individuals with schizophrenia (4 females and 2 males) who were well controlled on antipsychotic medications and 5 family members. Participants were recruited through a mental health support group. Baier reported that all participants described uncertainty as part of their illness experience and used probabilistic thinking defined as the ability to accept illness uncertainty and perceive alternative ways of living to varying degrees. Uncertainty was related to the effectiveness of drug therapy, symptom patterns, timing of relapses, mortality, and managing family responsibilities. Some participants suggested that uncertainty contributed to thoughts of fear, doubt, concerns, and obstacles, while one participant and the four family members of the same relative were able to perceive hope and optimism through their uncertainty.

Brashers et al. (1999) conducted a qualitative study exploring uncertainty in people living with HIV who initially thought that they would die from their disease but, due to successful treatment, were surviving. They recruited 33 individuals from an Adult AIDS Clinical Trials Unit in the midwestern United States to participate in focus group discussions. The interview guide focused on four main areas: (a) general experiences of being HIV positive, (b) sources of uncertainty related to HIV status, (c) how uncertainty impacted participants' lives, and (d) strategies used to manage uncertainty. Latent content analysis and constant comparative procedures guided data analysis. Participants described uncertainty related to ambiguous symptoms, complicated treatment regimens, inadequate education about diagnosis and prognosis, and the unpredictable disease trajectory. These

findings were congruent with Mishel's (1988) original UIT. Participants also discussed the need to restructure certain facets of their lives (life priorities, financial support, employment, interpersonal relationships, and long-term plans) to come to terms with a new reality. The authors described this as a process of renegotiation that prompted new uncertainties related to the future, social roles and identities, interpersonal relationships, and quality of life. These accounts lent some support for growth as an outcome of uncertainty as conceptualized within the RUIT.

Bailey, Wallace, and Mishel (2007) conducted a qualitative study with 10 men diagnosed with localized prostate cancer within the previous year who had opted for a watchful waiting approach. Time since diagnosis ranged from 4 months to 1 year. Participants were interviewed once by the primary investigator, who asked broad questions that addressed living with prostate cancer, treatment decision-making processes, sources of uncertainty, and strategies to cope with uncertainties and other illness challenges. Mishel's (1990) RUIT served as the guiding theoretical framework for this study and helped to organize findings into the following three categories: uncertainty, appraisal of danger, and appraisal of opportunity. Uncertainty resulted from the limited number of symptoms and ambiguous nature of symptoms, vague diagnostic and prognostic indicators, and multiple treatment choices. Participants most commonly appraised their illness and its uncertainty as danger as a result of unclear treatment guidelines (need to obtain a second opinion, and watchful waiting vs. more aggressive therapies), and treatment choices. Some participants did perceive their experience as positive and viewed their future optimistically. Bailey et al. reported that several participants "viewed their decision to watch and wait as an opportunity to successfully

manage their uncertainty through work, self-care, keeping options open, and the use of alternative medications and prayers” (p. 738).

### **Quantitative Studies**

Mast (1998) examined correlates of illness uncertainty and emotional distress in breast cancer survivors. The sample included 109 women, originally diagnosed with nonmetastatic breast cancer (stage I-III), who were 1 to 6 years post-treatment. Length of time since treatment ranged from 12 to 68 months, with a mean of 35 months. Mast hypothesized that positive appraisal was associated with greater time since completion of treatment and less emotional distress. They also hypothesized that time since treatment completion was negatively correlated with emotional distress among those reporting positive reappraisal. Positive reappraisal was measured using the GTUS. Emotional distress was measured using the Profile of Mood States-Short Form (POMS-SF). Scores on the GTUS (possible range, 39-234) ranged from 87 to 220 (mean 166; *SD* 28.1). Women who reported higher unpredictability on the MUIS did reported less personal growth. As hypothesized, GTUS scores were significantly and negatively correlated with distress. Using hierarchical regression, GTUS scores made a significant independent contribution to emotional distress controlling for coexisting illnesses, uncertainty, fear of reoccurrence, and symptom distress; this model predicted 51% of the variance in emotional distress. Mast (1998) did not find a significant association between length of time since treatment and positive reappraisal or between length of time since treatment and emotional distress. Furthermore, length of time since treatment did not predict higher GTUS scores, contradicting a key premise of the RUIT, that perceiving uncertainty as part of a new life view requires cognitive reframing over time.

Mishel et al. (2005) and Gil et al. (2006) reported 10-month and 20-month outcomes, respectively, from a randomized trial of a home-based uncertainty management intervention for African-American ( $n = 149$ ) and White ( $n = 360$ ) breast cancer survivors 5 to 9 years after treatment. Approximately 95% of the sample was surveyed at the 20-month follow-up (Gil et al., 2006). The intervention materials consisted of audiotapes of various cognitive strategies to promote emotion-focused coping (relaxation, imagery, calming self-talk, and distraction) and a self-help manual that reviewed information on symptoms and side effects of treatment, cancer resources, and other content individualized to each participant's needs. A trained nurse reinforced this information and allowed the participants to practice one of the four cognitive strategies during four weekly phone calls that lasted approximately 30 minutes. During the phone call, the researcher also discussed managing uncertainty in general. The women in the control group received usual care (Gil et al., 2006; Mishel et al., 2005).

At baseline, participants were initially blocked by race and then randomly assigned to the experimental or control group. Data collected at baseline, 10 months, and 20 months included assessments of uncertainty, uncertainty management (cancer knowledge, communication, social support, and cognitive reframing), coping, personal growth, and negative mood state. Measures included a survivor version of the MUIS to measure uncertainty, the Cancer Survivor Knowledge Scale to measure cancer knowledge, the satisfaction subscale of the Social Support Questionnaire to measure social support satisfaction, a patient-provider communication rating scale to measure communication, the problem-solving and cognitive reframing subscale of the Self-Control Schedule to measure cognitive reframing, a modified version of the Coping



Strategies Questionnaire to measure cognitive coping styles, a researcher-developed questionnaire to measure adequacy and helpfulness of information as a facet of coping, the POMS-SF to measure negative mood state, and the GTUS to measure personal growth. A detailed overview of instrument selection that included a description of each scale's psychometric properties was provided (Gil et al., 2006; Mishel et al., 2005). A research nurse not involved with baseline data collection or the intervention called each participant monthly for 8 months to collect data on the uncertainty triggers and symptoms that the women had experienced, the strategies used to deal with them, and the effectiveness of each strategy (Mishel et al., 2005).

Descriptive statistics at 10 months indicated that the women used the audiotapes to help manage their uncertainty between zero to nine times a month, with a mean of 2.24 ( $SD = 1.63$ ); calming self-talk was used the most frequently (75%), followed by distraction and relaxation (53%), and imagery was used the least (Mishel et al., 2005). The women reported that all strategies except imagery were helpful. In addition, the majority of women thought the manual was helpful in managing symptoms and referred to it between zero and seven times a month, with a mean of 2.45 times per month ( $SD = 1.88$ ; Mishel et al., 2005).

Results indicated that women in the treatment group reported significant reductions in uncertainty, increased use of cognitive reframing, improved cancer knowledge, greater use of distraction as a coping method, increased perceptions of the amount and helpfulness of information, and consistent levels of personal growth at 20 months compared with baseline. In addition to significant improvements in total personal growth scores, women in the treatment group also reported increases in the GTUS

subscales, flexibility and a new view of life. In the control group, total personal growth scores and flexibility and new view of life subscale scores decreased from baseline to 10 months and then decreased further from 10 months to 20 months. These findings were more pronounced in African American women. Mishel et al. (2005) and Gil et al. (2006) suggested that the results demonstrated preliminary evidence of effectiveness of a nurse-directed cognitive behavioral intervention in reducing uncertainty and facilitating personal growth through enhancing positive reappraisal skills in breast cancer survivors.

Porter et al. (2006) conducted a secondary analysis of the data from the intervention trial (Gil et al., 2006; Mishel et al., 2005). The secondary sample included 524 long-term breast cancer survivors (all female; 369 Whites, 155 African Americans; mean time since diagnosis = 81 [ $SD = 14$ ] months; 85% stage I or II at diagnosis). The purpose of this secondary analysis was to test a conceptual model (based in part on concepts from the UIT and RUIT) of mood state and personal growth using structural equation modeling. Predictors of mood state and growth included demographic variables (age and education), disease factors (number of symptoms, symptom distress, and other health problems), social factors (social support satisfaction and religious involvement), negative cognitive factors (uncertainty, troublesome thoughts, and catastrophizing), and cognitive reframing. The POMS-SF was used to measure negative mood state, and the GTUS was used to measure personal growth.

Religious involvement and social support satisfaction directly strengthened cognitive reframing in both White and African American participants. In both racial groups, a greater number of symptoms, more religious participation, more education, and younger age were directly correlated with greater personal growth. Although cognitive

reframing was significant in predicting personal growth for both groups, there was a larger effect in African American participants. Cognitive reframing also mediated the influence of social support and partially mediated the influence of religious involvement on growth. Negative cognitive state was directly correlated with less growth and mediated the influence of symptom distress and social support satisfaction on growth in both groups. In the final model for both ethnic groups, negative cognitive state explained 35% of the variance in negative mood state and 25% of the variance in growth, making the largest contributions to the model. Cognitive reframing explained 21% of the variance in growth for White women and 40% of the variance in growth for African American women, providing support for the relationship between positive reappraisal and growth proposed in the RUIT.

Bailey, Mishel, Belyea, Stewart, and Mohler (2004) tested the effectiveness of a watchful waiting intervention for men with prostate cancer. The intervention incorporated principles based on the RUIT, including cognitive reframing and positive reappraisal of uncertainty. The sample consisted of 39 men diagnosed with prostate cancer (nearly all Stage 1 or 2) who had opted for watchful waiting in place of more aggressive therapy. The average duration of watchful waiting was 52 months. Participants were randomly assigned to usual care or the intervention, which consisted of five weekly phone calls from a study nurse that were focused generally on providing factual information while encouraging probabilistic thinking to incorporate uncertainty into participants' worldviews. In addition, the calls emphasized maintaining an optimistic outlook, participation in activities, and ongoing awareness and monitoring of symptoms.

Findings post-intervention did not demonstrate a statistically significant difference between the intervention and control groups in total growth scores, although the increase in GTUS scores for the intervention group (approximately 15 points) was substantially greater than in the control group (approximately 5 points).

Santacroce and Lee (2006) examined relationships among post-traumatic stress symptoms, uncertainty, and health promotion behaviors in young adult cancer survivors ( $N = 45$ ). They hypothesized that symptoms of post-traumatic stress mediated the relationship between uncertainty and health promotion behaviors. As expected, uncertainty was positively and significantly associated with post-traumatic stress symptoms and inversely associated with health-promoting behaviors. Uncertainty and post-traumatic stress had statistically significant negative bivariate correlations with health-promoting behaviors. However, the hypothesized mediating role of post-traumatic stress was not supported. When modeled together with uncertainty, the relationship between post-traumatic stress and health-promoting behaviors was no longer statistically significant, whereas the negative association between uncertainty and health-promoting behaviors remained statistically significant and was similar in magnitude to the relationship before the hypothesized mediator was added to the model. A respecified model in which uncertainty mediated the relationship between post-traumatic stress and health-promoting behaviors was better supported.

Y. L. Lee, Gau, Hsu, and Chang (2009) subsequently developed a conceptual model of uncertainty, post-traumatic stress, and health behaviors in young adult and adolescent survivors of childhood cancer based on an integrative, narrative literature review. The model, based in part on the RUIT, proposed that reduced or time-limited

uncertainty was conducive to developing a new view of life and health-promoting behaviors (or decreases in risky health behaviors), whereas chronic, unresolved uncertainty was a risk factor for post-traumatic stress disorder and risky health behaviors (or decreases in health-promoting behaviors). However, the model posited post-traumatic stress as a potential mediator between uncertainty and health-promoting behavior, which was *not* supported in the earlier study by Santacroce and Lee (2006). The authors acknowledged that the model was in need of empirical validation before it could be claimed to support the RUIT.

### **Synthesis of Findings**

In summary, a small number of qualitative and quantitative studies were either informed by the RUIT or generated tentative support for uncertainty as a stimulus for growth. These studies examined the illness experiences of people living with heart disease (Fleury et al., 1995; Winters, 1999), schizophrenia (Baier, 1995), HIV (Brashers et al., 1999), breast cancer (Gil et al., 2006; Mast 1998; Mishel et al. 2005; Porter et al., 2006), prostate cancer (Bailey et al; 2004; Bailey et al., 2007), or childhood cancer (Santacroce & Lee, 2006). In addition, one study examined experiences of family members in the context of heart transplantation (Mishel & Murdaugh, 1987). Qualitative sample sizes ranged from 10 (Bailey et al., 2007) to 33 (Brashers et al., 1999), whereas quantitative sample sizes ranged from 39 (Bailey et al., 2004) to 524 (Porter et al., 2006).

The majority of studies were conducted in the United States, seven of which were conducted by researchers affiliated with the University of North Carolina (Mishel's academic home). The majority of participants were female, with the exception of participants in the HIV (Brashers et al., 1999) and prostate cancer (Bailey et al., 2004,

2007) investigations. Most studies included a greater percentage of older participants, with the exception of studies conducted by Baier (1995), Brashers et al. (1999), Santacroce and Lee (2006), and Mishel and Murdaugh (1987). Although the majority of participants were White, relevant ethnic differences between White and African American breast cancer survivors were reported by Mishel et al. (2005) and Gil et al. (2006).

Qualitative studies generated data related to growth through uncertainty by broadly exploring general illness experiences (Fleury et al., 1995; Mishel & Murdaugh, 1987) or illness knowledge and future concerns (Baier, 1995). In addition to examining the overall illness experience, two studies included an explicit focus on sources of uncertainty and approaches to managing uncertainty (Bailey et al., 2007; Brashers et al., 1999), providing data more congruent with appraisals of uncertainty. In particular, Bailey et al. (2007) specifically used the RUIT to help organize findings during data analysis.

Data were collected in either group sessions (Brashers et al., 1999; Fleury et al., 1995, Mishel & Murdaugh, 1987) or via one-time interviews (Baier, 1995; Bailey et al., 2007). The use of group sessions and the lack of audiotaping in two studies (Baier, 1995; Fleury et al., 1995) may have contributed to bias in study results. In two studies, longitudinal data collection provided better insights related to how uncertainty is processed over time (Fleury et al., 1995; Mishel & Murdaugh, 1987).

All of the qualitative studies concluded that some participants described the ability to adopt a new life perspective through illness uncertainty via a process of negotiation, redefining expectations, or restructuring ways of thinking or living. Themes or findings characterizing this process included redesigning the dream (Mishel &

Murdaugh, 1987), healing (Fleury et al., 1995), renegotiating the future (Brashers et al., 1999), and danger and opportunity appraisals (Baier, 1995; Bailey et al., 2007). Although a new view of reality was evident in all of these studies, this outcome was not consistently characterized favorably by participants. For example, Baier (1995), Brashers et al. (1999), and Mishel and Murdaugh (1987) reported, to a greater degree, new realities largely formed by adverse thoughts and emotions. Reports of positive perceptions arising from uncertainty in these studies were not as common, but when present, they described hope or optimism for the future, personal or spiritual growth, or finding joy. In one study, positive views reported by Baier (1995) were generated largely by members of the same family, suggesting another potential bias. Although qualitative evidence to support positive outcomes resulting from the appraisal of uncertainty is limited, this body of literature did reveal participants' abilities to reconstruct new realities that were concurrently shaped by negative and positive perceptions.

Fleury et al.'s (1995) study provided qualitative support for integrating uncertainty into positive cognitive changes, which is congruent with key propositions of the RUIT, despite the study not being explicitly based on the RUIT. Fleury et al. (1995) described this transition as an iterative process, which they characterized as being rooted initially in chaos and instability that evolved over time to create favorable cognitive and behavioral health changes. In conclusion, there is some qualitative, empirical support for Mishel's (1990) claim that individuals living with chronic illness can integrate uncertainty into a new reality, but no conclusive evidence about whether that process routinely results in the positive reappraisal of uncertainty, opportunity, or growth. Rather

this qualitative synthesis suggests that some individuals are capable of perceiving positive outcomes in the face of uncertainty.

In quantitative analyses, researchers discussed growth through uncertainty as a process or an outcome and characterized it as positive reappraisal (Mast, 1998) or personal growth (Bailey et al., 2004; Gil et al., 2006; Mishel et al., 2005; Porter et al., 2006) and often referred to it interchangeably as a new view of life. Researchers either examined relationships between this concept and other relevant variables (e.g., uncertainty, emotional distress, cognitive reframing, symptoms, comorbidities, social support, religious participation, coping strategies, or time), or they examined differences in these variables among groups. Quantitative investigations were conducted only with cancer populations: one with prostate cancer patients (Bailey et al., 2004), one with survivors of childhood cancers (Santacroce & Lee, 2006), and four with breast cancer survivors (Gil et al., 2006; Mast, 1998; Mishel et al., 2005; Porter et al., 2006). Three of these studies reported data from one larger program of research (Gil et al., 2006; Mishel et al., 2005; Porter et al., 2006). The GTUS was used to measure positive reappraisal or personal growth in all of these studies. All but one of the quantitative studies (Santacroce & Lee) were conducted by investigators affiliated with the University of North Carolina.

Significant negative correlations were found in breast cancer survivors between personal growth and unpredictability related to illness progression and prognosis (Mast, 1998) and emotional distress (Mast, 1998; Porter et al., 2006). Significant positive correlations were found between personal growth and a greater number of symptoms, more religious involvement, more education, and younger age (Porter et al., 2006).



Studies that examined differences in personal growth were intervention studies that evaluated the effects of interventions informed, to varying degrees, by the RUIT (Bailey et al., 2004; Gil et al., 2006; Mishel et al., 2005). Whereas both interventions addressed cognitive strategies to address uncertainty, the watchful waiting intervention (Bailey et al., 2004) more fully incorporated key principles of the RUIT, such as probabilistic thinking, integrating uncertainty into life, and positive reappraisal, consistent with the study's purpose, to help participants incorporate ongoing uncertainty into a new worldview via cognitive reframing. The uncertainty management intervention used in the other study, which aimed to help participants cope with uncertainty and manage symptoms, was based on more traditional cognitive-behavioral strategies, such as relaxation techniques and a more structured educational component. Significant differences in reports of total personal growth at 10 months and 20 months in both African American and White breast cancer survivors were found between the control and intervention groups, but not in men living with prostate cancer at follow-up. Both studies did report significant differences in the new view of life subscale of the GTUS at follow-up between the control and intervention groups.

Variations in findings most likely result from differences in population characteristics and in the interventions. In particular, although Bailey et al. (2004) provided a comprehensive description of key components of the watchful waiting intervention, the intervention nurse individualized content based on the unique concerns of each participant. It was not clear whether a structured template guided this intervention and the extent to which various components of the intervention (probabilistic thinking, incorporating uncertainty, optimism for the future, participation in activities, self-

monitoring and vigilance) were emphasized. In contrast, the uncertainty management intervention implemented with breast cancer survivors was based on specific topics and a consistent and structured process, although some content could be tailored to individual needs. Results from these two studies provide preliminary evidence that cognitive strategies aimed to help process uncertainty can help facilitate aspects of personal growth in cancer populations.

In addition to demonstrating whether uncertainty can serve as a stimulus for growth, qualitative and quantitative studies provided data related to the influence of time on the development of personal growth through uncertainty, a key premise within the RUIT. Time was considered in terms of time since diagnosis or treatment or in the context of phases of an illness (diagnosis, treatment, and recovery). Mishel and Murdaugh (1987) collected data weekly over 12 weeks, and Fleury et al. (1995) collected data weekly over 9 months, generating longitudinal qualitative insights that described how coping with illness uncertainty evolved over time through specific phases and resulted in a new reality in cardiac populations. Baier (1995) assessed the number of years participants had been diagnosed with schizophrenia and considered time since diagnosis in evaluating uncertainty as an opportunity; mixed responses limited the ability to draw definitive conclusions from this study related to time and growth through uncertainty.

Mast (1998) measured length of time since treatment and did not find a significant correlation between time and positive reappraisal in breast cancer survivors. In contrast, Mishel et al. (2005) and Gil et al. (2006) reported significant improvements in personal growth over 10 months and 20 months, respectively, in an uncertainty management

intervention group, and decreases in personal growth over this period in the control group. Similarly, Bailey et al. (2004) reported significant improvements in the new view of life subscale of the GTUS and, although not significant, trends toward total growth in the intervention group at the 10-week follow-up. These findings suggest that time may play a role in the appraisal of illness uncertainty, but there are not enough data to conclude that time alone contributes to the positive appraisal of uncertainty as an opportunity. Rather, interventions that promote cognitive restructuring of uncertainty, at least in cancer populations, likely contribute to personal growth over time. The small number of studies and variations in sample characteristics limit judgments about the influence of time on growth through uncertainty.

### **Nature of Illness**

The nature of an illness is conceptualized within the RUIT in terms of disease pattern (acute vs. chronic vs. disease reoccurrence) and illness duration. As described in Chapter 1, HF is a chronic disease resulting from structural and functional abnormalities of the heart and is characterized by varying degrees of symptoms and activity limitations, which can improve or worsen based on a variety of factors. The ACC/AHA guidelines (Hunt et al., 2001) and NYHA classifications of HF, also described in Chapter 1, are used to categorize HF's disease stage and activity limitations. Disease patterns in HF can best be understood in terms of disease stage (e.g., NYHA class), and changes in HF signs and symptoms that lead to acute exacerbations of HF. Acute or progressive worsening of chronic, stable HF results from increasing symptoms and/or deteriorating activity tolerance when individuals (a) are nonadherent with diet or drug therapy, (b) affected by a secondary physiological insult or concurrent illness, (c) experience adverse drug side

effects or interaction, or (d) are no longer responsive to existing treatments (Jessup et al., 2009). Clinical manifestations of acute exacerbations, such as respiratory distress, are normally preceded by fluid overload, significant reductions in cardiac output, or a combination of both (Jessup et al., 2009). Acute exacerbations (also referred to as acute HF syndromes or acute decompensated HF) may be followed by extended periods of stability (Hupcey et al., 2009; Jessup et al., 2009).

This unpredictable illness course complicates practitioners' ability to determine the number of years that someone can survive with HF (Hupcey et al., 2009; Jessup et al., 2009). Duration of illness in HF is often considered in terms of prognosis. Although the duration of time that an individual can live with HF has improved in recent years, the most current evidence still indicates that 50% of individuals diagnosed with HF will die within 5 years (Jessup et al., 2009; Levy et al., 2006). Sudden cardiac death from ventricular arrhythmias also contributes to mortality in HF. Although sudden cardiac death is more common in end-stage HF (stage D), individuals in less advanced stages can still succumb to sudden death (Jessup et al., 2009). In summary, although guidelines exist to categorize patterns in HF and guide prognosis, in general, the overall nature of HF remains unpredictable.

### **Symptom Status**

Over the last several decades, researchers have conceptualized symptoms in a variety of ways. Leventhal and Johnson (1983) defined symptoms within their theory of self-regulation as the actual representations of illness experienced by an individual via cognitive processing, characterizing the symptom as an objective occurrence distinct from an individual's emotional response to it. Rhodes and Watson (1987) emphasized the

subjective nature of symptoms, characterizing symptoms as a change perceived by an individual that is reflective of abnormalities in functioning, sensation, or appearance. Similarly, Lenz, Pugh, Milligan, Gift, & Suppe (1997) defined symptoms, within their middle-range theory of unpleasant symptoms, as perceived markers of alterations in normal functioning experienced by an individual. They also suggested that symptoms are multidimensional, they can be experienced individually or in combination, and symptom assessment should not only address the presence or absence of a symptom, but should also consider the frequency, severity, and distress associated with the symptom. Dodd et al. (2001) defined symptoms as subjective experiences that represent alterations in normal biopsychosocial abilities, cognition, or sensations; they are typically distressful and indicators of deteriorating health.

Understanding how an individual interprets a symptom (the meaning a person attributes to a symptom) is another important facet of more recent conceptualizations of the symptom experience (Armstrong, 2003). Symptom experience has been characterized as “the perception of the frequency, intensity, distress, and meaning occurring as symptoms are produced and expressed,” in which the situational and existential meaning of symptoms and the collective influence of multiple symptoms are considered (Armstrong, 2003).

Within the RUIT, symptoms are conceptualized in terms of pattern, that is, “the degree to which symptoms are present with sufficient consistency to be perceived as having a pattern or configuration,” and in terms of event congruence, that is, “the consistency between the expected and the experienced illness-related events,” in this case, symptoms (Mishel, 1990, p. 59). In the literature, researchers using this framework

have evaluated symptom pattern in terms of symptom ambiguity (inability to recognize a symptom as related to a particular illness) and severity of symptoms. The event congruence of symptoms has been evaluated via the predictability of the symptom (ability to predict the frequency, onset, duration, intensity, location, and meaning of a symptom) (Mishel & Clayton, 2008). For the purposes of this study, symptom status was conceptualized as an individual's ability to perceive symptoms and components of a symptom pattern to include occurrence, frequency, severity, distress and overall burden. In HF, inadequate cardiac output and insufficient venous return contribute to the presence of symptoms, such as dyspnea or abdominal fullness (Kemp & Conte, 2012). As described in Chapter 1, select symptoms during activity (notably fatigue, dyspnea, palpitations, and angina) contribute to the NYHA classification system, which is used to stage HF and as an approximate indication of prognosis. Therefore, although symptoms are a key component of disease severity, they do not on their own capture the full scope of disease severity. By the same token, estimates of disease stage do not entirely account for symptom severity. Consequently, disease severity in this study will be operationally defined as NYHA stage, whereas symptom status cannot be equated to disease stage.

### **Symptom Patterns in HF**

There is a large body of literature exploring symptoms in HF. Researchers have generated knowledge related to symptom status in HF through studies that explore the experience of HF broadly (Bekelman, Nowels, Retrum et al. 2011; Hopp et al., 2010; Yu et al., 2007); focus on specific symptoms, such as fatigue or dyspnea (Austin, Williams, & Hutchison, 2012; Falk et al., 2007; Jones, McDermott, Nowels, Matlock, & Bekelman, 2012; Parshall et al., 2001); assess HF symptoms in general (Janssen, Spruit, Uszko-

Lencer, Schols, & Wouters, 2011; Janssen et al., 2008; Walke et al., 2007); or evaluate symptom clusters (Jurgens, Moser et al., 2009; C. S. Lee et al., 2014; K. S. Lee et al., 2010; Song, Moser, Rayens, & Lennie, 2010). Research questions include how HF symptoms are related to comorbidities (Austin et al., 2012; Janssen et al., 2011; Jurgens, Hoke, Byrnes, & Riegel, 2009; Jurgens, Moser et al., 2009; Walke et al., 2007), age (Janssen et al., 2011; Jurgens, Hoke et al., 2009; Jurgens, Moser et al., 2009; Riegel et al., 2010; Zambroski, et al., 2005), gender (Austin et al., 2012; Jurgens, Hoke et al., 2009; K. S. Lee et al., 2010; Zambroski et al., 2005), HRQOL (Bekelman et al., 2007; Opasich et al., 2008; Zambroski et al., 2005), and overall morbidity or mortality (Ekman et al., 2005; Gallagher et al., 2012; C. S. Lee et al., 2014; Moser et al., 2011).

Researchers have used terms such as detect, recognize, identify, appraise, and experience somewhat interchangeably to characterize cognitive processes whereby individuals perceive symptoms. Symptom perception is assessed primarily via patient self-reports (spontaneous or in response to questionnaires or clinical interview). Self-reports may be real-time or retrospective based on patient recall, interviews, or medical record review (Lam & Smeltzer, 2012). Recall may involve questions about the usual pattern of the symptoms experienced over some recent time interval (e.g., past week or 2 weeks), or a specific episode (Parshall et al., 2012). Symptom perception is often discussed in terms of symptom severity, but terms that are used to convey symptom severity in the HF literature (e.g., burden, distress) are often used imprecisely and inappropriately, as though they were synonymous, even when they refer to different constructs (Landrum, 2009). The use of multiple descriptors, diverse instruments, and variations in aims of existing studies make it difficult to compare studies or draw

definitive conclusions from findings related to symptom perception, intensity, and predictability in HF (Landrum, 2009). For that reason, studies of symptoms in HF need to be examined closely to determine what was measured, as well as how and when it was measured. In this chapter, the focus is on studies that address symptom perception or reporting in HF in terms of patterns of occurrence, severity, or distress as relevant to evaluating HF or patient decisions to seek care.

### **Comorbidities**

Comorbidities are common in individuals living with HF (Janssen et al. 2011). In a large cross-sectional study drawn from a random sample of all Medicare recipients in the United States ( $N = 122,630$ ; aged 65 years or older), Braunstein et al. (2003) reported that more than 40% of participants had five or more comorbid conditions, of which the most common were HTN (55%), diabetes mellitus (31%), COPD (26%), eye conditions (24%), and high cholesterol levels (21%).

Walke et al. (2007) conducted an observational cohort study that examined the impact of comorbidities on the range and severity of symptoms reported by individuals living with either COPD ( $n = 74$ ) or HF ( $n = 59$ ; NYHA class III or IV). Participants were interviewed every 4 months for up to 24 months; 93 participants completed all phases of follow-up. Symptoms evaluated during data analysis included physical discomfort, pain, fatigue, lack of appetite, depression, anxiety, and shortness of breath. Symptom burden, which characterized a total symptom severity score, was calculated by totaling the individual symptom scores. Symptoms reported by the HF cohort in order of frequency included physical discomfort, fatigue, lack of appetite, shortness of breath, pain, depression, and anxiety. Symptoms present at baseline were not associated with



survival. The frequency of reports of shortness of breath, fatigue, pain, and depression increased significantly over time. The number of participants assessing symptoms as moderate to severe increased from baseline to follow-up for all symptoms. Using linear mixed-effects models, Walke et al. (2007) explored the relationships among symptom burden, length of time in the study, number of comorbidities, and survival. Symptom burden increased over time and in relation to an increased number of comorbidities, but not to a statistically significant degree.

### **Age, Gender, and Quality of Life**

In some HF studies, age and gender have been explored in relation to symptom perception and quality of life. In a sample of 77 men and women, aged 65 years and older, Jurgens, Hoke et al. (2009) explored factors associated with symptom recognition and response in an elderly cohort receiving care for worsening HF in the emergency center or in an inpatient unit of a tertiary care facility in the northeastern United States. The sample consisted of 40 men and 37 women; 66% were White, 48% were married, and the majority had at least a high school education. Approximately 80% of the participants met criteria for functional performance consistent with NYHA class III or IV.

Perception of symptom distress was measured using a researcher-modified version of The Heart Failure Somatic Perception Scale (HFSPS). The Response to Symptoms Questionnaire was used to measure cognitive, emotional, and social factors impacting symptom response. Researchers also collected data on HF history, symptom duration, onset, and care-seeking decisions. In addition, they conducted interviews with participants to better understand contextual factors that influenced decision-making and

care-seeking. Jurgens, Hoke et al. (2009) found that 56% of their participants were unable to identify HF symptoms or recognize their significance. Age, comorbidities, and gender did not contribute to significant differences in symptom distress scores. Almost half of the sample reported experiencing shortness of breath for more than 3 days prior to seeking medical care, but a majority of participants did not know that their symptoms were related to their HF diagnosis. Among participants who had been hospitalized for HF previously ( $n = 53$ ), approximately 20% did not know the etiology of their symptoms and were inclined to attribute HF symptoms to other causes, such as colds or strenuous activity.

Riegel et al. (2010) examined differences in symptom identification and interpretation between two age groups of individuals with NYHA class II-III: younger than 73 years of age ( $n = 13$ ) and 73 years of age or older ( $n = 16$ ). Most participants were male, were married, were born in Australia, had a high school education, and met criteria for NYHA class II. The only significant difference between age groups was a higher percentage of retired individuals in the older group. To assess symptom detection, the participants and a researcher rated shortness of breath and perceived exertion before, immediately after, and 5 minutes after a 6-minute walk test (6MWT) using a visual analog scale and the Borg scale of perceived exertion. Ratings between the participants and the researcher were compared for differences in scores (the ability to detect symptoms) and then compared by age groups. Inter-rater reliability was established between two researchers employing the 6MWT on patients not enrolled in this study. Inter-rater reliability was highest for the Borg scale (0.91). Results showed that, at each time point, there were greater discrepancies between the older participants' ratings of

their shortness of breath and the researcher's assessments, compared with the younger participants' and researcher's ratings. Significant differences between age groups in symptom detection were only found in ratings collected immediately after the 6MWT.

In addition, qualitative semistructured interviews were conducted to better understand the participants' ability to detect and interpret their symptoms. Riegel et al. (2010) found that older individuals with HF had greater difficulty in identifying and interpreting shortness of breath and fatigue as relevant to their HF management compared with younger persons; older participants attributed shortness of breath to being out of shape, fatigue to poor sleep or excessive daytime activity, and ankle edema to arthritis. Younger participants reported the ability to independently recognize symptoms earlier and therefore act on them. Younger participants also perceived symptoms as having an adverse impact on their daily lives, which increased their self-monitoring, whereas older participants perceived their health more favorably and, as a result, were less attentive to the effects of their HF. Consistent with Winters' (1999) study, Riegel et al. (2010) found that older participants experienced greater uncertainty related to symptom identification.

Zambroski et al. (2005) evaluated the impact of age and gender on symptom prevalence, severity, distress, and burden, and the influence of these factors on HRQOL in a sample consisting of 53 participants recruited from an outpatient HF clinic in the midwestern United States. Participants were predominantly male (66%), with a mean age of 55 years ( $SD = 9.6$ ), 89% were non-Hispanic White, 64% were married, and the majority met criteria for NYHA class III (57%). Participants completed a symptom assessment using the Memorial Symptom Assessment Scale–Heart Failure (MSAS-HF), a 32-item scale that asks the participants to rate the frequency, severity, and distress of

physical, psychological and HF-specific symptoms experienced during the last week, using a Likert scale. Symptom burden scores were the mean of the frequency, severity, and distress scores for each symptom. Results related to symptom prevalence, severity, distress, and burden, and relationships with age and gender were reviewed.

More than 60% of the sample reported the following symptoms in order of decreasing prevalence: shortness of breath (85.2%), lack of energy (84.9%), dry mouth (74.1%), feeling drowsy (67.9%), difficulty sleeping (64.2%), and worrying (61.5%). Symptoms reported as having the greatest frequency (at least occasionally or more frequently as reported by  $\geq 85\%$  of participants), in ascending order, included feeling bloated, worrying, shortness of breath, diarrhea, numbness/tingling in hands and feet, difficulty concentrating, other (non-chest) pain, lack of energy, poor appetite, and difficulty sleeping. The most severe symptoms (at least moderately severe) reported by this sample included change in the way food tastes (100%), difficulty sleeping (96.8%), other pain (90%), lack of energy (88.6%), shortness of breath (88.6%), numbness and tingling in the hands and feet (87%), and feeling drowsy (87%). Participants reported that lack of energy (63.6%), difficulty sleeping (60.6%) and shortness of breath (60.5%) were the most distressful and that shortness of breath, other pain, feeling bloated, poor appetite, change in the way food tastes, numbness/tingling in hands and feet, problems with sexual interest/activity, and lack of energy were the most burdensome (Zambroski et al., 2005).

Significant differences by gender in baseline characteristics included that men were more likely to be married and have a high school education compared with women. Significant gender differences related to prevalence, severity, distress, and burden

included the following: significantly more women than men reported feeling nervous and sweating, and men reported a significantly higher frequency of sexual problems that were significantly more distressing and burdensome (after controlling for marital status), compared with reports by women (Zambroski et al., 2005).

Significant differences related to age included the following: nausea was significantly more prevalent in older participants (patients 55 years and older) compared with younger participants (54 years or younger), and shortness of breath and waking up breathless at night were significantly more distressing and burdensome in younger participants. The only significant difference in baseline characteristics between the older and younger groups was that older participants were more likely to be taking antiarrhythmic medications. Using hierarchical stepwise regression, the authors found that after controlling for age and NYHA class, symptom prevalence and symptom burden made independent contributions to explained variance in HRQOL. Younger age, worse functional status, and greater symptom prevalence and burden predicted decreased HRQOL in this sample.

Opasich et al. (2008) assessed symptom severity in a study designed to test the appropriateness of the Edmonton Symptom Assessment Scale (ESAS) in a cardiac population and to assess the relationship between symptoms and global health status or quality of life. The sample consisted of 46 inpatients admitted to an Italian medical facility with late-stage HF (NYHA class III or IV). The sample was mostly male (57%), with a mean age of 71 years ( $SD = 11$ ) living with HF for a mean duration of 42 months ( $SD = 36$ ). Symptom intensity was measured using the original 10-point ESAS. The ESAS was administered two times a day (morning and afternoon) for 5 days. A total

daily score for each symptom was calculated by adding the morning and afternoon scores and generating a mean score. An overall symptom distress score was calculated by adding mean scores of the total daily symptom scores from the 5 days. Global health status was measured using the Kansas City Cardiomyopathy Questionnaire (KCCQ) summary score.

Although shortness of breath was reported as the most frequent symptom (100%), generalized discomfort, tiredness, and anorexia were found to be more distressing than shortness of breath. The authors suggested that participants may have become accustomed to ongoing shortness of breath and therefore did not rate it as distressing. In addition, total symptom distress scores were correlated with the KCCQ summary score ( $r = -0.78$ ;  $p = .0001$ ), but none of the individual symptoms independently predicted quality of life.

### **Symptom Variability and Clinical Outcomes**

Other researchers have also focused explicitly on the variability of symptom occurrence and severity. Webel, Frazier, Moser, and Lennie (2007) evaluated daily changes in patients' reports of dyspnea, edema, and weight gain for 1 month. A secondary aim of this study was to explore the relationships among dyspnea, edema, and body weight. Forty-eight individuals diagnosed with HF participated in this study. The mean age was 48 years ( $SD = 15$ ), 55% were male, 54% were married, and the majority met criteria for NYHA class III (54%). Each day for 30 days, participants rated their shortness of breath and edema on a 0-to-10 scale, with 0 indicating the absence of the symptom and 10 indicating maximal symptom severity. To measure body weight, participants weighed themselves on the same scale, at the same time, each day. The

sample, as a whole, reported consistent and moderate levels of daily dyspnea, but individual participants differed in the variability of symptom intensity from day to day. The sample was divided into a stable group ( $n = 26$ ; 62%) and an unstable group ( $n = 16$ ; 38%), based on conventional criteria for clinical stability/instability. The unstable group demonstrated greater variability in symptom intensity over the 30-day period compared with the stable group. Moderate changes in edema were also reported for the group as whole, with minor to moderate fluctuations over time. A subset of participants, who typically reported consistent levels of edema for extended periods, at certain time points, reported drastic increases in the extent of their edema. Weibel et al. suggested that sudden changes in HF stability (exacerbations) or the inability of participants to accurately assess more subtle alterations in edema could account for this finding. A positive and a significant association was present between dyspnea and edema daily reports every day for 30 days, whereas dyspnea and edema were not significantly correlated with body weight for the majority of study days. The authors recognized that individual assessments of symptom severity may not be interpreted consistently among participants, making it difficult to objectively compare reports, and that the addition of a functional assessment would most likely improve the ability to detect symptom variability.

Moser et al. (2011) examined symptom variability as a predictor of event-free survival in 71 individuals living with HF (NYHA class I/II 45%; class III/IV 49%; not documented 6%). Participants had a mean age of 62 years ( $SD = 14$ ), 59% were male, 87% were White, and 63% were married or lived with a significant other. Comorbidities were reported as follows: HTN (63%), previous MI, CABG or coronary intervention (58%), diabetes (37%), reduced kidney function (20%), stroke (13%), and peripheral

vascular disease (PVD; 14%). Participants rated shortness of breath, swelling, fatigue, and difficulty sleeping every day for 30 days using the Daily Symptom Scale. This instrument assesses symptom severity on a 0-to-10 scale, with 0 indicating the absence of the symptom and 10 indicating the highest symptom severity. The researchers conducted monthly phone follow-ups to assess outcomes of event-free survival, specifically hospitalizations and/or death, and then verified verbal reports with hospital records.

Ten nurses with HF expertise used consensus procedures to organize symptom patterns using graphic representations of daily reports into the following categories: mild, moderate, or severe symptoms and high or low symptom variability. In addition, for each participant, 30-day symptom scores were totaled to derive a mean symptom score as a measure of symptom severity. Symptom variability for each participant was determined using standard deviations of the symptom scores over the 30-day period. The median of the standard deviations was used to categorize scores into a high variability and a low variability group. More than 95% of the participants reported experiencing each of the four symptoms during the 30 days. Approximately 94% of participants reported shortness of breath, 90% reported difficulty sleeping, 89 % reported fatigue, and 82% reported edema, to varying degrees, every day. On the whole, symptom ratings were low to moderate in severity.

Associations between symptom severity scores were assessed for each combination of symptoms and found to be both positive and significant, indicating that as the severity of one symptom increased, so did the severity of the others. Correlations between symptom variability scores were positive and significant for all symptom combinations, with the exception of fatigue and edema. Furthermore, an inverse



relationship was found between severity of shortness of breath and variability of shortness of breath, indicating that as variability increased, severity decreased.

Participants who reported more variability in their shortness of breath and/or edema were more likely to be hospitalized compared with those who reported less symptom variability. Using Cox proportional hazards models, the authors found that symptom variability related to shortness of breath and edema predicted event-free survival independent of age, gender, symptom severity, ejection fraction, and comorbidities. Symptom severity did not predict event-free survival.

Ekman et al. (2005) examined the predictive ability of self-reported severity of symptoms (breathlessness, fatigue, angina, orthopnea, and edema) on worsening HF, hospitalization, and mortality in a sample of 3,029 individuals. This study was a secondary analysis of a large, multicenter, randomized controlled trial which was conducted in 15 European countries to evaluate the effectiveness of beta-blocker therapy on HF outcomes. Participants were mostly men (79%), with a mean age of 62 years and designated as NYHA class II (48%), NYHA class III (48%), or NYHA class IV (4%). Breathlessness, fatigue, and angina were evaluated using a 5-point scale that assessed the presence of symptoms with different degrees of activity; orthopnea was measured as present or absent, and edema was measured as present or absent and by location. Data were collected at baseline and every 4 months for a mean of 58 months.

Univariate analysis revealed that breathlessness, orthopnea, and fatigue were significantly associated with mortality and deteriorating HF and that angina was significantly associated with mortality and all-cause hospitalization. The influence of symptom severity on selected outcomes was assessed using Cox proportional hazards

models controlling for multiple baseline characteristics (age, gender, NYHA classification, duration of illness, cause of HF, comorbidities, and drug therapy). Breathlessness significantly predicted increased mortality and all-cause hospitalization, and fatigue significantly predicted worsening HF, after controlling for baseline characteristics.

Gallagher et al. (2012) examined patterns and duration of symptoms prior to a first-time hospitalization for HF. Participants were recruited from an Australian HF registry ( $N = 242$ , 54% male; mean age = 79 years). A majority of participants met criteria for NYHA class II (38%) or III (24%). Participants were asked about the occurrence and duration of 10 HF-specific symptoms prior to their admission. The researchers used this information to construct two variables: duration of acute symptom onset and symptom pattern (gradual onset vs. multiple symptoms occurring simultaneously and more rapidly).

Participants reported having experienced up to seven symptoms (mean = 2.7) for a median of 4.5 (range, 1-7) days prior to hospitalization. The most frequently reported symptoms were worsening dyspnea on exertion (88%), swelling (49%), and cough (27%). Approximately one third of participants reported multiple simultaneous symptoms rather than a gradual onset of symptoms. Participants sought hospitalization more quickly for chest pain, worsening dyspnea with exertion, and nocturnal dyspnea, indicating that these symptoms were perceived as more intense or concerning. Symptom duration prior to hospitalization increased if symptoms occurred during the hours of 8:30 am to midnight versus in the middle of the night and if symptoms changed. Symptom duration decreased prior to hospitalization if participants experienced chest pain or were older.

Parshall et al. (2001) examined the impact of dyspnea duration, distress, and intensity on individuals' decisions to go to the emergency department (ED) and on admission status. The sample consisted of patients with an established diagnosis of HF ( $N = 57$ , 54% female) treated in a university hospital ED. The researchers collected data retrospectively via phone, in-person interviews, and/or medical record review. Prior to asking questions specifically about dyspnea, the researchers asked broad questions about the general nature of the symptoms that prompted the participant to seek emergency care. Data were also collected on demographic and clinical factors, daily activities, quality of life, and the participants' comprehension of and compliance with HF management. The Specific Activity Scale (Goldman et al., as cited in Parshall et al., 2001) was used to measure functional status. To measure dyspnea distress, participants were asked to rate how much their breathing bothered them using a 5 point scale, with responses ranging from 0 (*not at all*) to 4 (*very much*), at two recalled time points: the time that they decided to go to the ED (Decision) and 1 week prior to this decision (Week Before). Duration was the number of days that the participants experienced dyspnea at the severity level reported at Decision. Participants were also asked what terms they would use to describe the breathing distress they experienced at the time they decided to go to the ED. Dyspnea intensity was measured using two versions of a researcher-developed dyspnea descriptor checklist (Elliot et al., 1991, and Simon et al., 1990, as cited in Parshall et al., 2001), which asked participants to select the descriptors that best characterized how their breathing felt prior to seeking emergency care and then to rate their intensity on a 0-to-10 scale, with 10 indicating the highest severity. Eleven items from this checklist were used to evaluate dyspnea intensity.

The majority of participants indicated that their HF symptoms routinely limited their ability to perform meaningful activities. Twenty three percent indicated that a primary concern at the time that they decided to go to the ED was related to functional limitations, with most (~70%) reporting an increase in dyspnea severity at this time, followed by reports of chest pain (~30%, cf. Gallagher et al., 2012; Parshall, 1999). At the Week Before time point, dyspnea distress was categorized by 39% as minimal or absent, by 15% as somewhat distressful, and by 46% as very distressful. At the Decision point, 12% reported dyspnea distress as minimal or absent, 8% reported it as somewhat distressful, and 80% reported it as very distressful, indicating an overall increase in distress over the week preceding the visit. Nearly half of the participants used distress-laden words, such as *couldn't breathe*, *couldn't get air*, *smothering*, or *choking* in response to open-ended questioning. More than one third added emotional descriptors, such as *awful* or *terrible*, to further emphasize their distress.

Approximately two thirds of participants recalled 3 days or less of dyspnea, whereas one third reported a duration of 6 days or more. Distress reports were not significantly different at the Decision point for participants reporting different durations of dyspnea (3 days or less vs. 6 days or more), and dyspnea duration prior to the ED visit was not associated with admission to the hospital. For the sample as a whole, the mean intensity rating was 6.7 ( $SD = 2.7$ ) points at Decision and 4.4 ( $SD = 3.3$ ) points 1 week prior. Those who experienced dyspnea for 6 or more days reported high levels of distress and intensity at both Week Before and Decision time points, whereas the participants experiencing dyspnea for 3 days or less had lower reports of distress and intensity 1 week before the visit that increased substantially over a few days prior to the visit.

## Symptom Clusters and Clinical Outcomes

Researchers have also studied the combined occurrence of multiple symptoms in HF populations to identify symptom clusters that may help individuals living with HF perceive their symptoms earlier and identify symptoms that are significant to their HF management. In a secondary analysis, Jurgens, Moser et al. (2009) retrieved data from the Heart Failure Quality of Life Trialist Collaborators registry to identify symptom clusters in hospitalized HF patients. The secondary sample consisted of 687 participants with a mean age of 71 years; 51% were female, 61% were White, and most participants were classified as either NYHA class III (45%) or class IV (38%). Participants assessed symptoms using nine items from the Minnesota Living with Heart Failure Questionnaire (MLHFQ): six physical symptoms and three emotional symptoms. The researchers used principal components analysis with oblique rotation to determine the following symptom clusters: (a) acute volume overload (shortness of breath, fatigue, and sleeping problems), (b) chronic volume overload (swelling, increased need to rest, and dyspnea on exertion), and (c) emotional (depression, memory problems, and worry). The authors found that, in general, older participants more frequently reported symptom clusters, but participants 75 years and older reported less overall symptom impact. Diabetes was the only comorbidity that was a significant independent predictor of a symptom cluster (emotional).

Using an agglomerative hierarchical clustering method, Song et al. (2010) identified a *dyspnea* cluster (shortness of breath, orthopnea, and awakening breathless from sleep) and a *weary* cluster (lack of energy and appetite, and problems sleeping) in a sample of 421 patients hospitalized with HF in Korea. In this study, the mean age was 62 years; 40% were female, and most were classified as either NYHA class II (38.2%) or

class III (34.2%). Participants reported symptom occurrence and severity over the previous 2 weeks using a modified version of the MSAS-HF, which addressed the following symptoms: shortness of breath, lack of energy, difficulty sleeping, orthopnea, waking up breathless at night, lower extremity or ankle edema, dizziness, chest pain, palpitations, and poor appetite. Using hierarchical Cox proportional hazards regression analysis, Song et al. (2010) found that increased severity related to the weary cluster independently predicted hospital readmission for a cardiac-related problem and that increased severity associated with the dyspnea cluster independently predicted cardiac death.

Finally, K. S. Lee et al. (2010) used data from 3 prospective longitudinal studies that included HF participants recruited from three outpatient settings in different states to better understand the influence of individual characteristics on symptom clusters and the effect of symptom clusters on morbidity and mortality. Sample characteristics included a mean age of 61 years; 65% were male, 81% were White, and 44% were classified as NYHA class III. Symptoms were assessed using eight items from the MLHFQ (edema, dyspnea, fatigue/increased need to rest, fatigue/low energy, sleep problems, worrying, feeling depressed, and cognitive problems). Using cluster analysis, the authors identified the following symptom clusters for both men and women: the *physical* cluster (dyspnea, fatigue/increased need to rest, fatigue/low energy, sleeping problems) and the *emotional/cognitive* cluster (worrying, depression, and cognitive disturbances). *Edema* constituted a third, single-symptom cluster. Total symptom distress scores from the physical and emotional/cognitive clusters were correlated ( $r = .64, p < .01$ ). The emotional/cognitive distress cluster was associated with younger age, and women were

significantly more likely than men to report greater physical distress. After controlling for age, gender, comorbidities, body mass index, NYHA class, and interaction between emotional/cognitive and physical clusters, total distress from the emotional/cognitive cluster was a significant independent predictor of cardiac events (a composite of death, hospitalization, or HF-related ED visit). Compared with participants categorized as low distress on both the physical and emotional/cognitive clusters, participants categorized as high distress on both clusters or on just the emotional/cognitive cluster were more than twice as likely to experience a cardiac event. The likelihood of a cardiac event was not increased among participants categorized as high physical distress only compared with those categorized as low distress on both the physical and emotional/cognitive clusters.

C. S. Lee et al. (2014) recently examined physical and psychological HF symptom profiles in relation to 1-year event-free survival (a composite of all-cause mortality, cardiac-related ED visit or hospitalization, cardiac transplant or ventricular assist device implantation). This prospective cohort study included 202 individuals recruited from an outpatient HF setting in the Pacific northwest. The mean age was 56.9 years, 50% of participants were male, 85.6% were White, and most met criteria for NYHA class III (55.9%) or class II (40.1%). To evaluate physical symptoms, participants completed the HFSPS, an 18-item scale that asks participants to rate how much they have been bothered by HF-specific physical symptoms on a 6-point scale (0 = *did not have symptom*; 5 = *extremely bothersome*). Researchers also collected data on daytime sleepiness using the Epworth Sleepiness Scale (ESS), depression using the 9-item Patient Health Questionnaire (PHQ9), anxiety and hostility using the Brief Symptom Inventory (BSI), and clinical event outcomes via electronic medical record review or patient report.

The researchers used latent class mixture modeling to distinguish symptom profiles using continuous HFSPS, ESS, and BSI anxiety and hostility scores and a binary PHQ9 score cut point (depressed, not depressed). Significant positive linear associations (range, .27-.66) existed among the four symptom measures. The researchers used symptom severity categories to create three distinct profiles of increasing symptom burden/severity: mild (41.7% of sample), moderate (30.2% of sample), and severe (28.1% of sample). None of the individual symptom measures independently predicted 1-year event-free survival, but the severity profiles did. After controlling for the Seattle Heart Failure Score (a proxy for disease severity), compared with the mild symptom profile (reference category), participants in the moderate (hazard ratio [HR] = 1.8, 95% CI: 1.1-3.1) and severe (HR = 2.1, 95% CI: 1.2-3.5) symptom classes were significantly more likely to experience at least one of the composite endpoint events within 1 year.

### **Synthesis of Findings**

In summary, researchers have examined symptoms in relation to occurrence, severity, and variability. They have also explored the influence of comorbidities, age, and gender on symptom patterns and the influence of symptom patterns on clinically important outcomes. Findings suggest that individuals living with HF experience a multitude of symptoms, of which shortness of breath and fatigue are the most frequent and distressing (Janssen, et al., 2011; Janssen et al., 2008; Jurgens, Hoke, et al., 2009; Parshall et al., 2001; Song et al., 2010). Other common HF symptoms include insomnia, pain, generalized discomfort, muscle weakness, edema, depression, anxiety, cough, anorexia, dry mouth, nausea, palpitations, dizziness, and difficulty concentrating and



urinating (Gallagher et al., 2012; Janssen et al., 2011; Janssen et al., 2008; Jurgens, 2006; Opasich et al., 2008; Walke et al., 2007; Zambroski et al., 2005).

Studies of symptom clusters are limited and somewhat idiosyncratic (i.e., primarily descriptive of specific samples with little agreement across studies). Symptom clusters have been characterized as pertaining to acute versus chronic volume overload and emotional symptoms (Jurgens, Moser et al., 2009); physical versus emotional/cognitive symptoms (K. S. Lee et al., 2010); and dyspnea versus weary clusters (Song et al., 2010). An alternate approach, creating composite severity classes based on multiple symptom indices (C. S. Lee et al., 2014), has also been used.

Although these studies indicate that individuals living with HF report a wide array of symptoms, variations in sample characteristics and design contribute to differences related to symptom perception, severity, and predictability. Mixed results related to symptom perception, severity, and predictability and the influence of comorbidities, age, and gender on these characteristics need to be considered in relation to variations in sample sizes and geographical regions. Primary studies in this review used sample sizes ranging from 29 (Riegel et al., 2010) to 421 (Song et al. 2010), whereas secondary analyses were conducted with data obtained from sample sizes ranging from 26 (Jones et al., 2012) to 3,029 (Ekman et al., 2005). Researchers recruited participants from diverse locations, including the Netherlands (Janssen et al., 2011), the United States (Jones et al., 2012; Jurgens, Hoke et al., 2009; Jurgens, Moser et al., 2009; C. S. Lee et al., 2014; K. S. Lee et al., 2010; Moser et al., 2011; Parshall et al., 2001; Walke et al., 2007; Webel et al., 2007; Zambroski et al., 2005), Korea (Song et al., 2010), Italy (Opasich et al., 2008), the United Kingdom (Austin et al., 2012), and throughout Europe (Ekman, et al. 2005).

Researchers assessed symptom patterns using the MLHFQ (or a subset of items) (Austin et al., 2012; Jurgens, Moser et al., 2009; K. S. Lee et al., 2010), the ESAS (Opasich et al., 2008; Walke et al., 2007), the MSAS-HF (Song et al., 2010; Zambroski et al., 2005), the HFSPS (Jurgens, Hoke et al., 2009; C. S. Lee et al., 2014), the Borg scale of perceived exertion (Riegel et al., 2010), the Daily Symptom Scale (Moser et al., 2011), and visual analog or numeric rating scales for various symptoms (Janssen et al., 2011; Parshall et al., 2001; Riegel et al., 2010; Webel et al., 2007), or researcher-developed rating scales (Ekman et al., 2005; Gallagher et al., 2012; Parshall et al., 2001). The variety of instruments and approaches to measuring symptom severity or distress complicates comparisons across studies.

Even when the same instrument was used, researchers varied time frames. For example, Zambroski et al. (2005) and Song et al. (2010) both used the MSAS-HF, but Song et al. (2010) used a modified version and asked participants to evaluate their symptoms over the last 2 weeks, whereas Zambroski et al. (2005) used the original version and asked participants to assess their symptoms over the last week.

The ability to assess variations in symptom perceptions or severity over time was limited by the use of cross-sectional study designs (Gallagher et al., 2012; Janssen et al., 2011; Jurgens, Hoke et al., 2009; C. S. Lee et al., 2014; Opasich et al., 2008; Parshall et al., 2001; Riegel et al., 2010; Song et al., 2010; Zambroski et al., 2005). Longitudinal data provided greater insights related to symptom variability over time. For example, Walke et al. (2007) demonstrated increases over 2 years in reports of and severity of HF-specific symptoms, such as shortness of breath and fatigue, as well as in symptoms that are less specific for HF, such as pain and depression.

Although comorbidities are important in clinical management, their relevance to severity, frequency, or patterns of HF symptoms is less clear. In examining contributions of comorbidities (lung disease, diabetes, renal disease, and PVD) to symptom clusters, Jurgens, Moser et al. (2009) found that diabetes mellitus was the only comorbidity to predict a symptom cluster (the emotional cluster) in patients with HF. Participants reporting high physical and emotional/cognitive distress in K. S. Lee et al.'s (2010) study had more comorbidities. Finally, Walke et al. (2007) found that symptom burden increased over time in relation to a higher number of coexisting illnesses, but this relationship was not statistically significant.

Findings that described the relationship between age and symptom pattern characteristics in HF also varied, in part because of widely variable criteria for age group comparisons across studies. Janssen et al. (2011) did not find a significant relationship between the number of symptoms and age in an HF group with a mean age 76.2 years. Alternatively, Jurgens, Moser et al. (2009) found that older age (75 years or older) made significant contributions to three symptom clusters. Also within this study, although older participants reported more symptoms, the impact of symptoms on their lives was less distressful compared with the younger group. This finding is consistent with findings of K. S. Lee et al. (2010) that participants who reported less emotional/cognitive distress were older. Jurgens, Hoke et al. (2009) found that age did not make significant contributions to differences in symptom distress scores, but that the majority of participants in this elderly cohort (65 years and older) were unable to identify HF symptoms or recognize their significance.

In Riegel et al.'s (2010) study, significant differences in symptom identification between the younger group (younger than 73 years) and the older group (age 73 years or older) were only found immediately after a 6MWT, not before or 5 minutes after the 6MWT. Similar to findings from Jurgens, Hoke et al.'s (2009) study, qualitative data also indicated that the older group had more difficulty in identifying and interpreting shortness of breath and fatigue as relevant to their HF management compared with the younger group. Older participants attributed shortness of breath to being out of shape, fatigue to poor sleep or excessive daytime activity, and ankle edema to arthritis (Riegel et al., 2010). Zambroski et al. (2005) found that nausea was significantly more common in older participants (patients 55 years and older) compared with younger participants (54 years or younger), and shortness of breath and waking up breathless at night were significantly more distressing and burdensome in younger participants.

Only a few studies found significant differences in symptom patterns by gender. Zambroski et al. (2005) found that a greater number of women reported feeling nervous and sweating compared with men. Men reported significantly greater reoccurrence of sexual problems and significantly more distress associated with sexual problems. Although K. S. Lee et al. (2010) found that women reported significantly greater distress from select symptoms (fatigue/increased need to rest, sleep problems, and depression) compared with men, the authors did not detect significant differences by gender in symptom clusters. In addition, Jurgens, Hoke et al. (2009) did not find significant differences in symptom distress scores by gender.

In conclusion, HF is characterized by a wide array of symptoms that may occur in isolation or together with varying degrees of frequency, severity, and patterns of onset or

relief. Some individuals living with HF may not recognize that certain symptoms are likely due to their HF. Ambiguity in symptom patterns and the unpredictability of these patterns contribute to uncertainty in HF and create challenges for individuals living with HF over time. Researchers' ongoing attention to a better understanding of symptom patterns and how these patterns can impact clinically important outcomes and patient-centered care highlights the significance of symptom management as a key component of improving the experience of living with HF.

## **CHAPTER 3**

### **METHODS**

This chapter addresses: (1) study design; (2) specific aims and research questions; (3) site and setting; (4) sample; (5) study procedures, including recruitment, enrollment, consent, data collection, and handling; (6) variables and measurements; (7) data analysis; and (8) human protection issues.

#### **Study Design**

A descriptive, exploratory design with cross-sectional data collection was used to examine reports of personal growth and to explore potential relationships between personal growth and relevant demographic, clinical, and cognitive factors in community-residing adults living with class II-IV HF. This research was guided by Tedeschi and Calhoun's (2004) work on PTG and Mishel's (1990) RUIT. A convenience sample of participants meeting study criteria was recruited from an outpatient cardiology clinic. Once informed consent was obtained, participants were asked to complete questionnaires assessing personal growth, uncertainty, and symptoms. In addition, demographic and clinical data were collected either via participant self-report, provider report, or through a medical record review.

#### **Specific Aims and Research Questions**

The specific aims of this exploratory study were to: (1) describe levels of personal growth in adults living with NYHA class II-IV HF; (2) explore the relationship of personal growth with age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels; and (3) determine the extent to which variance in personal

growth in individuals living with NYHA class II-IV was accounted for by age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty. The following research questions addressed these specific aims:

1. Do adults living with NYHA class II-IV HF report personal growth following their diagnosis of HF?
2. To what extent are age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels associated with personal growth in individuals with HF?
3. Which variables (age, sex, ethnicity, disease severity, time since diagnosis, symptom status, or uncertainty levels) make independent contributions to personal growth in individuals living with NYHA class II-IV HF?

### **Site and Setting**

This study was conducted at an outpatient cardiology clinic located in San Antonio, Texas. San Antonio is the seventh largest city in the United States and the second largest city in the state of Texas (City of San Antonio, 2012). Approximately, 1,785,704 individuals live in San Antonio and the surrounding area of Bexar County, which spans approximately 1,240 square miles (U.S. Department of Commerce, 2012). In Bexar County, more than 60% of the population is 18 years and older, with 10.4% of the population estimated to be 65 years and older. Approximately 50.9% of this population is female. People of Hispanic or Latin origins make up the majority (58.9%), whereas White persons of non-Hispanic origin make up 30.2% of the population (U.S. Department of Commerce, 2012).

The cardiology clinic serves a large local and referral HF population. The practice was established in 1975 and currently employs three physician providers and two advanced practice nurses (APNs). HF patients are primarily managed by one physician and one APN. Patients classified as NYHA class II are seen at least annually and NYHA class III-IV patients are seen weekly to monthly, based on their level of stability. The goal of the HF clinic is to optimize outpatient treatment to prevent hospital admissions (V. Paparelli, personal communication, September 13, 2014).

### **Sample**

A convenience sample was recruited from this outpatient cardiology clinic. Inclusion criteria for the participants were (1) adults ( $\geq 18$  years of age) with NYHA class II-IV HF, (2) community-residing, (3) able to speak and understand English, and (4) capable of providing informed consent. Exclusion criteria were (1) pregnant women, (2) children ( $< 18$  years of age), and (3) prisoners.

Sample size was estimated using G\*Power (version 3.17; Heinrich Heine Universität Düsseldorf, 2013). The target sample established for this study was 120 to achieve 80% power to detect a medium standardized effect size ( $f^2 = .15$ , equivalent to a model  $R^2 = .13$  against a null hypothesis that  $R^2 = 0$ ) at an alpha error level of .05 for a regression model with up to seven predictors, while allowing for up to 15% incomplete or nonreturned surveys.

### **Recruitment, Enrollment, and Consent**

Prior to submitting the protocol to the Human Research Review Committee (HRRC) at the University of New Mexico (UNM) Health Sciences Center, I made initial contact with an APN, who had been working in a local cardiology clinic for several



years, helping to manage the clinic's HF population. Over the next 3 months, the two of us communicated on a regular basis to assess the feasibility of conducting my study at this clinic. Subsequently, the clinic provided a letter of support to the HRRC, indicating that they were willing and eager to serve as the primary research site for the study, that the target sample size was realistic and achievable based on their current population, and that they were prepared to help ensure that study procedures met the requirements of the HRRC.

After obtaining approval from the HRRC at UNM, recruitment commenced. Participants were recruited primarily through recruitment flyers (Appendix C), which were available in the office and given to HF patients by providers during scheduled appointments. The role of the clinical staff was limited to providing the flyer, verifying patients' interest in learning more about the study, and referring potentially interested patients to me. If potentially eligible participants verbalized interest in the study and I was present in the clinic, I met with them in person before or after scheduled appointments. If I was not available in the clinic, initial contact occurred over the phone, at the request of the patient, and a time was scheduled to meet in person at the clinic. At this time, I provided interested participants with a verbal and written description of the study and screened them for eligibility.

In addition to the use of flyers as a recruitment strategy, I also sent recruitment letters to potentially eligible patients (Appendix D), which indicated that the study was ongoing and had the endorsement of the clinic. A Health Insurance Portability and Accountability Act (HIPAA) Waiver of Authorization for recruitment only, obtained from the HRRC, permitted review of medical records using HF diagnostic criteria to

identify potentially eligible participants who may not have had scheduled appointments during the recruitment phase. A total of 180 recruitment letters were mailed. I received 16 calls from individuals who had received letters. Three of these individuals chose not to participate, expressing concerns related to distance, a recent change in cardiology providers, and, in one case, a limited ability to understand English. Thirteen of the callers were interested in participating and most set up appointments to meet with me at the clinic during a scheduled appointment or at a time that was mutually convenient and were subsequently enrolled in the study. In a few cases, individuals were unable to meet me in person, so a modification request was obtained from HRRC to allow me to screen participants over the phone and obtain signed consent and HIPAA authorization through the mail.

In all cases, after screening potential participants for eligibility, a signed informed consent and HIPAA Authorization for Use and Disclosure of Protected Health Information (Appendix E) was obtained from all who agreed to participate. Participants were given a copy of the combined informed consent/HIPAA document after a copy was scanned into their medical record.

A total of 107 individuals were enrolled in the study. Two participants withdrew: 1 female participant, who had a phone interview scheduled, called to indicate that she was too busy to participate, and 1 male participant called after completing the survey data to indicate that he no longer felt comfortable participating in the study. In addition, 2 participants did not return the survey data, resulting in a final sample of 103, which was adequate to achieve 80% power based on the power analysis.

### **Data Collection and Handling**

Once informed consent and HIPAA authorization were obtained, each participant was assigned a unique study identification (ID) number. Participants were asked to complete the following questionnaires: (a) a demographic and clinical questionnaire, (b) the PTGI (Appendix F), (c), the MUIS-C (Appendix G), and (d) MSAS-HF (Appendix H). These questionnaires were combined into one survey that did not include any protected health information (Appendix I). Supplementary clinical data were obtained from the medical record or via provider report and stored in a separate data file that could be linked to the survey data by study ID number (Appendix J). Both the survey data file and the clinical data file were stored in REDCap<sup>TM</sup> (Research Electronic Data Capture), an encrypted, web-based data collection system developed specifically to ensure confidentiality of study records. REDCap<sup>TM</sup> is made available to UNM Health Sciences Center faculty by the UNM Clinical and Translational Science (CTSC).

Participants were given the option of completing the survey electronically or on paper. Electronic access was via a secure web portal to REDCap<sup>TM</sup> from the electronic device of the participant's choice. Participants who did not feel comfortable completing the surveys electronically or did not have Internet access completed paper copies of the survey either in person or via the mail. Participants were also given the option to complete the survey via a phone or in-person interview conducted by the researcher. All data that were documented on paper by either the participant or the researcher were entered into REDCap<sup>TM</sup> by the researcher as soon as possible. Original copies of surveys were kept in a locked file cabinet, separate from any files that included identifiable information and were only accessible to the primary researcher.

## **Variables and Measures**

Variables examined in this study included personal growth (the dependent variable included in the regression analysis) and the following independent or predictor variables: age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty.

### **Demographic and Clinical Data**

Demographic and clinical data that were collected and examined as predictor variables in this investigation included age; sex; ethnicity; NYHA class, as a measure of disease severity; and time since diagnosis in years. In addition, to better assess significant differences in population characteristics and to support possible additional exploratory analyses, the following data were also collected: race, years of education, highest educational degree, marital/partner status, etiology of HF, number of hospitalizations within the last year for HF, ejection fraction (if documented within the last year) and how ejection fraction was established, comorbidities, and current cardiac medications. Demographic data were collected as part of the combined questionnaire (Appendix I). Clinical data were predominantly collected by the researcher through a medical record review or, in a few cases in which clinical data were not available in the medical record, via provider report (Appendix J).

### **Growth**

Personal growth was measured using total growth scores from the PTGI (Tedeschi & Calhoun, 1996). The PTGI is a 21-item instrument that measures an individual's perceptions of favorable changes that occur as a result of dealing with a traumatic life event (see Appendix F). It consists of the following five domains: (a) new

possibilities (5 items); (b) relating to others (7 items); (c) personal strength (4 items); (d) appreciation of life (3 items); and (e) spiritual change (2 items). For items within each domain, participants are asked to rate the degree of change that occurred as a result of their adverse life event on a 6-point Likert scale, with zero indicating no change and five indicating the greatest degree of positive change. A total growth score is calculated by adding the individual items scores. The maximum total growth score that can be obtained is 105.

Although the PTGI was originally developed and tested in a sample of healthy college students, it has been widely used in older individuals with medical illnesses, including populations with cancer, heart disease, HIV, and neurological, orthopedic, or burn injuries (Barskova & Oesterreich, 2009). Initial construct validity was established by comparing total PTG scores from a group of individuals who reported experiencing a major trauma in the last year with scores from a group of individuals who denied experiencing a major trauma in the last year. Participants who reported a major trauma reported greater growth and results were significant (Tedeschi & Calhoun, 1996).

Concurrent validity was established by demonstrating significant, positive correlations between total PTG scores and scores of optimism, extraversion, openness to experience, agreeableness, conscientiousness, and religious involvement, personality factors and variables theoretically thought to be related to growth. Correlations between total PTG scores and scores of neuroticism were not associated, supporting discriminant validity (Tedeschi & Calhoun, 1996). In addition, to ensure that PTG scores did not simply reflect social desirability, correlations between PTG scores and scores from the

Marlowe-Crowne Social Desirability Scale were analyzed and found to be unrelated (Tedeschi & Calhoun, 1996).

In a review of growth measurement scales, Park and Lechner (2006) reported scale intercorrelations ranging from  $r = 0.62$  to  $r = 0.83$ , Cronbach's alpha values ranging from 0.67 (appreciation of life subscale) to 0.90 (total growth score), and adequate test-retest reliability values over 2 months for the total growth score ( $r = 0.71$ ), but weaker test-retest reliability values for select subscales, such as the personal strength scale ( $r = 0.37$ ). Test-retest reliability assessments may not be the most appropriate measure of reliability because personal growth may not reflect a stable construct. Studies that used an English version of the PTGI in populations with heart disease demonstrated Cronbach's alpha values for total growth scores of 0.96 (Leung et al., 2010; Sheikh, 2004). Leung et al. (2010) also reported Cronbach's alpha values for the individual subscales as follows: new possibilities, 0.87; relating to others, 0.92; personal strength, 0.85; appreciation of life, 0.74; and spiritual change, 0.87.

### **Symptom Status**

Symptom status was measured using the MSAS-HF, which is a 32 item instrument that assesses the presence, frequency, severity, and distress of symptoms experienced in HF (Zambroski et al., 2004; Appendix H). The MSAS-HF is a modified version of the original Memorial Symptom Assessment Scale (MSAS) which was designed for use in cancer populations (Portenoy et al., 1994). The MSAS-HF includes five additional HF-specific symptoms (chest pain, palpitations, waking up breathless at night, difficulty breathing while lying flat, and weight gain) and excludes five of the original cancer-related symptoms (don't look like myself, mouth sores, hair loss,

difficulty swallowing, and changes in skin). The MSAS-HF consists of the following three subscales, physical symptoms, psychological symptoms, and HF-specific symptoms.

Participants initially indicate the presence or absence of a variety of symptoms over the previous week. If a symptom is present, the participant is then asked to assess its frequency on a 1- to 4-point scale, with 1 indicating *rarely* and 4 indicating *almost always*, and to report both its severity on a 1- to 4-point scale, with 1 indicating *mild severity* and 4 indicating *very severe*, and its distress on a 0- to 4-point scale, with lower scores indicating *no distress* and 4 indicating *very much distress*. Higher scores indicate greater symptom frequency, severity, and distress. Consistent with guidelines established by Portenoy (1994) for the original MSAS and adopted by Zambroski et al., (2004), distress scores are calculated using the following scale: 0.8 for *not at all*, 1.6 for *a little bit*, 2.4 for *somewhat*, 3.2 for *quite a bit*, and 4 for *very much*. A total symptom prevalence score is calculated by adding the number of symptoms present. A symptom burden score is calculated by adding the symptom frequency, severity, and distress scores of individual symptoms, as applicable, and determining the mean. A total symptom burden score is determined by summing the symptom burden scores for each symptom and then determining the overall mean of all reported symptoms. In this study, the total symptom burden score was used to measure symptom status.

Construct validity of the MSAS-HF was established by demonstrating greater symptom prevalence in an HF population compared with healthy adults not diagnosed with HF (Zambroski et al., 2004) and supported by findings that demonstrated significant associations between symptom presence and burden scores and HF HRQOL (Bekelman

et al. 2007; Zambroski et al., 2005) Preliminary reliability of the MSAS-HF has been established (Zambroski et al., 2004). Zambroski et al. (2005) reported Cronbach's alpha coefficients of 0.92 for the total symptom score, 0.83 for the psychological subscale, 0.87 for the physical subscale, and 0.73 for the HF-specific subscale. Song et al. (2010) used a modified version of the MSAS-HF to measure prevalence and distress of select physical symptoms and reported a Cronbach's alpha coefficient of 0.81.

### **Uncertainty**

Uncertainty was measured using the MUIS-C. The MUIS-C is a 23-item, one-factor scale that was developed from the original MUIS-A (Mishel, 1981) to measure perceived uncertainty in illness in individuals not acutely ill or hospitalized (Mishel, 1997). The MUIS-C contains the same items as the MUIS-A, with the exception of items related to treatment and communication in a hospital setting (Appendix G). Participants respond to questions using a 5-point Likert scale, with 1 indicating *strongly disagree* and 5 indicating *strongly agree*. After reverse scoring select items according to established instructions, items are summed to provide a total uncertainty score. Composite uncertainty scores range from 23, reflective of low levels of uncertainty, to 115, indicative of very high levels of uncertainty.

Construct validity and sensitivity have been established in studies primarily using the original MUIS-A (Mishel, 1997). Cronbach's alpha values for the MUIS-C have been reported to be between 0.53 and 0.92, with the majority in the moderate-to-high range (Mishel, 1997). In an HF population, Jurgens (2006) reported a Cronbach's alpha of 0.78. In other cardiac populations, a Cronbach's alpha of 0.87 has been reported (Carroll, Hamilton, & McGovern, 1999).



Normative data synthesized from 20 studies using the MUIS-C in a variety of illness populations indicated no differences in mean uncertainty scores related to sex or age, but demonstrated a differences in mean uncertainty scores related to education, with mean uncertainty scores decreasing with greater education (Mishel, 1997).

### **Data Analysis**

Statistical analysis was performed using IBM® SPSS® Statistics (version 22). Preliminary analyses using descriptive statistics and graphical displays were conducted to check for missing data or out-of-range values and to describe the sample. For demographic and clinical data and questionnaire scores, descriptive statistics included frequencies and percentages, means and standard deviations, or medians and percentages, as appropriate, based on measurement level and distributional characteristics. In addition, preliminary analyses were used to help assess assumptions for planned statistical procedures.

Internal consistency of the measures of growth, uncertainty, and burden scores for each symptom were assessed using Cronbach's alpha coefficients. Inter-item correlations, Cronbach's alpha if the item was deleted, and corrected item total correlations were also reviewed. (Cronbach's alpha cannot be estimated for the total burden score because individuals differ in the symptoms they report.)

Bivariate correlations between continuous variables (age, time since diagnosis, total growth scores, total symptom burden scores, and total uncertainty scores) were analyzed using Pearson product-moment correlation coefficients. Hierarchical multiple regression with variables entered in three successive blocks was conducted to determine whether PTGI scores were predicted by a model consisting of the following independent

variables: age, sex, ethnicity, disease severity, time since diagnosis, symptom burden scores, and uncertainty scores. Demographic variables (age, sex, and ethnicity) were entered first, followed by clinical variables (disease severity and time since diagnosis) and then total symptom burden and uncertainty scores.

Analysis to determine which predictors made significant independent contributions to the model, while controlling for the other predictors in the model, was planned. Supplemental analyses assessed whether assumptions of normality, linearity, homoscedasticity, multivariate outliers, and independence of residuals were satisfied and whether multicollinearity was problematic.

Two-sample *t* tests were conducted to determine whether personal growth scores differed by sex, ethnicity, and disease severity. For any significant differences, point-biserial correlations were used as an effect size estimate. Additional exploratory analyses were performed to generate a better depiction of symptom prevalence and burden and reports of uncertainty in this sample.

### **Human Protection**

This study was approved by the HRRC at UNM. The study did not include any vulnerable populations. Each phase of the study, from recruitment to completion, was clearly outlined in the HRRC-approved protocol to ensure adherence to principles of responsible conduct of research with human subjects. Participants who were eligible and agreed to participate signed a combined informed consent and HIPAA Authorization for Use and Disclosure of Protected Health Information (Appendix E). The HIPAA authorization allowed the researcher to access the participants' medical record for clinical information relevant to the study; these data were clearly described within the informed

consent. The informed consent provided a detailed description of the study so that the participants had all the information they needed to make an informed choice about whether to participate given the study's risks and benefits. Participants were reassured that their involvement was voluntary and that declining to participate would not impact their usual medical care. Participants were notified that they could withdraw from the study at any time without any adverse ramifications.

Because the study primarily involved questionnaire measures and did not involve sampling of blood or tissues, risks of participation were mainly fatigue or distress from answering several questionnaires. The questionnaires themselves did not involve questions about highly sensitive matters, but did focus on significant life events in relation to a diagnosis of HF. Participants were informed that they could skip any questions that made them uncomfortable, stop answering questions at any time, or withdraw if they preferred. Participants were also given the choice of how they preferred to complete the survey (on paper, electronically, or via a researcher-conducted interview) to minimize fatigue, distress, or any perceived inconvenience from completing multiple questionnaires. There were no direct benefits to participation, but participants were informed that the results of the study were expected to enhance understanding of psychosocial aspects of HF and could contribute to future improvements in care that may benefit others with the condition. Once the survey was completed and returned, participants were given a \$20.00 gift card as a token of appreciation for their time and effort.

As with all research, there was a risk of loss of confidentiality and/or privacy. A HIPAA Waiver of Authorization for recruitment only was approved by the HRRC to

facilitate recruitment of potentially eligible participants not seen in the clinic during the recruitment phase. In addition, the primary researcher signed a Medical Record Access Agreement, Confidentiality and Non-Disclosure Agreement, and HIPAA Confidentiality Agreement with the cardiology clinic. Names and addresses of potentially eligible participants were documented on a recruitment tracking form that was kept in a locked file cabinet in a secure office space, only accessible to the primary researcher. Recruitment letters were addressed by hand by the primary researcher while in the clinic and mailed as soon as possible, at which time, the recruitment tracking form was destroyed.

Participants who agreed to take part in the study signed an informed consent and HIPAA authorization form that clearly outlined potential risks. Participants were also provided a copy of this document for their records. To minimize the risk of loss of confidentiality, participants' names and other identifying information was maintained in a locked file cabinet, separate from the survey data, in a secure office space, only accessible to the primary researcher. At the completion of the study, any personal identifying information and any record linking that information to the study identification numbers were shredded and destroyed. For any survey data entered into REDCap<sup>TM</sup> and subsequently exported to SPSS, the only identifiers were unique study identification numbers, which were assigned to each participant. Only members of the research team had access to these data. These data were stored and accessible to the research team for a period consistent with the policies and procedures of the UNM CTSC and HRRC.

To protect participants' privacy, participants were only approached if they verbalized interest in learning more about the study after receiving a recruitment letter or

a flyer. Recruitment materials clearly indicated that participation was voluntary and outlined how to contact the researcher if an individual was interested. Private space in the clinic was provided to the primary researcher to meet with interested patients to discuss the study, obtain informed consent, and complete the survey if participants chose to do so while in the clinic.

## CHAPTER 4

### RESULTS

A sample of 103 participants completed the surveys. The majority (58%) completed the surveys via an in-person interview with the researcher, 40% completed the surveys on paper, and 2% completed the surveys electronically. Survey responses entered into REDCap<sup>TM</sup> and exported to SPSS were reviewed for missing data. Participants responded to all clinical and demographic questions, with the exception of 3 participants who did not answer the question regarding the number of years of education; however, those individuals did respond to the item addressing highest educational (degree) level. Survey questionnaires had a minimal amount of missing data. Participants had been informed that they could skip questions that made them uncomfortable or that they preferred not to answer. Eight cases included missing data for only one or two items on the combined questionnaires. In one case, a participant did not respond to six items on the MUIS-C and one symptom on the MSAS-HF. This individual wrote “No answer fit” next to items that were skipped on the MUIS-C. The highest percentage (4%) of missing data on any one item addressed problems with sexual interest/activity on the MSAS-HF. Of the cases with missing data, six were completed on paper, two via in-person interview, and one electronically.

#### Sample Description

Sample demographic and clinical characteristics are shown in Tables 1 and 2. The sample was predominantly White, male, married or living with a partner, and educated at or above the high-school level, with ages ranging from 27 to more than 90 years.

Table 1  
*Demographic Characteristics (N = 103, except as noted)*

Characteristic	N (%)	Mean (SD)
Age, years		73.71 (12.58)
Sex		
Male	78 (75.7)	
Female	25 (24.3)	
Married or living with a partner		
Yes	72 (69.9)	
No	31 (30.1)	
Race		
Asian	1 (1.0)	
African American	2 (1.9)	
White	96 (93.2)	
Other	2 (1.9)	
Prefer not to answer	2 (1.9)	
Ethnicity		
Hispanic	19 (18.4)	
Not Hispanic	83 (80.6)	
Prefer not to answer	1 (1.0)	
Highest number of years of education <sup>a</sup>		14.82 (3.51)
Highest educational level		
< 12 years	5 (4.9)	
High school graduate/GED	44 (42.7)	
Associate's degree	6 (5.8)	
Bachelor's degree	26 (25.2)	
Graduate degree	22 (21.4)	

<sup>a</sup>N = 100.

In most cases, ischemic heart disease was documented as the cause of HF. The majority of participants met criteria for NYHA functional class II or III. Diabetes and pulmonary disease were the two most common noncardiac comorbidities, followed by peptic ulcer disease, cancer, chronic kidney disease, and peripheral vascular disease. More than half of the sample had lived with a diagnosis of HF for more than 10 years (range 1 to 30 years).

Table 2  
*Clinical Characteristics (N = 103 except as noted)*

Characteristic	n (%)
Ejection fraction documented within last year <sup>a</sup>	
≤ 40%	45 (49.5)
> 40%	46 (50.5)
Etiology of heart failure <sup>b</sup>	
Ischemic heart disease	67 (65.0)
Hypertension	19 (18.4)
Cardiomyopathy	38 (36.9)
Other	7 (6.8)
NYHA functional class	
II	53 (51.5)
III	46 (44.7)
IV	4 (3.9)
Hospitalized within last year for heart failure	40 (38.8)
Significant medical history	
Peripheral vascular disease	18 (17.5)
Stroke	9 (8.7)
Diabetes	35 (34.0)
Chronic pulmonary disease	34 (33.0)
Connective tissue disorder	4 (3.9)
Cancer	28 (27.2)
Peptic ulcer disease	29 (28.2)
Chronic kidney disease	26 (25.2)
Depression	17 (16.5)
Anxiety/mood disorder	11 (10.7)
Medications	
ACE inhibitor	53 (51.5)
Angiotensin receptor blocker	26 (25.2)
Beta blocker	92 (89.3)
Diuretic	82 (79.6)
Digoxin	28 (27.2)
Vasodilator	30 (29.1)
Milrinone	13 (12.6)
Years since diagnosis	
0-1 year	6 (5.8)
2-3 years	8 (7.8)
4-5 years	13 (12.6)
6-9 years	18 (17.5)
10-19 years	24 (23.3)
20-29 years	17 (16.5)
≥ 30 years	17 (16.5)

*Note.* NYHA = New York Heart Association; ACE = angiotensin converting enzyme.

<sup>a</sup>N = 91; 12 participants did not have an ejection fraction documented within the last year. <sup>b</sup>Some participants had multiple etiologies documented.

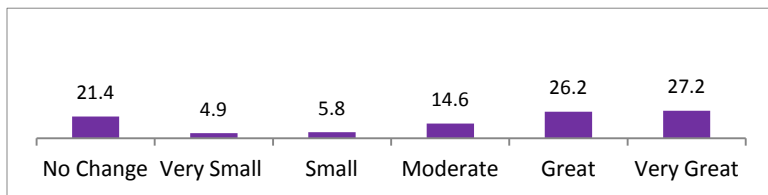


### Personal Growth in HF

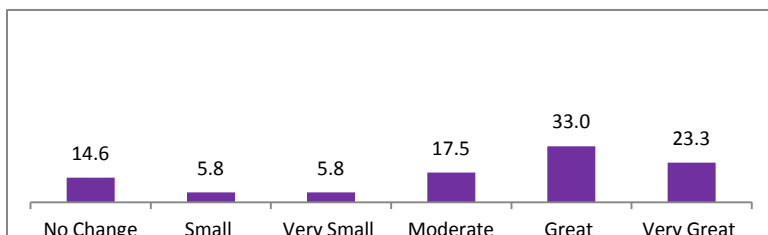
Total growth scores from the PTGI were examined to answer the first research question, “Do adults living with NYHA class II-IV HF report personal growth following their diagnosis of HF?” Only one case had missing data for a single item that addressed improvements in religion. The PTGI total growth score demonstrated very good internal consistency (Cronbach’s  $\alpha = .96$ ); the deletion of any single item on the PTGI did not improve reliability. Inter-item correlations ranged from .23 to .75, with a mean of .52. The weakest correlation ( $r = .229$ ) was between the items *I discovered that I am stronger than I thought I was* and *I changed my priorities about what is important in life*. The corrected item total correlations ranged from .59 to .78.

The mean for the total growth score was 48.6 ( $SD = 28.6$ ), with a range of possible scores of 0 to 105, indicating that this sample reported experiencing a moderate degree of personal growth as a result of their HF diagnosis. Responses to individual items ranged from 0, if the participant did not experience any degree of change, to 5, indicating that the participant experienced a change to a very great degree as a result of his or her HF diagnosis. As shown in Figure 1, four items had modal categories greater than or equal to 4, indicating that participants experienced change in these areas either to a great or very great degree. Alternatively, as outlined in Table 3, 13 items had a mode of 0, indicating that participants did not report any change in these areas. A closer examination of responses to individual items demonstrated that in some areas in which greater change was reported by a high percentage of participants, a substantial number of individuals in these same areas reported no change and vice versa.

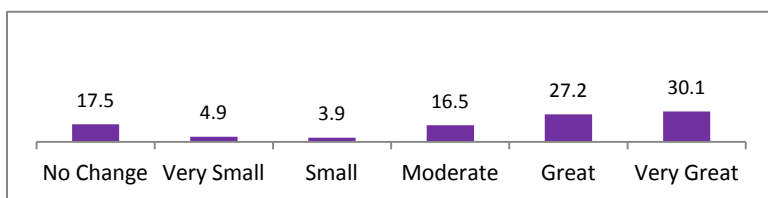
**I have a greater appreciation for the value of my own life.**



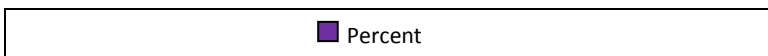
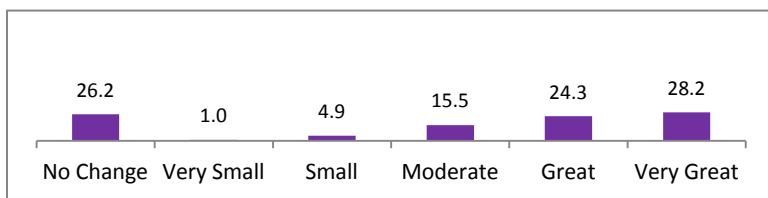
**I more clearly see that I can count on people in times of trouble.**



**I can better appreciate each day.**



**I learned a great deal about how wonderful people are.**



*Figure 1.* Percentages for PTGI items with modes  $\geq 4$ .

Table 3  
*Frequencies and Percentages for PTGI Items With Modes Equal to Zero<sup>a</sup>*

Item	N (%)
<b>Change in priorities</b>	
No change	35 (34.0)
Very small	5 (4.9)
Small	8 (7.8)
Moderate	20 (19.4)
Great	18 (17.5)
Very great	17 (16.5)
<b>Developed new interests</b>	
No change	54 (52.4)
Very small	5 (4.9)
Small	13 (12.6)
Moderate	11 (10.7)
Great	14 (13.6)
Very great	6 (5.8)
<b>Greater feeling of self-reliance</b>	
No change	54 (52.4)
Very small	5 (4.9)
Small	5 (4.9)
Moderate	16 (15.5)
Great	14 (13.6)
Very great	9 (8.7)
<b>Better understanding of spiritual matters</b>	
No change	45 (43.7)
Very small	3 (2.9)
Small	6 (5.8)
Moderate	10 (9.7)
Great	23 (22.3)
Very great	16 (15.5)
<b>Established a new path for my life</b>	
No change	48 (46.6)
Very small	2 (1.9)
Small	5 (4.9)
Moderate	20 (19.4)
Great	15 (14.6)
Very great	13 (12.6)
<b>Greater sense of closeness with others</b>	
No change	32 (31.1)
Very small	3 (2.9)
Small	9 (8.7)
Moderate	20 (19.4)
Great	24 (23.3)
Very great	15 (14.6)
<b>More willing to express emotion</b>	
No change	38 (36.9)
Very small	3 (2.9)
Small	7 (6.8)
Moderate	31 (30.1)
Great	20 (19.4)
Very great	4 (3.9)

Table 3 (cont.)

Item	<i>N</i> (%)
<b>Know better that I can handle difficult situations</b>	
No change	33 (32.0)
Very small	5 (4.9)
Small	8 (7.8)
Moderate	23 (22.3)
Great	27 (26.2)
Very great	7 (6.8)
<b>Able to do better things with my life</b>	
No change	43 (41.7)
Very small	7 (6.8)
Small	8 (7.8)
Moderate	23 (22.3)
Great	11 (10.7)
Very great	11 (10.7)
<b>Better able to accept the way things work out</b>	
No change	33 (32.0)
Very small	3 (2.9)
Small	7 (6.8)
Moderate	28 (27.2)
Great	20 (19.4)
Very great	12 (11.7)
<b>New opportunities are available</b>	
No change	62 (60.2)
Very small	6 (5.8)
Small	7 (6.8)
Moderate	9 (8.7)
Great	12 (11.7)
Very great	7 (6.8)
<b>Stronger religious faith<sup>b</sup></b>	
No change	42 (40.8)
Very small	2 (1.9)
Small	7 (6.8)
Moderate	10 (9.7)
Great	23 (22.3)
Very great	18 (17.5)
<b>Discovered I am stronger than I thought I was</b>	
No change	37 (35.9)
Very small	2 (1.9)
Small	7 (6.8)
Moderate	20 (19.4)
Great	24 (23.3)
Very great	13 (12.6)

<sup>a</sup>*N* = 103. <sup>b</sup>*N* = 102.

For example, although more than 50% of participants reported that they learned a great deal about how wonderful people are to at least a great degree as a result of living with HF, 26% reported no change in this area. Alternatively, although 44% of individuals reported that they did not develop a better understanding of spiritual matters, more than 37% reported experiencing enhanced spirituality to a great or very great degree as a result of their HF diagnosis.

To generate a better understanding of the type of personal growth experienced in this population, descriptive statistics with Cronbach's alpha coefficients were generated for the PTGI subscales and are outlined in Table 4. Participants in this study reported the greatest change in appreciation for life and the least amount of growth in new possibilities. All of the mean per-item scores except for new possibilities fall on average between a small (2) and moderate (3) degree of change.

Table 4  
*Characteristics of PTGI Subscales*

Subscale	Mean ( <i>SD</i> )	Cronbach's $\alpha$	No. of Items	Mean score per-item	Percentage of maximum subscale score
Appreciation for life	8.53 (4.82)	.82	3	2.8	56.9
Relating to others	18.32 (10.15)	.91	7	2.6	52.3
Spiritual change <sup>a</sup>	4.32 (3.85)	.86	2	2.2	43.2
Personal strength	8.50 (5.98)	.82	4	2.1	42.5
New possibilities	8.97 (7.38)	.87	5	1.8	35.9

*Note.*  $N = 103$ .

<sup>a</sup> $N = 102$

### **Demographic, Clinical, and Cognitive Factors Related to Personal Growth**

Bivariate correlations were analyzed using Pearson product-moment correlation coefficients for all continuous variables and dichotomous categorical variables to answer the second research question, “To what extent are age, sex, ethnicity, disease severity, time since diagnosis, symptom status, and uncertainty levels associated with personal growth in individuals with HF?”

#### **Assumptions for Correlation Analysis**

Descriptive statistics and graphical displays were generated to assess for violations of assumptions. Total personal growth scores, uncertainty scores, and total symptom burden scores examined as part of the correlation analysis were at an interval level of measurement. Age and time since diagnosis in years were also continuous variables. Age was negatively skewed, with three outliers appearing to the far left of the distribution and a significant Kolmogorov–Smirnov (K-S) statistic ( $p = .001$ ). Age was recoded to treat values  $\leq$  to 50 years as a single, lowest age, leaving all other values as reported.

Personal growth scores had a multimodal distribution and a significant K-S statistic ( $p = .037$ ), but near-zero skewness. The K-S test was also significant for uncertainty scores ( $p = .026$ ), but the histogram showed a fairly normal distribution, with only slightly positive skewness and no outliers. One outlier appeared on the boxplot for the total symptom burden score, but there was no significant difference between the mean (2.01339) and 5% trimmed mean (2.01066) for this variable, so the case was not excluded (Field, 2009). Given the sample size, departures from normality were within acceptable limits. Scatterplots examining personal growth scores, age, symptom burden,

and uncertainty did not show any obvious nonlinearity. (Field, 2009; Shadish, Cook, & Campbell, 2002).

Sex and ethnicity (Hispanic or Latino vs. Not Hispanic or Latino) were dichotomous. One participant preferred not to answer the question assessing ethnicity so this case was excluded from the analysis. Only 4 participants met criteria for NYHA class IV HF. As a result, disease severity was recoded by combining NYHA class III and IV responses, resulting in a dichotomous variable with similar category frequencies. Time since diagnosis was recoded into ordinal categories: 1 = 0-1 year, 2 = 2-3 years, 3 = 4-5 years, 4 = 6-9 years, 5 = 10-19 years, 6 = 20-29 years, and 7 = 30 or more years. Table 5 shows the descriptive statistics for continuous variables.

### **Correlation Results**

Pearson product-moment correlation coefficients are outlined in Table 6. Results showed that there was a small, negative correlation between age and total personal growth scores ( $r = -.204, p < .05$ ), indicating that younger participants reported higher personal growth. Total symptom burden scores showed a small, positive correlation with personal growth ( $r = .204, p < .05$ ) and a moderate, positive association with uncertainty scores ( $r = .492, p < .01$ ), suggesting that a higher symptom burden is associated with greater personal growth and increased levels of uncertainty. Disease severity showed a small, positive correlation with age ( $r = .282, p < .01$ ) and uncertainty scores ( $r = .279, p < .01$ ), indicating that more severe HF was related to older age and greater reports of uncertainty. There were no significant associations between personal growth and sex, ethnicity, time since diagnosis, or uncertainty.

Table 5  
*Descriptive Statistics for Continuous Variables*

Variable	Min	Max	Mean	SE	SD	Skewness (SE)	Kurtosis (SE)
Age	50	96	74.26	1.083	10.99	-.536 (.238)	-.213 (.472)
Time since diagnosis <sup>a</sup>	1	7	4.60	.171	1.734	-.376 (.238)	-.684 (.472)
Personal growth	0	105	48.64	2.820	28.616	-.061 (.238)	-1.075 (.472)
Uncertainty	27	92	52.85	1.430	14.241	.237 (.238)	-.566 (.472)
Symptom status	.933	3.340	2.01	.0428	.434	.007 (.238)	.133 (.472)

Note.  $N = 103$ .  $SE$  = standard error;  $SD$  = standard deviation.

<sup>a</sup>1 = 0-1 years, 2 = 2-3 years, 3 = 4-5 years, 4 = 6-9 years, 5 = 10-19 years, 6 = 20-29 years, 7 =  $\geq 30$  years.

Table 6  
*Pearson Product-Moment Correlation Matrix Between Measures of Personal Growth and Age, Sex, Ethnicity, Disease Severity, Time Since Diagnosis, Symptom Status, and Uncertainty*

Variables	Personal Growth <sup>a</sup>	1	2	3	4	5	6
1. Age	-.204*						
2. Sex	.080	-.012					
3. Ethnicity	-.120	.076	-.035				
4. Disease severity	-.076	.282**	.039	-.013			
5. Time since diagnosis	.038	.088	-.184	-.100	.168		
6. Symptom status <sup>b</sup>	.204*	-.151	.060	-.054	.185	-.015	
7. Uncertainty <sup>c</sup>	.057	.152	.027	-.138	.279**	-.054	.492**

<sup>a</sup>Personal growth as measured by the Posttraumatic Growth Inventory total growth score. <sup>b</sup>Symptom status as measured by the Memorial Symptom Assessment Scale–Heart Failure total symptom burden score.

<sup>c</sup>Uncertainty as measured by the Mishel Uncertainty in Illness Scale–Community Version.

\* $p < .05$  (2-tailed). \*\* $p < .01$  (2-tailed).

### Predictors of Personal Growth in HF

Hierarchical multiple regression was conducted. Demographic variables (age, sex, and ethnicity) were entered first, followed by clinical variables (disease severity and time since diagnosis) and then total symptom burden scores and uncertainty scores, to answer the third research question, “Which variables (age, sex, ethnicity, disease severity, time since diagnosis, symptom status, or uncertainty levels) make independent contributions to personal growth in individuals living with NYHA class II-IV HF?”



### **Assumptions for Multiple Regression**

The final sample of 103 was satisfactory for 80% power to detect a medium standardized effect size ( $f^2 = .15$ , equivalent to a model  $R^2 = .13$  against a null hypothesis that  $R^2 = 0$ ) at an alpha error level of .05 for a regression model with up to seven predictors. Assumptions related to outliers, normality, linearity, homoscedasticity, and multicollinearity were assessed.

As previously noted, there were no serious concerns about univariate normality for the continuous variables and no obvious curvilinear bivariate relationships among them. There were no significant multivariate outliers as determined by the maximum Mahalanobis distance for the continuous variables ( $df = 4$ ) and for the full regression model ( $df = 7$ ), based on chi-square critical values for  $p < .001$  at the given degrees of freedom as the cutoff.

The histogram of standardized residuals was approximately normally distributed in relation to personal growth scores, albeit with fewer cases at the far right. The scatterplot of standardized residuals by standardized predicted scores revealed scores widely but essentially equally distributed across the ranges for the x and y axes, consistent with the assumption of homoscedasticity. There was no indication of problematic multicollinearity (maximum variance inflation factor = 1.51 for the full model).

### **Multiple Regression Results**

Hierarchical multiple regression was conducted. Demographic variables (age, sex, and ethnicity) were entered in Step 1, explaining 5.8% of the variance in personal growth. After entry of clinical variables (disease severity and time since diagnosis) in Step 2, the

total variance explained by the model was 6.3%. Finally, after adding uncertainty and symptom scores in Step 3, the total variance in personal growth explained by the model as a whole was 9.5%,  $F(7, 95) = 1.430$ ,  $p = .202$ . The model as a whole was not statistically significant and individual regression coefficients in the model were also not significant. See Table 7 for a summary of the regression model and Table 8 for coefficients.

Table 7  
*Regression Model Summary*<sup>a</sup>

Model	<i>R</i>	<i>R</i> <sup>2</sup>	<i>R</i> <sup>2</sup> Change	<i>F</i> Change	<i>df</i> 1	<i>df</i> 2	<i>p</i>
Step 1 <sup>b</sup>	.241	.058	.058	2.033	3	99	.114
Step 2 <sup>c</sup>	.251	.063	.005	.254	2	97	.777
Step 3 <sup>d</sup>	.309	.095	.032	1.701	2	95	.188

*Note.*  $N = 103$ .

<sup>a</sup>Dependent variable: personal growth scores. <sup>b</sup>Predictors: age, sex, and ethnicity. <sup>c</sup>Predictors: age, sex, ethnicity, disease severity, and time since diagnosis. <sup>d</sup>Predictors: age, sex, ethnicity, disease severity, time since diagnosis, uncertainty, and symptom scores.

### Additional Exploratory Analyses

Additional descriptive analyses were conducted to generate a better depiction of symptom prevalence and burden and reports of uncertainty in this sample. In addition, differences in personal growth scores were examined by sex, ethnicity, and disease severity.

### Symptom Prevalence and Burden

As outlined in Table 9, symptoms that were reported by at least 50% of the participants included lack of energy (73.8%), feeling drowsy (58.3%), dry mouth

Table 8  
*Regression Model Coefficients*<sup>a</sup>

Model	B	SE(B)	$\beta$	<i>t</i>	<i>p</i>
Step 1					
Constant	93.406	23.715			
Age	-.508	.255	-.195	-1.994	.049
Sex	4.944	6.483	.074	.763	.448
Ethnicity	-7.221	6.891	-.103	-1.048	.297
Step 2					
Constant	86.454	25.830		3.347	.001
Age	-.496	.268	-.191	-1.852	.067
Sex	5.890	6.670	.089	.883	.379
Ethnicity	-6.768	6.991	-.096	-.968	.335
Years since diagnosis	1.117	1.689	.068	.661	.510
Disease severity	-2.163	5.921	-.038	-.365	.716
Step 3					
Constant	54.243	31.187		1.739	.085
Age	-.391	.280	-.150	-1.400	.165
Sex	5.390	6.633	.081	.813	.418
Ethnicity	-6.279	7.042	-.089	-.892	.375
Years since diagnosis	1.224	1.692	.074	.723	.471
Disease severity	-4.832	6.139	-.085	-.787	.433
Symptom status	12.379	7.739	.188	1.600	.113
Uncertainty	.000	.241	.000	.001	.999

Note. *N* = 103. *SE* = standard error.

<sup>a</sup>Dependent variable: personal growth scores.

(55.3%), shortness of breath (52.4%), and worrying (50.5%). Individual symptom burden scores as shown in Table 9 demonstrated acceptable internal consistency with Cronbach alpha values  $\geq 0.8$  for 16 symptoms, and  $\geq 0.7$  for 12 symptoms. Symptoms with Cronbach's alpha values  $\geq 0.6$  but less than 0.7 included feeling nervous, problems with sexual interest or activity, weight loss, and waking up breathless at night. Symptoms that were most burdensome included problems with sexual interest or activity ( $M = 2.81$ ,  $SD = 0.66$ ), other pain ( $M = 2.51$ ,  $SD = 0.7$ ), lack of energy ( $M = 2.41$ ,  $SD = 0.78$ ), difficulty sleeping ( $M = 2.4$ ,  $SD = 0.73$ ), and shortness of breath ( $M = 2.35$ ,  $SD = 0.77$ ). The mean

for the total symptom burden scale was 2 ( $SD = .43$ ), indicating that on average participants reported symptoms occurring occasionally and as somewhat distressful and moderately severe.

### **Uncertainty**

In the current study, the Cronbach's alpha coefficient for the MUIS-C was 0.92. The mean for the MUIS-C was 52.85 ( $SD = 14.24$ ), indicating that participants reported moderate levels of uncertainty. Of the 23 items on the MUIS-C, 21 items had modal categories of 2, indicating that a higher number of participants either disagreed with statements that were indicative of greater uncertainty, such as, "I have a lot of questions without answers" or "I am unsure if my illness is getting better or worse," or agreed with statements that were suggestive of greater certainty, such as "The purpose of each treatment is clear to me." In this sample, more than 50% of participants reported that they strongly disagreed with the statement, "I don't know what is wrong with me," indicating that participants were aware of their HF diagnosis.

Items that addressed the future had the highest percentage of individuals responding with some degree of uncertainty. The item that was reflective of the highest degree of uncertainty in this sample was "I am certain they will not find anything else wrong with me," with 46% of participants indicating that they disagreed with this statement and 15% indicating that they strongly disagreed. The three other items that had the highest reports of uncertainty included "The course of my illness keeps changing. I have good days and bad days," with 37% agreeing and 11% strongly agreeing with this statement and "It is not clear what is going to happen to me" and "Because of the

unpredictability of my illness, I cannot plan for the future,” with more than 30% of participants either agreeing or strongly agreeing with both of these items.

Table 9  
*Prevalence and Burden of Symptoms and Reliability of Burden Scores*

Symptom	Prevalence		Burden		Alpha
	<i>N</i>	%	Mean	<i>SD</i>	
Lack of energy	76	73.8	2.41	0.78	.88
Feeling drowsy	60	58.3	2.09	0.72	.80
Dry mouth	57	55.3	2.20	0.67	.76
Shortness of breath	54	52.4	2.35	0.77	.84
Worrying	52	50.5	2.16	0.61	.78
Dizziness	51	49.5	1.91	0.66	.82
Numbness or tingling in hands or feet	49	48.0	2.32	0.74	.72
Other pain	46	44.7	2.51	0.70	.74
Cough	43	42.2	2.03	0.70	.79
Difficulty sleeping	43	41.7	2.40	0.73	.82
Feeling irritable	43	41.7	2.03	0.59	.76
Feeling sad	33	32.0	2.06	0.69	.88
Swelling of arms or legs	31	30.4	1.99	0.83	.71
Itching	31	30.1	2.26	0.73	.81
Problems with sexual interest or activity	28	28.3	2.81	0.66	.64
Feeling nervous	29	28.2	2.15	0.54	.67
Difficulty concentrating	28	27.2	2.30	0.67	.76
Problem with urination	28	27.2	2.18	0.66	.72
Weight loss	27	26.2	1.30	0.49	.62
Weight gain	26	25.2	1.68	0.87	.77
Constipation	24	23.5	2.21	0.71	.84
Palpitations	24	23.3	1.82	0.58	.83
Lack of appetite	24	23.3	2.01	0.63	.74
Change in the way food tastes	23	22.3	2.00	0.71	.84
Difficulty breathing when lying flat	22	21.8	2.12	0.72	.79
Chest pain	21	20.4	1.95	0.72	.80
Feeling bloated	20	19.4	2.32	0.75	.82
Sweats	18	17.5	2.08	0.76	.82
Waking up breathless at night	13	12.6	2.14	0.53	.60
Diarrhea	12	11.7	1.87	0.74	.84
Nausea	11	10.7	2.02	0.58	.89
Vomiting	4	3.9	1.38	0.73	.93

*Note.* *N* = 103. Burden scores only calculated for participants who report symptoms.

### **Differences in Personal Growth by Sex, Ethnicity, and Disease Severity**

To highlight differences in personal growth by sample characteristics, additional analysis was conducted. Differences in levels of personal growth by sex, ethnicity, and disease severity were examined to assess whether statistically significant differences existed in personal growth scores by groups using independent samples *t* tests.

#### **Assumptions of Independent Samples *t* Tests**

Each independent variable consisted of two groups; sex (male/female), ethnicity (Hispanic/not Hispanic), and disease severity (NYHA class II/NYHA class III or IV). The dependent variable, personal growth scores, was measured at an interval level. As previously noted, there were no serious departures from normality assumptions. Levene's test for equality of variance by sex ( $F = .916, p = .34$ ), by ethnicity ( $F = .489, p = .49$ ), and by disease severity ( $F = .603, p = .44$ ) indicated that equal variances between groups could be assumed (Pallant, 2007).

#### **Results of Independent Samples *t* Tests**

There was no significant difference in personal growth scores for males ( $M = 47.35, SD = 29.38$ ) and females ( $M = 52.68, SD = 26.24$ );  $t(df = 101) = -.810, p = .42$  (two-tailed). The magnitude of differences in the means ( $-5.334$ ; 95% CI:  $-18.403$  to  $6.735$ ) was small (Cohen's  $d = .19$ ).

Reports of personal growth also did not differ significantly by ethnicity,  $t(df = 100) = 1.486, p = .14$  (two-tailed). Hispanic persons reported, on average, slightly higher levels of personal growth ( $M = 57.21, SD = 26.28$ ), compared with reports by individuals not Hispanic ( $M = 46.43, SD = 28.98$ ). The mean difference ( $10.777$ ; 95% CI:  $-3.611$  to  $25.165$ ) reflected a small-to-moderate effect size (Cohen's  $d = .39$ ).

Participants meeting criteria for NYHA class II HF reported higher levels of personal growth ( $M = 50.74$ ,  $SD = 29.29$ ) compared with those individuals with NYHA class III or IV HF ( $M = 46.42$ ,  $SD = 28.00$ ), but this difference was not statistically significant;  $t(df = 101) = .763$ ,  $p = .44$  (two-tailed). The mean difference (4.316; 95% CI: -6.899 to 15.530), again, only represented a small effect size (Cohen's  $d = .15$ ). In summary, there were no significant differences in reports of personal growth by sex, ethnicity, or disease severity in this sample.

## **CHAPTER 5**

### **DISCUSSION**

This study provided the first known examination of reports of personal growth in community-residing adults living in the United States with a diagnosis of HF. Findings highlighted the relevance of demographic and clinical factors to the development of personal growth in HF. In addition, findings enhanced the theoretical understanding of relationships among growth, uncertainty, and symptoms in chronic illness. This was the first known study to quantitatively explore personal growth with respect to uncertainty and symptoms in HF, providing empirical data that supported select relationships proposed by Mishel (1990) in the RUIT.

Community-residing adults living with stable HF reported moderate levels of personal growth, suggesting that individuals living with HF can perceive some degree of favorable psychosocial change as a result of their illness experience. Personal growth showed a weak negative association with age and a weak positive association with symptom burden. Personal growth was not accounted for by disease severity, time since diagnosis, uncertainty, symptom burden, or demographic variables other than age. Study results are first reviewed in relation to past research examining personal growth in cardiac populations and other illness groups and then in relationship to conceptualizations and assumptions of personal growth belonging to Tedeschi and Calhoun's (2004) model of PTG and the RUIT (Mishel, 1990). Lastly, results are discussed in light of study limitations.



### Reports of Personal Growth

This is the first study to explore personal growth exclusively in an HF population. Personal growth has been studied previously in patients with cardiovascular disease, including Canadian patients with a diagnosis of HF ( $n = 178$ ) or other major cardiovascular conditions ( $n = 1,090$ ; Leung et al., 2010); U.S. ( $n = 28$ ) and U.K. ( $n = 82$ ) patients with a history of heart disease or cardiac arrest who were enrolled in cardiac rehabilitation or support group programs (Sheikh, 2004), and U.S. patients who had experienced an MI ( $n = 205$ ; Affleck et al., 1987).

PTGI scores in the current study ( $M = 48.6$ ,  $SD = 28.6$ ) were similar to those reported by Leung et al. (2010;  $M = 50.3$ ,  $SD = 27.2$ ) but lower than those reported by Sheikh (2004;  $M = 55.9$ ,  $SD = 24.2$ ). In the current study, participants reported the greatest degree of personal growth in appreciation for life and the least amount of personal growth in new possibilities. Leung et al. (2010) also found that participants more commonly endorsed items on the appreciation for life subscale and less commonly endorsed items related to new possibilities and spiritual change. Demographic characteristics of participants within these three studies were similar; however, participants in the current study were slightly older ( $M = 74.5$ ,  $SD = 10.99$ ) compared with participants in the studies by Leung et al. (2010;  $M = 67.3$ ,  $SD = 11.16$ ) and Sheikh (2004;  $M = 63.5$ ,  $SD = 9.7$ ). In addition, although participants in the current study may have had a history of cardiac surgery or cardiac arrest, these events were not accounted for in the current study. By contrast, participants in the study by Sheikh (2004) had a history of cardiac arrest, which may have contributed to greater adversity and therefore higher reports of growth. The relationship between adversity and growth is discussed in

more detail in upcoming sections examining personal growth in relation to the RUIT and PTG model.

Compared with studies cited by Leung et al. (2010) that used the PTGI in other patient populations, PTGI scores in the present study were higher than have been reported among patients with hepatobiliary cancer, prostate cancer survivors, and HIV/AIDS, but lower compared with those that have been reported for breast cancer, stage IV liver cancer, colorectal cancer, bone marrow transplant, and multiple sclerosis. However, variations in study design and sample characteristics make it difficult to generalize from such comparisons. That said, results of this study provide a preliminary baseline for future study of personal growth in HF and add to the overall literature on personal growth in chronic illness.

### **Correlates of Personal Growth**

#### **Age**

Personal growth showed a weak, negative correlation with age in this study, indicating that younger participants reported more growth. This finding is consistent with results reported by Leung et al. (2010) in cardiac patients, with studies in cancer survivors and HIV populations that measured growth with the PTGI (Barskova & Oesterreich, 2009), and with research in breast cancer survivors that used the GTUS to assess growth (Porter et al., 2006).

Petrie et al. (1999) conducted the only other study that examined the relationship between growth (as measured by a single item question) and age in a cardiac sample (individuals 3 months post-MI) living in New Zealand and did not find a significant association between the two variables. Several studies conducted with other illness

populations demonstrated nonsignificant associations between age and growth, but only one of these studies used the PTGI (Barskova & Oesterreich, 2009).

### **Sex**

In the current study, personal growth was not significantly associated with sex, consistent with findings demonstrated in other cardiac populations (Leung et al., 2010; Petrie et al., 1999; Sheikh, 2004) and in bone marrow transplant patients (Widows et al., 2005). However, the current study had a small number of female participants ( $n = 25$ ; 24.3%) which may have limited the ability to detect differences in personal growth by sex. In contrast, Barskova and Oesterreich (2009) found that among cancer survivors and HIV patients women tended to report greater growth than men in their systematic review of PTG in serious illness.

### **Ethnicity**

There was no significant relationship between personal growth and ethnicity or differences in growth scores by ethnicity in the current study. However, the majority of participants ( $n = 96$ ; 93.2%) were White and were not Hispanic ( $n = 83$ ; 80.6%). In contrast, Leung et al. (2010) reported significant differences in personal growth by race (their Canadian sample did not include Hispanic participants), with Asian participants reporting the highest growth, followed by African American participants, and then White participants. According to Barskova and Oesterreich (2009), studies that had only a small percentage of minority participants tended not to find significant associations between growth and race or ethnicity, whereas studies in cancer and HIV populations that found greater growth in African-Americans and Hispanics compared with Whites included larger numbers of ethnically/racially diverse participants.

**Disease Severity**

Disease stage was not significantly associated with personal growth in the current study, congruent with results reported by Petrie et al. (1999), who did not find significant differences between reports of growth and illness severity in an MI population. Two studies using the PTGI in cancer groups demonstrated nonsignificant associations with disease stage (Thornton & Perez, 2006; Widows et al., 2005), whereas one study using the PTGI demonstrated greater growth in individuals with stage II cancer compared with stage I or stage IV cancer (Lechner et al., 2003). Overall, evidence that disease stage at the time of study participation impacted growth is equivocal at best.

**Time Since Diagnosis**

Time since diagnosis was not significantly associated with personal growth in HF, consistent with findings from earlier studies in cardiac and cancer populations, in which growth was measured using the PTGI (Lechner et al., 2003; Morris et al., 2007; Sheikh, 2004). Alternatively, studies in breast cancer survivors 2 years post-diagnosis (Cordova et al., 2001) and 18 months after diagnosis (Sears et al., 2003), and in brain injury patients at 10 to 11 years post-insult (McGrath & Linley, 2006; Powell et al., 2007) have shown significant correlations between longer time since diagnosis and reports of greater growth. In the present study, a majority of participants (56.3%) had been living with HF for more than 10 years, and more than 30% of the sample had been living with HF for more than 20 years. The extended length of time that participants had to adjust to their HF diagnosis may have influenced the nonsignificant findings between time since diagnosis and personal growth in the current study. In addition, cross-sectional data

collection may have limited the ability to detect associations between time since diagnosis and personal growth.

### **Symptom Status and Uncertainty**

No other studies were found that examined the relationship between personal growth and uncertainty or symptom status in HF. Studies investigated variables such as disease severity and morbidity (Affleck et al., 1987) and functional abilities (Leung et al., 2010) that may be influenced by symptoms, but that influence cannot be teased out after the fact. Therefore, this is the only study that specifically examined the relationships among personal growth, uncertainty, and symptom status in HF. Symptom status had a weak positive correlation with personal growth ( $r = .204, p < .05$ ), but correlations between uncertainty and growth were not significant.

### **Theoretical Implications of Study Results**

The primary guiding framework for this study was Mishel's (1990) RUIT. In addition to the RUIT, Tedeschi and Calhoun's (2004) conceptualization of PTG and related assumptions also informed this study. In this section, study results are reviewed in relation to these concepts and other studies that have been informed by the RUIT.

Theoretically derived variables included in this analysis were disease severity, time since diagnosis, symptom status, uncertainty, and personal growth.

The first aim of this study was to determine whether individuals living with HF report personal growth, as characterized within the above conceptual frameworks.

Tedeschi and Calhoun (1996, 2004) suggested that personal growth represents a process in which individuals move beyond traditional coping/adaptation to achieve positive psychosocial outcomes in response to significant adversity. Congruent with this

conceptualization of growth, Mishel (1990) argued that over time, individuals living with ongoing uncertainty in chronic illness may be able to perceive opportunities for growth through the discovery of new life meaning.

Based on the literature, which suggests that HF is associated with significant mortality, symptom burden, uncertainty due to an unpredictable illness trajectory, high rates of depression, and poor quality of life (Adler et al., 2009), this study was rooted in the assumption that living with a diagnosis of HF could create significant challenges that subsequently disrupt an individual's fundamental beliefs about his or her health and future, and encourage personal growth. Descriptive statistics of disease severity, symptom status, and uncertainty (variables that the literature suggests contribute to the challenges of HF) helped to depict the presence of these negative factors within this HF sample.

### **Adversity in HF**

In terms of disease severity, approximately 52% of the sample met criteria for NYHA class II HF, indicating that they had slight limitations with usual activity due to symptoms, whereas the other half met criteria for either NYHA class III or IV HF, indicating that they had at least moderate limitations with less than usual activity due to their symptoms.

As shown in Table 9, participants reported a variety of symptoms. The symptoms reported most commonly (lack of energy, feeling drowsy, dry mouth, shortness of breath, and worrying) were consistent with symptom prevalence findings reported by Zambroski et al. (2005), who also used the MSAS-HF to assess symptoms in an outpatient HF population. The most burdensome symptoms in the current study were problems with

sexual interest/activity, pain, lack of energy, difficulty sleeping, and shortness of breath. Zambroski et al. (2005) also reported that these symptoms were among the most burdensome in their sample. In general, mean burden scores in Zambroski et al.'s (2005) study were higher than were those reported in the current study. Variations in mean burden scores could result from the higher number of participants (77.4%) with either NYHA class III-IV HF in Zambroski et al.'s (2005) sample compared with the current study.

The mean for the MUIS-C was 52.85 ( $SD = 14.24$ ), indicating that participants reported moderate levels of uncertainty. Uncertainty levels were essentially consistent with uncertainty levels measured by the MUIS-C ( $M = 54.9$ ,  $SD = 7.7$ ) reported by Winters (1999) in an outpatient HF population and lower than uncertainty scores ( $M = 71.4$ ,  $SD = 9.56$ ) reported by Jurgens (2006) in hospital inpatients with HF.

In summary, this HF sample reported slight to moderate limitations in activity from their symptoms. Symptom prevalence and burden reports and levels of uncertainty were comparable to other outpatient HF populations. These results support a finding that negative factors thought to contribute to distress in HF were present to a small to moderate degree in this sample.

### **Reports of Personal Growth**

In this study, participants reported a moderate degree of personal growth. The areas of greatest growth involved appreciation for life followed by relationships with others, spiritual change, and personal strength. These results are congruent with results of qualitative studies that either informed the development of the RUIT or used the RUIT as a guiding framework, which found that some individuals living with uncertainty in

chronic illness perceive positive outcomes (Baier, 1995; Bailey et al. 2007; Brashers et al., 1999; Fleury et al., 1995; Mishel & Murdaugh, 1987). Positive perceptions in these studies included hope or optimism for the future, lifestyle change, personal or spiritual growth, and finding joy in small accomplishments, but were typically described in conjunction with more pervasive negative thoughts or emotions. The PTGI, which was used to evaluate personal growth in the current study, did not account for concurrent negative perceptions or outcomes.

Results from the current study also supplement the literature that has quantitatively examined uncertainty in relationship to growth in other illness populations, specifically in men with prostate cancer (Bailey et al. 2004) and breast cancer survivors (Gil et al., 2006, Mast 1998, Porter et. al, 2006), using Mishel and Fleury's (1994) GTUS. A synthesis of these findings is discussed below.

### **Correlates and Predictors of Personal Growth**

In the RUIT, Mishel (1990) suggests that disease severity and symptom status can contribute to greater levels of uncertainty, but that over time, individuals may be able to positively reappraise uncertainty and perceive growth. Time since diagnosis was examined in the current study to assess the influence of time on this process in HF. Time since diagnosis was not significantly associated with growth in the current study, consistent with findings demonstrated by Mast (1998), who measured growth via the GTUS in breast cancer survivors. However, both of these studies used cross-sectional data collection, which may have limited the ability to detect findings related to growth over time. In addition, although personal growth evolves over time, time in and of itself may not be sufficient to produce personal growth on its own.



Disease severity was also not significantly related to personal growth in this study; however, NYHA class did demonstrate significant relationships with age and uncertainty, indicating that individuals with more severe HF were older and had higher levels of uncertainty. This finding supports relationships outlined in Mishel's (1988, 1990) UIT and RUIT. In these theories, disease severity and symptom status are included as components of the stimuli frame, which is characterized as an antecedent of uncertainty. Consistent with findings from this study, Mishel (1988, 1990) proposes that greater illness severity increases uncertainty. The positive association between disease severity and uncertainty in this study is also consistent with the fact that with increased duration of chronic HF, the frequency of sudden, acute exacerbations tends to increase and intervening periods of stability may be shorter in duration (Hupcey et al., 2009; Jessup et al., 2009).

Symptom burden showed a weak positive association with personal growth. However, in the regression model, symptom burden did not account for significant variance in personal growth after controlling for demographic and clinical factors and uncertainty. The overall negative finding indicates that variables that were not included in this analysis may account for personal growth in HF. Symptom burden did demonstrate a moderate, positive correlation with uncertainty, suggesting that higher symptom burden is associated with greater uncertainty. This finding also supports the relationship outlined by Mishel (1988, 1990) between symptoms and uncertainty and is congruent with the literature, which suggests that symptoms can contribute to uncertainty in HF (Aldred et al., 2005; Beckelman, Nowels, Retrum et al., 2011; Brännström et al., 2006; Brännström et al., 2007; Falk et al., 2007; Jurgens, 2006; Russell et al., 1998; Winters, 1999).

There was no significant association between uncertainty and personal growth in the current study. This finding contrasts with a previous study of uncertainty as a component of a negative cognitive state, which showed an association between uncertainty and less growth, a relationship that was mediated by higher symptom distress and less social support satisfaction in breast cancer survivors (Porter et al., 2006). Mishel (1990) proposed that reappraising uncertainty requires a cognitive restructuring of reality that occurs over time and that achieving growth through uncertainty is supported by self-organization (integrating uncertainty into one's life) and probabilistic thinking; in addition, the propensity for growth may be influenced by past life experience, physiologic states, social support, and interactions with health care providers. With the exception of disease severity and symptom burden as measures of physiologic state, these other factors were not assessed in the current study, which could have contributed to the nonsignificant findings.

Other researchers who have studied symptoms and uncertainty as correlates or predictors of growth, as characterized within the RUIT, have included variables thought to facilitate psychosocial well-being or positive reappraisal (Bailey et al. 2004; Gil et al., 2006; Mast, 1998; Porter et. al, 2006). For example, Porter et al. (2006) demonstrated that greater symptom prevalence, when combined with increased religious participation, higher levels of education, and younger age, was significantly associated with increased reports of growth in breast cancer survivors. In addition, cognitively reframing events in a positive way helped to explain growth in both African American and White breast cancer survivors and mediated the influence of social support and religious involvement on personal growth (Porter et al., 2006). Examining variables thought to facilitate

psychosocial health and cognitive reframing may be necessary to better understand personal growth in HF.

In conclusion, this study found that community-residing adults with stable HF report on average moderate levels of personal growth that is not explained by age, sex, ethnicity, time since diagnosis, symptom burden, or uncertainty. Several factors could help to explain why reports of personal growth were not higher in this HF sample and why study variables did not help to explain variance in personal growth.

The overall stability of this HF sample could suggest that participants did not experience adversity significant enough to challenge their fundamental worldviews, a prerequisite required for PTG as described by Tedeschi and Calhoun (2004). The long duration of time that most participants had been living with HF could have supported more traditional adjustment to their illness not characterized by personal transformations necessary for growth. In addition, growth may have been a more salient feature in earlier stages of HF that, for a majority of patients, would have occurred many years earlier.

In addition, characteristics of the cardiology clinic and/or providers that were not accounted for in this study but observed by the researcher could have minimized potential adversity. Patients were routinely evaluated by consistent providers who had been affiliated with the clinic for several years. In addition, practitioners provided patients with ongoing education related to their HF diagnosis and management and comprehensive follow-up for changes in their clinical condition. On several occasions during research interviews, participants made unsolicited remarks about their satisfaction with and confidence in the care provided by the cardiology clinic. At the same time, providers predominantly focused on managing the physical consequences of HF, rather than on

providing psychosocial or cognitive support, which is consistent with national guidelines for the treatment of HF (Heart Failure Society of America, 2010a, 2010b; Jessup et al., 2009). Therefore, variables not included in this analysis, such as psychological, social or spiritual support, or interventions that promote cognitive reappraisal may be more important in the development of personal growth. Bekelman, Nowels, Allen et al. (2011) found that individuals living with HF receiving outpatient palliative care services reported significant needs related to psychosocial support which was lacking in traditional HF management. Integrating supportive care into HF management programs might help to facilitate personal growth.

### **Limitations**

Several limitations need to be considered when interpreting results from this study. Most notably, convenience sampling of participants who could speak and understand English from one private practice cardiology clinic in San Antonio, TX, reduced the external validity of findings (Shadish et al., 2002). Participants were predominantly White, male, married or living with a partner, educated at or above a high school level, and older, limiting the ability to generalize findings to more diverse populations. The small number of female, Hispanic, and Class IV HF participants may have limited the ability to detect significant relationships between growth and sex, ethnicity, and disease severity in this study. In addition, the cardiology clinic has been well established in the community for many years and has a strong reputation for providing quality cardiac care. Characteristics of the clinic and its providers could have also influenced results, especially related to symptom burden and uncertainty reports. Results might differ in settings that do not provide the same level of comprehensive,

coordinated HF management, limiting the ability to generalize findings to more diverse settings.

Reliability of the MSAS-HF has been established for the total symptom prevalence score and the physical, psychological, and HF-specific subscales (Zambroski et al., 2005). Because the total symptom burden score on the MSAS-HF depends on unique combinations of symptoms for each respondent, an overall reliability coefficient cannot be estimated. This is a potential threat to statistical conclusion validity. However, reliability coefficients for the burden scores of individual symptoms could be estimated, and most were, satisfactory (especially in view of being based on just 2 or 3 items per symptom).

Investigator expectancy (Shadish et al., 2002) is a plausible threat to construct validity in this study. Participants who chose to complete the survey via a researcher-conducted interview in the clinic rather than independently may have been inclined to respond to items differently due to the presence of the researcher or clinic staff. In particular, participants may have been more inclined to provide favorable responses to items on the MUIS-C, which asked specific questions about their HF management.

To minimize these risks, participants were given the option of completing the survey independently, either electronically or on paper. In addition, when the participant opted for a researcher-conducted interview, the researcher read the survey directions and questions exactly as they were written on the survey. Interviews were conducted in private rooms before or after patients were evaluated by their providers and participants were assured that their responses would not be shared with clinic staff. To assess for this threat, independent samples *t* tests were conducted to examine differences in PTGI,

MUIS-C, and MSAS-HF scores by survey administration methods. No significant differences in questionnaire scores between participants who completed the survey independently on paper and those who participated in a researcher-conducted interview were found. Only 2% of participants completed the survey electronically, so this group was excluded from this analysis. These findings suggest that threats to construct validity resulting from unintended researcher/staff expectancies were most likely limited.

Although the aims of this descriptive, exploratory study were not to test causal relationships, threats to internal validity also need to be considered when interpreting results. As described above, convenience sampling was used to enroll participants, potentially contributing to selection bias (Shadish et al., 2002). Individuals who perceived their HF experience as more positive may have been more interested in participating. To ensure that all potentially eligible participants were informed of the study, recruitment letters were sent to individuals meeting diagnostic criteria for HF; recruitment flyers were also available in all patient rooms and the waiting room and were given to all HF patients by providers during scheduled visits.

In addition to selection bias, threats to ambiguous temporal precedence could influence internal validity. Cross-sectional data collection limited inferences regarding both the onset of growth and its trajectory in HF over time (Shadish et al., 2002). Although the PTGI asked participants to rate the degree of positive change in response to their HF diagnosis in this study, other adverse life events not accounted for within this research may have influenced participants' responses.

### **Implications for Future Research**

This study provides the first known examination of personal growth exclusively in HF and specifically in relation to symptoms and uncertainty. Findings provide a beginning understanding of personal growth in HF by demonstrating that community-residing adults living with stable HF report moderate levels of personal growth that is not explained by demographics, time since diagnosis, disease stage, uncertainty, or symptom burden. The results create a foundation for future research to build on in advancing our understanding of personal growth in HF. A more in-depth knowledge of personal growth in HF may be useful in informing supportive care models being developed to supplement traditional medical management of HF. Enhanced understanding of personal growth could help to clarify how nurses and other health care providers facilitate or hinder personal growth for patients with HF.

To improve the ability to generalize findings, researchers should examine personal growth in more diverse HF populations that include a greater number of female participants and greater racial and ethnic diversity as well as greater variability in clinical condition (e.g., with more recently diagnosed or less stable patients). Reports of personal growth and correlates should also be examined in individuals living in rural and underserved regions and receiving care within public, academic, or hospital-based settings. Larger, more representative samples from multiple settings would also enhance the generalizability of findings.

Incorporating a greater range of sociodemographic and psychosocial variables (e.g., income, social support, coping strategies, and personality dispositions) might provide a more comprehensive representation of personal growth in HF and help to

identify potential mediating/moderating factors and predictors of growth. A better understanding of growth through uncertainty in relation to adversity would most likely result from studies that assess personal growth using both the PTGI and GTUS. Longitudinal assessment of personal growth beginning at the time of diagnosis and at regular intervals thereafter would generate a better understanding of the onset and trajectory of growth within HF. In addition to replicating quantitative assessments of growth, qualitative approaches that garner a deeper understanding of participants' experiences of growth would strengthen the science of personal growth in chronic illness. Finally, future research should include qualitative approaches and/or instruments that also assess cognitive processes, such as rumination, positive reappraisal, or probabilistic thinking to better understand how personal growth develops and to test relationships proposed by Tedeschi and Calhoun (2004) and Mishel (1990).



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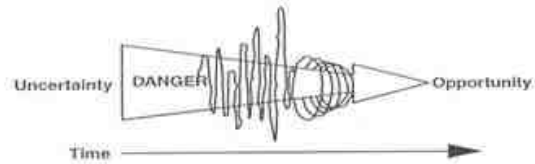
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## APPENDICES

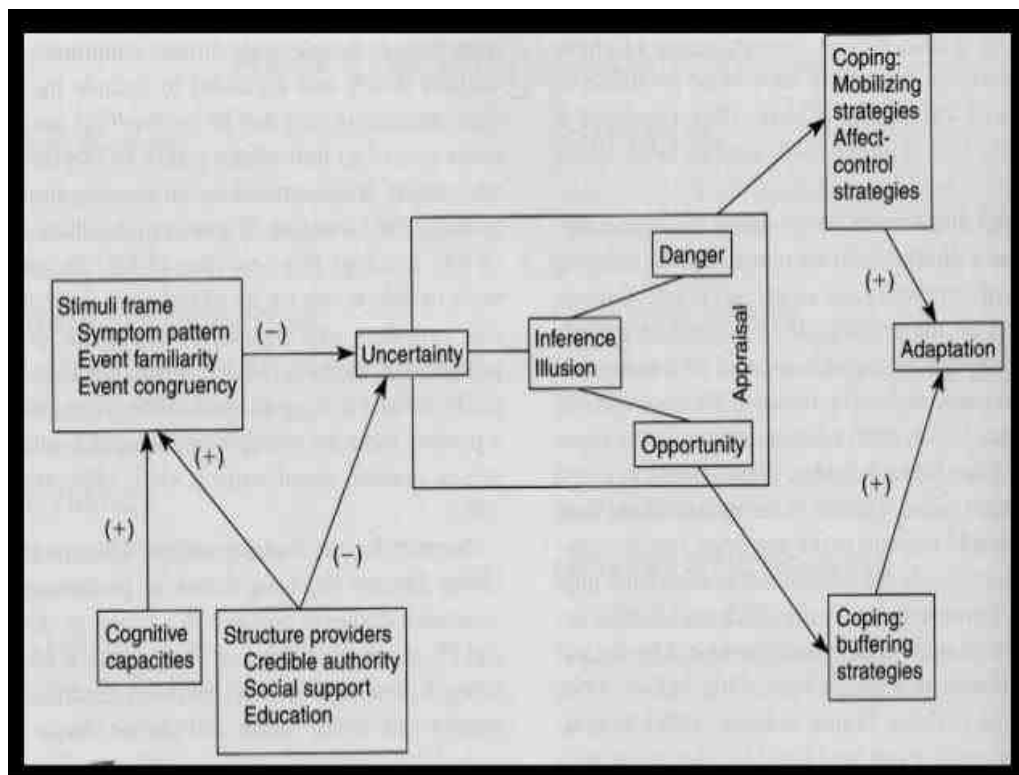
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**APPENDIX A****RECONCEPTUALIZED UNCERTAINTY IN ILLNESS CONCEPTUAL MODEL**

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## APPENDIX B

## UNCERTAINTY IN ILLNESS CONCEPTUAL MODEL



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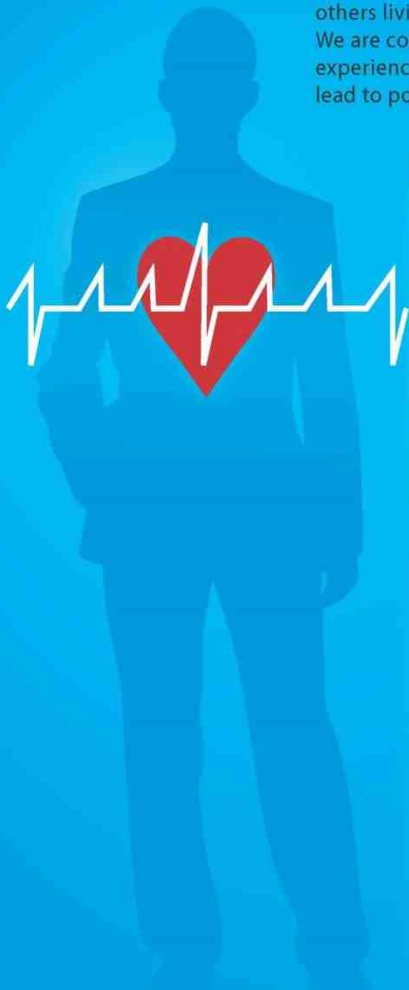


## APPENDIX C

## RECRUITMENT FLYER

## ARE YOU LIVING WITH HEART FAILURE?

If so, your experience matters and could make a difference to others living with heart failure. We are conducting a research study to better understand if the experience and challenges of coping with heart failure can lead to positive changes in life.



### Who are the Researchers and What is the Purpose of this Research?

#### Kristen Overbaugh RN, MSN,

is a PhD candidate at the University of New Mexico College of Nursing and nursing faculty at the University of Texas Health Science Center at San Antonio, School of Nursing.

#### Mark Parshall, PhD, RN

is Associate Professor and Regents' Professor, University of New Mexico College of Nursing.

The purpose of the research is to determine if patients with heart failure perceive positive changes in life as a result of their heart failure experience and what factors may be related to those positive changes.

### What does the Research Involve?

Participation in this study is voluntary and can be stopped at anytime, for any reason.

Participation will consist of providing some basic information about yourself and answering 3 questionnaires and should take less than 1 hour of your time. You will be given the option of completing the questionnaires electronically, on paper, or via a researcher conducted phone or in-person interview.

Participants will be compensated for their time and effort with a \$20.00 gift card after completing the questionnaires.

Please contact Kristen Overbaugh at one of the following numbers if you are interested in learning more about this study. She looks forward to hearing from you.

**Kristen Overbaugh RN, MSN, PhD candidate at  
484-515-3816 or 210-567-2165**

## APPENDIX D

### RECRUITMENT LETTER

#### SCHNITZLER CARDIOVASCULAR CONSULTANTS, P.L.L.C.

January 20, 2014

Robert N. Schnitzler, MD  
FACC, FACP, FSCAI, FCCP

Roberta C. Bogaev, MD, FACC, FACP

Kevin Steel, DO, FACC

Victoria Paparelli, MSN,  
RN, CCNS-AC  
Clinical Nurse Specialist

Denise Vega, MSN  
MBA, GNP-BC, ACNP-BC  
Acute Care Nurse Practitioner

Maria Cristina Rodriguez,  
RN, BSN  
Chief Executive Officer

Angela Del Carmen Ortiz  
Chief Operating Officer

SCC Nuclear Cardiology Lab  
Kimberly Dawn Gibson,  
CNMT, RT (N)  
Nuclear Technician



SCC Echocardiography Lab  
Patricia Torchia, RDMS  
Echocardiography Technician



SCC Vascular Lab  
Debra L. Monastra, RDMS, RVT  
Vascular Technician

Dear Mr/s. \_\_\_\_\_

This letter is being sent to you because you may be eligible to participate in a research study being conducted at Schnitzler Cardiovascular Consultants. The purpose of this study is to determine if individuals diagnosed with heart failure can perceive positive changes from the challenges of living with heart failure, and to better understand the factors that may be related to those positive changes. This study is being conducted by Kristen Overbaugh RN, MSN, a PhD candidate at the University of New Mexico (UNM) College of Nursing and a Clinical Assistant Professor at the University of Texas Health Science Center at San Antonio, School of Nursing, under the supervision of Mark Parshall PhD, RN, Associate Professor at the UNM College of Nursing. This study has the approval of the University of New Mexico Health Sciences Center Human Research Protections Office.

Participation is voluntary. Your treatment will be the same, regardless of whether or not you participate in the research. You can choose to withdraw from this study at any time, for any reason. There is no direct benefit to participating, but it is hoped that the knowledge gained through this research will increase understanding of patients' perspectives on living with heart failure.

Participation will involve completing three questionnaires and providing some basic information, and should take no more than 60 minutes. The basic information includes questions such as your age, gender, marital status, ethnicity, and how long ago you were diagnosed with heart failure. The first questionnaire will ask you to rate the degree to which you have experienced changes in your life as a result of your heart failure diagnosis, for example, the degree to which you, "changed priorities about what is important in life" or "have a greater sense of closeness with others". The second questionnaire will ask you about uncertainty related to your heart failure diagnosis and treatment, for example, "I am unsure if my illness is getting better or worse". The third questionnaire will ask you to identify which of several heart failure symptoms, such as shortness of breath or fatigue you have experienced over the last week, and will ask you to rate the frequency of those symptoms and how much you were bothered by them.

The questionnaires can be completed on paper or computer; if you prefer, the researcher can conduct a phone or in-person interview to complete them. Questionnaires can be completed at home, or at the cardiology office at a time that is convenient for you when the researcher can be present. Participants will be given a \$20.00 gift card in appreciation of their time and effort. If you are interested in participating in this study or have questions, please call Kristen Overbaugh at 484-515-3816 or at 210-567-2165.

Sincerely,

Kristen Overbaugh MSN, RN, PhD candidate  
Version 1: 11/4/13 HRPO#13-581

SCC • SA WELLNESS PROGRAM • SCC NUCLEAR CARDIOLOGY LAB • SCC ECHOCARDIOGRAPHY LAB  
8122 DATAPOINT DRIVE, SUITE 700 • SAN ANTONIO, TEXAS 78229 • TEL 210-615-0600 • FAX 210-615-1899 • 1-800-DR-HEART  
Non-Invasive Procedures-Holters, Echocardiography, 24-hour Blood Pressure Monitoring, Sonography, PFT's,  
Cardiac Catheterization- Stents/Angioplasty/Electrophysiology /Cardiac Pacing/Implantable Defibrillators/Ablation/Nuclear Lab Services

## APPENDIX E

### COMBINED INFORMED CONSENT AND HIPAA AUTHORIZATION

Version 1: 11/4/13

#### The University of New Mexico Health Sciences Center Consent to Participate in Research

#### Exploring Personal Growth in Individuals Living with Heart Failure

##### Purpose and General Information

You are being asked to participate in a research study that is being done by Dr. Mark Parshall, who is the Principal Investigator, and being conducted by Kristen Overbaugh RN, MSN, a PhD candidate at the University of New Mexico Health Science Center, College of Nursing, and also a Clinical Assistant Professor at the University of Texas Health Science Center at San Antonio, School of Nursing. This research is being done to evaluate if individuals with heart failure can perceive positive outcomes or change from the challenges of living with heart failure and to better understand those factors that may be related to this outcome. You are being asked to participate because you are living with a diagnosis of heart failure. Approximately 120 people will take part in this study at Schnitzler Cardiovascular Consultants in San Antonio TX.

This form will explain the study to you, including the possible risks as well as the possible benefits of participating. This is so you can make an informed choice about whether or not to participate in this study. Please read this Consent Form carefully. Ask the investigators or study staff to explain any words or information that you do not clearly understand.

##### What will happen if I participate?

If you agree to be in this study, you will be asked to read and sign this Consent Form. After you sign the Consent Form, the following things will happen:

You will be asked to provide some basic information about yourself such as your age and sex, and to complete three questionnaires, one time only. The questionnaires will ask you general questions about your symptoms, any uncertainty that you have experienced as a result of living with heart failure, and changes that have occurred in your life as a result of coping with heart failure.

Examples of items addressed on the questionnaires include (a) the presence or absence of a variety of symptoms, such as shortness of breath or chest pain, over the last week, and the frequency, severity, and distress associated with each symptom, (b) the predictability of your illness, symptoms, and treatment, and (c) the degree to which you changed priorities about what is important in life or have a greater sense of closeness with others.

You will be given the option of completing these questionnaires in the following ways:

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 The University of New Mexico Institutional Review Board (HRRC)		

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1. Electronically using the research electronic data capture system (REDCap), a secure, anonymous web-based program. Electronic questionnaires will be made available to you either by a (a) researcher owned computer/tablet which you can use during a visit at the cardiology office, or (b) through a secure web link (an email address) provided to you, in which you can use the device of your choice (computer, laptop, tablet) from a location outside of the office. You will have the option of saving your answers and returning to the questionnaires at a later time if you become tired. If you choose to do this, you will need to click on the "Save and Return button" and write down the code provided at the top of the questionnaire. You will use this code to return to your questionnaires. If you misplace your code, you should contact Kristen Overbaugh at 484-515-3816 for assistance.

2. On paper. Paper copies of the surveys will be provided for you at the time of informed consent. You can complete them at the cardiology clinic or take them home to complete and return the questionnaires in the mail using a stamped, returned addressed envelope which will be given to you.

3. Via an interview conducted by the researcher over the phone or in person at the cardiology office.

Questionnaires that are completed on paper or via an interview will be kept locked in a secure filing cabinet only available to the research team and entered into REDCap as soon as possible by the researcher. Paper copies will then be destroyed.

In addition, you will also be asked for permission to collect the following information from your medical record or from your healthcare provider at the cardiology office: the cause of your heart failure, severity of your heart failure, medications and any other significant medical problems.

Participation in this study will take a total of 1 hours over a period of 1 to 2 days depending on whether or not you choose to complete the questionnaires in their entirety in one sitting or choose to complete them partially and return to complete the questionnaires at another time . There is no other follow-up to the study.

#### **What are the possible risks or discomforts of being in this study?**

Every effort will be made to protect the information you give us. However, there is a small risk of loss of privacy and/or confidentiality that may create a problem or a hardship for you. The questionnaires themselves do not involve questions about highly sensitive matters. You may experience minimal risk during this study. Some questions might cause you to feel some anxiety or uneasiness. If you prefer not to answer certain questions, you have the right not to and may skip these questions. You also may experience fatigue from answering several questionnaires, but will be able to stop at anytime and resume at a later time, if you wish to complete all of the questions.

#### **How will my information be kept confidential?**

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Your name and other identifying information will be maintained in locked files, available only to authorized members of the research team, for the duration of the study. For any information entered into a computer, the only identifier will be a unique study identification (ID) number. Any personal identifying information and any record linking that information to study ID numbers will be destroyed when the study is completed. Information resulting from this study will be used for research purposes and may be published; however, you will not be identified by name in any publications.

Information from your participation in this study may be reviewed by federal and state regulatory agencies, and by the UNM Human Research Review Committee (HRRC) which provides regulatory and ethical oversight of human research. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

**What are the benefits to being in this study?**

There may or may not be direct benefit to you from being in this study. However, your participation may help find out if people with heart failure can perceive positive outcomes or change from the challenges of living with heart failure, and which factors may be related to the ability to perceive positive outcomes or change. This knowledge may help improve the care of people living with heart failure and may benefit others in the future.

**What other choices do I have if I don't participate?**

Taking part in this study is voluntary so you can choose not to participate.

**Will I be paid for taking part in this study?**

As a result of participation in this study, you will receive a gift card valued at \$20.00 for compensation. This gift card will be given to you after you have completed the questionnaires.

**How will I know if you learn something new that may change my mind about participating?**

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

**Can I stop being in the study once I begin?**

Yes. You can withdraw from this study at any time without affecting your heart failure care at the cardiology office.

The investigators have the right to end your participation in this study if they determine that you no longer qualify to take part, if you do not follow study procedures, or if it is in your best interest or the study's best interest to stop your participation.

**HIPAA Authorization for Use and Disclosure of Your Protected Health Information (HIPAA)**

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As part of this study, we will be collecting health information about you and because this study is being conducted under the oversight of the University of New Mexico's Health Protection and Resource Office, this information may need to be disclosed to federal and state regulatory agencies, as required by law. This information is "protected" because it is identifiable or "linked" to you.

**Protected Health Information (PHI)**

By signing this Consent Document, you are allowing the investigators and other authorized personnel to use your protected health information for the purposes of this study. This information may include: you name, date of birth, and medical record number.

In addition to researchers and staff at UNMHSC and other groups listed in this form, there is a chance that your health information may be shared (re-disclosed) outside of the research study and no longer be protected by federal privacy laws. Examples of this include disclosures for law enforcement, judicial proceeding, health oversight activities and public health measures.

**Right to Withdraw Your Authorization**

Your authorization for the use and disclosure of your health information for this study shall not expire unless you cancel this authorization. Your health information will be used or disclosed as long as it is needed for this study. However, you may withdraw your authorization at any time provided you notify the UNM investigators in writing. To do this, please send a letter notifying them of your withdrawal to:

Kristen Overbaugh  
MC 7975  
7703 Floyd Curl Dr.  
San Antonio, TX 78229-3900

or

Dr. Mark Parshall  
MSC 09 5350 PhD, RN  
1 University of New Mexico  
Albuquerque New Mexico 87131

Please be aware that the research team will not be required to destroy or retrieve any of your health information that has already been used or shared before your withdrawal is received.

**Refusal to Sign**

If you choose not to sign this consent form and authorization for the use and disclosure of your PHI, you will not be allowed to take part in the research study.

**What if I have questions or complaints about this study?**

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If you have any questions, concerns or complaints at any time about the research study, Kristen Overbaugh RN, MSN, or Dr. Mark Parshall, Ph. D, RN will be glad to answer them. You can contact Ms. Overbaugh at 484-515-3816 or 210-567-2165 and Dr. Parshall at 505-272-4540 at anytime. If you would like to speak with someone other than the research team, you may call the Human Research Review Committee (HRRC) at (505) 272-1129. The HRRC is a group of people from UNMHSC and the community who provide independent oversight of safety and ethical issues related to research involving human participants.

**What are my rights as a research participant?**

If you have questions regarding your rights as a research participant, you may call the Human Research Protections Office (HRPO) at (505) 272-1129 or visit the HRPO website at <http://hsc.unm.edu/som/research/hrrc/>.

**Consent and Authorization**

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this Consent Form, you are not waiving any of your legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this Consent Form, I agree to participate in this study and give permission for my health information to be used or disclosed as described in this Consent Form. A copy of this Consent Form will be provided to me.

\_\_\_\_\_  
Name of Adult Participant (print)

\_\_\_\_\_  
Signature of Adult Participant

\_\_\_\_\_  
Date

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information in this consent form and freely consents to participate.

\_\_\_\_\_  
Name of Research Team Member

\_\_\_\_\_  
Signature of Research Team Member

\_\_\_\_\_  
Date

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12/25/2014



Human Research Protections Office

The University of New Mexico Institutional Review Board (HRRC)

**APPENDIX F**  
**POSTTRAUMATIC GROWTH INVENTORY**

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your heart failure diagnosis, using the following scale.

*0= I did not experience this change as a result of my crisis.*

*1= I experienced this change to a very small degree as a result of my crisis.*

*2= I experienced this change to a small degree as a result of my crisis.*

*3= I experienced this change to a moderate degree as a result of my crisis.*

*4= I experienced this change to a great degree as a result of my crisis.*

*5= I experienced this change to a very great degree as a result of my crisis.*

<b>1. I changed my priorities about what is important in life.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>2. I have a greater appreciation for the value of my own life.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>3. I developed new interests.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>4. I have a greater feeling of self-reliance.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>5. I have a better understanding of spiritual matters.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>6. I more clearly see that I can count on people in times of trouble.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>7. I established a new path for my life.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>8. I have a greater sense of closeness with others.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>9. I am more willing to express my emotions.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>



<b>10. I know better that I can handle difficulties.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>11. I am able to do better things with my life.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>12. I am better able to accept the way things work out.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>13. I can better appreciate each day.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>14. New opportunities are available which wouldn't have been otherwise.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>15. I have more compassion for others.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>16. I put more effort into my relationships.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>17. I am more likely to try to change things which need changing.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>18. I have a stronger religious faith.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>19. I discovered that I'm stronger than I thought I was.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>20. I learned a great deal about how wonderful people are.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>21. I better accept needing others.</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

## APPENDIX G

## MISHEL UNCERTAINTY IN ILLNESS SCALE–COMMUNITY FORM

## MISHEL UNCERTAINTY IN ILLNESS SCALE– COMMUNITY FORM

**INSTRUCTIONS:**

Please read each statement. Take your time and think about what each statement says. Then place an “X” under the column that most closely measures how you are feeling TODAY.

If you agree with a statement, then you would mark under either “Strongly Agree” or “Agree.” If you disagree with a statement, then mark under either “Strongly Disagree” or “Disagree.”

If you are undecided about how you feel, then mark under “Undecided” for that statement. Please respond to every statement.

**1. I don’t know what is wrong with me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**2. I have a lot of questions without answers.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**3. I am unsure if my illness is getting better or worse.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**4. It is unclear how bad my pain will be.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**5. The explanations they give about my condition seem hazy to me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**6. The purpose of each treatment is clear to me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**7. My symptoms continue to change unpredictably.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**8. I understand everything explained to me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**9. The doctors say things to me that could have many meanings.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**10. My treatment is too complex to figure out.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**11. It is difficult to know if the treatments or medications I am getting are helping.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**12. Because of the unpredictability of my illness, I cannot plan for the future.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**13. The course of my illness keeps changing. I have good and bad days.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**14. I have been given many differing opinions about what is wrong with me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**15. It is not clear what is going to happen to me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**16. The results of my tests are inconsistent.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**17. The effectiveness of the treatment is undetermined.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**18. Because of the treatment, what I can do and cannot do keeps changing.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**19. I'm certain they will not find anything else wrong with me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**20. The treatment I am receiving has a known probability of success.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**21. They have not given me a specific diagnosis.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**22. The seriousness of my illness has been determined.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

**23. The doctors and nurses use everyday language so I can understand what they are saying.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

## APPENDIX H

### MEMORIAL SYMPTOM ASSESSMENT SCALE-HEART FAILURE

MEMORIAL SYMPTOM ASSESSMENT SCALE-HEART FAILURE	
NAME/ ID#:	DATE:

**SECTION 1:**

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

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

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

Modified from MSAS (Portenoy et al, 1994) by C. Zambroski et al, 2004



## SECTION 2:

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

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

Modified from MSAS (Portenoy et al, 1994) by C. Zambroski et al, 2004

## APPENDIX I

### COMBINED REDCAP™ SURVEY

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## Exploring Personal Growth in Individuals Living with Heart Failure (HF)

Thank you for agreeing to complete this survey. This survey will first ask you to provide some basic information about yourself and to complete the following three questionnaires:

1. The Posttraumatic Growth Inventory
2. The Mishel Uncertainty in Illness-Community Version
3. The Memorial Symptom Assessment Scale-Heart Failure

Each new questionnaire will be labeled with its name. It will include specific instructions to help you answer the questions included on that specific questionnaire.

Please read the below directions carefully before you begin.

You should be able to complete the entire survey in less than 60 minutes.

Once you start the survey, you will have 24 hours to complete the survey, unless you click on the SAVE and RETURN LATER OPTION.

If you need to stop for any reason, you can click on the SAVE and RETURN LATER OPTION and this will allow you to save your responses and return to the survey at any time, up until the time that the survey is closed.

Once you click on the SAVE and RETURN LATER OPTION, you will need to write down the RETURN CODE provided so that you can return to your survey at a later time.

If you need to go back and change a response that you have already provided or review directions, use the up and down arrow located on the right side of the survey to scroll up and down and then simply change your response. DO NOT CLICK ON THE WEB BROWSER BACK ARROW.

Please contact Kristen Overbaugh at 484-515-3816 or 210-567-2615 if you have any questions or problems with this survey.

Please list the Study ID number that was provided to you by the researcher.

(If you do not know your Study ID number, please STOP, and contact the researcher prior to continuing this survey)

Please indicate how this survey is being completed

- Electronically via the weblink provided
- On paper
- Via a researcher conducted phone interview
- Via a researcher in-person interview

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### Participant Demographic and Clinical Questions

What is your age in years?

(Enter only the number. You should not include the word years)

What is your sex?

- Male
- Female

Are you currently married or living with a partner?

- Yes
- No

What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to answer

What is your race?

- American Indian or Alaska Native
- Asian
- Black/African American
- Native Hawaiian/Pacific Islander
- White
- Other
- Prefer not to answer

What is the highest number of years of education that you have obtained?

(Enter only the number. You should not include the word years.)

Considering the following categories, what is the highest educational level that you completed?

- Less than 12 years
- Highschool graduate or GED
- Associate Degree
- Bachelor's Degree
- Graduate Degree

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In what year were you first diagnosed with heart failure?

- 2014
- 2013
- 2012
- 2011
- 2010
- 2009
- 2008
- 2007
- 2006
- 2005
- Prior to 2005
- Prior to 1995
- Prior to 1985

Have you been hospitalized within the last year for your heart failure?

- Yes
- No

If yes, how many times?

\_\_\_\_\_

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**Posttraumatic Growth Inventory (PTGI) Indicate for each of the statements below the degree to which this change occurred in your life as a result of your heart failure diagnosis.**

1. I changed my priorities about what is important in life.

- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

2. I have a greater appreciation for the value of my own life.

- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

3. I developed new interests.

- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

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4. I have a greater feeling of self-reliance.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
5. I have a better understanding of spiritual matters.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
6. I more clearly see that I can count on people in times of trouble.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
7. I established a new path for my life.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
8. I have a greater sense of closeness with others.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

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9. I am more willing to express my emotions.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
10. I know better that I can handle difficulties.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
11. I am able to do better things with my life.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
12. I am better able to accept the way things work out.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
13. I can better appreciate each day.
- I **did not** experience this change as a result of my heart failure diagnosis.
  - I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **small degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **great degree** as a result of my heart failure diagnosis.
  - I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

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14. New opportunities are available which wouldn't have been otherwise.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
15. I have more compassion for others.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
16. I put more effort into my relationships.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
17. I am more likely to try to change things which need changing.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
18. I have a stronger religious faith.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

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19. I discovered that I am stronger than I thought I was.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
20. I learned a great deal about how wonderful people are.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.
21. I better accept needing others.
- I **did not** experience this change as a result of my heart failure diagnosis.
- I experienced this change to a **very small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **small degree** as a result of my heart failure diagnosis.
- I experienced this change to a **moderate degree** as a result of my heart failure diagnosis.
- I experienced this change to a **great degree** as a result of my heart failure diagnosis.
- I experienced this change to a **very great degree** as a result of my heart failure diagnosis.

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**Mishel Uncertainty in Illness Scale - Community Version (MUIS-C) Please read each statement. Take your time and think about what each statement says. Then mark the option that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark either 'Strongly Agree' or 'Agree'. If you disagree with a statement, then mark "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark "Undecided" for that statement. Please respond to every statement.**

1. I don't know what is wrong with me.
- Strongly Agree
- Agree
- Undecided
- Disagree
- Strongly Disagree
2. I have a lot of questions without answers.
- Strongly Agree
- Agree
- Undecided
- Disagree
- Strongly Disagree



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3. I am unsure if my illness is getting better or worse.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
4. It is unclear how bad my pain will be.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
5. The explanations they give about my condition seem hazy to me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
6. The purpose of each treatment is clear to me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
7. My symptoms continue to change unpredictably.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
8. I understand everything explained to me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
9. The doctors say things to me that could have many meanings.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
10. My treatment is too complex to figure out.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
11. It is difficult to know if the treatments or medications I am getting are helping.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
12. Because of the unpredictability of my illness, I cannot plan for the future.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
13. The course of my illness keeps changing. I have good and bad days.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree

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14. I have been given many differing opinions about what is wrong with me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
15. It is not clear what is going to happen to me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
16. The results of my tests are inconsistent.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
17. The effectiveness of the treatment is undetermined.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
18. Because of the treatment, what I can do and cannot do keeps changing.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
19. I am certain they will not find anything else wrong with me.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
20. The treatment I am receiving has a known probability of success.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
21. They have not given me a specific diagnosis.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
22. The seriousness of my illness has been determined.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree
23. The doctors and nurses use everyday language so I can understand what they are saying.
- Strongly Agree  
 Agree  
 Undecided  
 Disagree  
 Strongly Disagree

---

**Memorial Symptom Assessment Scale-Heart Failure We have listed 26 symptoms below. Read each one carefully. If you have had the symptom during this past WEEK, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED OR BOTHERED you by marking the appropriate description. If you DID NOT HAVE the symptom, mark NO.**

1. Difficulty concentrating
- Yes  
 No
- 1a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 1b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very Severe
- 1c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
2. Chest pain
- Yes  
 No
- 2a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 2b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 2c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
3. Other pain
- Yes  
 No
- 3a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 3b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 3c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
4. Cough
- Yes  
 No

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- 4a. If YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 4b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 4c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
5. Feeling nervous
- Yes  
 No
- 5a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 5b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 5c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
6. Dry mouth
- Yes  
 No
- 6a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 6b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 6c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
7. Nausea
- Yes  
 No
- 7a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 7b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe

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- 7c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
8. Feeling drowsy
- Yes
  - No
- 8a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 8b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 8c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
9. Numbness or tingling in hands or feet
- Yes
  - No
- 9a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 9b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 9c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
10. Difficulty sleeping
- Yes
  - No
- 10a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 10b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 10c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
11. Feeling bloated
- Yes
  - No

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- 11a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 11b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 11c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
12. Problem with urination
- Yes  
 No
- 12a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 12b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 12c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
13. Palpitations
- Yes  
 No
- 13a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 13b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 13c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
14. Lack of energy
- Yes  
 No
- 14a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 14b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe

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- 14c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
15. Waking up breathless at night
- Yes
  - No
- 15a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 15b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 15c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
16. Vomiting
- Yes
  - No
- 16a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 16b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 16c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
17. Shortness of breath
- Yes
  - No
- 17a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 17b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 17c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
18. Diarrhea
- Yes
  - No

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- 18a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 18b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 18c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
19. Feeling sad
- Yes
  - No
- 19a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 19b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 19c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
20. Sweats
- Yes
  - No
- 20a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 20b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe
- 20c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all
  - A little bit
  - Somewhat
  - Quite a bit
  - Very much
21. Worrying
- Yes
  - No
- 21a. IF YES, How OFTEN did you have it?
- Rarely
  - Occasionally
  - Frequently
  - Almost constantly
- 21b. IF YES, How SEVERE was it usually?
- Slight
  - Moderate
  - Severe
  - Very severe



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- 21c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
22. Problems with sexual interest or activity
- Yes  
 No
- 22a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 22b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 22c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
23. Itching
- Yes  
 No
- 23a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 23b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 23c. IF YES, how much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
24. Lack of appetite
- Yes  
 No
- 24a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 24b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 24c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
25. Dizziness
- Yes  
 No

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- 25a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 25b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 25c. IF YES, how much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
26. Feeling irritable
- Yes  
 No
- 26a. IF YES, How OFTEN did you have it?
- Rarely  
 Occasionally  
 Frequently  
 Almost constantly
- 26b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 26c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much

---

**We have listed 6 symptoms below. Read each one carefully. If you have had the symptom during the past week, let us know how SEVERE it was usually and how much it DISTRESSED OR BOTHERED you by marking the appropriate description. If you DID NOT HAVE the symptom, mark NO.**

27. Change in the way food tastes
- Yes  
 No
- 27b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 27c. IF YES, how much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
28. Weight loss
- Yes  
 No
- 28b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe

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- 28c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
29. Constipation
- Yes  
 No
- 29b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 29c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
30. Swelling of arms or legs
- Yes  
 No
- 30b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 30c. IF YES, How much did it DISTRESS of BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
31. Weight gain
- Yes  
 No
- 31b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 31c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
32. Difficulty breathing when lying flat
- Yes  
 No
- 32b. IF YES, How SEVERE was it usually?
- Slight  
 Moderate  
 Severe  
 Very severe
- 32c. IF YES, How much did it DISTRESS or BOTHER you?
- Not at all  
 A little bit  
 Somewhat  
 Quite a bit  
 Very much
33. If you had any other symptom during the past week, please list here.
-

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33c. IF YES, How much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

34. If you have had any other symptom during the past week, please list it here.

---

34c. IF YES, How much did it DISTRESS or BOTHER you?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

## APPENDIX J

## MEDICAL RECORD REVIEW FORM: ADDITIONAL CLINICAL DATA

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**Medical Record Review Form: Additional Clinical Information**

Please complete the survey below.

Thank you!

- 1) Study ID Number \_\_\_\_\_
- 2) 1. Etiology of Heart Failure  
 Ischemic Heart Disease  
 Hypertension  
 Cardiomyopathy  
 Other
- 3) 2. Most recent NYHA class  
 NYHA II  
 NYHA III  
 NYHA IV
- 4) 3. Ejection fraction documented within the last year  
 Yes  
 No
- 5) 4. If yes, what was it?  
 Less than or equal to 40%  
 Greater than 40%
- 6) 5. How was the ejection fraction documented?  
 Echocardiogram  
 Catheterization  
 Nuclear Medicine Study  
 Source not documented
- 7) 6. Other significant medical history  
 Peripheral Vascular Disease (PVD)  
 Stroke  
 Diabetes  
 Chronic Pulmonary Disease  
 Connective Tissue Disorder  
 Cancer  
 Peptic Ulcer Disease  
 Chronic Kidney Disease
- 8) 7. Current Medications for Heart Failure  
 ACE Inhibitor  
 Angiotensin Receptor Blocker  
 Beta Blocker  
 Diuretic  
 Digoxin  
 Vasodilator