HEART FAILURE FAMILY CAREGIVERS:

PSYCHOMETRICS OF A NEW QUALITY OF LIFE SCALE

AND VARIABLES ASSOCIATED WITH CAREGIVER OUTCOMES

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ABSTRACT

Julie Ann Nauser

Heart Failure Family Caregivers: Psychometrics of a New Quality of Life Scale

and Variables Associated with Caregiver Outcomes

The number of patients with chronic heart failure (HF) is at an all-time high and

the incidence is expected to increase as our population ages. HF patients experience

impaired cognition, exertional shortness of breath, and persistent fatigue; therefore,

family members are needed to assist with their care at home. Although existing literature

suggests that HF caregivers experience negative physical, mental, and social outcomes,

there is a lack of studies guided by a conceptual model to determine factors associated

with these outcomes. The purpose of this study was to determine factors associated with

HF caregiver depressive symptoms, life changes, and quality of life guided by a

conceptual model derived from Lazarus and colleagues' transactional approach to stress.

Psychometric properties of a new HF caregiver-specific quality of life (HFCQL) scale

were also determined. Using a descriptive design, a convenience sample of 100 HF

caregivers was interviewed by telephone using established measures along with the new

HFCQL scale. The 16-item HFCQL scale, which measures physical, psychological,

social, and spiritual well-being demonstrated evidence of internal consistency reliability

($\alpha = .89$); 2-week test-retest reliability (ICC = .83); construct validity, as evaluated with

factor analysis (loadings > .32) and hierarchical multiple regression (59% variance, $p <$

.001); and criterion validity, as shown with significant ($p < .001$) correlations with the

Bakas Caregiving Outcomes Scale ($r = .73$), SF-36 general and mental health ($r = .45$;

.59), and a single overall QOL item ($r = .71$). Using hierarchical multiple regression, the

model constructs accounted for 35% variance of depressive symptoms, 46% variance of life changes, and 59% variance of HFCQL ($p < .001$). Factors significantly associated with these outcomes included caregiving task difficulty, uncertainty, social support, and threat appraisal. Support for the conceptual model was provided, and potential areas for intervention development were identified. The new HFCQL scale showed potential as a quality outcome measure in HF caregivers, and might be used to screen HF caregivers for poor quality of life. Further research using the proposed conceptual model and the HFCQL scale is warranted.

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1. THE NATURE OF THE STUDY

Introduction

Heart failure (HF), characterized by the heart's inability to pump blood efficiently to maintain adequate tissue perfusion and compensatory neurohormonal mechanisms, is associated with high mortality rates, frequent hospitalizations, and poor quality of life (American Heart Association, 2007). Over five million people are currently diagnosed with HF and 550,000 new cases are diagnosed annually (American Heart Association, 2007). The incidence of HF has not declined in the last two decades and survival after onset has increased (Roger et al., 2004) resulting in more people living with HF. Primarily affecting the elderly, HF incidence approaches ten for every 1,000 people over the age of 65 (Hurst, 2001). Undoubtedly the aging of the population will increase the incidence of HF (Bonow, Smaha, Smith, Mensah, & Lenfant, 2002) as the U.S. Census estimates there will be 55 million Americans 65 years and older in 2020 (U.S. Census Bureau, 2004).

Self-care management of HF at home is complex and demanding. To effectively and independently manage HF at home, the patient must be able to monitor for early symptom recognition and implement appropriate self-care or seek medical assistance; self-administer medications accurately and in a timely manner; and adhere to, as well as monitor, dietary sodium and water restrictions. However many patients with chronic HF have impaired cognition (Bennett & Sauve, 2003) and reduced functional capacity due to exertional shortness of breath and persistent fatigue (Carlson, Riegal, & Moser, 2001; Friedman & Griffin, 2001) making independent home management difficult or even impossible. Therefore, many patients with HF rely on family members to provide care,

such as medication administration, symptom monitoring and management, meal preparation, bathing, and transportation.

It is plausible to assume that providing care to this complex population can result in negative outcomes for family members. There is a substantial body of literature confirming that family caregivers of persons with other chronic or terminal illnesses experience emotional distress (Bakas & Burgener, 2002; Bakas, Austin, Jessup, Williams, & Oberst, 2004), perceived stress (Sanford, Johnson, Townsend-Rocchiccioli, 2005), and depression (Bakas, Kroenke, Plue, Perkins, & Williams, 2006; Farran et al., 2004; Given et al., 1993; Lee, Brennan, & Daly, 2001; Robinson, 1989; Schulz, O'Brien, Bookwala, & Fleissner, 1995). As a result of caregiving responsibilities, family caregivers have indicated their health has declined (Faison, Faria, & Frank, 1999), their life has changed for the worse (Bakas & Burgener, 2002; Bakas et al., 2004; Bakas, Champion, Perkins, Farran, & Williams, 2006), and their quality of life is poor (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Markowitz, Gutterman, Sadik, & Papadopoulos, 2003; Weitzner, McMillan, & Jacobsen, 1999).

In spite of the growing prevalence of HF and the likelihood that these caregivers experience negative outcomes, research concerning HF family caregiving is minimal compared to that conducted with other caregiving populations. However, the existing studies do suggest that providing care to persons with chronic HF is detrimental to the caregiver. Compared to the general population (Ware, 2000), HF family caregivers had lower ratings of general health (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Dracup et al., 2004), physical health (Martensson, Dracup, Canary, & Fridlund, 2003), and mental health (Bakas, Pressler, et al., 2006; Dracup et al., 2004; Martensson et al.,

2003; Scott, 2000). Likewise, HF family caregivers had lower ratings of life satisfaction compared to the general population (Luttik, Jaarsma, Veeger, & Veldhuisen, 2005; Meagher-Stewart & Hart, 2002). These caregivers often experience depression (Barnes et al., 2006; Martensson et al., 2003; Molloy et al., 2006; Rohrbaugh et al., 2002; Schwarz & Elman, 2003; Scott, 2000), perceived stress (Karmilovich, 1994; Meagher-Stewart & Hart, 2002; Schwarz & Dunphy, 2003; Schwarz & Elman, 2003), and anxiety (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007; Molloy et al., 2006; Rohrbaugh et al., 2002; Scott, 2000). Providing care to a family member with HF can be socially isolating for the caregiver (Aldred, Gott, & Gariballa, 2005; Bohackick & Anton, 1990; Dracup et al., 2004; Murray et al., 2002). HF family caregivers have indicated their health has declined (Scott, 2000) and their life has changed for the worse (Bakas, Pressler, et al., 2006) as a result of their caregiving responsibilities. While these studies contribute to our initial understanding, there is a lack of studies that focus on relationships among HF-specific caregiver concepts guided by a conceptual model.

Understanding the relationships between associated variables and caregiver outcomes is essential to develop appropriate, relevant interventions to support family caregivers. To date, only five variables associated with outcomes have been examined in HF family caregivers: caregiving tasks, perceived control, threat appraisal, involvement in hospital discharge planning, and preparedness. The number of tasks and perception of task difficulty have been associated with perceived stress (Karmilovich, 1994), poor mental health and negative life changes (Bakas, Pressler, et al., 2006). The HF caregiver's perception of control over their family member's heart problems has been correlated with outcomes in two studies; lower levels of perceived control was related to

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poor mental health (Bakas, Pressler, et al., 2006) and emotional well-being (Dracup et al., 2004). Threat appraisal was significantly related to negative life changes and poor mental health in family caregivers of HF patients (Nauser, 2005).

Caregiver involvement in hospital discharge planning was associated with better caregiver general health and mental health (Bull, Hansen, & Gross, 2000a; Bull, Hansen, & Gross, 2000b) and lower levels of caregiver preparedness were associated with negative impacts on caregiver health, finances, and daily schedules (Scott, 2000) in studies of HF family caregivers. Both caregiver involvement in discharge planning and preparedness may reduce uncertainty, an important variable that has been examined in caregivers of persons with other disorders. In caregivers of women with recurrent breast cancer (Northouse et al., 2002) and caregivers of persons with Parkinson's disease (Sanders-Dewey, Mullins, & Chaney, 2001), uncertainty was correlated with poorer mental health outcomes. While not studied in HF family caregivers, social support has been shown to be significantly associated with outcomes for other caregivers. In caregivers of persons with Alzheimer's disease and related dementias (Chang, Brecht, & Carter, 2001) and caregivers of functionally impaired persons (Schwarz, 2000), social support was related to mental health outcomes. Social support was shown to be a significant predictor of caregiver life satisfaction in a study of stroke caregivers (Grant, Elliot, Giger, & Bartolucci, 2001).

While the small body of literature addressing outcomes of HF family caregivers (seventeen quantitative studies, ten qualitative studies) has contributed to our initial understanding of their experiences, usefulness of the findings is limited. Most of the studies did not specify a conceptual model; only 4 of the 17 quantitative studies were

guided by a conceptual model (Bakas, Pressler, et al., 2006; Bull et al., 2000b; Nauser, 2005; Scott, 2000). Very few studies have identified variables associated with outcomes of HF family caregivers (Bakas, Pressler, et al., 2006, Bull et al., 2000a; Bull et al., 2000b; Dracup et al., 2004; Nauser, 2005).

In most studies, caregiver outcomes were measured with generic quality of life instruments, such as the Medical Outcomes Study Health Survey Short-Form (SF-12, SF-36) (Bakas, Pressler, et al., 2006; Bull et al., 2000a; Bull et al., 2000b; Dracup et al., 2004; Evangelista et al., 2002; Martensson et al., 2003; Scott, 2000), Life Satisfaction Index Z (Meagher-Stewart & Hart, 2005), and Cantril Ladder of Life (Luttik et al., 2005; Meagher-Stewart & Hart, 2005). While allowing comparison to other populations, generic quality of life instruments may not adequately measure caregiver-specific outcomes. In one HF study, the researchers did use a caregiver-specific instrument, the Bakas Caregiving Outcomes Scale (Bakas, Pressler, et al., 2006) which measures the degree of change in physical, social, and subjective-well-being as a result of providing care, but does not capture the HF caregiver's current state with regard to these domains. Furthermore, the Bakas Caregiving Outcomes Scale does not include items that address spiritual well-being, which has been shown to be an important domain among caregivers of patients with cancer (Ferrell, 1995) and Alzheimer's Disease (Spurlock, 2005).

As the prevalence of HF among the elderly continues to increase in the future, more family members will be exposed to the challenges of providing care for patients with chronic HF. It is imperative to fully understand the HF family caregiver's unique experience so that health care providers can intervene and support these caregivers in their difficult roles. A caregiver-specific quality of life instrument is needed to

adequately measure quality of life for this population. Studies guided by an empirically

supported conceptual model are essential to identify factors associated with depressive

symptoms, life changes, and quality of life to identify priority areas for intervention

development. However, the limitations in the existing HF family caregiving literature

make it impossible to intervene to effectively support this population.

<center>Problem Statement</center>

The problems associated with the existing HF caregiving literature are a lack of

studies guided by a conceptual framework, an absence of a HF caregiver-specific quality

of life instrument with documented psychometric properties, and a lack of identification

of variables associated with HF caregiver outcomes. In order to develop and implement

appropriate and relevant interventions to support this neglected population, there is a

need for HF family caregiving studies that are guided by theoretically-based, empirically

supported conceptual model. To understand their unique experience, a HF caregiver-

specific quality of life instrument is needed to identify the most relevant variables

associated with negative outcomes so that health care providers can begin to identify

priority areas for intervention and test the effectiveness of these interventions.

<center>Purposes</center>

The purposes of this study were 1) to determine the psychometric properties of

the Heart Failure Caregiver Quality of Life (HFCQL) scale and 2) to identify variables

associated with depressive symptoms, life changes, and HF caregiver-specific quality of

life in family caregivers of HF patients. The study was based on a conceptual model

derived from the work of Lazarus and colleagues (Lazarus, 1966, 1991; Lazarus and

Folkman, 1984) and Bakas and colleagues (Bakas & Burgener, 2002; Bakas &

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Champion, 1999; Bakas, Champion, Perkins, Farran, & Williams, 2006) who theorized

that antecedent person and situation factors are mediated by cognitive appraisal which

influences emotional responses and adaptational outcomes. This study also expanded on

an existing conceptual model used in HF caregivers provided by Bakas and colleagues

(Bakas, Pressler, et al., 2006) by adding the theory-based variables of social support,

uncertainty, appraisal, depressive symptoms, and HF caregiver-specific quality of life.

Essentially this study has provided much needed knowledge regarding HF family

caregivers using a conceptual model derived from prior work and psychometrically

testing a new HF caregiver-specific quality of life instrument.

The situation factors of social support, caregiving task difficulty, uncertainty

about the illness-related events, and perceived control over heart problems; mediating

variable of threat appraisal; and emotional response of depressive symptoms were

selected because of relevance to HF family caregiving circumstances and potential for

intervention. Adaptational outcomes under investigation are life changes resulting from

caregiving and HF-caregiver-specific quality of life. The specific aims and hypotheses

are presented next, followed by conceptual and operational definitions of the variables

under investigation, and assumptions and limitations.

<u>Specific Aims and Hypotheses</u>

Specific Aim 1. To evaluate the psychometric properties of the Heart Failure Caregiver

Quality of Life scale (HFCQL).

Hypothesis 1a. The HFCQL items demonstrate means close to the midpoint,

good variability in relation to the means, floor and ceiling effects less than 10%,

and item-to-total correlations greater than or equal to .30 among caregivers of HF patients.

Hypothesis 1b. The HFCQL scale and potential domains have evidence of internal consistency reliability with Cronbach alphas greater than or equal to .70 among caregivers of HF patients.

Hypothesis 1c. The HFCQL scale and potential domains have evidence of 2-week test-retest reliability with an intra-class correlation coefficient greater than .60 among caregivers of HF patients.

Hypothesis 1d. The HFCQL has evidence of construct validity with factor loadings of .32 and above for the scale or each domain as determined through factor analysis among caregivers of HF patients.

Hypothesis 1e. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of HF caregiver-specific quality of life as measured by the HFCQL scale and potential domains, as determined through factor analysis, in family caregivers of patients with HF, to provide evidence of construct validity.

Hypothesis 1f. To show evidence of criterion-related validity, the HFCQL scale and potential domains are significantly correlated with the BCOS, SF-36 general health and mental health subscales, and the HFCQL and domain well-being overall items, among caregivers of HF patients.

Specific Aim 2. To determine the combination of independent variables that explains depressive symptoms, life changes, and HF caregiver-specific quality of life in family caregivers of HF patients using a theoretically based conceptual model.

Hypothesis 2a. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, and threat appraisal explain a significant amount of variance of depressive symptoms in family caregivers of patients with HF.

Hypothesis 2b. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of life changes in family caregivers of patients with HF.

Hypothese 2c. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of HF caregiver-specific quality of life as measured by the HFCQL scale and/or domains as determined by psychometric testing in family caregivers of patients with HF.

<center>Conceptual and Operational Definitions</center>

Caregiver Characteristics

Conceptual definition. Caregiver characteristics were collected to provide a detailed description of the sample and to determine if any of the characteristics are associated with other variables in the study. The caregiver characteristics included: 1) demographic and clinical data (age, gender, race, ethnicity, relationship to the care recipient, education, co-morbidities, perception of the degree that income meets their

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needs, and employment status) and 2) caregiving situation characteristics (length of time in the caregiving role since HF diagnosis in months, time spent caregiving in hours per week, and living arrangements).

Operational definition. An investigator-developed demographic data form measured the caregiver characteristics as described above.

Patient Characteristics

Conceptual definition. Patient characteristics were collected from the caregiver to provide a detailed description of the sample and to determine if any of the characteristics are associated with other variables in the study. Patient characteristics included: 1) demographic and clinical data (age, gender, race, ethnicity, education, co-morbidities), 2) caregiver's perception of patient's symptoms with activities, 3) presence of implanted ventricular assist device, and 4) caregiver's perception of patient's cognitive status.

Operational definition. An investigator-developed demographic data form measured the patient characteristics as described above. The caregiver's perception of patient's symptoms, such as shortness of breath, fatigue, and chest pain, with activities was determined through a single item asking the family caregiver to identify patient symptoms with activity: 1) no symptoms, 2) symptoms with moderate activity, 3) symptoms with minimal activity, and 4) symptoms at rest. Caregivers were asked if the patient has an implanted ventricular assist device. The patient's cognitive status was measured with the eight-item Cognitive Status Scale (CSS); on a 5-point response scale ranging from 1 ("can't do at all) to 5 ("not at all difficulty"). Family caregivers rate the patient's level of difficulty associated with memory, communication, and recognition (Pearlin, Mullan, Semple, & Skaff, 1990).

Social Support

Conceptual definition. Social support was conceptually defined as the family caregiver's perception about the availability of support and relationships that serve particular functions (Sherbourne & Stewart, 1991). Five different types of social support are emotional, informational, tangible, affectionate, and positive social interaction. Emotional support refers to expressing positive affect, empathetic understanding, and encouraging expression of feelings. Informational support refers to offering advice, information, and guidance. Tangible support is providing material aid or behavior assistance. Positive social interaction is the availability of other persons to do fun things with. Affectionate support involves expressions of love and affection (Sherbourne & Stewart, 1991).

Operational definition. The Medical Outcomes Study (MOS) Social Support Survey was used to measure social support (Sherbourne & Stewart, 1991). On the first item, which is open-ended, respondents indicate the number of close friends and relatives they have. On the remaining 19 items, respondents rate the availability of perceived support on a 5-point response scale ranging from 1 ("none of the time") to 5 ("all of the time"). The survey yields a total score as well as four subscale scores, emotional/informational support (8 items), tangible support (4 items), positive social interaction (3 items), and affectionate support (3 items). The overall total score is calculated by summing the 19 responses; higher scores indicate higher perceived availability of social support (Sherbourne & Stewart, 1991; Westlake et al., 2002).

Caregiving Task Difficulty

Conceptual definition. Caregiving task difficulty was conceptually defined as the caregiver's perceived difficulty with direct, instrumental, and interpersonal tasks carried out to assist their family member (Oberst, 1990). Direct care tasks refer to medical or nursing treatments, personal care (bathing, dressing), and assistance with mobility; instrumental care tasks refer to provision of transportation, management of finances, planning activities, household tasks, and coordinating services; and interpersonal care tasks refer to emotional support, managing behavior problems, communication, and seeking information from health professionals (Oberst, 1990).

Operational definition. The difficulty subscale of the Oberst Caregiving Burden Scale (OCBS) was used to measure caregiving task difficulty (Bakas et al., 2004; Oberst, 1990). For this 15-item subscale, caregivers indicate the level of difficulty associated with 15 direct, instrumental, and interpersonal caregiving tasks on a 5-point response scale ranging from 1 ("not difficult") to 5 ("extremely difficult"). The subscale is scored by summing the 15 items; higher scores reflect greater caregiving task difficulty (Bakas et al., 2004; Oberst, 1990).

Uncertainty

Conceptual definition. Uncertainty was conceptually defined as the family caregiver's inability to determine the meaning of their family member's illness-related events (Mishel, 1997). This cognitive state is created when the family member cannot adequately structure or categorize an event due to a lack of sufficient cues and results in the inability to assign a definite value to the event and/or accurately predict outcomes (Mishel, 1997). Ambiguity and complexity of illness-related events increase uncertainty

perceived by family caregivers. Ambiguity refers to vague and indistinct cues about the

state of the illness which tend to blur and overlap and complexity refers to multiple and

varied cues about the treatment and system of care (Mishel, 1997).

Operational definition. Uncertainty was measured with the 31-item Parents'

Perception Uncertainty in Illness Scale for Family Members (PPUS-FM) developed by

Mishel (1997). This instrument, while originally designed for parents of ill children, can

be used with family caregivers by changing the word 'child' to the appropriate relational

descriptor, such as 'family member' (Mishel, 1997). On a scale of 1 ("strongly

disagree") to 5 ("strongly agree"), respondents indicate the degree to which they agree

with uncertainty statements concerning their family member's illness, treatment, and

communication with health care providers (Mishel, 1997) The PPUS-FM is scored by

summing the 30 items; the last item is not included in the scoring (Mishel, 1997). A

higher score is indicative of greater uncertainty (Mishel, 1997).

Perceived Control

Conceptual definition. Perceived control was conceptually defined as the

caregiver's belief that they have the internal resources to positively influence the

adversity of an event and can influence their environment to bring about positive

outcomes (Thompson, 1981; Wallston, 1989). Control does not have to be exercised nor

real, only perceived, to influence outcomes (Litt, 1988). For this study, perceived control

refers to the caregiver's perceived level of control over their family member's heart

problems (Moser & Dracup, 2000), and is therefore situation-specific (Lyon & Rice,

2000). For this reason, it is different than locus of control, which refers to a person

factor.

Operational definition. Perceived control was measured with the family version of the Control Attitudes Scale (CAS) (Dracup et al., 2004; Moser & Dracup, 2000). On the 4-item CAS, family caregivers rank their level of perceived control over heart problems (and conversely, feelings of helplessness) on a 7-point response scale ranging from 1 ("not at all") to 7 ("very much"). The instrument has items related to both the family caregiver's own perception of control (3 items) and their perception of the degree to which they feel the heart failure patient feels control (1 item). After reverse scoring items 3 and 4, the item rankings are summed for the score; higher scores indicate higher feelings of control (Dracup et al., 2004; Moser & Dracup, 2000).

Threat Appraisal

Conceptual definition. Threat appraisal was conceptually defined as the caregiver's perception that their caregiving situation is potentially harmful and/or resulting in loss to their well-being. As a cognitive process with subjective interpretation, threat appraisal is a type of stress appraisal which occurs when the demands of the situation exceeds the person's resources (Lazarus, 1966; Lazarus & Folkman, 1984). The perception of threat, which centers on the potential harms or losses, is characterized by negative emotions such as fear, anxiety, and anger (Lazarus & Folkman, 1984).

Operational definition. Threat appraisal was measured by the threat subscale of the Appraisal of Caregiving Scale (ACS) (Oberst, 1991), as adapted by Bakas and colleagues (1999, 2002) in their studies of family caregivers of stroke survivors. For this 12-item subscale, respondents indicate their level of perceived threat on a 5-point response scale ranging from 1 ("strongly disagree") to 5 ("strongly agree") in the areas of caregiving tasks, relationships and interpersonal support, lifestyle, emotional and physical

health, and overall personal impact (Oberst, Thomas, Gass, & Ward, 1989). Individual

item scores are summed for a total score with higher scores indicating higher levels of

threat.

Depressive Symptoms

Conceptual definition. Depressive symptoms were conceptually defined as the

severity of symptoms associated with depression (Kroenke, Spitzer, & Williams, 2001),

such as feeling down, sleep changes, diminished interest or pleasure in activities, weight

loss or weight gain, insomnia or hypersomnia, psychomotor agitation or retardation

observed by others, fatigue or loss of energy, feelings of worthlessness or excessive guilt,

inability to think or concentrate or indecisiveness, and suicidal ideation (American

Psychiatric Association, 1994).

Operational definition. Depressive symptoms were measured by the nine item

depression scale of the Primary Health Questionnaire (PHQ-9). The items correspond

with criteria as delineated by Diagnostic and Statistical Manual of Mental Disorders, 4th

edition (DSM-IV) major depressive disorder category (Kroenke & Spitzer, 2002), such as

little interest or pleasure in doing things, feeling down, problems with sleeping, and

trouble concentrating. Respondents indicate the frequency of problems over the last two

weeks on a 4-point response scale, ranging from 0 ("not at all") to 3 ("nearly every day").

The scores are summed with a range of 0 to 24 and level of severity of depressive

symptoms can be described as none (score 1 to 4), mild (5 to 9), moderate (10-14),

moderately severe (15-19), and severe (20-27) (Kroenke & Spitzer, 2002).

Life Changes

Conceptual definition. Life changes were conceptually defined as perceived changes in the caregiver's life as a result of providing care (Bakas & Champion, 1999). These life changes include changes in social functioning, subjective well-being, and somatic health, which is consistent with Lazarus' (1991) conceptualization of adaptational outcomes. Social functioning refers to performance of problem-solving, employment, social activity and family; subjective well-being refers to how the caregiver feels about their life and situation; and somatic health refers to the physical health status of the caregiver (Lazarus, 1991).

Operational definition. Life changes was operationalized with the Bakas Caregiving Outcome Scale (BCOS) which measures caregiver perceptions of how their life has changed since they assumed the role of caregiver for their family member (Bakas & Champion, 1999; Bakas, Champion, et al., 2006). On this 15-item instrument, respondents indicate their perceived changes in social functioning, subjective well-being, and physical health on a scale ranging from -3 ("changed for the worst") to +3 ("changed for the best"). After recoding to a scale of 1 to 7, individual items are summed for a total score and higher scores are indicative of more positive changes as a result of caregiving responsibilities (Bakas & Champion, 1999; Bakas, Champion, et al., 2006).

HF Caregiver-Specific Quality of Life

Conceptual definition. HF caregiver-specific quality of life was conceptually defined as the family caregivers' perception of their well-being stemming from physical, psychological, social and spiritual domains as impacted by their caregiving responsibilities (Ferrell, Grant, & Dow, 2001) for a family member with HF. The

physical well-being domain captures the impact of caregiving on physical health and related symptoms, such as sleep disturbances and appetite changes (Ferrell, 1995; Ferrell et al., 2001). The psychological well-being domain captures the impact of caregiving on psychological symptoms, such as depression, emotional distress, and stress (Ferrell, 1995; Ferrell et al., 2001). The social well-being domain captures the impact of caregiving on social conditions, such as roles and relationships (Ferrell, 1995; Ferrell et al., 2001). The spiritual well-being domain captures the impact of caregiving on spirituality, such as a sense of inner strength and purpose (Ferrell, 1995; Ferrell et al., 2001).

Operational definition. Heart failure caregiver-specific quality of life was measured with the proposed Heart Failure Caregiver Quality of Life scale (HFCQL) that was psychometrically tested in this study. With a 5-point response scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"), the HFCQL measures quality of life with potentially four subscales (physical, psychological, social, and spiritual well-being), as determined by fctor analysis. After selective deletion of items with low inter-item correlations and factor loadings, the initial pool of 46 items for the HFCQL was reduced to 16. Respondents rate the impact of caregiving responsibilities on various areas in their life reflecting physical (4 items), psychological (4 items), social (4 items), and spiritual (4 items) well-being domains. After reverse scoring of appropriate items, individual items within each domain, as determined by factor analysis, are summed and averaged, so that higher scores are indicative of higher perceptions of quality of life.

General Health

Conceptual definition. General health refers to the caregiver's perception of their overall personal health. In this study, the variable of general health was primarily used to establish criterion validity of the proposed HFCQL instrument that was psychometrically tested in this study. However, if the HFCQL did not have satisfactory psychometrics, general health would have served as an outcome measure.

Operational definiton. General health was measured by the general health subscale of the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36). For one of the five items of the general health subscale, respondents rate their health on a scale of 1 ("excellent") to 5 ("poor") (Ware, 1993). On a 5-point response scale ranging from 1 ("definitely true") to 5 ("definitely false"), respondents compare their health to others, if they expect their health will get worse, and if they believe their health is excellent for the remaining four items (Ware, 1993). After recoding of appropriate items, the individual items are summed and transformed to a 0-100 scale so that a higher score is indicative of better general health perceptions (Ware, 1993).

Mental Health

Conceptual definition. Mental health was conceptually defined as the caregiver's perception of their mental health, including psychological distress, such as anxiety, depression, loss of behavioral or emotional control, as well as psychological well-being (Ware & Sherbourne, 1992). In this study, the variable of mental health was used primarily to establish criterion validity of the proposed HFCQL scale that was psychometrically tested in this study. However, if the HFCQL did not have satisfactory psychometrics, mental health would have served as an outcome measure.

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Operational definition. Mental health was operationalized by the mental health subscale of the SF-36. On this five item scale, respondents rate the frequency of various emotions on a 6-point response scale of 1 ("all of the time") to 6 ("none of the time") (Ware, 1993). Emotions include nervousness, feeling down in the dumps, calm and peaceful, downhearted and blue, and happiness. After recoding of appropriate items, the individual items were summed and transformed to a 0-100 scale so that a higher score indicates perceptions of better mental health (Ware, 1993).

Conceptual Model

The conceptual model guiding this study was derived from the work of Lazarus and colleagues (Lazarus, 1966, 1991; Lazarus & Folkman, 1984) and Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006). As illustrated in Figure 1 on page 20, the conceptual model depicts the hypothesized relationships among the caregiver and patient characteristics; situation factors of social support, caregiving task difficulty, uncertainty, and perceived control; mediating variable of threat appraisal; emotional response of depressive symptoms; and adaptational outcomes of life changes and HF caregiver-specific quality of life.

The relationships among caregiving task difficulty, threat appraisal, depressive symptoms, and life changes have been empirically supported with stroke caregivers (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). Although the pathophysiological mechanisms differ between HF and stroke, chronic HF patients experience impaired cognition and functional limitations similar to stroke survivors which have been correlated with negative family caregiver outcomes (Clark et

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al., 2004; Phillips et al., 1995; Schwarz & Blixen, 1997). In a study comparing HF

family caregivers to stroke caregivers, researchers found no significant differences in

levels of perceived stress and life satisfaction suggesting their experiences are similar

(Meagher-Stewart & Hart, 2002). For these reasons, this model was posited to be

relevant to HF family caregivers.

Figure 1

Conceptual model
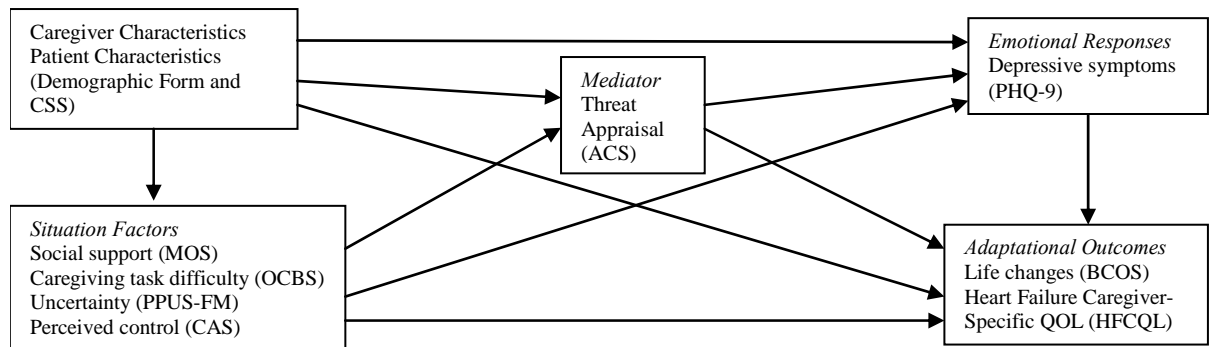
While not empirically studied as antecedents in Bakas and colleagues' conceptual

model with stroke caregivers (Bakas & Burgener, 2002; Bakas, Champion, et al., 2006),

the situation factors of social support, uncertainty, and perceived control are hypothesized

to be associated with appraisal, depressive symptoms, and adaptational outcomes of life

changes and HF caregiver-specific quality of life. As situation factors, these variables are

antecedents in Lazarus' (1966) and Lazarus' and Folkman's (1984) transactional

approach to stress, thereby influencing the mediator and outcomes (Lyon & Rice, 2000).

Social support, uncertainty, and perceived control are all pertinent to HF family

caregiving and amenable to intervention.

Four assumptions and four limitations of the study follow to complete the overall

nature of the study.

<u>Assumptions</u>

1. The selected instruments will accurately measure the constructs under investigation.

2. Family caregivers will respond honestly and accurately to the instrument items.

3. The relationships as theoretically hypothesized are accurate depictions of HF family caregivers' experiences.

4. Nurses can intervene to influence HF family caregivers' perceptions of social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms to reduce negative life changes and improve quality of life.

<u>Limitations</u>

1. A non-probability, convenience sample will be utilized which limits generalizability of the findings.

2. The study will be cross-sectional and stress is a dynamic process thereby limiting causal references.

3. Multicollinearity and singularity among instruments are possible thereby resulting in potential statistical analyses errors.

4. Quality of life domains are interrelated which may decrease the probability that HFCQL will psychometrically test to have four distinct quality of life domains.

The limitations in this study were acceptable considering the early exploratory nature of the conceptual model. Very few researchers examining the experience of HF

family caregivers have used a conceptual model to guide their study and those that have

are limited by small sample sizes (Bakas, Pressler, et al., 2006; Nauser, 2005; Scott,

2000). Findings from this study will guide future research to refine the conceptual model

and instrumentation. Using procedures by Tabachnick and Fidell (2001),

multicollinearity and singularity was examined and no corrective strategies were needed.

While the construct quality of life is complex and multidimensional, it is still important

that researchers try to capture its unique domains in order to develop relevant supportive

interventions. Psychometric evaluation of the HFCQL was conducted before including

the adaptational outcome of HF caregiver-specific quality of life in the conceptual model.

2. REVIEW OF LITERATURE

The nature of the proposed study, including problem, purpose, study aims and hypotheses, conceptual and operational definitions of variables, conceptual model, and assumptions and limitations, was presented in the previous chapter. This chapter provides a review of the Lazarus' (1966, 1991) and Lazarus & Folkman's (1984) transactional approach to stress, conceptual models used in caregiving studies by Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006), and research findings pertinent to this proposed study.

Overview of Lazarus and Colleague's Transactional Approach to Stress

Lazarus (1966, 1991) and Lazarus and Folkman (1984) define psychological stress as a relationship between the person and the environment where a situation is cognitively appraised by the person as exceeding his or her resources and endangering his or her well-being. Antecedents in Lazarus' (1966) and Lazarus and Folkman's (1984) transactional approach to stress include person and situation factors. Person factors influence appraisal by determining what is important for well-being in a certain encounter, shaping the person's understanding of the event, and providing the basis for evaluation of outcomes (Lazarus & Folkman, 1984). Examples include, but are not limited to, motivational characteristics, commitments, beliefs, and intellectual resources (Lazarus, 1966; Lazarus & Folkman, 1984). Situation factors refer to properties of encounters that influence a person's appraisal of the event. Examples include, but are not limited to uncertainty, duration, perceived social support and sense of control (Lazarus & Folkman, 1984; Lyon & Rice, 2000).

A key element in Lazarus' and colleagues' transactional approach to stress is the mediating variable of appraisal which occurs in three forms: primary appraisal, secondary appraisal, and reappraisal (Lazarus, 1966; Lazarus & Folkman, 1984). In primary appraisal, a person evaluates the balance of demands and resources. When the demands exceed the resources, there is the potential for three stress appraisals: potential for harm/loss resulting in threat, actual harm/loss that has already occurred, or potential for gain or benefit resulting in challenge (Lazarus, 1966; Lazarus & Folkman, 1984). Other types of cognitive appraisals, which are not stressful, are benign and benefit appraisal (Lazarus & Folkman, 1984). Benign appraisal refers to judgment that a situation is irrelevant and having no effect on future outcomes, whereas a benefit appraisal refers to judgment that a situation will result in positive outcomes (Lazarus & Folkman, 1984).

Emotional responses are generated as a consequence of primary appraisal (Lazarus, 1991). Of the stress appraisals, a challenge appraisal triggers pleasurable emotions, such as eagerness, excitement, and exhilaration, whereas a threat appraisal and actual harm/loss appraisal triggers negatively toned emotions, such as fear, anxiety, anger, and depression (Lazarus, 1991). The emotional response associated with the perception of threat mobilizes secondary appraisal, which is the person's evaluation of what coping strategies are available to manage the stress emotions caused by the threat. Reappraisal is the ongoing process of continual evaluation and modification of previous primary or secondary appraisals based on new information (Lazarus, 1966; Lazarus & Folkman, 1984).

Long-term adaptational outcomes resulting from interaction of person, environment, and situation factors, appraisal, emotions, include social, psychological, and

physical adaptational outcomes. Specifically, Lazarus and Folkman (1984) propose three

types of adaptational outcomes: social functioning, morale, and somatic health. Social

functioning refers to the ways that a person fulfills their various roles, satisfaction with

interpersonal relationships, and the skills necessary for maintaining roles and

relationships (Lazarus & Folkman, 1984). Morale refers to how people feel about

themselves and their life conditions. The terms 'satisfaction', 'subjective well-being' and

'psychological well-being' have been used to reflect morale (Lazarus & Folkman, 1984).

Somatic health refers to the physiological outcome of person, environment, and situation

factors, appraisal, emotions and coping processes. Relationships between social

functioning, morale, and somatic health are complex. Good functioning in one domain

may be directly related to poor functioning in another and good functioning in one

domain does not mean that the person is functioning well in the other domains (Lazarus

& Folkman, 1984).

Lazarus' and colleagues (Lazarus, 1966, 1991; Lazarus & Folkman, 1984)

approach to stress addresses the entire stress experience. The central element of this

theory is cognitive appraisal, which mediates antecedent person and situation factors, to

produce emotional responses, and adaptational outcomes in response to a particular

situation. The conceptual model proposed for this study (see Figure 1) was derived from

the work of Lazarus' and colleagues (Lazarus, 1966, 1991; Lazarus & Folkman, 1984)

transactional approach to stress. While person factors, per se, are not under investigation,

caregiver and patient characteristics, such as demographics and co-morbidites, represent

antecedents in the model. Social support, caregiving task difficulty, uncertainty, and

perceived control represent situation factors. Threat appraisal represents the mediating

variable of cognitive appraisal. Depressive symptoms represent the emotional response associated with a threat appraisal, while life changes and HF caregiver-specific quality of life represent long-term adaptational outcomes.

<div align="center">Relevance to Family Caregiving and the Practice of Nursing</div>

Lazarus' and colleagues (Lazarus, 1966, 1991; Lazarus & Folkman, 1984) transactional approach to stress has been used to guide studies with large samples (n = 92, 104, 147) of caregivers of stroke survivors (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). Many of the relationships in the conceptual model directing the proposed study have been empirically validated in Bakas and colleagues' studies (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). Caregiving task difficulty was found to be predictive of emotional distress, which is an emotional response that includes depressive symptoms (Bakas & Burgener, 2002), and the adaptational outcome of negative life changes (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). Appraisal of the caregiving situation was related to emotional distress (Bakas & Burgener, 2002) and adaptational outcomes, such as general health (Bakas & Burgener, 2002) and life changes (Bakas & Burgener, 2002; Bakas, Champion, et al., 2006). The relationship between emotional responses and adaptational outcomes has been documented in these stroke caregiver studies as well. Negative emotions such as depressive symptoms (Bakas, Champion, et al., 2006) and emotional distress were related to negative life changes (Bakas & Burgener, 2002; Bakas & Champion, 1999).

Bakas, Pressler, and colleagues (2006) applied a similar caregiving model to study a small sample of HF family caregivers using the variables of caregiving task

difficulty, perceived control, and adaptational outcomes of life changes, general health, and mental health. Consistent with stroke caregivers, caregiving task difficulty was associated with poorer mental health and negative life changes. Adding perceived control as a situation factor to their model, Bakas, Pressler, and colleagues (2006) found correlations between control and mental health in HF family caregivers. Using the same sample to do a secondary analysis to examine the influence of threat appraisal on adaptational outcomes, Nauser (2005) found that caregiving task difficulty was related to threat appraisal, and threat appraisal was related to poorer mental health and negative life changes. Although the sample was small, these studies support continued use of Lazarus and colleagues (Lazarus, 1966, 1991; Lazarus & Folkman, 1984) transactional approach to stress, as adapted by Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al. 2006; Bakas, Pressler, et al., 2006) to study the stress experience of HF family caregivers.

While ensuring that the variables chosen to examine in the proposed study were consistent with Lazarus (1966) and Lazarus and Folkman's (1984) transactional approach to stress, the potential for intervention was considered as well. Interventions in the form of providing information and offering emotional support have been associated with improved problem-solving skills, preparedness, and mental health, and lessened depressive symptoms (Grant, Elliot, Weaver, Bartolucci, & Giger, 2002), and improved general health and quality of life (Mant, Carter, Wade, & Winner, 2000) in caregivers of stroke survivors. Similar findings have been found with caregivers of patient with Alzheimer's disease; enhanced counseling and support lessened depressive symptoms in this population (Mittelman, Roth, Coon, & Haley, 2004). Using a conceptual model

derived from Lazarus (1966, 1991) and Lazarus and Folkman (1984), researchers found that interventions targeted at providing education to reduce uncertainty resulted in less negative appraisal of their situation for caregivers of patients with cancer (Northouse, Kershaw, Mood, & Schafenacker, 2005).

The research findings from stroke (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006) and HF (Bakas, Pressler, et al., 2006; Nauser, 2005) caregiver studies which used conceptual models derived from Lazarus (1966, 1991) and Lazarus and Folkman (1984) provided empirical support to justify the conceptual model used in this study. Intervention studies have documented that appraisal and outcomes, such as depressive symptoms, mental health, general health, and quality of life, can be improved by relevant and appropriate interventions (Grant et al., 2002; Mant et al., 2000; Mittelman et al., 2004; Northouse, et al., 2005). The next section provides a review of literature that support the relationships proposed in the conceptual model for this study depicted in Figure 1.

<u>Review of Literature</u>

To evaluate the existing literature concerning stress variables and outcomes for family caregivers of HF patients, a literature search was conducted using the electronic databases CINAHL, MEDLINE, and PsycINFO. The keywords selected were family caregivers, informal caregivers, carers, heart failure, congestive heart failure, and cardiac failure; the search was limited from 1990 through May 2007. Ninety-seven abstracts were reviewed for possible relevance to this study. Many of these studies reported on patient experiences only and therefore were considered irrelevant; only 24 were considered relevant to family caregiver outcomes and associated variables. Two

additional articles were collected through the ancestry approach. The findings from an additional study, which was conducted by Nauser (2005) and is unpublished, is included in this review. Therefore a total of 27 articles addressing HF family caregivers are reported in this review of literature. Since the research literature concerning family caregiver outcomes and related variables for caregivers of other diseases, such as stroke, cancer, and Alzheimer's, is more substantial, many of these articles are included to supplement this review of literature.

Key findings from the caregiving literature that are pertinent to this study are presented in the following sections. The major headings are the dependent variables of depressive symptoms, life changes, and HF caregiver-specific quality of life. Relationships between these dependent variables and the independent variables of social support, caregiving task difficulty, uncertainty, perceived control, and caregiver and patient characteristics, and the mediating variable of threat appraisal, as depicted in Figure 1, are addressed in the subheadings within each major section. Tables summarizing each of the studies reviewed are located in Appendix A.

Depressive Symptoms

Depressive symptoms refer to the severity of the symptoms which correspond with DSM-IV depression criteria of depressed mood, sleep changes, diminished interest or pleasure in activities, weight loss or weight gain, insomnia or hypersomnia, psychomotor agitation or retardation observed by others, fatigue or loss of energy, feelings of worthlessness or excessive guilt, inability to think or concentrate or indecisiveness, and suicidal ideation (American Psychiatric Association, 1994; Kroenke et al., 2001). These depressive symptoms are consistent with Lazarus' (1966, 1991) and

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Lazarus' and Folkman's (1984) conceptualization of an emotional response due to a threatening appraisal.

The prevalence of depressive symptoms has been documented in studies of family caregivers of persons with various diagnoses, including dementia, cancer, and stroke. In a review article by Schulz and colleagues (1995) of 41 studies of caregivers of patients with dementia, it was found that elevated levels of depression were found in nearly all studies. Later reports have continued to document the prevalence of depressive symptoms in these caregivers. In a large sample of caregivers of patients with dementias ($n = 295$), the mean score of the overall group was indicative of high depressive symptomology (Farran et al., 2004). Other researchers have documented that 27% and 29% of the caregivers in fairly large samples ($n = 140, 97$, respectively) experienced depressive symptoms (Lee et al., 2001; Lu & Austrom, 2005).

Caregivers of patients with cancer also experience significant levels of depressive symptoms. Recent studies have documented ranges of 26% to 52% of cancer caregivers experiencing depressive symptoms (Bradley et al., 2004; Carter and Acton, 2006). In a large sample of family caregivers ($n = 152$) of patients with cancer at the end of life, the group overall experienced moderate to high levels of depressive symptoms (Given et al., 2004).

Depressive symptoms are prevalent among caregivers of stroke survivors as well. In two studies, more than one-third of stroke caregivers experienced high levels of depressive symptoms (Grant, Weaver, Elliot, Bartolucci, & Giger, 2004; Grant, Bartolucci, Elliot, & Giger, 2000). In another study of 146 caregivers of stroke survivors, researchers found that only 18.1% of stroke caregivers in a sample of 146 experienced

moderate depressive symptoms (Bakas, Champion, et al., 2006). However, an additional 18.1% indicated they were currently taking antidepressant medications, which suggests that as many as 36% suffered from depression (Bakas, Champion, et al., 2006). Comparing caregivers of stroke survivors to caregivers of Alzheimer's disease, Clark and King (2003) found no significant difference in depressive symptoms between the two groups. However 44% of both groups had high levels of depressive symptoms.

Depressive symptoms have been examined in HF family caregivers in seven studies. Researchers found that the mean score of a depression inventory exceeded the cutoff for depression (Schwarz & Dunphy, 2003) in a study of 75 HF caregivers, indicating the prevalence of depression among this population. Other researchers of HF family caregivers have found that the group overall was not depressed, as reflected by a low mean score, but that a significant percentage of the group did experience depressive symptoms. In a large sample of HF spouses ($n = 177$), 39.8% qualified for a distress-related psychiatric diagnosis using a tool measuring anxiety and depression combined (Rohrbaugh et al., 2002). Other studies with sample sizes ranging from 48 to 213 have shown that 14% to 23% of HF family caregivers experienced depressive symptoms (Barnes et al., 2006; Martensson et al., 2003; Molloy et al., 2006; Schwartz & Elman, 2003). In a small sample of caregivers of HF patients ($n = 18$) receiving community-based inotropic infusions, 45% indicated they felt depressed as measured by a single item (Scott, 2000). Considering that in any given year, 6.7% of adults aged 18 and older experience a major depressive disorder (Kessler, Chiu, Demler, & Walters, 2005), the percentages reported by existing HF studies are note-worthy.

Social support and depressive symptoms. Social support refers to the family caregiver's perception about the availability of support and relationships that serve particular functions, such as emotional/informational support, tangible support, positive social interaction, and affectionate support (Sherbourne & Stewart, 1991). As a situation factor in Lazarus' (1966) and Lazarus' and Folkman's (1984) transactional approach to stress, social support has the potential to reduce the severity of depressive symptoms.

Research findings in studies of caregivers of patients with varying diagnoses suggest that social support is related to the severity of depressive symptoms experienced by the caregiver. Difficulty in arranging support from friends correlated with depressive symptoms ($r = .34$, $p < .002$) in a study of family caregivers ($n = 81$) of Alzheimer's patients (Chang et al., 2001). Lower emotional support was related to depressive symptoms ($r = -.28$, $p < .05$) in a group of 60 family caregivers of persons with a variety of chronic illnesses (Schwarz, 2000). Caregivers of stroke survivors who experienced higher levels of depressive symptoms perceived significantly less tangible support than their counterparts with no or low depressive symptoms (Grant et al., 2000). Social support was a significant predictor of depressive symptoms accounting for 24% of the variance in a small sample of 40 stroke caregivers (Grant et al., 2001). The relationship between social support and depressive symptoms has not been empirically determined in the HF caregiving literature. Studies of caregivers of patients with other disorders suggest social support is an important variable to examine in the HF caregiver population.

Caregiving task difficulty and depressive symptoms. Caregiving task difficulty refers to the caregiver's perceived difficulty with direct, instrumental, and interpersonal tasks carried out to assist their family member (Oberst, 1990). Caregiving task difficulty

is posited to be a situation factor in the conceptual model guiding this proposed study and therefore has the potential to influence the severity of depressive symptoms.

Existing research findings indicate a relationship between emotional responses and caregiving tasks. Examining depressive symptoms and the number of caregiving tasks in 127 caregivers of patients with a variety of chronic illnesses, Nieboer and colleagues (1998) found slight correlation between these two variables ($r = .25, p < .01$). Furthermore, these researchers noted that depressive symptoms were significantly higher ($p < .05$) for caregivers with at least four caregiving tasks (Nieboer et al., 1998). The relationship between caregiving task difficulty and emotional distress, which includes other negative emotions such as anger and anxiety in addition to depression, was examined in family caregivers of stroke survivors. Caregiving task difficulty was found to be a significant predictor of emotional distress in two large samples ($n = 116, n = 104$) of stroke caregivers (Bakas et al., 2004; Bakas & Burgener, 2002). As a matter of fact, the four tasks identified as the most difficult by caregivers ($n = 116$) accounted for 37% of variance in emotional distress ($p < .001$) in one of the studies (Bakas et al., 2004). To date, only one study has addressed caregiving tasks difficulty in relationship to emotional responses in HF family caregivers (Karmilovich, 1994). Measuring perceived stress, Karmilovich (1994) found a moderate correlation between task difficulty and stress in a sample of 41 HF family caregivers ($r = .43, p = .01$).

Uncertainty and depressive symptoms. Uncertainty refers to the family caregiver's inability to determine the meaning of their family member's illness-related events (Mishel, 1997). This cognitive state is created when the family member cannot adequately structure or categorize an event due to a lack of sufficient cues and results in

the inability to assign a definite value to the event and/or accurately predict outcomes (Mishel, 1997). Ambiguity and complexity of illness-related events increase uncertainty perceived by family caregivers (Mishel, 1997). Posited to be a situation factor in Lazarus' (1966) and Lazarus' and Folkman's (1984) transactional approach to stress, uncertainty has the potential to influence the severity of depressive symptoms experienced by family caregivers.

Even though uncertainty has been studied extensively in patient populations and found to correlate with negative emotional outcomes (Christman et al., 1988; Padilla, Mishel, & Grant, 1992; Webster & Christman, 1988), the impact of uncertainty on caregiver depressive symptoms has been documented in only one study. In family caregivers ($n = 44$) of patients with Parkinson's disease, uncertainty was correlated with depressive symptoms ($r = .35$, $p < .05$) (Sanders-Dewey et al., 2001). Since HF has an unpredictable illness trajectory and a complex treatment regime, uncertainty is an important variable to explore in HF family caregivers as noted in two qualitative studies (Boyd et al., 2004; Mahoney, 2001). These researchers found that HF family caregivers felt a sense of incoherence and a lack of congruence when trying to make sense of their family member's illness (Mahoney, 2001) and the uncertainty of the prognosis made knowing how imminent death would be difficult (Boyd et al., 2004).

Perceived control and depressive symptoms. Perceived control refers to the caregiver's perception that they have the internal resources to positively influence adversity of an event and can influence their environment to bring about positive outcomes (Thompson, 1981; Wallston, 1989). As a situation factor in the conceptual model guiding this study, it is posited that a family caregiver's perception of their control

over their family member's heart problems will reduce the severity of depressive symptoms.

The relationship between mastery, which is similar to control, and depressive symptoms has been studied in caregivers of patients with cancer and Alzheimer's disease. Mastery refers to control individuals feel they can exercise over important forces affecting their life (Pearlin et al., 1990). In cancer caregivers ($n = 51$), mastery was moderately and negatively correlated with depressive symptoms ($r = -.54, p < .001$) (Carter & Acton, 2006) and in Alzheimer's caregivers ($n = 215$), a sense of low mastery was found to be a significant predictor of caregiver depressive symptoms ($p < .01$) (Miller, Campbell, Farran, Kaufman, & Davis, 1995). Personal control in regards to managing problems was moderately correlated with depressive symptoms ($r = .54, p < .05$) in stroke caregivers (Grant et al., 2001). Family caregiver studies addressing control suggest an important association with depressive symptoms and therefore, were examined in this study.

Threat appraisal and depressive symptoms. A threat appraisal is a type of stress appraisal that occurs when caregiving demands exceed the caregiver's resources and they appraise their situation as potentially harmful and/or resulting in loss (Lazarus, 1966; Lazarus & Folkman, 1984). Depending on the caregiver's coping strategies, the perception of threat may be characterized by negatively-toned emotions (Lazarus & Folkman, 1984), which may be expressed as depressive symptoms.

The relationship between threat appraisal and depressive symptoms has been documented in studies of caregivers. In a large group of 140 caregivers of older adults with Alzheimer's disease or related dementia, threat appraisal was moderately associated

with depressive symptoms ($r = .55$, $p < .001$) (Lee et al., 2001). Positive appraisal, which

is the inverse of threat appraisal, was negatively correlated with depressive symptoms in

100 caregivers of patients with a variety of disorders (Schwarz, 1999). Threat appraisal

was found to be a significant predictor of emotional distress, which includes other

negative emotions such as anger and anxiety, in addition to depression, in stroke

caregivers ($n = 104$) (Bakas & Burgener, 2002). In a study of 392 caregivers, Schultz

and colleagues (1997) found that caregivers who appraised their situation as straining

experienced significantly more depressive symptoms than age- and gender-matched non-

caregivers ($n = 427$). The results of these studies supported exploration of the

relationship between threat appraisal and depressive symptoms in HF family caregivers.

Caregiver and patient characteristics and depressive symptoms. The influence of

age on depressive symptoms was noted in caregivers of persons with cancer at the end of

life (Given et al., 2004) and caregivers of persons with chronic varied illnesses (Lee et

al., 2001). Middle aged cancer caregivers (ages 45-54) experienced significantly more

depressive symptoms than younger and older caregivers (Given et al., 2004). Increasing

age was found to be a significant predictor of depressive symptoms in caregivers of older

persons with chronic varied illnesses (Lee et al., 2001).

Gender differences have been addressed in the caregiver literature. Female

caregivers of persons with stroke, cancer at end of life, and varied chronic illnesses had

higher levels of depressive symptoms (Bakas et al., 2006; Given et al., 2004; Lee et al.,

2001) and higher levels of distress (anxiety and depression combined) (Rohrbaugh et al.,

2002) than males. However, one study documented no gender differences in depressive

symptoms in 52 stroke caregivers (Grant et al., 2000). Additionally, neither education

level nor race influenced the level of depressive symptoms in the same study (Grant et al., 2000). However, in a large study ($n = 215$) of caregivers of persons with dementias, researchers found that African Americans were less likely to report depressive symptoms (Miller et al., 1995).

Studies examining the differences in depressive symptoms based on caregiver relationship to the patient have shown inconsistent results. In 100 caregivers of persons with diverse chronic illnesses, there were no significant difference in depressive symptoms between spouses and adult children (Schwarz, 1999). However, in 152 caregivers of persons with cancer at end of life, adult children experienced higher levels of depressive symptoms than spouses (Given et al., 2004), while in 140 caregivers of persons with varied chronic illnesses, being a spousal caregiver was predictive of depressive symptoms (Lee et al., 2001). Family caregivers who are employed and those who are unemployed but looking for a job had significantly more depressive symptoms than those who were unemployed (Given et al., 2004). Higher levels of total household income and caregiver education is related to lower levels of depressive symptoms in 140 caregivers of persons with varied chronic illness (Lee et al., 2001).

Patient characteristics examined in relationship to caregiver depressive symptoms include age, cognitive impairment, and New York Heart Association (NYHA) class. In a study of 48 dyads of HF patients and their caregivers, younger age of the patient was related to higher levels of caregiver depressive symptoms (Martensson et al., 2003). Cognitive impairment was found to influence the severity of depressive symptoms in 100 caregivers of persons with varied chronic illnesses; caregivers of patients with cognitive impairment had significantly higher levels of depressive symptoms (Schwarz & Blixen,

1997). Findings concerning correlations between NYHA class and caregiver depressive symptoms have been inconsistent. In 48 HF caregivers, NYHA class and depressive symptoms were inversely related ($r = -.34$, $p < .05$), suggesting that caregivers experience more depressive symptoms when the HF patient is in a better functional class (Martensson et al., 2003). In a large sample of HF spousal caregivers ($n = 177$), NYHA class correlated with patient anxiety and depression, but did not correlate with the caregivers anxiety and depression (Rohrbaugh, 2002). NYHA class did not correlate with caregiver emotional distress in a study of 41 caregivers of HF patients in NYHA Class III and IV (Karmilovich, 1994).

The research literature concerning the prevalence of depressive symptoms among family caregivers of patients with dementia (Schulz et al., 1995), cancer (Given et al., 2004), and stroke (Bakas et al., 2006) strongly supports the notion that they do experience increased levels of depressive symptoms compared to the general population (Kessler et al., 2005). Studies of depressive symptoms among HF family caregivers suggest their experiences are similar; however, there are limitations that warrant further investigation of depressive symptoms and correlating variables in HF family caregivers.

Research findings concerning depressive symptoms in caregivers of patients with other disorders (Bakas et al., 2006; Given et al., 2004; Schulz et al., 1995) were based on much larger sample sizes than the findings reported in the five studies of HF family caregivers (Martensson et al., 2003; Rohrbaugh et al., 2002; Schwarz & Dunphy, 2003; Schwarz & Elman, 2003; Scott, 2000). Granted, the largest HF caregiver sample was 177 caregivers (Rohrbaugh et al., 2002), but the researchers used an instrument that measured both anxiety and depression combined limiting the usefulness of the findings to the

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current study which examined depressive symptoms only. One study that reported 45% depressive symptoms among HF family caregivers had a sample size of 18 and measured depression with a single item (Scott, 2000). To accurately measure the prevalence of depressive symptoms among HF family caregivers, additional studies are warranted with larger sample sizes and reliable and valid instruments.

The examination of the relationships between depressive symptoms and associated variables is markedly absent in the HF caregiving literature. To date, no published study was found that addressed social support, caregiving task difficulty, uncertainty, control, and threat appraisal, in relationship to HF family caregiver depressive symptoms, as guided by a conceptual model. Considering the prevalence of depressive symptoms among family caregivers, it is vital to understand the influence of these variables on depressive symptom severity. This study addressed this gap in the literature by using reliable and valid instruments to measure depressive symptoms and associated variables, as determined by a conceptual model, in a sample of 100 family caregivers of patients with HF.

Life Changes

Life changes refers to the caregiver's perception of how his or her life has changed as a result of providing care and includes changes in social functioning, subjective well-being, and somatic health (Bakas & Champion, 1999; Bakas, Champion, et al., 2006). As a long-term adaptational outcome, life changes is an important outcome likely to be influenced by caregiver and patient characteristics, situation factors (social support, caregiving task difficulty, uncertainty, and control), threat appraisal, and depressive symptoms. Consistent with Lazarus' (1966) and Lazarus' and Folkman's

(1984) conceptualization of adaptational outcomes, life changes include social, psychological, and physical outcomes as a result of family caregiving.

Life changes have been examined in family caregivers of stroke survivors. Findings from these studies ($n = 92, 104, 159$) indicate that in general, stroke caregivers' lives have changed for the worse in the areas of social functioning, subjective well-being, and somatic health due to their caregiving responsibilities (Bakas et al., 2004; Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). The importance of this concept has been highlighted in qualitative studies of HF family caregivers (Luttik et al., 2007; Mahoney, 2001). These researchers noted that these caregivers reported multiple life changes ranging from daily routines and relationship with the patient to physical, emotional, social, economic, and spiritual changes. To date, only one quantitative study has examined life changes experienced by HF family caregivers as a result of their caregiving responsibilities. Bakas, Pressler, and colleagues (2006) found that overall HF family caregivers perceive their life has changed for the worse. As measured by individual items, more than half of the HF caregivers (57%) rated their emotional well-being as changed for the worse, while nearly one-half (48%) rated their future outlook, level of energy, time for social activities, and financial well-being as changed for the worse (Bakas, Pressler, et al., 2006). Findings from studies of caregivers of stroke survivors indicate that caregivers consistently perceive their life has changed for the worse. Understanding of the HF caregiver's perception of life changes is essential to detecting caregiver needs.

Social support and life changes. The relationship between social support and life changes has not been documented in the literature. It seems reasonable to assume that a

caregiver's perception about the availability of support and relationships would influence

their perception of their life changes. Social support has been shown to be related to

lower levels of depressive symptoms in caregivers (Chang et al., 2001; Grant et al., 2000;

Grant et al., 2001; Schwarz, 2000). Depressive symptoms (Bakas, Champion, et al.,

2006) and emotional distress (Bakas & Burgener, 2002) have been correlated with life

changes, which is discussed in more detail below. It seems likely that social support has

the potential to influence the caregiver's perception of how their life has changed.

Caregiving task difficulty and life changes. The relationship between caregiving

task difficulty and life changes has been documented in caregivers of stroke survivors

(Bakas et al., 2004; Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas,

Champion, et al., 2006). In a sample of 147 stroke caregivers, task difficulty was

negatively correlated with life changes ($r = -.35, p < .001$) indicating that as tasks were

perceived as more difficult, caregivers perceived their life had changed for the worse

(Bakas, Champion, et al., 2006). In another study of 116 stroke caregivers, the four most

difficult tasks accounted for 19% of the variance in life changes ($p < .001$), which

emphasizes the importance of examining task difficulty (Bakas et al., 2004). The

relationship between task difficulty and life changes was supported in a study of 21 HF

family caregivers by a moderate correlation ($r = -.46, p < .05$) (Bakas, Pressler, et al.,

2006). These findings support continued investigation of caregiving task difficulty in

relation to life changes.

Uncertainty and life changes. The relationship between uncertainty and caregiver

life changes has not been documented in the literature. When uncertain events are

evaluated as harmful, coping strategies are employed to reduce the uncertainty and

promote adaptation (Mishel, 1988). It is likely that HF family caregivers feel a sense of uncertainty concerning their family member's illness since HF can be unpredictable and the treatment is complex. Therefore, it is imperative to understand how uncertainty influences long term adaptational outcomes, such as life changes.

Perceived control and life changes. The association between perceived control and life changes has not been adequately documented in the caregiving literature. In a small sample of 21 HF caregivers, researchers found no significant correlation between control over managing their family member's heart problems and the caregiver's perception of how their life has changed as a result of providing care (Bakas, Pressler, et al., 2006). However, nearly 43% of these caregivers perceived a lack of control which warrants further investigation of the relationship between control and the long-term adaptational outcome of life changes in a larger sample.

Threat appraisal and life changes. The relationship between threat appraisal and life changes has been examined in family caregivers of stroke survivors. Threat appraisal was found to be a significant individual predictor of life changes in 147 stroke caregiver ($R^2 = .30, p < .05$) (Bakas, Champion, et al., 2006) and was moderately correlated with life changes in 104 caregivers ($r = -.53, p < .001$) (Bakas & Burgener, 2002). In a small study of 21 HF caregivers, a strong association was found between threat appraisal and life changes ($r = -.68, p < .001$) (Nauser, 2005). These findings concerning the relationship between threat appraisal and life changes support additional investigation of this relationship in HF family caregivers.

Depressive symptoms and life changes. The association between life changes and depressive symptoms has been studied in stroke caregivers. In 147 stroke caregivers, the

severity of depressive symptoms was a significant independent predictor of life changes, accounting for 6% unique variance of life changes (Bakas, Champion, et al., 2006). Emotional distress, which includes other negative emotions such as anger and anxiety in addition to depression, was found to be a significant predictor of negative life changes (4% unique variance) in 104 stroke caregivers (Bakas & Burgener, 2002). Since depressive symptoms are prevalent among HF family caregivers (Barnes et al., 2006; Martensson et al., 2003; Molloy et al., 2006; Schwartz & Elman, 2003), it is essential to determine how depressive symptoms impact the adaptational outcome of life changes in order to intervene.

Caregiver and patient characteristics and life changes. Differences in life changes based on caregiver gender, patient gender, and caregiver relationship to patient have been documented in stroke caregiver literature (Bakas & Champion, 1999, Bakas, Champion, et al., 2006). Consistently, female caregivers have reported more negative life changes than male caregivers in large samples of stroke caregivers (Bakas & Champion, 1999; Bakas, Champion, et al., 2006). In one study, the gender of the patient was implicated in caregiver life changes. Those caring for male stroke survivors reported significantly more negative life changes than those caring for female stroke survivors (Bakas, Champion, et al., 2006). Adult children caregivers perceived more negative life changes than spousal caregivers in two samples of stroke caregivers (Bakas & Champion, 1999). In a study of 21 HF caregivers, there was no association between age and life changes.

The adaptational outcome, life changes, has been studied extensively in caregivers of stroke survivors with the BCOS, a caregiver-specific instrument that measures perception of life changes in the areas of social functioning, subjective well-being, and

somatic health. Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999, Bakas et al., 2004, Bakas et al, 2006; Bakas, Champion, et al., 2006) have documented that in general, stroke caregivers' lives have changed for the worse as a result of providing care. These findings were consistent in a small sample of HF caregivers (Bakas, Pressler, et al., 2006).

Variables associated with life changes, such as task difficulty, control, and threat appraisal, have been explored in HF family caregivers (Bakas, Pressler, et al., 2006; Nauser, 2005), but the sample size is too small to make formal conclusions. Other variables posited to be associated with life changes, such as social support, uncertainty, and depressive symptoms, have not been explored in the HF family caregiving literature. As an adaptational outcome, life changes reflect the culmination of the stress experience for family caregivers. Understanding the relationship between life changes and theoretically associated variables, including caregiver and patient characteristics, would allow health care professionals to develop relevant interventions and to target those interventions to caregivers most in need.

Heart Failure Caregiver-Specific Quality of Life

In the past, many researchers measured only one dimension, such as physical function or economic concerns, but recently, researchers have emphasized the need for a multidimensional definition (Grant & Dean, 2003). A commonly accepted model of health-related quality of life used for evaluating patient outcomes is by Wilson and Cleary (1995), which has been revised and clarified by Ferrans, Zerwic, Wilbur, and Larson (2005) to advance the use of the concept of health related quality of life in nursing and health care. Wilson and Cleary (1995) depict overall quality of life as an outcome of

biological and physiological factors, symptom status, functional status, and general health perceptions, all of which are influenced by individual characteristics, and psychological and social factors. It is important to note that Wilson and Cleary (1995) defined symptoms as the individual's perception of abnormal physical, emotional, or cognitive state and they defined functioning as the ability to perform tasks in multiple domains, such as physical function, social function, role function, and psychological function. These definitions highlight the multiple dimensions of quality of life. The consideration of the subjective nature, or the individual's perception, of their quality of life and the term 'well-being' are commonly found in definitions of quality of life (Ferrans & Powers, 1985; Ferrell et al., 1995; Ferrell et al., 2001; Taylor, Jones, & Burns, 1995; World Health Organization, 1947, as cited in King & Hinds, 2003).

For this study, HF caregiver-specific quality of life refers to the family caregivers' perception of their well-being stemming from physical, psychological, social and spiritual domains as impacted by their caregiving responsibilities (Ferrell et al., 2001) for a family member with HF. The construct of HF-caregiver-specific quality of life is consistent with long-term adaptational outcomes, as described by Lazarus (1966) and Lazarus and Folkman (1984). In the proposed study, HF caregiver-specific quality of life is conceptualized as being situation-specific and likely to be influenced by caregiver and patient characteristics, situation factors (social support, caregiving task difficulty, uncertainty, and control), and depressive symptoms. HF caregiver-specific quality of life includes physical, psychological, and social well-being, as suggested by Lazarus (1966) and Lazarus and Folkman (1984), as well as spiritual well-being. The impact of caregiving on HF caregivers' spiritual well-being has been documented by qualitative

researchers (Mahoney, 2001; Murray et al., 2004) and therefore, the spiritual domain of HF caregiver-specific quality of life was considered to be important as well. While HF caregiver-specific quality of life is an adaptational outcome in the conceptual model, as is life changes, it differs from life changes in that HF caregiver-specific quality of life addresses the current state, as opposed to changes, and includes spiritual well-being, whereas life changes does not include this domain.

There is a substantial body of literature confirming that family caregivers of persons with other chronic and terminal illnesses experience poor quality of life as reflected by ratings of general and mental health on the SF-36 health survey, which measures health-related quality of life. In studies of caregivers of stroke survivors (Bakas & Burgener, 2002), patients with Alzheimer's disease (Markowitz et al., 2003), and patients with cancer (Kershaw et al., 2004), family caregivers reported general health and mental health values below the normative population mean, as published by Ware (2000).

Reports of general health and mental health of HF family caregivers are consistent with stroke, Alzheimer's, and cancer caregivers. General health and mental health ratings by HF caregivers were below published normative population values (Ware, 2000) in four studies (Bakas, Pressler, et al., 2006; Dracup et al., 2004; Martensson et al., 2003; Scott, 2000). Other HF caregiver researchers have examined life satisfaction, a construct similar to quality of life, and found that HF caregivers report poorer life satisfaction than the general, healthy, elderly population (Luttik et al., 2005, Meagher-Stewart & Hart, 2002).

While research findings associated with generic quality of life instruments allow comparison to the general population, it is unclear if these ratings are due to the impact of

caregiving or due to other personal issues experienced by the caregiver, such as their own chronic illnesses. To determine the impact of caregiving responsibilities on caregiver's quality of life, many researchers have used instruments that measure what they termed "burden" on various quality of life domains. Using the Zarit Caregiver Burden Interview to assess the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of providing care, researchers have found a low level of burden in HF caregivers (Hooley, Butler, & Howlett, 2005) and rural caregivers (Sanford et al., 2005). In contrast, when asked to compare their overall health at the present time to prior to caregiving, caregivers of HF patients (Scott, 2000) and chronically ill elderly (Faison et al., 1999) perceived a decline in their overall health due to caregiving. Caregivers of patients with HF, chronic obstructive pulmonary disease, or cancer ($n = 1883$) reported a moderate level of burden, reflecting a negative impact on psychological and social well-being, as measured by the Montgomery Scale (Hughes et al., 2000).

Negative outcomes in the domain of social well-being have been documented in studies focused on HF caregivers. Using an instrument to measure psychosocial adjustment to illness in 90 HF spouses, researchers found that most of the caregiver problems were in the social domain (Bohachick & Anton, 1990). Using the Carer Strain Index, which measures the psychological impact of caring, Barnes and colleagues (2006) found that 13% of HF family caregivers experienced strain. With the role alterations scale of the Caregiving Demands Scale, Karmilovich (1994) found that caregiving responsibilities had a negative impact on work participation, social participation, and interpersonal relationships, which is reflective of social well-being. Findings in

qualitative studies have supported the notion that HF caregivers feel socially isolated

(Aldred et al., 2005; Martensson, Dracup, & Fridlund, 2001; Murray et al., 2002) which

has negative consequences on their social well-being.

Qualitative studies have documented the impact of caregiving on the spiritual

well-being domain in HF caregivers (Mahoney, 2001; Murray et al., 2004). Caregivers

referred to struggles associated with managing their own spiritual needs and knowing

how to support their family member spiritually (Murray, Kendall, Boyd, Worth, &

Benton, 2004). Collectively, these studies indicate that family caregivers do experience

negative outcomes in multiple domains of quality of life.

Social support and quality of life. The association between social support and

quality of life has not been adequately addressed in the literature. In a study of 40 stroke

caregivers (Grant et al., 2001), social support was not related to general health, but was

related to life satisfaction, a construct similar to quality of life ($r = .36$, $p < .05$).

Examining the relationship between social support and HF caregiver-specific quality of

life will determine the importance of targeting interventions at social support, a situation

factor in the conceptual model.

Caregiving task difficulty and quality of life. The relationship between

caregiver's perception of task difficulty and quality of life has been documented in the

research literature. In a study of 88 caregivers of chronically ill elderly, the degree of

both direct and indirect care required by the patient correlated with a negative impact on

physical, psychological, and social well-being (Faison et al., 1999). In 21 HF caregivers,

task difficulty was moderately associated with poorer mental well-being ($r = -.51$,

p < .05) (Bakas, Pressler, et al., 2006). HF caregivers made reference to their caregiving tasks interfering with their usual activities thereby negatively impacting their social well-being in a qualitative study (Martensson et al., 2001). These studies suggest there is a relationship between task difficulty and quality of life, but additional investigation is needed to determine the relationship between task difficulty and HF caregiver-specific quality of life.

Uncertainty and quality of life. The influence of uncertainty on the caregiver's quality of life has not been documented in the literature. Considering the likelihood that HF caregivers feel a great deal of uncertainty, determining how this impacts their situation-specific quality of life is imperative to determine appropriate interventions.

Perceive control and quality of life. The relationship between perceived control and selected domains of quality of life has been documented in stroke and HF caregivers. Personal control, in relation to problem solving, was correlated to general health (*r* = -.38, *p* < .05) in 40 caregivers of stroke survivors (Grant et al., 2001. Caregiver perceived control over managing their family member's heart problems has been moderately associated with mental health (*r* = .44, *p* <. 05) (Bakas, Pressler, et al., 2006) and a composite of mental and general health (*p* = .001) (Dracup et al., 2004) in studies of HF family caregivers showing that higher perceived control correlates with better outcomes. These studies indicate the importance of exploring control as a correlate of quality of life, but examining control in relation to HF caregiver-specific quality of life will offer the specificity necessary to evaluate the impact of control on caregivers' lives.

Threat appraisal and quality of life. The relationship between threat appraisal and general health, physical health, and life satisfaction has been documented in the

caregiving literature. Threat appraisal was shown to be a significant predictor of general health ($p < .001$) in 104 stroke caregivers accounting for 5% of the unique variance (Bakas & Burgener, 2002). In 140 caregivers of older adults with varied disorders, threat appraisal was correlated with physical health ($r = -.32, p < .001$) and life satisfaction ($r = -.49, p <. 001$) (Lee et al., 2001). Appraisal of a situation as threatening has the potential for negative emotions, which ultimately may impact the HF caregiver's quality of life.

Depressive symptoms and quality of life. The relationship between depressive symptoms and various quality of life domains has been documented in the research literature. Depressive symptoms was strongly correlated with caregiver overall health in caregivers of patients with Alzheimer's disease and related dementias (Robinson, 1989). In caregivers of older adults with a variety of chronic illnesses, depressive symptoms was associated with reports of poorer physical health (Lee et al., 2001) and poorer physical functioning (Nieboer et al., 1998). Stroke caregivers experiencing more severe depressive symptoms also reported poorer general health (Grant et al., 2000). In two studies of caregivers of HF patients, higher levels of depressive symptom severity were associated with reports of poorer mental well-being, an important domain of quality of life (Barnes et al., 2006; Martensson et al., 2003). Other researchers have found an association between depressive symptoms and poorer life satisfaction, in caregivers of stroke survivors (Grant et al., 2000) and chronically ill elders (Lee et al., 2001).

Examining caregiver perception of the impact of depressive symptoms on various quality of life domains, researchers have found important relationships. The severity of depressive symptoms was correlated with perception of negative impact on overall health

in cancer caregivers (Given et al., 1993; Kurtz, Kurtz, Given, & Given, 1995). While some studies of cancer caregivers have shown that social well-being has been influenced by depressive symptoms as reflected by correlation between depressive symptoms and impact on caregiver daily schedules (Given et al., 1993; Kurtz et al., 1995), others have not supported the relationship (Given et al., 2004).

The relationship between depressive symptoms and caregiver burden, a concept similar to caregiver-specific quality of life, has been examined in a study of 50 HF family caregivers (Hooley et al., 2005). Using the Zarit Caregiver Burden Interview, which measures the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of providing care, researchers found a significant correlation between burden and depressive symptoms ($r = .61, p < .001$).

Caregiver and patient characteristics and quality of life. Existing literature has documented that demographics and other characteristics, such as living arrangement and household income, influence the caregiver's perception of their quality of life in various domains. Female caregivers of patients with a variety of disorders reported more negative outcomes in the domain of social well-being than male caregivers (Schwarz, 1999). In two studies of HF family caregivers, younger caregivers perceived more negative mental health outcomes (Bakas, Pressler, et al., 2006; Dracup et al., 2004) than older caregivers. In a study of 213 HF family caregivers, the patient's self-reported NYHA class was a significant predictor of negative impact of the caregiver's psychological status. The influence of caregiver relationship to the patient on the caregiver's social well-being has been documented in several studies. Adult children

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experience a more negative impact on social well-being than spouses in caregivers of

persons with a variety of illnesses (Schwarz, 1999) and cancer (Given et al., 2004). In a

study of mostly adult children of chronically ill elderly, sons reported less negative

impact on social well-being than daughters, extended family, friends, neighbors (Faison

et al., 1999). Living arrangements, caregiver education, and household income have been

shown to correlate with general health for caregivers of stroke survivors. Caregivers who

did not live with the stroke survivor had significantly lower reports of general health

(Bakas & Burgener, 2002). Caregivers with less education (Grant et al., 2001) and lower

household incomes (Bakas & Burgener, 2002) reported lower levels of general health.

Collectively these studies provide documentation that family caregivers of stroke

survivors (Bakas & Burgener, 2002), Alzheimer's disease (Markowitz et al., 2003) and

cancer (Kershaw et al., 2004) do experience a poorer quality of life than the general

population as measured by generic general health and mental health instruments. Studies

of HF family caregivers reported similar findings with general and mental health

instruments (Bakas, Pressler, et al., 2006; Scott, 2000) and life satisfaction instruments

(Luttik et al., 2005; Meagher-Stewart & Hart, 2002). Generic tools do not provide

information about the caregiver's specific situation; however to capture the impact, or

burden, of caregiving on various domains of the caregiver's quality of life, researchers

have used a variety of tools (Given et al., 1993; Given et al., 2004; Kurtz et al., 1995;

Schwarz, 1999). Because conceptual and operational definitions differ among these

studies, analysis and synthesis of findings is difficult to nearly impossible. Additionally,

none of these studies measured quality of life comprehensively, as physical,

psychological, social, and spiritual well-being and most are not in the HF family caregiver population.

While measuring the impact of caregiving will provide more specific information concerning the outcome of caregiving than generic instruments, the existing instruments are not HF caregiver-specific. Population-specific quality of life instruments have been used in cancer caregivers (Ferrell, 1995; Ferrell et al., 2001; Weitzner, McMillan, et al., 1999; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). In two large studies of cancer family caregivers, researchers found that a cancer caregiver specific tool was more responsive to caregiver mental health issues than the SF-36 (Weitzner, McMillan, et al., 1999; Weitzner, Jacobsen, et al., 1999). Comparing quality of life of cancer caregivers to noncaregivers, researchers found a significant difference between these two groups by using a caregiver specific quality of life instrument, which suggests that the population-specific instrument was able to differentiate between levels of quality of life for caregivers and noncaregivers (McMillan & Mahon, 1994). These studies support the value of developing and testing a HF caregiver-specific quality of life instrument.

An additional gap in the literature which limits direction to develop appropriate interventions is a lack of HF caregiving studies examining relationships between quality of life and conceptually associated variables. The findings from existing HF caregiving studies suggests relationships between various domains of quality of life and caregiving task difficulty (Bakas, Pressler, et al., 2006), control (Bakas, Pressler, et al., 2006), threat appraisal (Nauser, 2005) and depressive symptoms (Martensson et al., 2003). However, two of these reports had a small sample size (Bakas, Pressler, et al., 2006; Nauser, 2005) and quality of life was measured with generic instruments, discounting the HF family

caregiver's specific situation. Furthermore, Dracup et al. (2004) used a composite of mental and general health resulting in questionable validity since the scoring of the SF-36 was modified from published recommendations (Ware, 1993).

The body of literature documenting negative outcomes in selected domains of quality of life for caregivers of other populations, such as stroke, cancer, and dementias is substantial (Bakas & Burgener, 2002; Kershaw et al., 2004; Markowitz et al., 2003). The smaller studies of HF caregivers (Bakas, Pressler, et al., 2006; Martensson et al., 2003; Scott, 2000) suggest the same findings. However, to identify priority areas for interventions to support HF family caregivers, it is imperative to determine variables associated with negative quality of life outcomes. Additionally, a HF caregiver-specific quality of life instrument that assesses all domains of quality of life is needed to measure the effectiveness of interventions.

<u>Summary and Critique</u>

The body of research literature addressing outcomes of family caregivers of stroke, cancer, and dementias, is fairly extensive and documents that caregivers do experience negative outcomes, such as depressive symptoms (Bakas, Champion, et al., 2006; Given et al., 2004; Schulz et al., 1995), negative life changes (Bakas, Champion, et al., 2006), and poor quality of life (Bakas & Burgener, 2002; Kershaw et al., 2004; Markowitz et al., 2003). In contrast, the literature concerning outcomes of HF family caregivers is minimal and limited by small sample sizes. However, these studies do suggest that HF family caregivers do experience significant levels of depressive symptoms (Barnes et al., 2006; Hooley et al., 2005; Martensson et al., 2003; Molloy et al., 2006; Schwarz & Dunphy, 2003; Schwarz & Elman, 2003), negative life changes

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(Bakas, Pressler, et al., 2006), and poor quality of life as measured by general and mental health on generic instruments (Bakas, Pressler, et al., 2006; Dracup et al., 2004; Martensson et al., 2003; Scott, 2000). HF family caregivers have reported a negative impact to their social-well-being (Bohachick & Anton, 1990; Karmilovich, 1994). Qualitative researchers have documented a negative impact of caregiving on the spiritual well-being on the family caregiver, which emphasizes examination of this domain (Mahoney, 2001; Murray et al., 2004).

The variables posited to be associated with family caregiving outcomes, such as social support, task difficulty, uncertainty, and perceived control, have not been examined adequately in the literature using a conceptual model as a guide. However, there is some support for many of the relationships depicted in the conceptual model in Figure 1. In caregivers of patients with stroke, cancer, and dementias, social support was found to be related to depressive symptoms (Chang et al, 2001; Grant et al., 2001; Schwarz, 2000) and life satisfaction, a construct related to quality of life (Grant et al., 2001). The influence of social support on HF family caregivers has not been documented. Larger studies of caregivers with other disorders have confirmed that there is a relationship between caregiving task difficulty and the outcomes of depressive symptoms, negative life changes, and quality of life (Bakas et al., 2004; Bakas & Burgener, 2002; Bakas, Champion, et al., 2006); however, these relationships have been documented in only one small HF caregiver study (Bakas, Pressler, et al., 2006). The association between uncertainty and the outcomes of depressive symptoms, life changes, and quality of life has not been documented in the caregiver literature in general. This is surprising considering that studies measuring patient outcomes have found important

correlations between uncertainty and negative emotional outcomes (Christman et al., 1988; Padilla, Mishel, & Grant, 1992).

The situation factor of control has been shown to related to depressive symptoms in Alzheimer's caregivers (Miller et al., 1995) and to life changes (Bakas, Pressler, et al., 2006) and quality of life, in terms of general and mental health, in HF family caregivers (Bakas, Pressler, et al., 2006; Dracup et al., 2004). There is a significant amount of literature supporting relationships between threat appraisal and negative emotional responses (Bakas & Burgener, 2002; Lee et al., 2001), negative life changes (Bakas, Champion, et al., 2006), and poor quality of life, such as general health, mental health, and life satisfaction (Bakas & Burgener, 2002; Bakas, Champion, et al., 2006; Lee et al., 2001) in other caregivers. In a small sample of HF caregivers, Nauser (2005) noted a strong correlation between threat appraisal and negative life changes; otherwise, the relationship between threat appraisal and HF caregiver outcomes has not been documented in the HF caregiver literature.

The relationship between the emotional response of depressive symptoms and life changes (Bakas, Champion, et al., 2006) and elements of quality of life, such as overall health (Grant et al., 2000; Robinson, 1989), physical health (Lee et al., 2001), mental well-being (Martensson et al., 2003), and social well-being (Given et al., 1993; Kurtz et al., 1995) has been documented in the caregiving literature. However, only one study assessed HF family caregivers (Martensson et al., 2003). Reports of the association between caregiver and patient characteristics and caregiver outcomes have been minimal and inconsistent. Some general themes reported included that females reported more depressive symptoms (Bakas, Champion, et al., 2006; Given et al., 2004; Lee et al.,

2001), negative life changes (Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas et al., 2006), and negative impact on social well-being (Schwarz, 1999) than male caregivers. Adult children report more depressive symptoms (Given et al., 2004; Lee et al., 2001), negative life changes (Bakas & Champion, 1999), and negative impact on social well-being (Schwarz, 1999; Given et al., 2004) than spousal caregivers. Age was found to be correlated with negative mental health outcomes in two HF caregiver studies (Bakas, Pressler, et al., 2006; Dracup et al., 2004).

In summary, the current body of literature concerning the negative outcomes experienced by family caregivers of stroke, cancer, and Alzheimer's patients is substantial and provided justification for examining the outcomes for HF family caregivers. The problems associated with the existing HF caregiving literature were a lack of studies guided by a conceptual framework, an absence of a HF-specific caregiver quality of life instrument with documented psychometric properties, and a lack of identification of variables associated with HF caregiver outcomes as depicted in Figure 1. No HF caregiver studies documented the influence of social support or uncertainty, and the studies addressing caregiving tasks, control, and threat appraisal had small sample sizes (Bakas, Pressler, et al., 2006; Nauser, 2005). Additionally, there was no instrument that measured the multidimensional construct of quality of life specific to the HF family caregiver. By using an empirically-supported conceptual model, this study identified variables associated with negative HF caregiver outcomes so that health care providers can develop and test individualized, multi-component caregiver interventions applicable to the HF population. Additionally, this study psychometrically evaluated a much needed population-specific quality of life instrument that can be used to test these interventions.

3. METHODOLOGY

<u>Design</u>

This study involved psychometric evaluation of the HF Caregiver Quality of Life (HFCQL) scale followed by identification of variables associated with HF caregiver outcomes based on a conceptual model derived from the work of Lazarus (1966, 1991), Lazarus & Folkman (1984), and Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006). First, a psychometric design was employed to determine the psychometric properties of the HFCQL scale. Second, a descriptive design with cross-sectional data was used to determine the combination of independent variables that explained depressive symptoms, life changes, and HF caregiver-specific quality of life, if the HFCQL scale showed acceptable psychometric properties. The dependent variables were depressive symptoms, life changes, and HF caregiver-specific quality of life. If the HFCQL scale did not show acceptable psychometric properties, general health and mental health were to be used as dependent variables. The independent variables were social support, caregiving task difficulty, uncertainty, perceived control, and threat appraisal. Caregiver and patient characteristics were measured to provide a description of the sample and to control for extraneous influences in associated relationships.

The participants for this study were 100 persons who had responsibility for providing unpaid care for a family member or close friend with chronic HF in the home. To compute factor analysis for psychometric testing of the HFCQL scale, a sample size of at least 100 subjects was considered adequate (Munro, 2001). While the initial HFCQL contained 46 items, it was posited that at least 30% of the items would be

deleted following item analysis resulting in a total of no more than 32 items. According

to Knapp and Brown (1995), three subjects per item may be acceptable; therefore a

sample size of 96 was considered adequate. Based on a power analysis for multiple

regression, a minimum sample size of 98 subjects was needed for a moderate effect size

of .50, power of .80, and alpha of .05 with a maximum of six predictor variables (Cohen,

1987). This recommended sample size is consistent with the general rule of $N > 50 + 8$

(IV) suggested by Tabachnick and Fidell (2001). Applying this rule to this study, the

suggested sample size would be $50 + 8$ (social support, caregiving task difficulty,

uncertainty, control, threat appraisal, and depressive symptoms) to total 98. Based on

these recommendations, a sample size of 100 was sought for this study. Since this study

was exploratory in nature and the sample size was considered adequate, data was

collected on a convenience sample. The inclusion criteria of the sample were as follows:

1. Caregiver must be a non-paid family member or significant other of the HF
   patient (i.e. spouse, ex-spouse, fiancé, adult child, adult child in-law, grandchild,
   sibling, aunt, uncle, close friend, etc).

2. Caregiver must be identified by the HF patient as the person who helps them the
   most at home or in a non-institutionalized setting. Caregivers of persons who
   reside in an extended care facility or nursing home are ineligible.

3. Caregiver must be providing at least two caregiving tasks as identified on the
   Oberst Caregiving Burden Scale.

4. Caregiver must be 21 years or older.

5. Caregiver must be able to read, write, and speak English.

6. Caregiver must have access to a telephone.

7. Caregiver must be able to hear conversation on the telephone.

8. Caregiver must be willing to participate in at least one telephone interview and possibly a 2-week test-retest.

The exclusion criteria of the sample were as follows:

1. Caregiver is providing one or no caregiving tasks as identified on the Oberst Caregiving Burden Scale.

2. HF patient is residing in an extended care facility or nursing home.

3. Caregiver is currently a prisoner.

4. Caregiver is 20 years of age or younger.

<u>Procedure</u>

After approval from Indiana University Purdue University Institutional Review Board and recruiting sites was attained (see Appendix B), study participants were recruited from private cardiology offices, inpatient cardiac units, and outpatient heart failure clinics located at Research Medical Center, St. Luke's Hospital, and Menorah Medical Center in the greater Kansas City area. Recruitment letters, which had an attached response card, were signed by the patients' cardiologists, the patient's HF nurse clinician, or member of the patient's HF team who had initial contact with the HF patient (see Appendix C). The recruitment letter described the study purpose and the voluntary nature of the study, and provided a telephone number that they could call if they did not wish to be contacted for the study.

Registered nurses at the sites identified patients with a medical diagnosis of chronic heart failure and 1) provided a list of contact information for the chronic HF patient and next of kin (if available) to the researcher, 2) distributed the study packet and

provided contact information for the patient and next of kin (if available) to the researcher, or 3) distributed the recruitment letter with the response card. Study packets contained a signed recruitment letter with attached response card, two copies of the informed consent (see Appendix D), three copies of the gift voucher receipts, an interview response scale, and a postage paid, self-addressed stamped envelope to return one of the signed consent forms and two of the gift voucher receipts. If the next of kin contact information was available, the packet was mailed directly to the next of kin. If the next of kin contact information was not available, the packet was mailed to the HF patient and they were asked to give the packet to the person who helps them the most at home.

Within one week of the mailing by the researcher or distribution by the registered nurse, the patient or next of kin was called to see if they received the packet and determine who helps the patient the most at home. If this person is someone other than the next of kin identified on the HF patient list, they were asked to give the packet to their primary caregiver and their contact information was obtained from the HF patient or next of kin. The primary caregiver was then contacted by the researcher who provided additional information about the study, explained that their participation is voluntary, and determined their interest. For those not interested, they were informed that they would not be contacted in the future.

Interested persons were screened for inclusion and exclusion criteria; a medical diagnosis of HF was also validated with the caregiver with 'Has your family member been diagnosed by a physician as having chronic heart failure?' Informed consent was obtained verbally over the telephone for those who were eligible prior to data collection.

Those who met the inclusion criteria were asked to initial, sign, and date the informed

consent form and two copies of the gift voucher receipts and return these documents in

the self-addressed, stamped envelope. They were instructed to keep a copy of the

informed consent statement and gift voucher receipt for their files. A telephone

appointment was scheduled at a time convenient for the caregiver to participate in a

telephone interview, which was anticipated to last approximately one hour.

Participants were contacted by telephone by the researcher at the previously

scheduled time for the initial interview. Prior to starting the interview, participants were

asked if they had any questions and were reminded that their participation was voluntary

and they could decline participation at any time. During the telephone interview, the

participants were asked questions using an interview guide (see Appendix E) containing

the Caregiver and Patient Characteristics form, Medical Outcomes Study Social Support

Survey, Oberst Caregiving Burden Scale – difficulty subscale, Uncertainty in Illness

Scale for Family Members, Control Attitudes Scale, Appraisal of Caregiving threat

subscale, Primary Health Questionnaire, Bakas Caregiving Outcomes Scale, HF Family

Caregiver Quality of Life scale, and Medical Outcomes Study SF-36 General Health and

Mental Health subscales. To test for instrument test-retest reliability of the HF Family

Caregiver Quality of Life scale, participants were asked if they were willing to participate

in a follow-up telephone interview which was anticipated to last approximately 15

minutes. For those wishing to participate in the 2-week retest, the next appointment was

made.

Once the initial interview was completed and the signed informed consent and gift

vouchers were received by the researcher, a $10 gift card for Target was mailed to their

home. For those who participated in the 2-week test retest telephone interview, an additional gift card for $10 gift card for Target was mailed to their home following that interview.

<div align="center">Protection of Human Subjects</div>

Following approval of the study proposal from the researcher's dissertation committee, approval was obtained from the Institutional Review Boards at Indiana University Purdue University at Indianapolis (IUPUI - IRB) and the recruiting sites in the greater Kansas City area, Research Medical Center, St. Luke's Hospital, and Menorah Medical Center, prior to data collection. In the study letter signed by the patient's cardiologist, HF nurse clinician, or member of the HF team, potential participants were provided a telephone number to call to request that they not be contacted by the researcher. The study purposes, risks, and benefits were explained to interested participants who were required to sign an informed consent prior to conducting the telephone interview. Participants were told they could decline participation at any time before or during the telephone interview. All information was collected by self report from the family caregiver. No medical records were accessed for this study.

Data were collected using an interview schedule. No names or identifying information, other than the subject identification number, were added to the interview schedule to protect participant anonymity. The results were reported as group summaries; individual data was not reported. There was minimal risk of negative consequences as a result of participating in the study in that some of the questions could evoke negative emotions. Participants were informed that they could decline answering any questions that made them feel uncomfortable. Contact information was provided for

caregivers to call in the case of emotional distress, or any concerns regarding their rights as research participants. There was one item on the PHQ-9 that addresses suicidal ideation. If caregivers endorsed this item, or if at any time, caregivers mentioned suicidal thoughts about themselves, or the patients, an established suicide protocol approved by the IUPUI IRB was initiated and followed (see Appendix F).

The list of HF patients with information regarding next of kin and/or family caregiver and the list of subject name and corresponding identification number was kept in a locked cabinet separate from the completed interview schedules. Only the researcher had access to the key. The data from the interview schedules were entered into the researcher's password-protected personal computer networked to the IUSON secure network by the researcher only. All electronic data was password-protected and backed up nightly on the IUSON data drive. The hard copies of the completed interview schedules will be kept by the researcher in a locked cabinet for at least 7 years and then will be shredded.

<div align="center">Variables and Instruments</div>

The variables social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, depressive symptoms, life changes, HF caregiver-specific quality of life, caregiver and patient characteristics, and general and mental health were measured in this study. A detailed description of instruments used to operationalize these variables follows. Formal permission was attained for use of Parents' Perception Uncertainty in Illness Scale for Family Members, Control Attitudes Scale, Appraisal of Caregiving Threat Subscale, Primary Health Questionnaire-9, and Bakas Caregiving Outcomes Scale (see Appendix G). The Caregiver and Patient Characteristics form and

the HF Caregiver Quality of Life Scale were developed for this study. The Cognitive Status Scale, Medical Outcomes Study (MOS) Social Support Survey, Oberst Caregiving Burden Scale, MOS 36-Item Short Form Health Survey (SF-36) – General Health Subscale, and MOS SF-36 – Mental Health Subscale are all in the public domain.

Caregiver and Patient Characteristics

The caregiver characteristics examined in this study were: 1) demographic and clinical data, specifically age, gender, race (American Indian or Alaskan Native, Asian, Native Hawaiian or Other Pacific Islander, Black or African American, or White), ethnicity (Hispanic or Latino, Not Hispanic or Latino), relationship to the care recipient, education, co-morbidities, perception that income meets needs, and employment status and 2) caregiving situation characteristics, specifically length of time in the caregiving role since HF diagnosis in months, time spent caregiving hours per week, and living arrangements.

Patient characteristics were reported by the caregiver and included 1) demographic and clinical data, specifically age, gender, race (American Indian or Alaskan Native, Asian, Native Hawaiian or Other Pacific Islander, Black or African American, or White), ethnicity (Hispanic or Latino, Not Hispanic or Latino), education, co-morbidities, 2) caregiver's perception of the patient's symptoms with activities, 3) presence of implanted ventricular assist device, and 4) cognitive impairment.

Demographic Data Form. An researcher-developed demographic data form measured the caregiver and patient characteristics as described above. The caregiver's perception of patient's symptoms, such as shortness of breath, fatigue, and chest pain, with activities was determined through a single item asking the family caregiver to

identify patient symptoms with activity: 1) no symptoms, 2) symptoms with moderate activity, 3) symptoms with minimal activity, and 4) symptoms at rest. Caregivers were asked if the HF patient whom they provide care for had an implanted ventricular assist device.

Cognitive Status Scale. HF patient cognitive impairment was measured with the eight item Cognitive Status Scale (CSS). Family caregivers rate the patient's level of difficulty associated with memory, communication, and recognition on a 5-point response scale ranging from 1 ("can't do at all") to 5 ("not at all difficult") (Pearlin et al., 1990). Internal consistency reliability was adequate in a study of family caregivers of patients with Alzheimer's disease (α = .86) (Pearlin et al., 1990) and stroke survivors (α = .84) (Bakas & Champion, 1999). Validity of the CSS was supported by a strong correlation (r = .65) between the ratings caregivers gave their family members on the CSS and the ratings of the same family members made by clinical workers using the Mini-Mental Test developed by Folstein, Folstein, and McHugh (1975; as cited by Pearlin et al., 1990).

Social Support

Social support was conceptually defined as the family caregiver's perception about the availability of support and relationships that serve particular functions (Sherbourne & Stewart, 1991). Five different types of social support are emotional, informational, tangible, affectionate, and positive social interaction. Emotional support refers to expressing positive affect, empathetic understanding, and encouraging expression of feelings. Informational support refers to offering advice, information, and guidance. Tangible support is providing material aid or behavior assistance. Positive

social interaction is the availability of other persons to do fun things with. Affectionate support involves expressions of love and affection (Sherbourne & Stewart, 1991).

      Medical Outcomes Study Social Support Survey. The Medical Outcomes Study (MOS) Social Support Survey was used to measure social support (Sherbourne & Stewart, 1991). The first item, which is open-ended, asks respondents to indicate the number of close friends and relatives they have. The remaining 19 items asks respondents to rate the availability of perceived support of a 5-point response scale ranging from 1 ("none of the time") to 5 ("all of the time"). The survey yields a total score as well as four subscale scores, emotional/informational support (8 items), tangible support (4 items), positive social interaction (3 items), and affectionate support (3 items). While this instrument can measure four subscales, only the total score will be used in this study. The overall total score is calculated by averaging the 19 responses; higher scores indicate higher perceived availability of social support (Sherbourne & Stewart, 1991; Westlake et al., 2002).

      The MOS Social Support Survey was psychometrically tested in a large sample of patients with chronic conditions ($n = 2987$) and demonstrated strong evidence of internal consistency reliability ($\alpha = .97$) and stability over one year ($r = .78$). Construct validity was supported by strong correlations between the MOS and measures of loneliness ($r = -.67$, family functioning ($r = .53$), and marital functioning ($r = .56$) and weak correlations between the MOS and measures of physical function ($r = .11$) and pain severity ($r = -.19$) (Sherbourne & Stewart, 1991). While this instrument was originally developed for people with chronic conditions, it is relevant for family caregivers since

many are older and likely to experience chronic illnesses themselves (Sanford et al., 2005).

Caregiving Task Difficulty

Caregiving task difficulty was conceptually defined as the caregiver's perceived difficulty with direct, instrumental, and interpersonal tasks carried out to assist their family member (Oberst, 1990). Direct care tasks refer to medical or nursing treatments, personal care (bathing, dressing), and assistance with mobility; instrumental care tasks refer to provision of transportation, management of finances, planning activities, household tasks, and coordinating services; and interpersonal care tasks refer to emotional support, managing behavior problems, communication, and seeking information from health professionals (Oberst, 1990).

Oberst Caregiving Burden Scale. The difficulty subscale of the Oberst Caregiving Burden Scale (OCBS) was used to measure caregiving task difficulty (Oberst, 1990; Bakas et al., 2004). This 15-item subscale asks caregivers to indicate the level of difficulty associated with 15 direct, instrumental, and interpersonal caregiving tasks on a 5-point response scale ranging from 1 ("not difficult") to 5 ("extremely difficult"). The subscale is scored by summing the 15 items with a possible range of 15 to 75. Higher scores reflect greater caregiving task difficulty (Oberst, 1990; Bakas et al., 2004).

Content validity was initially established in the original version, titled "Caregiver Load Scale" (Oberst et al., 1989). Construct validity has been documented in caregivers of patients with cancer through testing of theoretically and empirically derived hypotheses relating to association between OCBS difficulty scores and antecedent factors as well as outcomes (Carey, Oberst, McCubbin, & Hughes, 1991; Oberst, 1990). In

studies of stroke caregivers, factor analysis supported a one factor solution (Bakas et al., 2004) and correlations between task difficulty and theoretically related variables of emotional distress ($r = .60$) and caregiving outcomes ($r = -.56$) (Bakas & Burgener, 2002) provided evidence of construct validity. Internal consistency has been previously established ($\alpha = .84$ to .97) in studies of cancer and stroke caregivers (Bakas & Burgener, 2002; Bakas et al., 2004; Bakas & Champion, 1999; Carey et al., 1991). The difficulty subscale of the OCBS was used in a small sample of 21 HF caregivers (Bakas, Pressler, et al., 2006). With scores being normally distributed, the OCBS difficulty subscale had evidence of high internal consistency reliability ($\alpha = .92$).

 Uncertainty

Uncertainty was conceptually defined as the family caregiver's inability to determine the meaning of their family member's illness-related events (Mishel, 1997). This cognitive state is created when the family member cannot adequately structure or categorize an event due to a lack of sufficient cues and results in the inability to assign a definite value to the event and/or accurately predict outcomes (Mishel, 1997). Ambiguity and complexity of illness-related events increase uncertainty perceived by family caregivers. Ambiguity refers to vague and indistinct cues about the state of the illness which tend to blur and overlap and complexity refers to multiple and varied cues about the treatment and system of care (Mishel, 1997).

Uncertainty in Illness Scale for Family Members. The 31-item Parents' Perception Uncertainty in Illness Scale for Family Members (PPUS-FM) (Mishel, 1997) was used to operationalize uncertainty. This instrument, while originally designed for parents of ill children, can be used with family caregivers by changing the word 'child' to

the appropriate relational descriptor, such as 'family member' (Mishel, 1997). On a scale of 1 ("strongly disagree") to 5 ("strongly agree"), respondents were asked to indicate the degree to which they agree with uncertainty statements concerning their family member's illness, treatment, and communication with health care providers (Mishel, 1997) The PPUS-FM is scored by summing the 30 items; the last item is not included in the scoring (Mishel, 1997). A higher score is indicative of greater uncertainty (Mishel, 1997).

Psychometric testing of the 28-item version of the PPUS-FM was conducted with a normative data base of 509 family members of patients with cancer, Alzheimer's disease, dementias, and myocardial infarction. With factor analysis, two factors emerged, ambiguity and complexity (Mishel, 1997). However, the reliability coefficient for the complexity subscale was not satisfactory, so the total scale is recommended for use with family members (Mishel, 1997). Internal consistency reliability for the total scale has been satisfactory for each of the reported family caregiver samples (α = .81 to .92) as reported by Mishel (1997).

Perceived Control

Perceived control was conceptually defined as the caregiver's belief that they have the internal resources to positively influence the adversity of an event and can influence their environment to bring about positive outcomes (Thompson, 1981; Wallston, 1989). Control does not have to be exercised nor real, only perceived, to influence outcomes (Litt, 1988). For this study, perceived control referred to the caregiver's perceived level of control over their family member's heart problems (Moser & Dracup, 2000), and therefore, was situation-specific (Lyon & Rice, 2000). For this reason, it is different than locus of control, which refers to a person factor.

Control Attitudes Scale. Perceived control was measured with the family version
of the Control Attitudes Scale (CAS) (Dracup et al., 2004; Moser & Dracup, 2000). The
4-item CAS asks family caregivers to rank their level of perceived control over heart
problems (and conversely, feelings of helplessness) on a 7-point response scale ranging
from 1 ("not at all in control") to 7 ("very much in control"). The instrument has items
related to both the family caregiver's own perception of control (3 items) and their
perception of the degree to which they feel the heart failure patient feels control (1 item).
After reverse scoring items 3 and 4, the item rankings are summed for the score; higher
scores indicate higher feelings of control (Dracup et al., 2004; Moser & Dracup, 2000).

The CAS was originally developed for use in cardiac patients (Moser & Dracup,
1995). In a sample of 325 cardiac patients, psychometric testing showed evidence of
internal consistency reliability ($\alpha = .89$) and test-retest reliability ($r = .62$). Construct
validity was supported with correlation ($r = .58$) with a control-like measure of health
care orientation (Moser & Dracup, 1995). The family version of the CAS was used in a
study of 196 spouses of cardiac patients and internal consistency reliability was high
($\alpha = .88$) (Moser & Dracup, 2000). The CAS has also been used in a small sample of 21
HF caregivers (Bakas, Pressler, et al., 2006). With scores being normally distributed, the
CAS had evidence of satisfactory internal consistency reliability ($\alpha = .75$)

Threat Appraisal

Threat appraisal was conceptually defined as the caregiver's perception that their
caregiving situation is potentially harmful and/or resulting in loss to their well-being. As
a cognitive process with subjective interpretation, threat appraisal is a type of stress
appraisal which occurs when the demands of the situation exceeds the person's resources

(Lazarus, 1966; Lazarus & Folkman, 1984). The perception of threat, which centers on

the potential harms or losses, is characterized by negative emotions such as fear, anxiety,

and anger (Lazarus & Folkman, 1984).

Appraisal of Caregiving Threat Subscale. Threat appraisal was measured by the

threat subscale of the Appraisal of Caregiving Scale (ACS) (Oberst, 1991), as adapted by

Bakas (1996) in a study of family caregivers of stroke survivors. This 12-item subscale

asks respondents to indicate their level of perceived threat on a 5-point response scale

ranging from 1 ("strongly disagree") to 5 ("strongly agree") in the areas of caregiving

tasks, relationships and interpersonal support, lifestyle, emotional and physical health,

and overall personal impact (Oberst et al., 1989). Individual item scores were summed

for a total score with higher scores indicating higher levels of threat.

The original version of the threat subscale of the ACS, which had 15 items

(Oberst et al., 1989), was psychometrically tested in a sample of 240 caregivers. Support

was provided for the subscale of threat through factor analysis and construct validity was

made evident through correlations of the threat subscale and measures of mood

dysfunction ($r = .60$), task difficulty ($r = .58$), and family hardiness ($r = -.36$) (Oberst,

1991). The ACS was revised by Bakas (1996) to the current 12-item version and has

subsequently been used in studies of family caregivers of stroke patients (Bakas &

Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006) where

internal consistency reliability has been high ($\alpha = .86, .92$).

Depressive Symptoms

Depressive symptoms were conceptually defined as the severity of symptoms

associated with depression (Kroenke et al., 2001), as specified by the DSM-IV criteria of

depressed mood, sleep changes, diminished interest or pleasure in activities, weight loss or weight gain, insomnia or hypersomnia, psychomotor agitation or retardation observed by others, fatigue or loss of energy, feelings of worthlessness or excessive guilt, inability to think or concentrate or indecisiveness, and suicidal ideation (American Psychiatric Association, 1994).

Primary Health Questionnaire-9. Depressive symptoms were measured by the nine item depression scale of the Primary Health Questionnaire (PHQ-9). The items correspond with criteria as delineated by Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) major depressive disorder category (Kroenke & Spitzer, 2002), such as little interest or pleasure in doing things, feeling down, problems with sleeping, and trouble concentrating. Respondents are asked to indicate the frequency of problems over the last two weeks on a 4-point response scale, ranging from 0 ("not at all") to 3 ("nearly every day"). The scores are summed with a range of 0 to 27 and level of severity can be described as none (scores 1 to 4), mild (scores 5 to 9), moderate (scores 10-14), moderately severe (scores 15-19), and severe (scores 20-27) (Kroenke & Spitzer, 2002).

The PHQ-9 was psychometrically tested in a sample of 6000 primary care and obstetric/gynecological patients (Kroenke et al., 2001). Internal consistency reliability (α = .86, .89) and test-retest reliability (r = .84) were high. Criterion validity was established through correlation with mental health professional structured interview results and construct validity was supported through correlations between the PHQ-9 and measures of functional status, disability days, symptom-related difficulty, and health care utilization (Kroenke et al., 2001). The PHQ-9 was found to be sensitive and specific for

diagnosing major depression in patients with stroke (Kroenke et al., 2001; Williams et al., 2005). The PHQ-9 has been used with family caregivers of stroke patients and internal consistency reliability (α = .80 to .86) was satisfactory (Bakas, Champion, et al., 2006; Bakas et al., 2006).

<u>Life Changes</u>

Life changes were conceptually defined as perceived changes in the caregiver's life as a result of providing care (Bakas & Champion, 1999). These life changes include changes in social functioning, subjective well-being, and somatic health, which is consistent with Lazarus' (1991) conceptualization of adaptational outcomes. Social functioning refers to performance of problem-solving, employment, social activity and family; subjective well-being refers to how the caregiver feels about their life and situation; and somatic health refers to the physical health status of the caregiver (Lazarus, 1991).

<u>Bakas Caregiving Outcome Scale</u>. Life changes were operationalized with the Bakas Caregiving Outcome Scale (BCOS) which measures caregiver perceptions of how their life has changed since they assumed the role of caregiver for their family member (Bakas & Champion, 1999; Bakas, Champion, et al., 2006). On this 15-item instrument, respondents indicated their perceived changes in social functioning, subjective well-being, and physical health on a scale ranging from -3 ("changed for the worst") to +3 ("changed for the best"). Items are recoded to a range of 1 to 7. Individual items are summed for a total score; higher scores are indicative of more positive changes as a result of caregiving responsibilities (Bakas & Champion, 1999; Bakas, Champion, et al., 2006).

The 15-item BCOS has been psychometrically tested in 147 family caregivers of stroke survivors and has satisfactory evidence of internal consistency (α = .90) and 2-week test-retest reliability (*ICC* = .66; 95% *CI* = .42-.81) (Bakas, Champion, et al., 2006). Construct validity was established through both exploratory and confirmatory factor analysis showing that the BCOS was a unidimensional scale. Construct validity was also established through hierarchical multiple regression where 30% of the BCOS was explained by the constructs in the conceptual model criterion validity was established by correlations with the SF General Health scale (*r* = .32) and criterion variable measuring overall life changes (*r* = .67) (Bakas, Champion, et al., 2006). A 12-item and 10-item version of the BCOS have been used with stroke caregivers with satisfactory internal consistency reliability (α = .90, .77) and criterion and construct validity (Bakas & Champion, 1999). The 15-item version has been used in a small sample of 21 HF caregivers (Bakas, Pressler, et al., 2006). With scores being normally distributed, the BCOS had evidence of satisfactory internal consistency reliability (α = .88)

HF Caregiver-Specific Quality of Life

HF caregiver-specific quality of life was conceptually defined as the family caregivers' perception of their well-being stemming from physical, psychological, social and spiritual domains as impacted by their caregiving responsibilities (Ferrell et al., 2001) for a family member with heart failure. The physical well-being domain captures the impact of caregiving on physical health and related symptoms, such as sleep disturbances and appetite changes (Ferrell, 1995; Ferrell et al., 2001). The psychological well-being domain captures the impact of caregiving on psychological symptoms, such as depression, emotional distress, and stress (Ferrell, 1995; Ferrell et al., 2001). The social

well-being domain captures the impact of caregiving on social conditions, such as roles and relationships (Ferrell, 1995; Ferrell et al., 2001). The spiritual well-being domain captures the impact of caregiving on spirituality, such as a sense of inner strength and purpose (Ferrell, 1995; Ferrell et al., 2001).

Heart Failure Caregiver Quality of Life Scale. HF caregiver-specific quality of life was measured with the proposed Heart Failure Caregiver Quality of Life scale (HFCQL) that was psychometrically tested in this study. Using a 5-point response scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"), the HFCQL measured quality of life with potentially four subscales (physical, psychological, social, and spiritual well-being) pending factor analysis. Initially, the HFCQL had 46 items for respondents to rate the impact of caregiving responsibilities on various areas in their life reflecting physical, psychological, social, and spiritual well-being domains. It was anticipated that some of these items would be deleted following item analysis. There were an additional five items on the scale concerning overall impact in physical, psychological, social, and spiritual domains and quality of life that were intended to be used to assess for criterion-related validity. After reverse scoring of appropriate items, individual items within each domain are summed and averaged, so that higher scores are indicative of higher perceptions of quality of life.

Content validity of the HFCQL scale was determined by five professional experts and two personal experts who reviewed the item pool. The professional experts were doctoral prepared nurses: two with a background in heart failure research, two with a background in caregiver research, and one who was the director of a heart failure clinic. The personal experts were HF family caregivers: one was an adult child who had been

caring for her mother for 10 years and the other was a spousal caregiver who had been

caring for her husband for 6 years. The experts were asked to review a pool of 58 items

for three criteria. First, they were to determine which QOL domain (physical,

psychological, social, or spiritual) was most appropriate for each item. Secondly, using a

4-point response scale ranging from 1, indicating not relevant, to 4, indicating very

relevant, experts were asked to rate each item for relevance to their assigned domain.

And finally, the experts were asked to critique the clarity of items, provide suggestions

for revisions, and identify topics missing from each domain (Grant & Davis, 1997).

Content validity was quantified using the procedures described by Lynn (1986).

The content validity index (CVI), or the proportion of experts endorsing an item

compared to the total number of experts, was computed for relevance to domain

assignment. If a different domain was selected by the expert than the domain the item

was originally intended, their relevance rating was considered to be 1, indicating not

relevant, regardless of their response. This was to ensure that the relevance ratings

reflected the particular domain that the item was intended to measure. With seven

experts, at least six needed to endorse an item to achieve a CVI of .86 which is an

acceptable value representative of content validity (Lynn, 1986). Because of the

interrelatedness of QOL domains, experts occasionally assigned more than one domain to

a single item. In these circumstances, the domain most consistent with other experts was

included in the computation. Items with a relevance ratings of 3 (relevant) or 4 (very

relevant) were considered endorsed by the experts (Waltz & Bausell, 1981).

Of the original 58 items, 34 items had a minimum CVI of .86 for both domain

assignment and relevance, indicating that six out of seven experts agreed. Minor wording

changes were made in the 34 items as suggested by the experts. An additional six items

that had a CVI of .71 were retained due to conceptual importance and reworded

according to expert comments. An additional six items were added based on written

feedback from the experts. Thus a total of 46 items were psychometrically tested (10

physical, 17 psychological, 11 social, and 8 spiritual items). Prior to using the findings

from the HFCQL to test the relationships in the model, psychometric testing was

conducted to determine quality of item distribution and acceptable inter-item and item-to-

total correlations, evidence of acceptable internal consistency and test-retest reliability,

and construct and criterion-related validity. It was presumed that irrelevant or redundant

items would be deleted during item analysis resulting in fewer items. At the end of the

instrument, four domain items and one overall quality of life item were added to assess

for criterion-related validity. These domain items (physical, psychological, social, and

spiritual) and the overall quality of life item are rated on a scale from 1 ("very poor") to 5

("excellent"). The variables of life changes, general health, and mental health were also

used to determine evidence of criterion-related validity. If the HFCQL scale or domain

scales were found to lack evidence of reliability and validity, it was planned that general

health and mental health were to be used in the study as dependent variables representing

generic health-related quality of life.

General Health

General health refers to the caregiver's perception of their overall personal health.

In this study, the variable of general health was used primarily to establish criterion

validity of the proposed HF Caregiver quality of life instrument that was

psychometrically tested in this study. However, if the HFCQL did not have satisfactory

psychometrics, general health would have represented an outcome measure.

Medical Outcomes Study 36-Item Short Form Health Survey – General Health

Subscale. General health was measured by the general health subscale of the Medical

Outcomes Study 36-item Short-Form Health Survey (SF-36). One of the five items of

the general health subscale asks respondents to rate their health on a scale of 1 (excellent)

to 5 (poor) (Ware, 1993). Using a 5-point response scale ranging from 1 (definitely true)

to 5 (definitely false), the other four items asks respondents to compare their health to

others, if they expect their health will get worse, and if they believe their health is

excellent (Ware, 1993). After recoding of appropriate items, the individual items are

summed and transformed to a 0-100 scale so that a higher score is indicative of better

general health perceptions (Ware, 1993).

The SF-36, which consists of eight subscales, was psychometrically tested in a

large sample of 3,445 outpatients (McHorney, Ware, Lu & Sherbourne, 1994). The SF-

36 had evidence of internal consistency reliability and discriminant validity for each of

the eight subscales. The general health subscale had satisfactory internal consistency

reliability (α = .78) and satisfactory correlations between the items and other scales

(McHorney et al., 1994).   The SF-36 general health subscale has shown acceptable

reliability in stroke caregivers (α = .85; .85) (Bakas & Burgener, 2002; Bakas &

Champion, 1999) and HF caregivers (α = .86) (Bakas, Pressler, et al., 2006). The SF-36

general health subscale was chosen as a criterion variable for the HFCQL in this study

because it has been extensively used with evidence of reliability and validity (Ware,

2000) and measures perceptions of overall personal health, a variable related to quality of

life.

<u>Mental Health</u>

Mental health was conceptually defined as the caregiver's perception of their

mental health, including psychological distress, such as anxiety, depression, loss of

behavioral or emotional control, as well as psychological well-being (Ware &

Sherbourne, 1992). In this study, the variable of mental health was used primarily to

establish criterion validity of the proposed HF Caregiver quality of life instrument that

will be psychometrically tested in this study. However, if the HFCQL did not have

satisfactory psychometrics, mental health would have represented an outcome measure.

<u>Medical Outcomes Study 36-Item Short Form Health Survey – Mental Health

Subscale.</u> Mental health was operationalized by the mental health subscale of the SF-36.

The five items of the mental health subscale asks respondents to rate the frequency of

various emotions on a 6-point response scale of 1 ("all of the time") to 6 ("none of the

time") (Ware, 1993). Emotions include nervousness, feeling down in the dumps, calm

and peaceful, downhearted and blue, and happiness. After recoding of appropriate items,

the individual items are summed and transformed to a 0-100 scale so that a higher score

is indicative of better mental health perceptions (Ware, 1993).

As described above, the SF-36 was psychometrically tested in a large sample of

3,445 outpatients and had evidence of internal consistency reliability and discriminant

validity for each of the eight subscales (McHorney et al., 1994). The mental health

subscale had satisfactory internal consistency reliability ($\alpha = .90$) and satisfactory

correlations between the items and other scales (McHorney et al., 1994). Reports of

internal consistency reliability of the SF-36 mental health subscale in HF family

caregivers have varied. Bakas, Pressler, and colleagues (2006) reported an acceptable α

of .93 with a normal distribution, while Scott (2000) reported α of .42. Both of these

samples were small ($n = 21$ and 18, respectively). Since the SF-36 mental health

subscale has been extensively used with evidence of reliability and validity in other

populations (Ware, 2000), it was chosen as a criterion variable for the HFCQL in this

study.

<center>Data Analysis</center>

The data analysis plan for the study included data screening procedures, a

description of the sample and instruments, and testing of the aims and hypotheses.

Data Screening Procedures

All data entered into SPSS statistical software program (SPSS, Chicago, IL) was

double checked for accuracy of input prior to data analysis. Using univariate descriptive

statistics, out-of-range values, means, standard deviations, and outliers were evaluated as

an additional method of assessing for accuracy of input (Tabachnick and Fidell, 2001).

Missing data was assessed and managed according to procedures suggested by

Tabachnick and Fidell (2001). Descriptive statistics were analyzed on all data to assess

for normality, linearity, and homoscedasticity, multicollinearity, and singularity and was

managed as recommended by Tabachnick and Fidell (2001).

Description of Sample and Instruments

To provide a detailed description of the sample and instruments, descriptive

statistics, such as means, standard deviations, and variability for continuous variables,

was examined using SPSS statistical software program (SPSS, Chicago, IL). Descriptive

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statistics for discrete data, such as gender, race, and ethnicity, was summed in the form of frequencies and percents. Internal consistency reliability was estimated using Cronbach's alpha for the MOS social support survey, OCBS difficulty subscale, PPUS-FM, CAS, ACS threat subscale, PHQ-9, BCOS, CSS, and SF-36 general health and mental health subscales. An internal consistency reliability of .70 was considered satisfactory for these instruments (Polit & Beck, 2004).

Specific Aims and Hypotheses

Data analysis for each hypothesis was conducted using SPSS statistical software program (SPSS, Chicago, IL). The level of significance to test the hypotheses was set at $p < .05$. The specific aims, related hypotheses, and data analysis plan for each hypothesis follows.

Specific Aim 1. To evaluate the psychometric properties of the Heart Failure Caregiver Quality of Life scale (HFCQL).

Hypothesis 1a. The HFCQL items demonstrate means close to the midpoint, good variability in relation to the means, floor and ceiling effects less than 10%, and item-to-total correlations greater than or equal to .30 among caregivers of HF patients.

Individual items were analyzed for means close to the midpoint, good variability in relation to the means, floor and ceiling effects, and item-to-total correlations greater than or equal to .30. Interitem correlations were also be assessed to determine how well the items related to each other and therefore, to the concept of quality of life. According to Ferketich (1991), items with average interitem correlations less than .30 may indicate insufficient correlation while items with average interitem correlations greater than .70

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may indicate redundancy. Therefore items with correlations less than .30 or greater than .70 were evaluated for possible irrelevance or redundancy. Corrected item-to-total correlations were also examined. Nunnelly and Bernstein (1994) suggest correlations greater than .30 are satisfactory. Therefore, items with correlations less than .30 were assessed and considered for deletion pending further investigation using exploratory factor analysis.

Hypothesis 1b. The HFCQL scale and potential domains have evidence of internal consistency reliability with Cronbach alphas greater than or equal to .70 among caregivers of HF patients.

Internal consistency reliability was evaluated by a Cronbach's alpha coefficient for the total HFCQL scale and the domains, as determined by factor analysis. A Cronbach's alpha coefficient of .70 was considered acceptable for the total scale and each of the possible domains (Polit & Beck, 2004).

Hypothesis 1c. The HFCQL scale and potential domains have evidence of 2-week test-retest reliability with an intra-class correlation coefficient greater than .60 among caregivers of HF patients.

The stability of the instrument was assessed with 2 week test-retest method (Carmines & Zeller, 1979). Participants were given the HFCQL scale twice, two weeks and correlation between the two scores was computed using the intraclass correlation coefficient (ICC) (Shrout & Fleiss, 1979). An ICC of 0-0.2 indicates slight agreement, 0.21-0.4 indicates fair agreement, 0.41-0.60 indicates moderate agreement, 0-0.61-0.80 indicates substantial agreement, and 0.81-1.0 indicates almost perfect agreement (Landis

& Koch, 1977). An ICC greater than .60 was considered satisfactory for this study, indicating at least substantial agreement between the two scores.

Hypothesis 1d. The HFCQL has evidence of construct validity with factor loadings of .32 and above for the scale or each domain as determined through factor analysis among caregivers of HF patients.

Since quality of life domains are theoretically interrelated and items may overlap, exploratory factor analysis using principal axis factoring with varimax rotation was computed to determine dimensionality of the HFCQL (Netemeyer, Bearden, & Sharma, 2003). The Kaiser-Meyer-Olkin measure and Bartlett's test of sphericity was computed and examined to support the use of factor analysis (Munro, 2001). Eigenvalues and the scree plots were examined; using Cattell's scree test (1966, as cited by DeVillis, 2003), factors that lie above the elbow were retained. The rotated component matrix was examined to determine which items have the highest loading factors on the components, most likely representing the quality of life domains. Individual items were assessed in relation to the other items within the assigned domain for conceptual relevance and consistency. These quality of life domains were labeled accordingly, and item-to-total correlations and Cronbach's alpha were reexamined for the individual domains.

Hypothesis 1e. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of HF caregiver-specific quality of life as measured by the HFCQL scale and potential domains, as determined through factor analysis, in family caregivers of patients with HF, to provide evidence of construct validity.

Using the conceptual model in Figure 1 on page 19 as a guide for order entry of variables, hierarchical multiple regression was employed to further assess construct validity. According to Munro (2001), finding the smallest group of variables that will account for the greatest proportion of variance in the dependent variable is desirable. Tabachnick and Fidell (2001) stated that regression is best when each independent variable is strongly correlated with the dependent variable, but uncorrelated with the other independent variables. Pearson product-moment correlation coefficients were used to screen for potential continuous independent variables and MANOVA univariate F was used to screen for potential discrete independent variables to be entered into the regression equations predicting HFCQL and domains, as determined by factor analysis. Discrete independent variables found to be significant were dummy coded according to procedures outlined by Tabachnick and Fidell (2001) prior to inclusion in the multiple regressions. Only variables with significant values ($p < .05$) with the HFCQL scores and domains were entered into the regression equation.

Caregiver and patient characteristics were entered in step 1 to control for their influence. In step 2, the situation factors of social support, caregiving task difficulty, and uncertainty were entered to determine significant predictors of HFCQL scores and individual domain scores. In step 3, the mediating variable of threat appraisal was entered in step 3 to evaluate its influence on HFCQL scores and individual domain scores. In step 4, depressive symptoms was entered to determine predictability on scores of HFCQL and individual domains. If the HFCQL was found to be unidimensional, the total HFCQL score would serve as the dependent variable and one regression will be computed. If the HFCQL was found to be multidimensional, a separate regression

equation would be computed for each domain. While hierarchical multiple regression

was used to assess construct validity of the HFCQL, this same procedure will be used in

Specific Aim 2 to determine factors associated with HF caregiver-specific quality of life,

as well as life changes, in family caregivers of heart failure patients.

Hypothesis 1f. To show evidence of criterion-related validity, the HFCQL scale

and potential domains are significantly correlated with the BCOS, SF-36 general

health and mental health subscales, and the HFCQL and domain well-being

overall items, among caregivers of HF patients.

Criterion validity of the HFCQL scale was assessed by computing Pearson

product-moment correlation coefficients between the overall HFCQL scale, and

individual domains as determined by factor analysis, and the BCOS, SF-36 general health

and mental health subscales, and individual HFCQL items measuring overall well-being.

The HFCQL has five overall items measuring quality of life, physical well-being,

psychological well-being, social well-being, and spiritual well-being. Based on

dimensionality of the scale as determined by factor analysis, correlations were computed

between the total and dimension score and the respective individual items.

Specific Aim 2. To determine the combination of independent variables that explains

depressive symptoms, life changes, and HF caregiver-specific quality of life in family

caregivers of HF patients using a theoretically based conceptual model.

Hypothesis 2a. Caregiver and patient characteristics, social support, caregiving

task difficulty, uncertainty, perceived control, and threat appraisal explain a

significant amount of variance of depressive symptoms in family caregivers of

patients with HF.

Hypothese 2b. Caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of life changes in family caregivers of patients with HF.

Hypothesis 2c. Caregiver and patient characteristics, social support, task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of HF caregiver-specific quality of life as measured by the HFCQL scale and/or domains as determined by psychometric testing in family caregivers of patients with HF.

Pearson product-moment correlation coefficients were computed to determine the strength and significance of correlation between the demographic variables with continuous data, such as caregiver and patient age, caregiver and patient education, length of time in the caregiving role since HF diagnosis, time spent caregiving hours per week, and patient cognitive status and the dependent variables of depressive symptoms, life changes, and HF caregiver-specific quality of life. MANOVA was used for the discrete data of caregiver and patient gender, caregiver and patient race, caregiver and patient ethnicity, perception that income meets needs, employment status, living arrangements, caregiver chronic illnesses, patient co-morbidities, caregiver's perception of the patient's symptoms with activities, and presence of implanted ventricular assist device to examine differences between groups in relation to depressive symptoms, life changes, and HF caregiver-specific quality of life. Some variables were regrouped because of empty cells and unequal group sizes.

Pearson product-moment correlation coefficients were computed for each of the proposed theoretical relationships among the variables of social support, task difficulty, uncertainty, perceived control, threat appraisal, depressive symptoms, life changes, and HF caregiver-specific quality of life, in the conceptual model to determine their strength and direction.

Three hierarchical multiple regression equations were employed to determine best predictors of depressive symptoms, life changes, and HF caregiver-specific quality of life. An additional four more hierarchical multiple regression equations were employed to determine the best predictors of the four domains of HF caregiver-specific quality of life. Only variables with significant Pearson r's or univariate F's with depressive symptoms, life changes, or HF caregiver-specific quality of life, were entered into the regression equations. Demographic variables were entered in step 1 to control for their influence. In step 2, the situation factors of social support, caregiving task difficulty, uncertainty, and control were entered and in step 3, the mediating variable of threat appraisal was entered in the regression equation. To test hypotheses 2b and 2c, depressive symptoms was entered in step 4.

4. RESULTS

This chapter begins with a description of data cleaning procedures which are necessary to ensure an honest analysis of the data (Tabachnick & Fidell, 2001). Results obtained from the instruments measuring the variables in the conceptual model (see Figure 1, page 20) were examined. Descriptions of the sample and instruments are then provided, followed by results pertaining to the specific aims and hypotheses.

Data Cleaning Procedures

Data, which were collected by telephone interviews with 100 family caregivers of chronic heart failure patients, were coded with a subject identification number and entered into SPSS statistical software program (SPSS, Chicago, IL). All data were double-checked for accuracy of input and corrected accordingly. As an additional method of assessing for accuracy of input, out-of-range values, means, standard deviations, and outliers were evaluated using univariate statistics (Tabachnick & Fidell, 2001). No procedures were needed to manage missing data as it was minimal, as noted in Tables 1 and 2. One caregiver did not know the patient's educational level or if they had a history of a myocardial infarction or stroke.

Normality was assessed with all dependent and independent variables using the statistical test Kolmogorov-Smirnov (K-S) with a significance level of $p < .001$ (Mertler & Vannatta, 2005). The only variables found to have a significant K-S value were patient cognitive status, HFCQL social domain, and time spent caregiving (hours/week). As noted by histograms, time spent caregiving was positively skewed, while patient cognitive status and quality of life social domain were negatively skewed. Once the negatively skewed variables were reflected to positive skewness, square root and

logarithmic transformations were computed in SPSS (SPSS, Chicago, IL) for all three variables, as recommended by Tabachnick and Fidell (2001). For all three variables, the most ideal transformation was square root. Skewness and kurtosis were reduced for all three variables with this transformation. Therefore, the transformed values, as well as original nontransformed values, were used in statistical computations. However, the outcome was the same for these two values and it was decided to retain the original nontransformed values for all statistical analyses. Further assumptions for normality, homoscedasticity, multicollinearity, and singularity were evaluated prior to analyzing regression equation findings, which are discussed with the regression findings. The Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity were computed for the HFCQL items and found to support the use of factor analysis (Munro, 2001); specifics are discussed with the factor analysis findings.

Prior to screening discrete variables for possible inclusion as independent variables in the regression equations, some variables were regrouped due to empty cells and unequal group sizes. Caregiver and patient race were collapsed from five categories to two: 1) white or 2) black or African American. Caregiver relationship with the patient was collapsed from six categories to three: 1) spouse, 2) son, son in-law, daughter, or daughter in-law, or 3) other relative or friend. Employment status was collapsed from six categories to two: 1) employed full- or part-time, or 2) homemaker, retired, unemployed, or disabled. Living arrangements was collapsed from three groups to two: 1) house, or 2) apartment or assisted living facility.

To recruit the sample of 100 HF family caregivers for this study, 273 study packets were either mailed by the researcher or distributed by the registered nurses at the recruitment site to the HF patient or family caregiver. The researcher was unable to make contact with 33 (12%) of these patients or caregivers to determine their eligibility for the study; the packet was returned or the phone was disconnected for 21 (7.7%) patients or caregivers and the researcher was unable to reach 12 (4.4%) patients or caregivers by phone after multiple attempts. Fifty-three caregivers were not interested or too busy to participate in the study, resulting in a refusal rate of 19.4%. The remaining 187 potential subjects were screened for eligibility. Reasons for ineligibility ($n = 87$) included no family caregiver ($n = 49$, 56%), patient deceased ($n = 20$, 23%), patient institutionalized ($n = 12$, 14%), patient did not have chronic HF ($n = 4$, 5%), and caregiver unable to hear on the phone ($n = 2$, 2%). The sample of 100 was recruited from private cardiologist offices (59%), inpatient cardiac units (34%), and outpatient heart failure clinics (7%) located at three hospitals, Research Medical Center, St. Luke's Hospital, and Menorah Medical Center, all in the greater Kansas City area.

Caregiver and patient age and education are displayed in Table 1. The caregivers' ages ranged from 21 to 91years with a mean age of 62.6, while the patients' ages ranged from 26 to 92 years with a mean of 72.5. Overall, the caregivers had a higher level of education with a mean of 13.8 years (range 7 to 24) than the patients who had a level of education with a mean of 12.5 years (range 6 to 24). The duration and frequency of caregiving are in Table 1. The number of months of providing care varied in the sample with a range of 1 month to 264 months; the mean was 51.1 and median was 31.5. Hours

per week of providing care varied greatly too, with a range of 1 hour to 140 hours; the mean was 25.1 hours and the median was 14.

Table 1

Caregiver and patient age and education and caregiving duration and frequency

Characteristic	*n*	Mean (SD)	Median	Range
Caregiver age	100	62.6 (13.3)	62	21-91
Patient age	100	72.5 (13.25)	74	26-92
Caregiver education	100	13.8 (2.43)	13	7-24
Patient education	99	12.5 (2.8)	12	6-24
Number of months of providing care	100	51.1 (56.38)	31.5	1-264
Hours per week of providing care [a]	100	25.1 (31.5)	14	1-140

[a] Significant non-normality using one-sample Kolmogorvov-Smirnov *Z* tests ($p < .001$).

Caregiver and patient gender, ethnicity, and race are displayed in Table 2. The majority of the sample of caregivers was female (89%), who provided care mostly for males (68%). Both the caregivers and patients were primarily non-hispanic or latino, 98% and 99% respectively. The majority of caregivers in this sample were white (73%), as were the patients (74%).

Table 2

Caregiver and patient gender, ethnicity, and race

Characteristic	*n*	*f* (%)
Caregiver gender	100	
Male		11 (11%)
Female		89 (89%)
Patient gender	100	
Male		68 (68%)
Female		32 (32%)
Caregiver ethnicity	100	
Hispanic or Latino		2 (2%)
Not Hispanic or Latino		98 (98%)

Characteristic	n	f (%)
Caregiver race	100	
American Indian or Alaska Native		1 (1%)
Black or African American		26 (26%)
White		73 (73%)
Patient ethnicity	100	
Hispanic or Latino		1 (1%)
Not Hispanic or Latino		99 (99%)
Patient race	100	
Black or African American		26 (26%)
White		74 (74%)

Caregiver relationship to patient, living arrangements, household income, employment status and job change are shown in Table 3. Most of the caregivers were spouses (62%) of the patients, while 26% were sons or daughters. The remainder of caregivers was son-in-law or daughter-in-law (2%), mother (1%), brother (1%), cousin (1%), niece (1%), grandson (1%), or friends (5%) of the patient. Caregivers perceived that the patients had symptoms, such as shortness of breath or fatigue, with moderate activity (37%), minimal activity (35%), and at rest (28%). Eighty-six percent of the caregivers lived with the patient. The majority of patients lived in a house (84%), while smaller percentages lived in an apartment (12%) or assisted living facility (4%).

Table 3

Caregiver relationship to patient, patient symptoms with activity, living arrangements, household income, employment status and job change

Characteristic	n	f (%)
Caregiver Relationship to Patient	100	
Spouse		62 (62%)
Son or daughter		26 (26%)
Son in-law or daughter in-law		2 (2%)
Mother		1 (1%)
Brother		1 (1%)
Cousin		1 (1%)
Niece		1 (1%)
Grandson		1 (1%)
Friend		5 (5%)

Characteristic	*n*	*f* (%)
Caregiver perception of patient symptoms with activity	100	
No symptoms with activity		0 (0%)
Symptoms with moderate activity		37 (37%)
Symptoms with minimal activity		35 (35%)
Symptoms at rest		28 (28%)
Living Arrangements		
Caregiver living with patient	100	
Yes		86 (86%)
No		14 (14%)
Patient living in	100	
House		84 (84%)
Apartment		12 (12%)
Assisted living facility		4 (4%)
Household income	100	
Comfortable		55 (55%)
Just enough to make ends meet		33 (33%)
Not enough to make ends meet		12 (12%)
Caregiver employment status	100	
Employed full-time		33 (33%)
Employed part-time		14 (14%)
Homemaker		8 (8%)
Retired		38 (38%)
Unemployed		2 (2%)
Disabled		5 (5%)
Caregiver changed jobs to provide care	100	
Yes		17 (17%)
No		83 (83%)

Household income and caregiver employment status are also displayed in Table 3.

The majority of family caregivers described their household income as comfortable

(55%), while 33% indicated they had just enough to make ends meet and 12% indicated

they did not have enough to make ends meet. Most of the caregivers were retired (38%)

or employed full-time (33%); only 17% indicated they had changed jobs to provide care.

As shown in Table 4, overall, the caregivers in this study had a minimal number

of co-morbidities as reflected by a mean of 2.1 co-morbidities, with a range of 0 to 8

from a list of 14 possible co-morbidities, as listed in Table 5. The patients' number of

co-morbidities was higher, as indicated by a mean of 5.3, with a range of 2 to 9 from a

list of 14 possible illnesses.

Table 4

Descriptives of the number of caregiver and patient co-morbidities

Characteristic	n	Mean (SD)	Median	Range
Caregiver co-morbidities	100	2.1 (1.62)	2.0	0-8
Patient co-morbidities	99	5.3 (1.73)	5.0	2-9

The frequencies of each chronic illness for both caregivers and patients are

represented in Table 5. For caregivers, the four most commonly reported chronic co-

morbidities were osteoarthritis (57%), hypertension (47%), ulcer disease (29%), and

diabetes (17%). For the patients, the four most commonly reported co-morbidities were

heart failure (100%), which was an eligibility requirement for the caregiver to be in the

study, hypertension (72%), myocardial infarction (62%), and osteoarthritis (59%).

Table 5

Frequencies of caregiver and patient co-morbidities

Co-morbidities	Caregiver		Patient	
	n	f (%)	n	f (%)
Heart failure	100	2 (2%)	100	100(100%)
Myocardial infarction	100	5 (5%)	99	62 (62%)
Stroke	100	6 (6%)	99	27 (27%)
Peripheral vascular disease	100	11 (11%)	100	58 (58%)
Hypertension	100	47 (47%)	100	73 (73%)
Diabetes	100	17 (17%)	100	49 (49%)
Cancer	100	1 (1%)	100	1 (1%)
Osteoarthritis	100	57 (57%)	100	59 (59%)
Connective tissue disease	100	2 (2%)	100	1 (1%)

Co-morbidities	Caregiver		Patient	
	n	*f* (%)	*n*	*f* (%)
Pulmonary disease (COPD or asthma)	100	15 (15%)	100	23 (23%)
Renal disease	100	2 (2%)	100	18 (18%)
Ulcer disease	100	29 (29%)	100	28 (28%)
Chronic hepatitis or cirrhosis	100	0 (0%)	100	0 (0%)
Alzheimer disease or other dementia	100	0 (0%)	100	9 (9%)

Instruments

Descriptive statistics for instruments measuring the independent variables of cognitive status, social support, task difficulty, uncertainty, perceived control, and threat appraisal are presented in Table 6. In this sample, the caregivers perceived that the patients had a high cognitive status level, as measured by the CSS. The mean was 37.4 with an actual range of 25 to 40, from a possible range of 8 to 40.

Caregiver's perception of social support, as measured by the MOS, was fairly high. The mean was 75.9 (natural midpoint 57) with an actual range of 26 to 95, from a possible range of 19 to 95. Overall, caregivers perceive their tasks to be minimally difficult, as measured by the OCBS. The mean was 23.3 (natural midpoint 45), with an actual range of 15 to 51, from a possible range of 15 to 75. In this sample, caregivers are more certain than uncertain, as determined by a mean of 77.8 on the PPUS-FM (natural midpoint of 90). The actual range was 42 to 126, from a possible of range of 30 to 150. With the CAS, overall caregivers had a moderate level of perceived control. The mean was 16.6 (natural midpoint 16) with an actual range of 4 to 27, from a possible range of 4 to 28. However, these results should be interpreted cautiously, as the Cronbach's alpha did not meet with .70 level. Caregivers appraise their situation as minimally to moderately threatening, as measured by the ACS. The mean was 32.2 (natural midpoint

36) with an actual range of 12 to 58, from a possible range of 12 to 60. With the

exception of the CAS, which measures perceived control, all scales had satisfactory

Cronbach's alpha (.76 to .96), supporting internal consistency reliability. Since the CAS

had a Cronbach's alpha of .63, the variable perceived control was not used in further data

analyses.

Table 6

Descriptive statistics for instruments measuring independent variables

Instrument	No. of items	*n*	Mean (SD)	Median	Actual range (Possible range)	Cronbach's alpha
Cognitive status (CSS) [a]	8	100	37.4 (3.25)	38	25-40 (8-40)	.76
Social support (MOS)	19	100	75.9 (17)	18	26-95 (19-95)	.96
Caregiving task difficulty (OCBS)	15	100	23.3 (8.03)	22	15-51 (15-75)	.86
Uncertainty (PPUS-FM)	30	100	77.8 (17.08)	77.5	42-126 (30-150)	.87
Perceived control (CAS)	4	100	16.6 (27.18)	16	4-27 (4-28)	.63
Threat appraisal (ACS)	12	100	32.2 (10.64)	31	12-58 (12-60)	.93

[a] Significant non-normality using one-sample Kolmogorvov-Smirnov *Z* tests ($p < .001$).

Descriptive statistics for instruments measuring the dependent variables of

depressive symptoms and life changes and the criterion variables of general health and

mental health are presented in Table 7. Overall the sample experienced no to minimal

depressive symptoms, as measured with the PHQ-9. The mean was 4.2, with an actual

range of 0 to 19, from a possible range of 0 to 27. The suicide protocol was triggered by

three caregiver, but it was determined that no suicidality existed. Caregivers in this

sample perceive their life has changed for the worse, as indicated with the BCOS. The

mean was 54.9 (natural midpoint 60) with an actual range of 28 to 67, from a possible

range of 15 to 105. The criterion variables of general health and mental health are also

presented in Table 7. With mean scores of 67.1 and 76.6, the caregivers in this sample

reported moderately high levels of general health and mental health, respectively. The

Cronbach's alpha for all instruments measuring these variables ranged from .78 to .86,

indicating satisfactory internal consistency reliability for these instruments.

Table 7

Descriptive statistics for instruments measuring dependent variables

Instrument	No. of items	n	Mean (SD)	Median	Actual range (Possible range)	Cronbach's Alpha
Depressive symptoms (PHQ-9)	9	100	4.2 (4.33)	3	0-19 (0-27)	.79
Life changes (BCOS)	15	100	54.9 (7.04)	56.5	28-67 (15-105)	.78
General health (GH)	5	100	67.1 (23.21)	72	10-100 (0-100)	.83
Mental health (MH)	5	100	76.6 (17.89)	80	20-100 (0-100)	.86

The descriptive statistics for HF caregiver-specific quality of life and the four

quality of life domains (physical, psychological, social and spiritual), as measured by the

HFCQL scale, are presented in Table 8. These findings are based on the results from

psychometric testing of this instrument in this study. Details concerning psychometric

testing are presented in Specific Aim 1. Eighty-five caregivers participated in the 2-week

test-retest for the purposes of testing reliability of the instrument. The scores from the 2-

week test-retest were very similar to the initial scores (see Table 8), therefore, only the

initial scores are described below.

In general, caregivers in this sample had a moderately high level of overall HF

caregiver-specific quality of life, as reflected with a mean of 61.5 (natural midpoint 48)

98

and actual range of 31 to 80, from a possible range of 16 to 80. All of the domain scores

exceeded the natural midpoint of 12 for the subscales, indicating these caregivers

reported moderately high quality of life in physical, psychological, social, and spiritual

domains. The highest domain score was physical, with a mean of 16.7, and the lowest

was psychological, with a mean of 13.9. The Cronbach's alpha for the initial and 2-week

test-retest instruments measuring overall HF caregiver-specific quality of life and the four

domains ranged from .80 to .90, indicating satisfactory internal consistency reliability.

Table 8

Descriptive statistics for instrument measuring HF caregiver-specific quality of life

Instrument	No. of items	n	Mean (SD)	Median	Actual range (Possible range)	Cronbach's Alpha
HF caregiver-specific quality of life (HFCQL)	16	100	61.5 (10.92)	62	31-80 (16-80)	.89
Overall HFCQL retest	16	85	61.5 (11.68)	62	29-80 (16-80)	.91
Physical domain	4	100	16.7 (3.11)	17	5-20 (4-20)	.84
Physical retest	4	85	17.1 (2.95)	18	8-20 (4-20)	.81
Psychological domain	4	100	13.9 (4.05)	14	4-20 (4-20)	.80
Psychological retest	4	85	13.8 (4.20)	14	4-20 (4-20)	.80
Social domain [a]	4	100	16.4 (3.40)	17	6-20 (4-20)	.86
Social retest	4	85	16.3 (3.56)	15	4-20 (4-20)	.87
Spiritual domain	4	100	14.6 (4.03)	15	4-20 (4-20)	.90
Spiritual retest	4	85	14.4 (3.82)	15	5-20 (4-20)	.90

[a] Significant non-normality using one-sample Kolmogorvov-Smirnov t test ($p < .001$).

This concludes the description of the data cleaning procedures, sample and instruments. The research findings associated with the specific aims and hypotheses are presented next.

<div align="center">Specific Aims and Hypotheses</div>

Specific Aim 1. To evaluate the psychometric properties of the Heart Failure Caregiver Quality of Life scale (HFCQL).

Hypothesis 1a. The HFCQL items demonstrate means close to the midpoint, good variability in relation to the means, floor and ceiling effects less than 10%, and item-to-total correlations greater than or equal to .30 among caregivers of HF patients.

Hypothesis 1a was partially met. The results presented in Tables 9, 10, 11 and 12 are based on 16 items retained from factor analysis with a four factor solution, representing the physical, psychological, social, and spiritual domains of quality of life. The factor analysis procedures are discussed in detail for Hypothesis 1d. Further analyses deemed that the 16-item HFCQL scale had satisfactory item-to-total correlations and Cronbach's alpha when used to measure overall HF caregiver-specific quality of life; these results are presented in Table 13. The 16-item HFCQL scale can be found in Appendix G.

The findings relevant to the physical domain of the HFCQL scale are presented in Table 9. These four items demonstrated means close to the midpoint and good variability in relation to the means. Inter-item correlations ranged from .45 to .70 and inter-item correlation averages ranged from .51 to .60 indicating sufficient correlation but not redundancy (Ferkitich, 1991). Item-to-total correlations ranged from .60 to .71

supporting satisfactory correlation (Nunnelly & Bernstein, 1994). However, ceiling effects exceeded 10% for all four items. In comparison to the other domain subscales, the physical items' ceiling effects were the highest with a range from 37 to 49%. The floor effects were less than 10% with a range of 1% to 3%.

Table 9

Item statistics for the HFCQL physical domain

Items	Mean (SD) Range	Strongly Agree f (%) Ceiling	Strongly Disagree f (%) Floor	Item-to-total Correlations	Alpha if Deleted [a]
Sick more often	4.34 (.82) 1-5	49 (49%)	1 (1%)	.60	.83
Physical health suffered	3.96 (1.08) 1-5	38 (38%)	2 (2%)	.71	.78
Exercise	4.05 (.99) 1-5	37 (37%)	2 (2%)	.70	.78
Dr. appointments	4.31 (.88) 1-5	48 (48%)	3 (3%)	.70	.78

[a] Cronbach's alpha for total physical domain subscale was .84.

The HFCQL psychological domain findings are presented in Table 10. These four items demonstrated means close to the midpoint and good variability in relation to the means. Inter-item correlations ranged from .30 to .62 and inter-item correlation averages ranged from .42 to .56 indicating sufficient correlation but not redundancy (Ferkitich, 1991). Item-to-total correlations ranged from .48 to .70 supporting satisfactory correlation (Nunnelly & Bernstein, 1994). Ceiling effects, ranging from 25% to 38%, exceeded the 10% hypothesized. The item concerning feeling tired had a floor effect of 11%, otherwise the other three items were below 10%.

Table 10

Item statistics for the HFCQL psychological domain

Items	Mean (SD) Range	Strongly Agree f (%) Ceiling	Strongly Disagree f (%) Floor	Item-to-total Correlations	Alpha if Deleted [a]
Overwhelmed	3.63 (1.14) 1-5	25 (25%)	4 (4%)	.70	.71
Feel selfish	3.43 (1.31) 1-5	25 (25%)	7 (7%)	.48	.81
Tired	3.13 (1.40) 1-5	25 (25%)	11 (11%)	.60	.76
Strained emotionally	3.69 (1.27) 1-5	38 (38%)	2 (2%)	.69	.71

[a] Cronbach's alpha for total psychological domain subscale was .80.

The findings pertaining to the HFCQL social domain are displayed in Table 11. The items demonstrated means close to the midpoint with good variability in relation to the means. Inter-item correlations ranged from .53 to .72; the items concerning religious activities and enjoyable activities were highly correlated at .72. Average inter-item correlations ranged from .58 to .67 supporting sufficient correlation without much redundancy (Ferkitich, 1991). Item-to-total correlations ranged from .65 to .78 supporting satisfactory correlation (Nunnelly & Bernstein, 1994). Ceiling effects were fairly high for this subscale, ranging from 32% to 48%, which exceeded the 10% hypothesized. The floor effects were acceptable with ranges from 1% to 5%.

Table 11

Item statistics for the HFCQL social domain

Items	Mean (SD) Range	Strongly Agree f (%) Ceiling	Strongly Disagree f (%) Floor	Item-to-total Correlations	Alpha if Deleted [a]
Socially isolated	3.95 (1.23) 1-5	43 (43%)	5 (5%)	.71	.84
Participate in enjoyable activities	3.96 (1.01) 1-5	32 (32%)	2 (2%)	.78	.80

Items	Mean (SD) Range	Strongly Agree f (%) Ceiling	Strongly Disagree f (%) Floor	Item-to-total Correlations	Alpha if Deleted [a]
Personal relationship with others	4.21 (.81) 1-5	38 (38%)	1 (1%)	.77	.81
Religious activities	4.26 (.94) 1-5	48 (48%)	1 (1%)	.65	.86

[a] Cronbach's alpha for total social domain subscale was .86.

The HFCQL spiritual domain findings are displayed in Table 12. With item means close to the midpoint, there was good variability in relation to the means. Inter-item correlations ranged from .65 to .75; the items concerning inner peace and meaning to life were highly correlated at .75. Average inter-item correlations ranged from .67 to .70 indicating sufficient correlation with minimal redundancy (Ferkitich, 1991). The item-to-total correlations were satisfactory with a range from .75 to .80 (Nunnelly & Bernstein, 1994). In comparison to other domains, the ceiling effects for this subscale were the lowest; however, they still exceeded 10% as stated in the hypothesis, with a range of 25% to 28%. The floor effects were acceptable with ranges from 4% to 7%.

Table 12

Item statistics for the HFCQL spiritual domain

Items	Mean (SD) Range	Strongly Agree f (%) Ceiling	Strongly Disagree f (%) Floor	Item-to-total Correlations	Alpha if Deleted [a]
Purpose/mission	3.71 (1.12) 1-5	28 (28%)	6 (6%)	.76	.87
Inner strength	3.72 (1.10) 1-5	27 (27%)	4 (4%)	.75	.88
Inner peace	3.62 (1.17) 1-5	27 (27%)	4 (4%)	.78	.87
Meaning to life	3.51 (1.21) 1-5	25 (25%)	7 (7%)	.80	.86

[a] Cronbach's alpha for total spiritual domain subscale was .90.

Once the HFCQL domain items were evaluated as described above, additional analyses were conducted for the overall 16-item HFCQL to examine inter-item averages and item-to-total correlations. Since the item statistics (mean, standard deviation, range, ceiling effects, and floor effects) are the same for the total HFCQL scale as for the domain subscales, only the item-to total and alpha if deleted statistics are presented in Table 13. Average inter-item correlations ranged from .27 to .52 for these 16 items. These values are lower than those reported for the individual domains, which supports the multi-dimensional nature of quality of life. However, only two items had average inter-item correlations slightly less than .30, suggesting the majority of these items had satisfactory correlations (Ferkitich, 1991). Likewise, the item-to-total correlations ranged from .39 to .74 which supports satisfactory correlations between the items and the total scale (Nunnelly & Bernstein, 1994).

Table 13

Item-to-total correlations and alpha if deleted statistics for the overall HFCQL

Items	Item-to-total Correlations	Alpha if Deleted [a]
Sick more often	.51	.89
Physical health suffered	.73	.88
Exercise	.64	.88
Dr. appointments	.59	.89
Overwhelmed	.56	.89
Feel selfish	.42	.89
Tired	.62	.88
Strained emotionally	.74	.88
Socially isolated	.62	.88
Participate in enjoyable activities	.69	.88

Items	Item-to-total Correlations	Alpha if Deleted [a]
Personal relationship with others	.55	.89
Religious activities	.53	.89
Purpose/mission	.39	.89
Inner strength	.39	.89
Inner peace	.49	.89
Meaning to life	.45	.89

[a] Cronbach's alpha for total spiritual domain subscale was .89.

In summary, hypothesis 1a was partially met. The HFCQL items demonstrated means close to the midpoint and good variability in relation to the means. Item-to-total correlations were greater than or equal to .30 among the caregivers of HF patients for all items in the individual domains as well as the total HFCQL. It was hypothesized that floor and ceiling effects would be less than 10%. In this sample, all 16 items had ceiling effects greater than 10% and one item had floor effects greater than 10%.

Hypothesis 1b. The HFCQL scale and potential domains have evidence of internal consistency reliability with Cronbach's alphas greater than or equal to .70 among caregivers of HF patients.

Hypothesis 1b was met. As noted in Table 7, the overall HFCQL scale and the four domain scales had Cronbach's alphas of .80 to .90 providing evidence of internal consistency reliability in this sample of HF caregivers (Polit & Beck, 2004).

Hypothesis 1c. The HFCQL scale and potential domains have evidence of 2-week test-retest reliability with an intra-class correlation coefficient greater than .60 among caregivers of HF patients.

Hypothesis 1c was met. The HFCQL was administered a second time, two weeks later, to 85 subjects. Reasons for not participating in the 2-week test-retest included

researcher unable to reach caregiver at 2-week time frame (*n* = 8, 53%), patient

hospitalized (*n* = 4, 27%), patient expired (*n* = 2, 13%), and caregiver declined (*n* = 1,

7%). The overall HFCQL and all four domains demonstrated substantial stability with

intraclass correlation coefficients (ICC). The overall HFCQL ICC was the highest at .83,

suggesting almost perfect agreement. The physical, psychological, social, and spiritual

domain ICC values were .76, .70, .72, and .76, respectively, suggesting substantial

agreement.

Hypothesis 1d. The HFCQL has evidence of construct validity with factor

loadings of .32 and above for the scale or each domain as determined through

factor analysis among caregivers of HF patients.

Hypothesis 1d was met. Prior to examining factor analysis with the 46 items in

the pool of items for the HFCQL, the Kaiser-Meyer-Olkin measure of sampling adequacy

was computed and found to be .85. According to Kaiser (1974, as cited in Munro, 2001),

values in the .80s range are considered meritorious, thereby supporting the use of factor

analysis. Likewise, Bartlett's test of sphericity was computed and found to have a

significance level of .000, which indicates the correlation matrix is suitable for factor

analysis (Munro, 2001).

Preliminary analyses of means, standard deviations, ranges, average inter-item

correlations, and item-total correlations were conducted with all 46 items in the pool for

the HFCQL. Only one item had a mean less than 3 (worry, 1.8); all others ranged from

3.1 to 4.5. The standard deviations ranged from .73 to 1.86 and indicated good variability

in relation to the means. Most of the items ranged from 1 to 5 with the exception of three

items, able to cope, anxious, and able to care for physical needs, which ranged from 2 to

5. Most of the items had satisfactory average inter-item correlations from .30 to .70; 15 of the 46 items had average inter-item correlations less than .30 and none exceed .70. Only two items had item-total correlations less than .30, worry and eat healthy. Even though some of the items in the original pool did not meet the criteria in hypothesis 1a, it was decided to keep all items in factor analysis since it was posited that the HFCQL may be multidimensional. Findings from the item analyses were utilized when determining which items to eliminate.

Exploratory factor analysis using principle axis factoring with varimax rotation was computed to determine the dimensionality of the HFCQL scale (Netemeyer et al., 2003). According to the eigenvalues, there were 10 factors greater than 1.0 but the scree plot suggested a possible three or four factor solution. Exploratory factor analysis was computed with extractions for three and four factors. The three factor solution accounted for 52.7% variance, while the four factor solution accounted from 56.7% variance. Since the HFCQL was developed with items that could potentially measure the four domains of quality of life, the four factor solution was examined closer.

Items with factor loadings .32 and greater, which suggest satisfactory loading (Tabachnich & Fidell, 2001), are depicted in Table 14. One item, worry, did not have satisfactory loading on any factors, and therefore, was eliminated from further analysis, resulting in 45 items in the initial analysis. Twenty-three items loaded on a single factor, 18 items loaded on two factors, and four items loaded on three factors. The 22 items that loaded on more than one factor were examined for highest loading and conceptual consistency and placed with the most appropriate factor to represent quality of life domains (Table 14). Two items presumed to be on the physical domain, strained

physically and body aches and pains, did not load on Factor IV, the physical domain, and

were eliminated from further analysis, reducing the pool to 43 items.

Table 14

Factor analysis for pool of items for the HFCQL scale

HFCQL item	Factor I [a]	Factor II [b]	Factor III [c]	Factor IV [d]
Psychological				
3. Feel guilty	.37			
4. Able to cope	.44			
5. Overwhelmed	.70			
7. Manipulated	.48	.48		
8. Selfish	.46			
14. Tired	.65			
18. Depressed	.70		.35	
19. More sad than usual	.60	.33		.35
20. Feel down in dumps	.62			
21. Stressed	.74			.33
22. Angry	.55			
23. Anxious	.55			
24. Strained emotionally	.78			
25. Cry a lot	.45	.32		.39
28. Life passing by	.60	.53		
33. Good night's sleep	.55			
34. Control	.45	.62		
Social				
9. Supported by providers		.53		
10. Supported by friends		.37		
11. Supported by family		.42		
12. Spiritual needs met		.62		
13. Good relationship w/patient		.39	.34	
26. Socially isolated	.53	.56		
27. Financial problems	.43	.37		
35. Participate in enjoyable activities	.43	.63		
36. Time with friends	.40	.57		
37. Okay financially	.39	.49		
38. Personal relationship with others	.36	.71		
39. Religious activities	.37	.61		
40. Time for family	.46	.62		.37
Spiritual				
41. Purpose/mission			.75	
42. Inner strength			.81	
43. Inner peace			.83	
44. Blessing to me			.82	
45. Happy			.85	
46. Adds meaning to life			.83	
Physical				
1. Sick more often	.39			.39
2. Eat healthy				.48

HFCQL item	Factor I [a]	Factor II [b]	Factor III [c]	Factor IV [d]
15. Physical health suffered	.67			.40
16. Strained physically	.72			
17. Body aches and pains	.65			
29. Able to care for physical needs		.48		.62
30. Time for health problems		.47		.67
31. Exercise	.49			.49
32. Able to go to Dr. appointments	.32	.49		.64

[a] Factor I eigenvalue = 17.5, 38.1% of the variance; [b] Factor II eigenvalue = 4.4, 9.7% of the variance; [c] Factor III eigenvalue = 2.3, 5% of the variance; [d] Factor IV eigenvalue = 4 = 1.8, 4% of the variance.

Inter-item and item-total correlations were examined for all items remaining within each factor. Items with consistent inter-item correlations less than .30 were eliminated from the pool as they did not demonstrate satisfactory correlation within the factor (Ferkitich, 1991). Items with inter-item correlations greater than .70 suggest redundancy (Ferkitich, 1991) and therefore, were examined for possible eliminations. These eliminations resulted in 20 items remaining in the pool across four factors, the physical (4 items), psychological (8 items), social (4 items), and spiritual (4 items) domains of quality of life.

With these 20 remaining items, exploratory factor analysis using principle axis factoring and varimax rotation was computed which resulted in a four factor solution, accounting for 69.4% variance. However, it was noted that four items in the psychological domain had high cross-loadings on more than one factor; these were eliminated from further analysis. The same factor analysis procedure was computed again with these 16 items (see Table 15). While some items loaded on more than one factor, the highest loading is consistent with domains as conceptualized in the development of the HFCQL scale, with the exceptions of two items, religious activities and tired. To see if the scale could be used as an overall score, the same factor analysis procedures were followed again with all 16 items and one factor forcing. Factor loadings

ranged from .31 (one item only) to .78 providing construct validity for the overall

HFCQL scale, suggesting an overall HFCQL score could be used.

Table 15

Factor analysis for 16-item HFCQL scale

HFCQL item	Factor I [a]	Factor II [b]	Factor III [c]	Factor IV [d]
Social				
26. Socially isolated	.64		.35	
35. Participate in enjoyable activities	.78			.33
38. Personal relationship with others	.68			
39. Religious activities	.79			.35
Spiritual				
41. Purpose/mission		.82		
42. Inner strength		.81		
43. Inner peace		.82		
46. Adds meaning to life		.84		
Psychological				
5. Overwhelmed			.80	
8. Feel selfish			.51	
14. Tired			.56	
24. Strained emotionally			.67	.32
Physical				
1. Sick more often				.62
15. Physical health suffered			.38	.70
31. Exercise	.36		.34	.58
32. Able to go to Dr. appointments	.45			.59

[a] Factor I eigenvalue = 6.5, 40.6% of the variance; [b] Factor II eigenvalue = 2.9, 17.9% of the variance; [c] Factor III eigenvalue = 1.2, 7.8% of the variance; [d] Factor IV eigenvalue = 1.0, 6.1% of the variance.

In summary, hypothesis 1d is met. As a four factor scale, the 16 items in the

HFCQL have factor loadings exceeding the criteria of .32 as established by Tabachnick

and Fidell (2001). Factor I (social domain) had factor loadings ranging from .64 to .79.

Factor II (spiritual domain) had factor loadings ranging from .81 to .84. Factor III

(psychological domain) had factor loadings ranging from .51 to .80. Factor IV (physical

domain) had factor loadings ranging from .58 to .70. Forcing one factor with all 16 items

resulted in loadings of .31 (one item only, purpose/mission) to .78.

Hypothesis 1e. Caregiver and patient characteristics, social support, task

difficulty, uncertainty, perceived control, threat appraisal, and depressive

symptoms explain a significant amount of variance of HF caregiver-specific

quality of life as measured by the HFCQL scale and potential domains, as

determined by psychometric testing, in family caregivers of patients with HF, to

provide evidence of construct validity.

Hypothesis 1e was partially met as evidenced by findings from hierarchical

multiple regressions of HFCQL and the four domains, as determined by factor analysis.

Prior to computing these regressions, Pearson r was used to screen for potential

continuous independent variables (see Tables 16 and 17) and MANOVA univariate F

(see Tables 18 and 19) was used to screen for potential discrete independent variables to

be entered into the regression equations predicting HFCQL and domains. The discrete

independent variables caregiver household income and patient symptoms with activity

were both dummy coded according to procedures outlined by Tabachnick and Fidell

(2001) prior to inclusion in the multiple regressions. Only variables with significant

values ($p < .05$) with the HFCQL scores and domains were entered into the regression

equation. Since the CAS did not have acceptable internal consistency reliability ($\alpha =$

.63), perceived control was not used in these regression equations.

Caregiver age was found to be significantly correlated ($r = .28$, $p < .01$) with the

psychological domain and time spent caregiving was significantly inversely related to the

social domain ($r = -.28$, $p < .01$) (see Table 16). These variables were entered into the

regression equations accordingly.

Table 16

Screening for continuous caregiver characteristics for regression to evaluate construct validity of HFCQL and domains using Pearson r

HFCQL and domains	Age	Education	Number of co-morbidities	Length of time caregiving	Time spent caregiving
Overall HFCQL	.10	-.10	-.07	.01	-.17
Physical Domain	.06	.00	-.15	-.01	-.16
Psychological Domain	.28**	-.09	.02	-.07	-.13
Social Domain	-.04	-.02	-.01	.05	-.28**
Spiritual Domain	-.01	-.16	-.09	.07	.01

*p < .05; **p < .01; ***p < .001.

As shown in Table 17, the patient's cognitive status was significantly correlated with overall HFCQL ($r = .38$, $p < .001$), and the physical ($r = .29$, $p < .01$), psychological ($r = .37$, $p < .01$), and social domain ($r = .38$, $p < .001$). The transformed value of cognitive status was also examined and found to have no impact in these findings; therefore the original nontransformed values were entered into the regression equations accordingly.

Table 17

Screening for continuous patient characteristics for regression to evaluate construct validity of HFCQL and domains using Pearson r

HFCQL and domains	Age	Education	Number of co-morbidities	Cognitive status
Overall HFCQL	.12	-.02	-.15	.38***
Physical Domain	.18	-.02	-.03	.29**
Psychological Domain	.13	.02	-.15	.37**
Social Domain	-.12	.04	-.19	.38***
Spiritual Domain	.16	-.10	-.08	.11

*p < .05; **p < .01; ***p < .001.

The only discrete caregiver characteristic that was significant was caregiver perception of their household income (see Table 18). With dummy coding, this variable was examined closer. Caregivers' perceptions of household income as being "comfortable" and "just enough to make ends meet" were not associated with significantly different HFCQL or domain scores. However perception that household income was 'not enough to make ends meet' did result in significant different scores in overall HF family caregiver-specific quality of life ($F=5.55$, $p < .05$), and physical ($F=7.54$, $p < .01$), psychological ($F=5.64$, $p < .05$) and social domains ($F=7.64$, $p < .01$). Therefore, household income "not enough to make ends meet" was entered into the regression equations accordingly.

Table 18

Screening for discrete caregiver characteristics for regression to evaluate construct validity of HFCQL and domains using MANOVA univariate F

HFCQL and domains	Gender[a]	Race[b]	Relationship to Patient[c]	Household Income[c]	Employment[a]	Job Change[a]
Overall HFCQL	.27	.23	1.44	5.55*	1.79	2.57
Physical Domain	.63	.01	2.35	7.54**	1.20	2.46
Psychological Domain	1.47	.27	2.47	5.64*	3.50	.97
Social Domain	.34	.22	1.46	7.64**	.12	2.11
Spiritual Domain	.004	.22	2.30	.16	.37	.80

[a]$df(1, 98)$, [b]$df(1, 97)$, [c]$df(2, 97)$
*$p < .05$; **$p < .01$; ***$p < .001$

The only discrete patient characteristic that was significant was caregiver perception of the patient's symptoms with activity (see Table 18). With dummy coding, this variable was examined closer. Symptoms with minimal activity and symptoms at rest were not associated with significantly different HFCQL or domain scores. However symptoms with moderate activity did result in significant different scores in overall

HFCQL ($F = 6.23$, $p < .05$), and psychological ($F = 6.47$, $p < .05$) and social domains ($F = 4.99$, $p < .05$). Therefore, caregiver perception of patient's symptoms with moderate activity was entered into the regression equations accordingly.

Table 19

Screening for discrete patient characteristics for regression to evaluate construct validity of HFCQL and domains using MANOVA univariate F

HFCQL and domains	Gender[a]	Race[a]	Living Setting[b]	Symptoms with Activity[b]
Overall HFCQL	.16	.40	.00	6.23*
Physical Domain	.16	.02	.02	2.72
Psychological Domain	1.79	.39	.02	6.47*
Social Domain	.14	.23	1.47	4.99*
Spiritual Domain	3.36	.35	.90	.98

[a]$df(1, 98)$, [b]$df(2,97)$
*$p < .05$; **$p < .01$; ***$p < .001$

As shown in Table 20, many situational factors, the mediator, and emotional response were significantly correlated with overall HFCQL and domains. These variables were entered into the regression equations accordingly. The transformed value of social domain was also examined; since there was no change in the outcome, the original value was used in the regression equation.

Prior to analyzing regression equation findings of the overall HFCQL, the residuals scatterplot versus the predicted values for the regression equations were inspected and appeared constant suggesting normality. By using Mahalanobis distance with χ^2 of 26.125, *df* of 8, and $p < .001$, no outliers were identified (Tabachnick & Fidell, 2001). Multicollinearity and singularity were not an issue, as only one condition index exceeded 30 with only one variance proportion greater than .50 (Tabachnick & Fidell, 2001).

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Table 20

Screening for continuous situational factors, mediator, and emotional response for regression for construct validity of HFCQL and domains using Pearson r

HFCQL and domains	Social support	Uncertainty	Task difficulty	Threat appraisal	Depressive symptoms
Overall HFCQL	.28**	-.54***	-.61***	-.61***	-.54***
Physical domain	.35**	-.51***	-.56***	-.57***	-.53***
Psychological domain	.15	-.45***	-.62***	-.58***	-.50***
Social domain	.47***	-.54***	-.58***	-.41***	-.41***
Spiritual domain	-.05	-.17	-.12	-.28**	-.20*

* $p < .05$; **$p < .01$; ***$p < .001$.

Patient cognitive status, caregiver perception of income not meeting needs, and caregiver perception of patient symptoms with moderate activity in step 1 accounted for 20% (18% adjusted) of the variance in overall HFCQL [$F(3, 96) = 8.16$, $p < .001$], as shown in Table 21. Caregiving task difficulty, uncertainty, and social support were entered in step 2 and accounted for an additional 29% of the variance [$F(6, 93) = 14.86$, $p < .001$]. Threat appraisal in step 3 accounted for an additional 6% of the variance [$F(7, 92) = 16.04$, $p < .001$]. Depressive symptoms was entered in step 4 of the regression equation and accounted for an additional 4% of the variance [$F(8, 91) = 16.56$, $p < .001$]. The model constructs accounted for 59% of variance of overall HFCQL providing evidence of construct validity. Significant individual predictors of overall HFCQL were caregiving task difficulty, uncertainty, threat appraisal, and depressive symptoms accounting for 4%, 3%, 14%, and 8% unique variance, respectively.

Table 21

Hierarchical multiple regression evaluating construct validity of overall HFCQL

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Cognitive status	.23	.07	.79	.38***	.00
Household income	1.64	.05	.70	.23*	.00
Symptoms with activity	-1.57	-.07	-.96	-.24**	.00

Step 1. $R = .45$; $R^2 = .20$; Adjusted $R^2 = .18$; F Change $(3, 96) = 8.16$***; R^2 Change $= .20$; $F(3, 96) = 8.16$***.

Caregiving task difficulty	-.40	-.30	-3.07**	-.61***	.04
Uncertainty	-.14	-.21	-2.42*	-.54***	.03
Social support	-.03	-.05	-.65	.28**	.00

Step 2. $R = .70$; $R^2 = .49$; Adjusted $R^2 = .46$; F Change $(3, 93) = 17.39$***; R^2 Change $= .29$; $F(6, 93) = 14.86$***.

Threat appraisal	-.20	-.19	-2.06*	-.61***	.14

Step 3. $R = .74$; $R^2 = .55$; Adjusted $R^2 = .52$; F Change $(1, 92) = 12.27$**; R^2 Change $= .06$; $F(7, 92) = 16.04$***.

Depressive symptoms	-.65	-.26	-3.11**	-.54***	.08

Step 4. $R = .77$; $R^2 = .59$; Adjusted $R^2 = .56$; F Change $(1, 91) = 9.64$**; R^2 Change $= .04$; $F(8, 91) = 16.56$***.

*$p < .05$; **$p < .01$; ***$p < .001$.

The residuals scatterplot versus the predicted values for the regression equations of the HFCQL physical domain were inspected and appeared constant suggesting normality. By using Mahalanobis distance with χ^2 of 24.322, df of 7, and $p < .001$, no outliers were identified (Tabachnick & Fidell, 2001). There was only one condition index that exceeded 30 and only one variance proportion greater than .50, so assumptions of collinearity and singularity were met (Tabachnick & Fidell, 2001).

Caregiver perception of income not meeting needs and patient cognitive status were the only two caregiver and patient characteristics that needed to be controlled for (see Table 22). These variables were entered in step 1, accounting for 15% (13% adjusted) of the variance in HFCQL physical domain [$F(2, 97) = 8.47$, $p < .001$].

Caregiving task difficulty, uncertainty, and social support were entered in step 2 and

accounted for an additional 28% of the variance [$F(5, 94) = 14.28, p < .001$]. Threat

appraisal in step 3 accounted for an additional 5% of the variance [$F(6, 93) = 14.45, p <$

.001]. Depressive symptoms was entered in step 4 of the regression equation and

accounted for an additional 4% of the variance [$F(7, 92) = 14.36, p < .001$]. Overall the

model constructs accounted for 52% of variance of HFCQL physical domain providing

evidence of construct validity. Caregiving task difficulty and depressive symptoms were

significant individual predictors of HFCQL physical domain accounting for 5% and 4%

unique variance, respectively.

Table 22

Hierarchical multiple regression evaluating construct validity of HFCQL physical domain

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Caregiver household income	1.04	.11	1.43	.27**	.01
Cognitive status	-.02	-.02	-.25	.29**	.00

Step 1: $R = .39$; $R^2=.15$; Adjusted $R^2=.13$; F Change (2, 97)= 8.47**; R^2 Change = .15; $F(2, 97)=$ 8.47***

Caregiving task difficulty	-.12	-.31	-3.04**	-.56***	.05
Uncertainty	-.03	-.16	-1.68	-.51***	.01
Social support	.01	.06	.71	.33***	.00

Step 2. $R = .66$; $R^2=.43$; Adjusted $R^2=.40$; F Change (3, 94) =15.60; R^2 Change = .28; $F(5, 94)$ =14.28***.

Threat appraisal	-.05	-.18	-1.75	-.56***	.02

Step 3. $R = .70$; $R^2=.48$; Adjusted $R^2=.45$; F Change (1, 93) = 9.15; R^2 Change = .05; $F(6, 93)$ =14.45***.

Depressive symptoms	-.18	-.24	-2.76**	-.53***	.04

Step 4. $R = .72$; $R^2=.52$; Adjusted $R^2= .49$; F Change (1, 92) = 7.64**; R^2 Change = .04; $F(7, 92)=$ 14.36***.

*$p < .05$; **$p < .01$; ***$p < .001$.

The HFCQL psychological domain residuals scatterplot versus the predicted values for the regression equation appeared constant upon inspection, thereby suggesting normality. No outliers were noted by using Mahalanobis distance with χ^2 of 26.125, *df* of 8, and *p* < .001 (Tabachnick & Fidell, 2001). Assumptions of collinearity and singularity were met as there was only one condition index that exceeded 30 and only one variance proportion greater than .50 (Tabachnick & Fidell, 2001).

In step 1 of the regression equation for HFCQL psychological domain, caregiver age, caregiver perception of income not meeting needs, patient cognitive status, and symptoms with moderate activity were entered to control their influence (see Table 23). Together these caregiver and patient characteristics accounted for 24% (21% adjusted) of the variance in overall HFCQL [$F(4, 95) = 7.62$, *p* < .001]. Caregiving task difficulty and uncertainty in step 2 accounted for an additional 23% of the variance [$F(6,93) = 14.12$, *p* < .001]. Threat appraisal in step 3 accounted for an additional 6% of the variance [$F(7,92) = 15.30$, *p* <.001]. Depressive symptoms was entered in step 4 of the regression equation and accounted for an additional 3% of the variance [$F(8, 91) = 15.14$, *p* < .001]. The model constructs accounted for 57% of variance of HFCQL psychological domain which provided evidence of construct validity. Caregiver age, caregiving task difficulty, threat appraisal, and depressive symptoms were significant individual predictors of HFCQL psychological domain accounting for 3%, 6%, 2%, and 3% unique variance, respectively.

Table 23

Hierarchical multiple regression evaluating construct validity of HFCQL psychological domain

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Caregiver age	.05	.17	2.45*	.28***	.03
Caregiver household income	.71	.06	.78	.23*	.00
Cognitive status	.03	.02	.27	.37***	.00
Symptoms with activity	-.64	-.08	-1.03	-.25**	.00

Step 1. $R = .49$; $R^2 = .24$; Adjusted $R^2 = .21$; F Change $(4, 95) = 7.62***$; R^2 Change $= .24$ $F (4,95) = 7.62***$.

Caregiving task difficulty	-.17	-.34	-3.45**	-.62***	.06
Uncertainty	-.02	-.08	-.92	-.45***	.00

Step 2. $R = .69$; $R^2 = .48$; Adjusted $R^2 = .44$; F Change $(2, 93) = 20.79***$; R^2 Change $= .23$; $F(6, 93) = 14.12***$.

Threat appraisal	-.08	-.21	-2.18*	-.58***	.02

Step 3. $R = .73$; $R^2 = .54$; Adjusted $R^2 = .50$; F Change $(1, 92) = 12.18**$; R^2 Change $= .06$; $F(7,92) = 15.30***$.

Depressive symptoms	-.21	-.22	-2.65**	-.50***	.03

Step 4. $R = .76$; $R^2 = .57$; Adjusted $R^2 = .53$; F Change $(1, 91) = 7.03 **$; R^2 Change $= .03$; $F(8, 91) = 15.14***$.

*$p < .05$; **$p < .01$; ***$p < .001$.

The residuals scatter plot versus the predicted values for the regression equation for the HFCQL social domain appeared constant upon inspection, thereby suggesting normality and supporting the decision to use the non-transformed value. No outliers were noted by using Mahalanobis distance with χ^2 of 27.877, *df* of 9, and $p < .001$ (Tabachnick & Fidell, 2001). Multicollinerarity and singularity were not an issue as there was only one condition index that exceeded 30 and only one variance proportion greater than .50 (Tabachnick & Fidell, 2001).

Caregiver perception of income not meeting needs, patient cognitive status time spent caregiving, and symptoms with moderate activity were entered in step 1 of the regression equation for HFCQL social domain (see Table 24). Together these caregiver

and patient characteristics accounted for 25% (21% adjusted) of the variance in HFCQL social domain $[F(4, 95) = 7.69, p < .001]$. Caregiving task difficulty, uncertainty, and social support in step 2 accounted for an additional 28% of the variance $[F(7, 92) = 14.64, p < .001]$. Threat appraisal in step 3 did not add any variance to HFCQL social domain $[F(8, 91) = 12.68, p < .001]$. In step 4, depressive symptoms was entered in the regression equation and accounted for an additional 2% of the variance $[F(9, 90) = 11.92, p < .001]$. Overall, the model constructs accounted for 54% of variance of HFCQL social domain which provided evidence of construct validity. Significant individual predictors of HFCQL social domain were caregiving task difficulty, uncertainty, and social support, accounting for 5%, 3%, and 4% unique variance, respectively.

Table 24

Hierarchical multiple regression evaluating construct validity of HFCQL social domain

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Caregiver household income	1.00	.10	1.27	.27**	.01
Cognitive status	.02	.02	.16	.38***	.00
Time spent caregiving	-.01	-.11	-1.49	-.28**	.01
Symptom with activity	-.19	-.03	-.36	-.22*	.00

Step 1. $R = .50$; $R^2 = .25$; Adjusted $R^2 = .21$; F Change $(4, 95) = 7.69***$; R^2 Change $= .25$ $F(4, 95) = 7.69***$.

Caregiving task difficulty	-.14	-.34	-3.28**	-.58***	.05
Uncertainty	-.05	-.24	-2.51*	-.54***	.03
Social Support	.05	.23	2.82**	.47***	.04

Step 2. $R = .73$; $R^2 = .53$; Adjusted $R^2 = .49$; F Change $(3, 92) = 18.30***$; R^2 Change $= .28$; $F(7, 92) = 14.64***$.

Threat appraisal	.02	.05	.54	-.41***	.00

Step 3. $R = .73$; $R^2 = .53$; Adjusted $R^2 = .49$; F Change $(1, 91) = .05$; R^2 Change $= .00$; $F(8, 91) = 12.68***$.

Depressive symptoms	-.13	-.16	-1.81	-.41***	.02

Step 4. $R = .74$; $R^2 = .54$; Adjusted $R^2 = .50$; F Change $(1, 90) = 3.27$; R^2 Change $= .02$; $F(9, 90) = 11.92***$.

*$p < .05$; **$p < .01$; ***$p < .001$.

The HFCQL spiritual domain residuals scatterplot versus the predicted values for the regression equations were inspected and appeared constant suggesting normality. By using Mahalanobis distance with χ^2 of 13.82, *df* of 2, and $p < .001$, no outliers were identified (Tabachnick & Fidell, 2001). Multicollinearity and singularity were not an issue, as no condition indices exceeded 30 and only one variance proportion was greater than .50 (Tabachnick & Fidell, 2001).

No caregiver or patient characteristics needed to be controlled for, and no situational factors were significantly related to the spiritual domain (see Table 25). Therefore, threat appraisal was entered in step 1, which accounted for 8% (7% adjusted) of the variance in HFCQL spiritual domain score [$F(1, 98)=8.30$, $p < .001$]. Depressive symptoms was entered in step 2, but did not account for any additional variance [$F(1, 97) = 4.25$, $p < .05$]. So overall, only 8% ($p < .05$) of the variance in spiritual domain was accounted for with only threat appraisal as a significant independent predictor of spiritual quality of life accounting for 4% unique variance. These findings do not support construct validity for HFCQL spiritual domain.

Table 25

Hierarchical multiple regression evaluating construct validity of HFCQL spiritual domain

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Threat appraisal	-.09	-.24	-2.06*	-.28**	.04

Step 1. $R = .28$; $R^2=.08$; Adjusted $R^2 = .07$; *F* Change (1, 98) = 8.20**; R^2 Change = .08; $F(1, 98) = 8.20$***.

Depressive symptoms	-.06	-.07	-.59	-.20	.00

Step 2. $R = .28$; $R^2 = .08$; Adjusted $R^2 = .06$; *F* Change (1, 97) = .35; R^2Change = .00; $F(2, 97) = 4.25$*

*$p < .05$; **$p < .01$; ***$p < .001$.

In summary, hypothesis 1e was partially met. The model constructs of caregiver and patient characteristics, social support, caregiving task difficulty, uncertainty, threat appraisal, and depressive symptoms explained the variance in overall HFCQL and physical, psychological, and social domains (59%, 52%, 57%, 54%, respectively; $p < .001$) providing evidence of construct validity. However, for HFCQL spiritual domain, only two variables were significant to be entered into the multiple regression equation, threat appraisal and depressive symptoms, which explained a small portion of the variance in HFCQL spiritual domain (8%, $p < .001$). Therefore, construct validity was established for overall HFCQL, and physical, psychological and social domains, but not for spiritual domain.

Hypothesis 1f. To show evidence of criterion-related validity, the HFCQL scale and potential domains are significantly correlated with the BCOS, SF-36 general health and mental health subscales, and the HFCQL and domain well-being overall items, among caregivers of HF patients.

Hypothesis 1f was met. The HFCQL and four domains demonstrated evidence of criterion-related validity by significant correlation with criterion variables (see Table 26). Overall HFCQL and physical, psychological, and social domains had significant correlations with life changes, general health, mental health, and their respective single overall item ($p < .001$, $p < .01$). The spiritual domain significantly correlated with life changes ($p < .001$), and general and mental health ($p < .05$). However, the spiritual domain did not correlate with the single overall spiritual item, in which respondents were asked to rate their overall spiritual well-being. Considering the magnitude and significance of other correlations, it was determined that hypothesis 1f was met.

Table 26

Correlations evaluating criterion-related validity for the HFCQL and domains using Pearson r

HFCQL	Life Changes (BCOS)	General Health (SF-36 GH)	Mental Health (SF-36 MH)	Single Overall Item
Overall HFCQL	.73***	.45***	.59**	.71***
Physical Domain	.67***	.49***	.54***	.46***
Psychological Domain	.59***	.34***	.49***	.54***
Social Domain	.55***	.29**	.51***	.69***
Spiritual Domain	.40***	.25*	.24*	.15

$* p < .05$ level; $**p < .01$ level; $***p < .001$.

Psychometric properties of the HFCQL scale and domain subscales are summarized in Table 27.

Table 27

Summary of evidence of psychometric properties for HFCQL scale and domain subscales

HFCQL and domains	Internal consistency reliability[a]	Stability reliability[b]	Construct valididy: Factor analysis[c]	Construct validity: Multiple regression[d]	Criterion validity: General health[e]	Criterion validity: Mental health[e]	Criterion validity: Overall item[e]
Overall HFCQL	X	X	X	X	X	X	X
Physical domain	X	X	X	X	X	X	X
Psychological domain	X	X	X	X	X	X	X
Social domain	X	X	X	X	X	X	X
Spiritual domain	X	X	X		X	X	

[a] $\alpha > .70$; [b] ICC $> .60$; [c] Factor loadings $> .30$; [d] $p < .001$; [e] $r > .50, p < .05$

Specific Aim 2. To determine the combination of independent variables that explains depressive symptoms, life changes, and HF caregiver-specific quality of life in family caregivers of HF patients using a theoretically based conceptual model.

To determine the smallest number of independent variables that result in the greatest proportion of variance in the dependent variables in the regression equations, the same screening procedures as discussed in hypothesis 1e were followed for hypothesis 2a and 2b. As represented in Tables 28, 29, 30, and 31, very few caregiver and patient characteristics were significantly correlated with or resulted in significantly different scores for depressive symptoms and life changes. Depressive symptoms was significantly correlated with the number of caregiver co-morbidities ($r = .24$, $p < .05$) (see Table 28). Life changes was significantly correlated with time spent caregiving ($r = -.21$, $p < .05$) and patient cognitive status ($r = .33$, $p < .05$) (see Tables 28 and 29). Caregivers who perceive their income is not enough to make ends meet had significantly different life changes than those who did not ($F = 4.14$, $p < .05$) (see Table 31). These significant caregiver and patient characteristics were entered in the regression equations accordingly to be controlled. All situation factors, the mediator, and emotional response correlated with the dependent variables and therefore were entered into the regression equations accordingly (see Table 32).

Table 28

Screening for continuous caregiver characteristics for regression for predicting depressive symptoms and life changes using Pearson r

Dependent variable	Age	Education	Number of co-morbidities	Length of time caregiving	Time spent caregiving
Depressive symptoms	-.07	.06	.24*	-.01	.04
Life changes	.09	-.13	-.06	.04	-.21*

*$p < .05$; **$p < .01$; ***$p < .001$.

Table 29

Screening for continuous patient characteristics for regression for predicting depressive symptoms and life changes using Pearson r

Dependent variable	Age	Education	Number of co-morbidities	Cognitive status
Depressive symptoms	-.11	.06	.10	.14
Life changes	.16	-.13	-.20	.33*

*$p < .05$; **$p < .01$; ***$p < .001$.

Table 30

Screening for discrete caregiver characteristics for regression for predicting depressive symptoms and life changes using MANOVA univariate F values

Dependent variables	Gender[a]	Race[c]	Relationship to Patient[b]	Household Income[b]	Employment[a]	Job Change[a]
Depressive Symptoms	.19	1.93	.99	1.04	2.51	.25
Life Changes	.002	.06	2.05	4.14*	.09	1.71

[a]$df(1, 98)$, [b]$df(2, 97)$
*$p < .05$; **$p < .01$; ***$p < .001$

Table 31

Screening for discrete patient characteristics for regression for predicting depressive symptoms and life changes using MANOVA univariate F values

Dependent variables	Gender[a]	Race[b]	Living Setting[b]	Symptoms with Activity[b]
Depressive symptoms	.08	1.80	.34	.06
Life Changes	.26	.06	.003	1.92

[a]$df(1, 98)$, [b]$df(2,97)$, [c]$df(1, 97)$
*$p < .05$; **$p < .01$; ***$p < .001$

Table 32

Screening for continuous situational factors, mediator, and emotional response for regression for predicting depressive symptoms and life changes using Pearson r

Dependent variables	Social support	Uncertainty	Task difficulty	Threat appraisal	Depressive symptoms
Depressive symptoms	.28**	.35***	.34**	.55***	
Life changes	.23*	-.40***	-.48***	-.49***	-.54***

* $p < .05$ level; **$p < .01$ level; ***$p < .001$.

Hypothesis 2a. Caregiver and patient characteristics, social support, task

difficulty, uncertainty, perceived control, and threat appraisal explain a significant

amount of variance of depressive symptoms in family caregivers of patients with

HF.

Hypothesis 2a met. Prior to analyzing regression equation results of depressive

symptoms, the residuals scatterplot versus the predicted values for the regression

equations was inspected and appeared fairly constant suggesting normality. By using

Mahalanobis distance with χ^2 of 20.52, df of 5, and $p < .001$, one outlier was identified

(Tabachnick & Fidell, 2001). However, it was decided to retain this outlier so the results

would be more reflective of the actual population and improve generalizability of the

findings. Multicollinearity and singularity were not an issue, as there were no condition

indices exceeding 30 and only one variance proportion greater than .50 (Tabachnick &

Fidell, 2001).

The number of caregiver co-morbidities was entered in step 1 of the regression

equation and accounted for 6% (5% adjusted) of the variance in depressive symptoms

$[F(1, 98) = 6.17, \; p < .05]$, as shown in Table 33. Caregiving task difficulty, uncertainty,

and social support in step 2 accounted for an additional 17% of the variance $[F(4, 95) =$

$6.92, p < .001]$. Threat appraisal was entered in step 3, accounting for an additional 13%

of the variance $[F(5, 94) = 10.24, p < .001]$. Overall the model constructs accounted for

35% of variance of depressive symptoms with caregiver co-morbidities and threat

appraisal as significant individual predictors accounting for 3% and 13% of the unique

variance, respectively.

Table 33

Hierarchical multiple regression predicting depressive symptoms

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Caregiver Co-morbidities	.48	.18	2.14*	.24**	.03

Step 1. $R = .24$; $R^2 = .06$; Adjusted $R^2 = .05$; F Change $(1,98) = 6.17*$ R^2 Change $= .06$ $F(1,98) = 6.17*$

Caregiving task difficulty	.05	.09	.93	.34***	.01
Uncertainty	.00	.00	.00	.35***	.00
Social Support	-.03	-.11	-1.17	-.28**	.01

Step 2. $R = .48$; $R^2 = .23$; Adjusted $R^2 = .19$; F Change $(3,95) = 6.80***$; R^2Change $= .17$; $F(4, 95) =$ 6.92***.

Threat appraisal	.19	.45	4.29***	.55***	.13

Step 3. $R = .59$; $R^2 = .35$; Adjusted $R^2 = .32$; F Change $(1, 94) = .18.44***$; R^2 Change $= .13$; $F(5,94) =$ 10.24***.

*$p < .05$; **$p < .01$; ***$p < .001$.

Hypotheses 2b. Caregiver and patient characteristics, social support, task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of life changes in family caregivers of patients with HF.

Hypothesis 2b met. The life changes residuals scatterplot versus the predicted values for the regression equations appeared constant upon inspection, thereby suggesting normality. One outlier was noted by using Mahalanobis distance with χ^2 of 26.125, *df* of 8, and *p* < .001 (Tabachnick & Fidell, 2001), however, it was decided to retain this outlier so the results would be more reflective of the actual population thereby improving generalizability of findings. Assumptions of collinearity and singularity were met as there was only one condition index that exceeded 30 and only one variance proportion greater than .50 (Tabachnick & Fidell, 2001).

Caregiver perception of income not meeting needs, patient cognitive status, and time spent caregiving were entered into step 1 of the regression equation for life changes

to control their influence (see Table 34). These caregiver and patient characteristics

accounted for 19% (16% adjusted) of the variance in life changes [$F(3, 96) = 7.42$, $p <$

.001]. Caregiving task difficulty, uncertainty, and social support were entered in step 2;

these situation factors accounted for an additional 13% of the variance [$F(6,93) = 7.19$, p

< .001]. Threat appraisal in step 3 accounted for an additional 6% of the variance

[$F(7,92) = 7, 94$, $p <.001$]. Depressive symptoms was entered in step 4 of the regression

equation and accounted for an additional 8% of the variance [$F(8, 91) = 9.55, p < .001$].

The model constructs overall accounted for 46% of variance of life changes, with

depressive symptoms as the only significant individual predictor accounting for 8%

unique variance.

Table 34

Hierarchical multiple regression predicting life changes

Independent Variables	B	Beta	t	Bivariate r	Unique r^2
Household Income	2.90	.14	1.64	.27**	.02
Cognitive status	.27	.12	1.26	.33***	.01
Time Caregiving	-.03	-.11	-1.36	-.21*	.01

Step 1. $R = .43$; $R^2 = .19$; Adjusted $R^2 = .16$; F Change (3, 96) = 7.42*** R^2 Change = .19; $F(3, 96) = 7.42***$

Caregiving task difficulty	-.13	-.15	-1.38	-.48***	.01
Uncertainty	-.03	-.07	-.64	-.40***	.00
Social Support	-.01	-.03	-.36	.23*	.00

Step 2. $R = .56$; $R^2 = .32$; Adjusted $R^2 = .27$; F Change (3, 93) = 5.85**; R^2 Change = .13; $F(6, 93) = 7.19***$

Threat appraisal	-1.0	-.16	-1.44	-.49***	.01

Step 3. $R = .61$; $R^2 = .38$; Adjusted $R^2 = .41$; F Change (1, 92) = 8.79**; R^2 Change = .06; $F (7, 92) = 7.94***$.

Depressive Symptoms	-.56	-.35	-3.65***	-.54***	.08

Step 4 $R = .68$; $R^2 = .46$; Adjusted $R^2 = .41$; F Change (1, 91) = 13.35***; R^2 Change = .08; $F(8, 91) = 9.55***$.

*$p < .05$; **$p < .01$; ***$p < .001$.

Hypothesis 2c. Caregiver and patient characteristics, social support, task

difficulty, uncertainty, perceived control, threat appraisal, and depressive

symptoms explain a significant amount of variance of HF caregiver-specific

quality of life as measured by the HFCQL scale and potential domains as

determined by psychometric testing in family caregivers of patients with HF.

Hypothesis 2c was partially met. The same multiple regression equations were

used to evaluate construct validity of the HFCQL and domains in hypothesis 1d; details

concerning the findings are described there. In summary, the model constructs of

caregiver and patient characteristics, social support, caregiving task difficulty,

uncertainty, threat appraisal, and depressive symptoms explained the variance in overall

HFCQL and physical, psychological, and social domains (59%, 52%, 57%, 54%,

respectively; $p < .001$). However, for HFCQL spiritual domain, only two variables were

significant to be entered into the multiple regression equation, threat appraisal and

depressive symptoms, which explained a small portion of the variance in HFCQL

spiritual domain (8%, $p < .001$). These findings provide partial support for hypothesis

2c.

5. DISCUSSION

This chapter begins with a discussion pertaining to the specific aims and hypotheses followed by theoretical, research, and practice implications. The chapter will conclude with a review of the limitations proposed in Chapter 3.

Specific Aims and Hypotheses

Specific Aim 1. To evaluate the psychometric properties of the Heart Failure Caregiver Quality of Life scale (HFCQL).

As the prevalence of HF continues to increase, more family members will be required to assume caregiving responsibilities for HF patients at home. Studies in the existing literature suggest that HF family caregivers do experience negative outcomes, such as poor mental and general health, but outcomes have been measured with generic instruments, which may not capture their unique experience. In order to develop and evaluate specific, individualized interventions for this population, there is a critical need for a reliable and valid instrument that measures HF family caregivers' quality of life. This study addressed this critical need in specific aim 1 with the HFCQL scale. Content validity was established prior to psychometric testing. In a sample of 100 family caregivers of patients with HF, this new HFCQL scale demonstrated adequate reliability and validity for overall HFCQL, and physical, psychological, and social domains. Reliability was established for the spiritual domain. Psychometric properties are summarized in Table 27; specific psychometric properties are described in hypothesis 1a through hypothesis 1f.

Hypothesis 1a. The HFCQL items demonstrate means close to the midpoint, good variability in relation to the means, floor and ceiling effects less than 10%,

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and item-to-total correlations greater than or equal to .30 among caregivers of HF patients.

The 16 items of the HFCQL demonstrated means close to the midpoint and good variability in relation to the means. All item-to-total correlations exceeded .30 among the caregivers of HF patients for all items in the individual domains as well as the total HFCQL; the lowest item-to-total was .42. It was hypothesized that floor and ceiling effects would be less than 10%. In this sample, all 16 items had ceiling effects greater than 10%, indicating perceptions of higher quality of life for these 16 items (see Tables 9, 10, 11, and 12). In general, the caregivers in this sample had fairly high overall HFCQL, as well as the four domains of physical, psychological, social, and spiritual suggesting caregiving did not have a negative affect their quality of life. One item on the psychological domain ("Because of caregiving, I am tired"), had floor effects at 11%, just exceeding the 10% as hypothesized (see Table 10). No other items demonstrated high floor effects.

One possible explanation for the high ceiling effects is that overall these caregivers had a low number of co-morbidities, high levels of social support; minimal task difficulty; and low levels of uncertainty, threat appraisal, and depressive symptoms, thereby experiencing a minimal negative impact on their quality of life (see Tables 4, 6 and 7). The mean score for mental health (76.6), which was collected and used as a criterion variable, actually exceeded the general U.S. normative value (74.7) (Ware, 2000).

Hypothesis 1b. The HFCQL scale and potential domains have evidence of

internal consistency reliability with Cronbach's alphas greater than or equal to .70

among caregivers of HF patients.

Internal consistency reliability was evident by Cronbach's alphas ranging from

.80 to .90 for the overall HFCQL 16-item scale, and the 4-item subscales measuring

physical, psychological, social, and spiritual domains (see Table 8).

Hypothesis 1c. The HFCQL scale and potential domains have evidence of 2-

week test-retest reliability with an intra-class correlation coefficient greater than

.60 among caregivers of HF patients.

Most of the sample ($n = 85$) participated in the 2-week test-retest. The overall

HFCQL scale and four domain subscales all demonstrated adequate stability reliability.

Using ICC and the criteria as established by Landis and Koch (1977), the overall HFCQL

retest had almost perfect agreement with the initial test, and the all domain retests had

substantial agreement with the initial tests.

Hypothesis 1d. The HFCQL has evidence of construct validity with factor

loadings of .32 and above for the scale or each domain as determined through

factor analysis among caregivers of HF patients.

The pool of 46 items was entered into exploratory factor analysis using varimax

rotation; a four factor solution was yielded (see Table 14). After selective deletion of

items with low inter-item and item-to-total correlations ($< .30$), high inter-item

correlations ($< .70$), and/or poor item statistics, a total of 16 items were retained for the

HFCQL scale. The same factor analysis procedures were followed again, resulting in the

four factors representing physical, psychological, social, and spiritual domains. All 16

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items remaining in the HFCQL had factor loadings exceeding the criteria of .32, as established by Tabachnick and Fidell (2001). The physical domain items had loadings of .58 to .70; psychological domain items had loadings of .51 to .80; social domain items had loadings of .64 to .79; spiritual domain items had loadings of .81 to .84 (see Table 15). The same factor analysis procedure with one factor forcing for all 16 items yielded factor loadings ranging from .31 (one time only, purpose/mission) to .78 supporting construct validity, and therefore, use of the overall HFCQL scale.

Based on the definition of HFCQL adapted from Ferrell and colleagues (2001), the pool of items was generated with the intent to measure the four quality of life domains (physical, psychological, social, and spiritual). Most of the items ($n = 14$) loaded on the domain identified by the content experts as the most appropriate domain, however, two of the items loaded on different domains. "Even though I'm a caregiver, I am able to practice religious activities as much as I want", which was intended to capture the spiritual domain, loaded on the social domain. "Because of caregiving, I am tired", what was intended to capture the physical domain, loaded on the psychological domain. While conceptually these factor loadings were not consistent with the original intent, these items do measure important elements and make sense with their actual loadings. Perhaps for this group of caregivers, religious activities, such as going to church, is considered a social activity, which would support the factor loading. While being "tired" can be a physical issue, these caregivers were emotionally tired, which explains the factor loading.

> Hypothesis 1e. Caregiver and patient characteristics, social support, task
> difficulty, uncertainty, perceived control, threat appraisal, and depressive

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symptoms explain a significant amount of variance of HF caregiver-specific

quality of life as measured by the HFCQL scale and potential domains, as

determined through factor analysis, in family caregivers of patients with HF, to

provide evidence of construct validity.

Hierarchical multiple regression equations were used to examine construct

validity for the HFCQL scale. Perceived control, as a situation factor, was not used in the

equations, due to low internal consistency reliability of the CAS ($\alpha = .63$). However, the

remainder of the variables, as hypothesized, was entered into the regression equations in

the order as conceptualized in Figure 1. The variance explained by these model

constructs supported construct validity for overall HFCQL (56%, $p < .001$), and physical

(52%, $p < .001$), psychological (57%, $p < .001$), and social (54%, $p < .001$) domains (see

Tables 21, 22, 23, 24). The multiple regression equation did not show support of

construct validity for the spiritual domain. Only two variables, threat appraisal and

depressive symptoms, were screened to be significant for the equation, which resulted in

only 8% ($p < .05$) of the variance for the spiritual domain, thereby construct validity was

not established for this domain (see Table 25).

The quality of life domains of physical, psychological, and social well-being

have been noted in health care research for many years, but spiritual well-being was not

added until the last decade as an important domain (Taylor, 2003). Spirituality, or

spiritual well-being, is an abstraction that often causes confusion with varied meanings,

such as religiosity, hope, or transcendence (Taylor, 2003). The definitions of HFCQL

and the domains for this study were adapted from the work of Ferrell (1995) and her

colleagues (2001) who used a four-dimensional quality of life tool for family caregivers.

These researchers provided evidence for construct validity of the spiritual domain by way of factor analysis, however they did not indicate the use of hierarchical multiple regression to support construct validity for this domain. Likewise, in this study, construct validity for the HFCQL spiritual domain was supported by factor analysis, but not by hierarchical multiple regression. Perhaps the varied meanings associated with this abstract concept make it impossible to identify many variables associated with or predictive of spirituality. However, since spiritual well-being has been implicated in negative outcomes for HF family caregivers in qualitative studies (Mahoney, 2001; Murray et al., 2004), closer examination of this quality of life domain is warranted.

Another unexpected finding noteworthy to mention in this discussion was the insignificant correlation between social support and the HFCQL psychological domain ($r = .15$). As a situation factor in the conceptual model (see Figure 1), it was hypothesized that social support was related to HFCQL and domains, and therefore would contribute to the variance in HFCQL and domain scores. However, social support was not entered into the multiple regression equation for the psychological domain due to the insignificant correlation found with screening. These findings are inconsistent with the transactional approach to stress, as theorized by Lazarus and Folkman (1984), and addressed by Lyon and Rice (2000). The relationship between social support and life satisfaction, which is similar to quality of life, has been documented with stroke caregivers (Grant et al., 2001). Possibly the lack of relationship between social support and the psychological domain in this study is due to the operational definition of social support which measured the availability of perceived social support, however, Grant and colleagues (2001) measured social support in a similar way. Since this variable is

amenable to intervention, additional studies are needed to clarify the relevance of social

support to HF caregiver outcomes.

Hypothesis 1f. To show evidence of criterion-related validity, the HFCQL scale

and potential domains are significantly correlated with the BCOS, SF-36 general

health and mental health subscales, and the HFCQL and domain well-being

overall items, among caregivers of HF patients.

Criterion-related validity was evident by significant correlations between the

HFCQL and domains and the criterion variables as measured by the BCOS (life changes),

SF-36 general health and mental health subscales, and their respective single overall item

(see Table 26). The only exception to this statement was the spiritual domain, which did

not correlate with the overall spiritual well-being item, "As a caregiver, my spiritual well-

being is (very poor, poor, average, good, or excellent)". As mentioned with hypothesis

1e, spirituality is an abstract concept confounded by varied definitions, which most likely

explains the lack of correlation between the domain score and the single overall item.

With factor analysis, it was noted that the HFCQL item concerning religious activity

loaded on the social domain (see Table 15); this relationship was further supported with a

moderate correlation between religious activities and the overall social well-being item (r

$= .56, p < .01$). There was a correlation between religious activities and overall spiritual

well-being, but it was considerably less ($r = .41, p < .01$). The correlations between the

spiritual domain and the other criterion variables were significant, with life changes being

the strongest ($r = .40, p < .001$); the correlations with general health ($r = .25, p < .05$) and

mental health ($r = .24, p < .05$) were minimal. All other correlations as noted in Table 15

were substantial and supported criterion-related validity.

Specific Aim 2. To determine the combination of independent variables that explains

depressive symptoms, life changes, and HF caregiver-specific quality of life in family

caregivers of HF patients using a theoretically based conceptual model.

To date, very few studies of HF family caregivers have been published that

identify variables associated with outcomes, and even less were guided by a conceptual

model. In order to develop appropriate and relevant interventions to support this growing

population, information about variables that influence the HF caregivers' experiences is

essential. Only one study of HF family caregivers used multiple regression to determine

the combination of variables that accounted for caregiver outcomes (Scott, 2000), and

regretfully, the sample was inadequate ($n = 18$) for multiple regression procedures, as

described by Tabachnick and Fidell (2001). By using hierarchical multiple regression

with an adequate sample size ($n = 100$), this study, which was based on a conceptual

model, addressed this gap in the literature by identifying variables that account for

depressive symptoms, life changes, and HFCQL and domains in HF family caregivers.

Hypothesis 2a. Caregiver and patient characteristics, social support, task

difficulty, uncertainty, perceived control, threat appraisal explain a significant

amount of variance of depressive symptoms in family caregivers of patients with

HF.

Overall, the caregivers in this sample did not have depressive symptoms, as

measured with a mean of 4.2 on the PHQ-9, where 0 to 4 indicates none (Kroenke &

Spitzer, 2002). The majority of the sample had no depressive symptoms (63%) and the

remainder had mild (26%), moderate (7%), or moderately severe (4%) depressive

symptoms. No caregivers in this sample had severe depressive symptoms. So in essence,

37% of the sample had some level of depressive symptoms which is higher than those reported in other HF family caregiver studies, where percentages ranged from 14 to 23% (Barnes et al., 2006; Martensson et al., 2003; Molloy et al., Schwartz & Elman, 2003). However, these studies used different instruments to measure depressive symptoms so comparison is limited.

With the model constructs of number of caregiver co-morbidities, caregiving task difficulty, uncertainty, social support, and threat appraisal, 35% ($p < .001$) of the variance of depressive symptoms was accounted for in this sample of HF caregivers (see Table 33). Caregiver co-morbidities and threat appraisal were found to be significant individual predictors of depressive symptoms. As mentioned earlier, perceived control was not used in this equation, as the CAS had unsatisfactory internal consistency reliability with this sample.

These findings are consistent with other caregiver studies. The relationships between social support and depressive symptoms have been documented in caregivers of stroke survivors (Grant et al. 2001) and persons with Alzheimer's disease (Chang et al., 2001). There was minimal correlation between uncertainty and depressive symptoms in caregivers of patients with Parkinson Disease (Sanders-Dewey et al., 2001). Caregiving task difficulty and threat appraisal have been identified as significant predictors of emotional distress in stroke caregivers (Bakas et al., 2004; Bakas & Burgener, 2002).

Other caregiver studies have noted the influence of age (Given et al., 2004; Lee et al., 2001), gender (Bakas et al., 2006; Given et al., 2004; Lee et al., 2001), race (Miller et al., 1995), caregiver relationship to the patient (Schwarz, 1999; Given et al., 2004; Lee et al., 2001), employment status (Given et al., 2004) and household income (Lee et al.,

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2001) on depressive symptoms. However in this study, none of these variables were found to be related to or result in differences of caregiver depressive symptoms. The only caregiver or patient characteristic that was significant in the multiple regression screening was the number of caregiver co-morbidities, which was found to be a significant individual predictor of depressive symptoms. As the number of caregiver co-morbidities increased, depressive symptoms increased.

Hypothesis 2b. Caregiver and patient characteristics, social support, task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of life changes in family caregivers of patients with HF.

In general, the HF caregivers in this sample perceived their life has changed for the worse as a result of caregiving responsibilities, which is consistent with findings from studies of large samples of stroke caregivers (Bakas et al., 2004; Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006) and a study with a small sample of HF caregivers ($n = 21$) (Bakas, Pressler, et al., 2006).

With the model constructs of household income, patient cognitive status, time spent caregiving, caregiving task difficulty, uncertainty, social support, threat appraisal, and depressive symptoms, 46% ($p < .001$) of the variance of life changes was accounted for in this sample of HF caregivers (see Table 34). In spite of multiple high correlations between independent variables and life changes, only depressive symptoms was found to be a significant individual predictor of life changes ($p < .001$), which highlights the shared variance between these model constructs.

Many of the relationships in the model have been supported in studies of stroke caregivers (Bakas et al., 2004; Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). These researchers noted that caregiving task difficulty was related to life changes, and threat appraisal and depressive symptoms were significant individual predictors of life changes. The findings of this present study of HF family caregivers builds on previous studies of a sample of 21 HF caregivers which documented a moderate correlation between life changes and caregiving task difficulty (Bakas, Pressler, et al., 2006) and a high correlation between life changes and threat appraisal (Nauser, 2005). Additional model constructs examined in the multiple regression equations in this present study were social support ($r = .23$, $p < .05$) and uncertainty ($r = -.40$, $p < .001$), both of which were found to contribute to the shared variance of life changes in HF family caregivers.

Caregiver gender, patient gender, and caregiver relationship to the patient have been shown to impact life changes in stroke caregivers (Bakas & Champion, 1999, Bakas, Champion, et al., 2006). Age was shown to influence life changes in HF caregivers (Bakas, Pressler, et al., 2006); younger caregivers experienced more negative outcomes. However, in the present study, the caregiver and patient characteristics noted to impact life changes were household income, patient cognitive status, and time spent caregiving. Those who perceive their income is not enough to make ends meet, have more negative life changes than those who perceive their income is adequate. HF family caregivers providing care for patients with a lower cognitive status and those who spend more time caregiving experience more negative life changes as well.

Hypothese 2c. Caregiver and patient characteristics, social support, task difficulty, uncertainty, perceived control, threat appraisal, and depressive symptoms explain a significant amount of variance of HF caregiver-specific quality of life as measured by the HFCQL scale and potential domains as determined by psychometric testing in family caregivers of patients with HF.

The HF family caregivers in this sample rated their HFCQL and physical, psychological, social, and spiritual domains fairly high, as measured by the instrument psychometrically tested in this study. To date, no study has been published that measured quality of life in this population with a scale specific to HF caregivers. Therefore, reports from studies using generic instruments were used to supplement this discussion. Hierarchical multiple regression findings for overall HFCQL are discussed first, followed by the findings for physical, psychological, social, and spiritual domains.

The model constructs of patient cognitive status, household income, patient symptoms with activity, caregiving task difficulty, uncertainty, social support, threat appraisal, and depressive symptoms accounted for 59% ($p < .001$) of the variance of overall HFCQL (see Table 21). Individual significant predictors of overall HFCQL were caregiving task difficulty, uncertainty, threat appraisal, and depressive symptoms. Among these predictors, threat appraisal accounted for 37% unique variance in HFCQL.

Some of these findings have been supported in the existing caregiving literature. Social support was noted to be moderately correlated with general health, a construct similar to quality of life, in stroke caregivers (Grant et al., 2001). Threat appraisal was a significant predictor of general health in stroke caregivers (Bakas & Burgener, 2002) and moderately correlated with life satisfaction (Lee et al., 2001). Depressive symptoms and

perception of overall health and general health were correlated in caregivers of patients with Alzheimer's disease (Robinson, 1989) and stroke (Grant et al., 2000). Caregiver education, household income, and living arrangements were correlated with general health in stroke caregivers (Bakas & Burgener, 2002). The impact of uncertainty and caregiving task difficulty, both significant individual predictors in the present study, on the caregiver's quality of life, have not been addressed in the caregiving literature.

The model constructs of household income, patient cognitive status, caregiving task difficulty, uncertainty, social support, threat appraisal, and depressive symptoms accounted for 52% ($p < .001$) of the variance of HFCQL physical domain (see Table 22). Individual significant predictors were caregiving task difficulty and depressive symptoms. Only one study was found that addressed relationships between independent variables and physical well-being. In a study of caregivers of elderly with varied disorders, threat appraisal was moderately related to physical health (Lee et al., 2001).

For HFCQL psychological domain, the model constructs of caregiver age, household income, patient cognitive status, patient symptoms with activity, caregiving task difficulty, uncertainty, threat appraisal, and depressive symptoms accounted for 57% ($p < .001$) of the variance (see Table 23). Individual significant predictors of HFCQL psychological domain were caregiver age, caregiving task difficulty, threat appraisal, and depressive symptoms. Mental health, a construct similar to HFCQL psychological domain, has been examined in HF caregiving literature. Correlates of poorer mental health include caregiving task difficulty (Bakas, Pressler, et al., 2006), depressive symptoms (Barnes et al., 2006; Martensson et al., 2003), and younger age (Bakas,

Pressler, et al., 2006; Dracup et al., 2004). These findings are consistent with the present study.

The model constructs of household income, patient cognitive status, time spent caregiving, patient symptoms with activity, caregiving task difficulty, uncertainty, social support, threat appraisal, and depressive symptoms accounted for 54% ($p < .001$) of the variance of the HFCQL social domain (see Table 24). Individual significant predictors were caregiving task difficulty, uncertainty, and social support. Social well-being has been addressed only minimally in the existing literature. Caregiver characteristics, such as gender (Schwartz, 1999) and relationship to the patient (Schwarz, 1999; Faison et al., 1999; Given et al., 2004) have been shown to have a negative impact on social well-being. No other variables were found to be relevant to social well-being in the literature.

Only two variables, threat appraisal and depressive symptoms were significant with screening procedures to be entered into the regression equation for HFCQL spiritual domain. These variables accounted for only 8% ($p < .05$) of the variance this domain, with threat appraisal being a significant individual predictor. Qualitative researchers have addressed the impact of caregiving on spiritual well-being (Mahoney, 2001; Murray et al., 2004), but it has not been examined in quantitative studies. As discussed in hypothesis 1e, construct validity using hierarchical multiple regression was not established for the HFCQL spiritual domain. Regretfully the findings from this study do not contribute any information relevant to correlates or predictors of HFCQL spiritual domain.

This study was guided by a conceptual model derived from the work of Lazarus (1966, 1991), Lazarus & Folkman (1984), and Bakas and colleagues (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006). In Bakas and colleagues' prior works, social support and uncertainty had not been studied (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006; Bakas, Pressler, et al., 2006). Additionally, the outcome of HF caregiver-specific quality of life was added to the present study to capture the unique experience of this population.

Most of the relationships in this study were consistent with findings as documented by Bakas and colleagues even though most of their studies were of stroke caregivers (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006) with only one concerning HF caregivers (Bakas, Pressler, et al., 2006). While social support and uncertainty were not significant individual predictors of depressive symptoms and life changes, they did contribute to the shared variance in most of these outcomes. Likewise, these variables were found to contribute to the shared variance of overall HFCQL and domains; social support was a significant predictor of the social domain and uncertainty was a significant individual predictor of both overall HFCQL and the social domain. These findings signify the importance of these two variables to HF family caregivers' experiences and therefore, should be included in conceptual models guiding future studies. There were three main issues with the existing conceptual model that warrant discussion here: perceived control, HFCQL spiritual domain, and overlap between life changes and HF caregiver-specific quality of life.

In their study of HF caregivers, Bakas and colleagues (Bakas, Pressler, et al., 2006) added perceived control to their conceptual model, which had not been present in previous studies of stroke caregivers (Bakas & Burgener, 2002; Bakas & Champion, 1999; Bakas, Champion, et al., 2006). Since less control was related to poorer mental health in these HF family caregivers (Bakas, Pressler, et al., 2006), it was added to the present study. However, the CAS did not have acceptable internal consistency reliability ($\alpha = .63$) and could not be used for statistical procedures. This was surprising as this instrument had demonstrated satisfactory internal consistency reliability in previous studies of cardiac (Moser & Dracup, 1995; Moser & Dracup, 2000) and HF caregivers (Bakas, Pressler, et al., 2006). One possible explanation may be that the CAS is consistently more reliable with caregivers of acute cardiac disorders than chronic disorders (D. Moser, personal communication, May 15, 2007).

Another issue with current conceptual model was the lack of relationships between spiritual domain of HFCQL and other variables in the model. As a domain of HFCQL, it was conceptualized that spiritual well-being would be influenced by all of the variables in the conceptual model (see Figure 1 on page 20), yet only threat appraisal and depressive symptoms were significantly related to spiritual well-being. Together, these two variables accounted for 8% of the variance. As discussed earlier with discussions of construct validity, this may be due to the varied definitions associated with the abstract concepts of spirituality and spiritual well-being. Prior to retaining this domain in the conceptual model in future studies of HF family caregivers, additional work needs to be done to clarify this abstract domain and re-examine the conceptual definition used in this study.

The third issue to be discussed was the overlap between the dependent variables life changes and HF caregiver-specific quality of life, both of which are adaptational outcomes in the conceptual model. There was a high correlation between the two instruments measuring these outcomes ($r = .73$, $p < .001$), however the conceptual definition differs for these two variables. Life changes refers to changes in social functioning, subjective well-being, and somatic health as a result of caregiving, while HF caregiver-specific quality of life refers to the caregiver's current state of well-being, which stems from physical, psychological, social, and spiritual domains, as impacted by their caregiving responsibilities. Including both variables in conceptual models guiding future studies will enhance our understanding of HF caregiver's experience, examining life changes as well as the current state of well-being.

Research Implications

In the past, HF caregiver's quality of life has been assessed with generic instruments that did not adequately measure the impact of caregiving for a family member with HF on their quality of life. These generic tools measured the caregiver's perception of their life satisfaction, general health or mental health, but did not adequately examine the actual impact of caregiving. The BCOS, as a caregiver-specific instrument, has been identified by Deeken, Taylor, Mangan, Yabroff, and Ingham (2003) as the caregiver instrument with the most psychometric testing. The BCOS measures life changes, positive and negative, in the areas of social functioning, subject well-being, and somatic health. The overall HFCQL scale measures the current state of the caregiver's multidimensional quality of life, including physical, psychological, social, and spiritual domains, as impacted by their caregiving responsibilities.

The HFCQL scale psychometrically tested in this study shows potential as a reliable and valid instrument to measure overall HFCQL, which has items measuring physical, psychological, social and spiritual well-being. The HFCQL domains of physical, psychological, and social well-being also had evidence of reliability and validity. While the spiritual domain had evidence of reliability, construct validity was not supported; therefore, the use of this individual domain subscale is not recommended. To verify dimensionality of the overall HFCQL and domains, confirmatory factor analysis should be conducted in future analyses.

As a short 16-item instrument with a 5-point response scale, the overall HFCQL is easy to administer and can be completed in three minutes. After reverse scoring of selected items, the items are summed so that higher scores indicate higher HFCQL. A range of 16 to 80 is possible. The subscales measuring HFCQL domains of physical, psychological, and social well-being each contain 4 items that can be completed in less than one minute; a range of 4 to 20 is possible. Additional studies using the overall HFCQL scale and physical, psychological, and social domain subscales are needed to confirm reliability and validity of this much needed instrument.

HF family caregivers have indicated that spirituality is an important aspect in their experiences as caregivers (Mahoney, 2001; Murray et al., 2004). Prior to attempting to measure this concept quantitatively as a individual domain, the existing literature should be reviewed for instruments that have measured spiritual well-being with documented psychometric properties, especially evidence of construct validity by hierarchical multiple regression. Conceptual definitions should be reviewed, and items could be revised accordingly, to accurately measure this domain for HF family caregivers.

However, changing any items on the overall HFCQL scale would require re-examination for adequate psychometric properties; therefore it is recommended the spiritual domain items remain for the overall HFCQL and additional studies conducted with this scale.

Perceived control has been shown to be related to outcomes for HF family caregivers in previous studies (Bakas, Pressler, et al., 2006; Dracup et al., 2004). Therefore, this situational factor should not be abandoned because the CAS had low internal consistency reliability in this study. D. Moser, author of the 4-item CAS, indicated that psychometric testing of a new 10-item CAS is underway that will hopefully more accurately measure perceived control of caregivers of patients with chronic cardiac problems (personal communication, May 15, 2007). Future studies of HF family caregivers should include perceived control, as measured by the 10-item CAS, pending satisfactory psychometric evaluation.

<div align="center">Practice Implications</div>

This study has documented the psychometric properties of a much needed instrument and identified variables associated with HF caregiver outcomes. The overall HFCQL scale and physical, psychological, and social domain subscales can be used to screen for negative outcomes experienced by HF family caregivers as a result of their caregiving responsibilities. As a short scale that is easy to administer, the HFCQL scale can be used in a variety of settings, such as the physician's office, acute care setting, and outpatient HF clinic. Once poor HF caregiver-specific quality of life is identified, health care providers can intervene to improve the quality of life of these caregivers. This new quality of life instrument might also be used to evaluate the effectiveness of interventions

targeted at improving HF caregiver-specific quality of life among this population,

however, further studies are needed to determine the scale's sensitivity to interventions.

Key variables associated with depressive symptoms, life changes, and HFCQL

were identified in this study. These findings will allow health care providers to develop

individualized interventions directed at associated variables. Caregiving task difficulty

was associated with depressive symptoms, life changes, and HFCQL, which suggests that

this is an area for intervention. Determining which tasks are more difficult and offering

recommendations to manage those tasks could reduce caregiving task difficulty, thereby

reducing depressive symptoms and negative life changes and improving HFCQL.

Uncertainty was associated with all three outcomes as well. HF is characterized by an

uncertain disease course with a gradual decline punctuated by episodes of acute

deterioration and sudden death. Anecdotally, in caregiver interviews, not knowing what

to expect was a common theme voiced by these caregivers. Validating their feelings of

uncertainty and teaching methods to cope with uncertainty, such as minimizing new

information and selective ignoring of negative aspects of unpredictability (Mishel, 1988),

may improve caregiver outcomes of depressive symptoms, life changes, and HFCQL.

Social support was associated with all three caregiver outcomes. Determining caregiver

needs for emotional/information support, tangible support, positive social interaction, and

affectionate support would direct the health care provider to the most appropriate

interventions to improve the caregiver's perception of social support, thereby improving

their outcomes.

As a mediating variable, threat appraisal was implicated in depressive symptoms,

life changes, and HFCQL. As a matter of fact, threat appraisal accounted for 27% of the

variance of overall HFCQL highlighting the importance of intervening for caregiver's with high threat appraisal. Teaching stress management techniques may reduce threat appraisal, which would reduce depressive symptoms, negative life changes, and improve quality of life. The emotional response of depressive symptoms was associated with life changes and HFCQL. Referring HF family caregivers for treatment, such as psychotherapy and/or pharmacological therapy, would hopefully lessen their depressive symptoms resulting in much improve outcomes.

Several caregiver and patient characteristics were found to be associated with negative outcomes in HF family caregivers. While these characteristics cannot be changed, knowing which characteristics are implicated will allow health care providers to identify those who may potentially need interventions. For example, caregiver co-morbidities was a significant individual predictor of depressive symptoms. Therefore, caregivers with higher number of co-morbidities could be screened for depressive symptoms and be treated accordingly.

<u>Limitations</u>

1. A non-probability, convenience sample will be utilized which limits generalizability of the findings.

The sample of 100 HF family caregivers were recruited mostly from private cardiologists' offices, with smaller percentages from inpatient cardiac units, and outpatient HF clinics. The response was fairly good at 42%. The sample of caregivers was primarily nonhispanic (98%), white (73%) and spouses of the patients (62%). This limits the generalizability of these findings to nonhispanic, white, spousal caregivers of patients with HF.

2. The study will be cross-sectional and stress is a dynamic process thereby limiting causal references.

The findings of this study could be strengthened by the use of a longitudinal design which would demonstrate changes over time and give a more accurate picture of the stress response as hypothesized by (1966, 1991), Lazarus & Folkman (1984). Additionally, a longitudinal design would contribute to the ability to establish causality. However, a longitudinal design was not within the scope of this study. In comparison to other studies of HF family caregivers, a major strength of this study was the use of multiple regression procedures which is a more robust statistical procedure than Pearson product-moment correlation coefficient.

3. Multicollinearity and singularity among instruments are possible thereby resulting in potential statistical analyses errors.

These violations to assumptions were assessed in the multiple regression equations using the criteria as established by Tabachnick and Fidell (2001). Multicollinearity and singularity were not found among the instruments in this study, so no corrective procedures were needed.

4. Quality of life domains are interrelated which may decrease the probability that HFCQL will psychometrically test to have four distinct quality of life domains.

There were significant correlations between physical, psychological, social, and spiritual domains as hypothesized. However, four factors were apparent with factor analysis representing four distinct quality of life domains.

In summary, this research study addressed three critical gaps in the HF caregiver literature. Guided by an empirically supported conceptual model, a new 16-item HFCQL scale demonstrated evidence of reliability and validity, and factors, such as caregiving task difficulty, uncertainty, social support, and threat appraisal, explained a significant amount of variance of depressive symptoms, life changes, and HF caregiver-specific quality of life, among a sample of 100 HF family caregivers. The findings associated with this research study can be used by researchers to advance our knowledge of this caregiving population and by health care providers to intervene and support these neglected caregivers.

APPENDIX A

Literature Review Table

Literature Review Summary

See pages 175-180 for brief description of instruments.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Aldred, Gott, & Gariballa (2005)	10 older persons with advanced HF and their informal carers Qualitative design	QUALITY OF LIFE: SOCIAL WELL-BEING.	Caregiver reported feeling isolated and having to give up enjoyable hobbies. Unable to plan activities because of unpredictability of symptom onset. Unable to spend time with grandchildren and other family members. Socially isolating impact. Change in usual roles; caregiver taking over patients usual responsibilities. Lack of professional support, information/ education about condition and prognosis. Comments: Interviews conducted with patient present creating potential for response bias.
Bakas, Austin, Jessup, Williams, & Oberst (2004)	116 stroke caregivers Cross-sectional, descriptive, correlational design and psychometric testing using Lazarus theory	TASK DIFFICULTY/difficulty subscale of Oberst Caregiving Burden Scale, α=.94. EMOTIONAL RESPONSES: DISTRESS/Profile of Mood States, α=.95. LIFE CHANGES/Bakas Caregiving Outcomes Scale (12-item version), α=.90.	Small to moderate task difficulty. Moderate emotional distress. Life had changed for the worse. Four most difficult tasks (behavioral problems, emotional support, household tasks, finances) accounted for 37% of variance in emotional distress (p<.001) and 19% of the total variance in life changes (p<.001). Significant independent predictors of emotional distress: difficulty with managing finances (3% variance), providing emotional support (3% variance) and managing behaviors (5% variance). Significant independent predictor of life changes: difficulty with providing emotional support (5% variance). Item-total correlations ranged between .55 and .78. Factor loadings .61 and .82; 54.4% variance explained support unidimensionality
Bakas, & Burgener (2002)	104 stroke caregivers Cross-sectional, descriptive, correlational design using Lazarus theory	COGNITIVE STATUS/Cognitive Status Scale, α=84. TASK DIFFICULTY/difficulty subscale of Oberst Caregiving Burden Scale, α=.84.	Patient had good cognitive function. Minimal to moderate task difficulty. Moderate threat appraisal. Moderate emotional distress. Life had changed for the worse. Overall good general health. Threat appraisal (6% of variance, p<.001) and task difficulty (5% of variance,

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Source	Sample and Design	Variables/ Instruments	Findings and Comments
		THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=.86. EMOTIONAL RESPONSE: DISTRESS/<u>Profile of Mood States</u>, α=.87. LIFE CHANGES/<u>Bakas Caregiving Outcomes Scale</u> (10 item version), α=.77. GENERAL HEALTH/subscale of <u>SF-36</u>, α=.85.	p<.001) were significant predictors of emotional distress. Self-esteem, appraisal (threat, benefit, benign), tasks (difficulty, time) accounted for 48% of the variance (p<.001). Caregivers who didn't live with patient and had lower income had poorer general health. Demographics accounted for 18% of the variance in general health (p<.001). Controlling for significant demographics, threat appraisal accounted for 5% of variance in general health. Controlling for demographics, appraisal (threat, benefit, benign), tasks (difficulty, time), self-esteem accounted for 25% of the variance for general health (p<.001). Emotional distress (4%, p<.001), benefit appraisal (4%, p<.001), task difficulty (3%, p<.001), and threat appraisal (2%, p<.001) were significant predictors of life changes.
Bakas, & Champion (1999)	Sample 1: 92 stroke caregivers Sample 2: 104 stroke caregivers Cross-sectional, descriptive, correlational design and psychometric testing using Lazarus theory	TASK DIFFICULTY/difficulty subscale of <u>Oberst Caregiving Burden Scale</u>, α=.94/84. THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=.92/86. EMOTIONAL RESPONSE: DISTRESS/<u>Profile of Mood States</u>, α=.95/87. LIFE CHANGES/ <u>Bakas Caregiving Outcomes Scale</u>; 27 item for psychometric testing. LIFE SATISFACTION/ <u>LIFE-3</u> for criterion validity, α=.94/.64.	Sample 1: 12 items, unidimensional scale with factor loadings of .58 to .78. α= .90. Relationship type accounted for 10% of the variance. Adding emotional distress (6%), benign appraisal (4%), task difficulty (3%), benefit appraisal (4%), tasks time (2%), and threat appraisal (0) to the hierarchical model resulted in 63% of variance. Emotional distress, benign appraisal, task difficulty and benefit appraisal were all significant predictors of BCOS. LIFE-3 and BCOS (r=.56, p<.01) and single overall item (r=.67, p<.01) supported criterion validity. Sample 2: (changed ACS to be future tense, changed a LIFE-3 item to be caregiver specific, added SF36). 10 items, α= .77. Unidimensional, factor loadings of .42 to .70. Relationship type accounted for 3% of the variance. All independent variables (see sample 1) explained 45% variance. Emotional distress, threat appraisal, benefit appraisal were significant predictors of BCOS, each with a unique variance of 3%. Shared variance 33%. Correlated with LIFE-3 (r=.54, p.01), SF36 (acceptable α) subscales (except pain)

Source	Sample and Design	Variables/ Instruments	Findings and Comments
			were significant, but low (r=.21 to .26). Adult child caregivers had more negative life changes than spouses in both samples.
			Comments: Low α for LIFE-3 for sample 2.
Bakas, Champion, Perkins, Farran, & Williams (2006)	147 stroke caregivers Psychometric testing using Lazarus theory of stress	TASK DIFFICULTY/difficulty subscale of <u>Oberst Caregiving Burden Scale</u>, α=.90. THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=.90. DEPRESSIVE SYMPTOMS/<u>Primary Health Questionnaire-9</u>, α=.86. LIFE CHANGES/<u>Bakas Caregiving Outcomes Scale</u>; 15 items on 7 point scale (1=changed for the worse to 7=changed for the best) about social functioning, subject well-being, and somatic health. Possible range 15-105. α=See results. GENERAL HEALTH/ subscale of <u>SF-36</u>; 5 items on a 5 point scale (1=excellent/definitely to 5=poor/definitely false). Possible range 0-100. α=.84.	Female caregivers (p<.01) and those caring for male pts (p<.01) had worse life changes. Minimal task difficulty. Moderate threat appraisal. Few depressive symptoms. Good general health. BCOS Item analysis: Good variability. Range 1-7, median 4 (natural midpoint). Item-to-totals .41-.74. Highest ceiling 10.7% and floor 14.1%. BCOS: α=.90; 2 weeks later .81. ICC 2 week test-retest .66 (substantial agreement), Pearson r for 2 week test-retest .67, p<.001, and t-test NS. Factor loadings .41 to .78 with 42.8% of variance accounted by first factor (Eigenvalue=6.4). Construct validity: Task difficulty accounted for 2% variance, p<.001. Threat, benign, and benefit appraisal accounted for 9% variable, p<.001. Depressive symptoms accounted for 6% of variance, p<.001. Threat appraisal, depressive symptoms individual predictors of life changes (p<.05). Criterion validity: Life changes correlated with general health (r=.32, p<.001) and a criterion variable measuring overall changes (r=.67, p<.001).
Bakas, Kroenke, Plue, Perkins, & Williams (2006)	159 stroke. Caregivers Descriptive, comparative. longitudinal design	TASK DIFFICULTY/difficulty subscale of <u>Oberst Caregiving Burden Scale</u>, α=.89, .90. DEPRESSIVE SYMPTOMS/<u>Primary Health Questionnaire-9</u>, α=80, .86. LIFE CHANGES/<u>Bakas</u>	Tasks slightly to moderately difficult. Depressive symptoms low but 18.1% were moderately depressed (>10) and another 18.1% reported taking antidepressants. Life changes were for the worse. Females had more difficulty with tasks (t= -3.23; -4.12, p<.01) depressive symptoms (t=-3.43; -4.70, p<.001), and more negative life changes (t= 2.88; 2.81, p<.01) than males at both measurement times.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		Caregiving Outcomes Scale (15 item version), α=85, .90.	
Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, (2006)	21 HF caregivers Descriptive design using Bakas & Burgener (2002) model, which was based on Lazarus theory of stress	TASK DIFFICULTY/difficulty subscale of Oberst Caregiving Burden Scale, α=.92. CONTROL/Control Attitude Scale, α=.75. LIFE CHANGES/Bakas Caregiving Outcome Scale, α=.88. MENTAL HEALTH/subscale of SF-36, α=.93. GENERAL HEALTH/ subscale of SF-36, α=.86.	Slight task difficulty. Younger caregivers perceive tasks to be more difficult than older caregivers (r= -.60, p<.01). Tasks associated with more negative life changes (r= -.46, p<.05) and poorer mental health (r= -.51, p<.05). Moderate amount of control; associated with poorer mental health (r=.44, p<.05). Life changes for the worse; correlated with poorer mental health (r=.66, p<.001). Younger caregivers experience more negative mental health than older caregivers (r=.43, p<.05). Poorer mental health associated with poorer perceived general health (r=.44, p<.05). Comments: Small convenience sample.
Barnes, Gott, Payne, Parker, Seamark, Gariballa, & Small (2006)	213 HF caregivers Quantitative and qualitative design	EMOTIONAL RESPONSE: DEPRESSION: Geriatric Depression Scale. MENTAL HEALTH/subscale of SF-36, α=.93. OUTCOME: IMPACT ON PSYCH DOMAIN/ Carer Strain Index.	22% symptoms of depression Predictors of mental health: depression (p<.001), being the spouse (p<.05), having 2 or more health conditions (p<.05). 13% evidence of strain. Depression predictive of strain (p<.05). Self-reported NYHA class predictive of strain (p<.01). Comments: Internal conistency reliability not reported for depression scale and carer strain index.
Bohachick, & Anton (1990).	90 married dyads (patient with HF) Descriptive, comparative design	PHYSICAL, PSYCHOLOGICAL, AND SOCIAL WELL-BEING/ Psychosocial Adjustment to Illness Scale, α for total = .91, α for domains >.70 except health care orientation (.61) and extended family relationships (.52).	Some psychosocial distress. Caregivers have more problems in the social environment than the patients. Other problems were sexual relationships, psychological distress, and vocational environment (mean 6.04). Spouses reported more problems in health care than patients (p<.001), reflecting a lower level of attention to their health. Spouses reported more problems in extended family relationships (p<.03) and psychological distress (p<.03) than patients.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Boyd, Murray, Kendall, Worth, Benton, & Clausen (2004)	20 HF caregivers Qualitative design	CAREGIVING TASKS UNCERTAINTY	Caregivers spoke of feeling responsible for 'balancing and monitoring' the situation. The uncertainty of the prognosis made it difficult to know who imminent death would be, even though they were aware of being very ill.
Bull, Hansen, & Gross (2000a)	130 HF caregivers Longitudinal, comparative design	UNCERTAINTY related variable: Preparedness, measured with 1 item, rate overall how prepared they felt to assist elders with managing their care from 0-10. GENERAL HEALTH/subscale of SF 36, α=satisfactory. ADAPTATIONAL OUTCOMES/Response to Caregiving Scale, α ranged from .75 to .90 for subscales.	At 2 wks: Family caregivers with greater involvement in discharge (DC) planning (mod-lot) reported better general health 2 wks post DC than family caregivers with minimal (none-little) (p=.033). Family caregivers with greater involvement reported greater feelings of preparedness (.001). More accepting of caregiving role (p=.025) At 2 mos: family caregivers with greater involvement more accepting of caregivers role (p=.027). Those more involved had less negative reaction to caregiving (p=.04) and reported slightly better scores on general health, but not significant. Comments: Lack of reliability and validity with 1 item measuring preparedness.
Bull, Hansen, & Gross (2000b)	Sample 1: 158 HF caregivers Sample 2: 140 HF caregivers Intervention, before & after nonequivalent control group design	TASK DIFFICULTY/Difficulties managing care. GENERAL HEALTH AND MENTAL HEALTH/subscales of SF 36, α=satisfactory. ADAPTATIONAL OUTCOMES/ Response to Caregiving scale, α ranged from .75 to .90 for subscales.	More than ½ in both control group and intervention group reported difficulty evaluating and managing symptoms following hospitalization. At 2 months, both intervention groups had better general health (p=.05, .001). At 2 wks, intervention group had higher general health perceptions (p=.05) and mental health (p=.046), and less negative reaction to caregivers (p=.015).
Carter, & Acton (2006)	51 cancer caregivers Cross-sectional, descriptive design	DEPRESSIVE SYMPTOMS/ Center for Epidemiological Studies Depression Scale, α= .90. CONTROL-LIKE VARIABLE: MASTERY/Self-Mastery Scale, α= .76.	52% have depressive symptoms. Mastery related to depressive symptoms (r= -.54, p<.001). Other variables related to stress and coping that were examined: optimism, neuroticism, sleep problems.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Chang, Brecht, & Carter (2001)	81 Alzheimers' dyads Correlation, descriptive design	EMOTIONAL RESPONSE/ burden scale of <u>Philadelphia Geriatric Center Caregivers Appraisal Scale (PGAS)</u>, α =.79. APPRAISAL/satisfaction scale of <u>PGAS</u>, α = .72. EMOTIONAL RESPONSE: STRESS/General Severity Index from the <u>Derogatis Brief Symptom Inventory</u>, α = .93(total); α = .83 (depression); α = .81 (anxiety); α = .70 (hostility). SOCIAL SUPPORT/<u>Family Caregiver Support Scale</u> (modified from Norbeck's social support scale), α = .71 to .76.	Difficulty arranging support from friends correlated with negative emotions (r=.38, p<.001); depression (r=.34, p=.002), and appraisal (r= -.28, p=.013). Intensity of contact with social support network members correlated with appraisal (r=.23, p=.035).
Clark, & Dunbar (2003)	32 HF dyads Qualitative design	TASK DIFFICULTY SOCIAL SUPPORT	"Lessons learned". During intervention session, caregivers identified stressors i.e. life style changes (increased time food shopping for low sodium, decreased activities due to patients fatigue, new roles), difficulties with hospitalizations and challenges when returning home, dealing with term 'HF' and its many connotations. Caregivers talked about lack of support and understanding of HF from members of extended family and how this made adherence to lifestyle changes more difficult.
Clark, & King (2003)	22 stroke caregivers and 23 Alzheimer caregivers Comparative, cross-sectional design	DEPRESSIVE SYMPTOMS/<u>Center for Epidemiological Studies Depression Scale</u>, α= .88. PHYSICAL/ PSYCHOLOGICAL WELL-BEING: FATIGUE)/<u>Piper Fatigue Scale</u>, α= .95.	Differences in depressive symptoms between the 2 groups were not significant. 44% of the total group scored ≥16. Fatigue was moderate. Differences between the 2 groups were not significant.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Dracup, Evangelista, Doering, Tullman, Moser, & Hamilton (2004)	69 spouses of patients with HF Cross-sectional correlational design	MENTAL HEALTH, GENERAL HEALTH/subscales of SF36, α=.75 for combined scale. Factor scores based on a principal components analysis of these 2 subscales formed a summary measure of emotional well-being. CONTROL/Control Attitudes Scale, α=.90. EMOTIONAL RESPONSE/ subjective burden scale of Philadelphia Geriatric Center Caregivers Appraisal Scale, α =.84. SOCIAL WELL-BEING/ impact scale of Philadelphia Geriatric Center Caregivers Appraisal Scale, α=.72.	Spouses report significantly lower total mental health and general health scores than age-adjusted norms than general population. Younger spouses reported greater emotional distress (composite score of mental and general health) (p=.001). More negative emotional response (p=.001) and lower control (p=.001) were associated with increased distress (emotional well-being = composite score of mental and general health). Spouses with higher perceived control reported higher emotional well-being than spouses with lover perceived control (p=.003). Comments: Measured 'emotional well-being' using a composite score from the mental health and general health subscales. Questionable validity since the researchers modified scoring of the SF-36. Unable to compare these results with others using SF-36.
Evangelista, Dracup, Doering, Westlake, Fonarow, & Hamilton (2002)	103 HF dyads Prospective, comparative design	EMOTIONAL WELL-BEING/ mental component summary of the SF-12.	Caregivers had higher emotional well-being than patients (p<.001). Female caregivers had lower emotional well-being than male caregivers (NS). High level of association (.649, p<.001) between patients' and caregivers' emotional well-being. Comments: Internal consistency reliability not reported for SF-12. Emotional well-being measured by composite scores which includes social functioning (items reflect changes in social functioning as a result of their own health, not caregiving responsibilities) – may not be valid in this sample.
Faison, Faria, & Frank (1999)	88 caregivers of chronically ill elderly Descriptive, cross-sectional, correlational design	PHYSICAL, PSYCHOLOGICAL, SOCIAL WELL-BEING/Zarit Burden Interview Scale.	ADL and caregivers burden correlated (r=.214, p<.05). Correlations with specific tasks: Bathing, r=.215, p<.05; Transfer, r=.255, p<.05; Continence, r=.269, p<.05 Indirect activities and burden correlated (r=.260, p<.05). Correlations with specific tasks: meal preparation: r=.325, p<.01;

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		CAREGIVING TASKS/<u>Index of Activities of Daily Living</u>.	medicines: r=.237; p<.05; housework: r=.294, p<.05. Sons reported less burden than did daughters or others (extended family, friends, and neighbors). Perceived level of health declined as a result of caregivers responsibilities. Comments: Demographics inconsistent with most studies, only 2.6% wives. No report actual burden score so unable to evaluate level of burden. Burden Scale contains items measuring tasks, behaviors, appraisal, and outcomes; however most of the items are outcome-directed.
Farran, Gilley, McCann, Bienias, Lindeman, & Evans (2004)	295 dementia caregivers Randomized, clinical trial, experimental design	DEPRESSIVE SYMPTOMS/<u>Center for Epidemiological Studies Depression Scale</u>.	Depressive symptoms high in both groups. CES-D scores improved greatly with both interventions, but there was not difference in efficacy between the 2 interventions. Comments: Modified scoring of CES-D from standard method.
Given, Stommel, Collins, King, Given (1990)	159 spousal caregivers of patients with various illnesses Descriptive, cross-sectional with psychometric testing.	PHYSICAL HEALTH and PSYCHOLOGICAL HEALTH measured with 1 item rating overall physical health and 1 item rating overall emotional health at present time. CAREGIVING TASKS measured with 16 items measuring frequency of needing to help with ADL (10 items) and IADL (6 items) tasks on 14 point scale (0=not at all or once a week to 14=several times a day). SOCIAL SUPPORT (affective)/<u>Social Provisions Scale</u>, α=.87. SOCIAL SUPPORT (instrumental) as measured by asking about number of times they received assistance in the past	Psychological (emotional) health associated with negative responses (p<.001). Number of assistances (p<.001) and affective support (p<.001) associated with family abandonment. Number of assistances (p<.05), affective support (p<.05), number of hrs/care (p<.05), involvement in IADL (p<.001), caregivers age (p<.05), emotional health (p<.001), and employment (p<.001). All the patients' characteristics, caregivers' characteristics, and caregivers' environment accounted for 53% of variance for negative responses, 62% of variance for family abandonment, and 51% of variance for impact on schedule. Comments: No report of possible or actual ranges for health scoring or Response to Caregiving Scale making interpretation difficult.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		month from family or friends. ADAPTATIONAL OUTCOMES/ Response to Caregiving Scale (42 item version), all subscale α >.81.	
Given, Stommel, Given, Osuch, Kurtz, & Kurtz (1993)	196 cancer caregivers Descriptive, cross-sectional design	DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale, α= .91. PHYSICAL AND SOCIAL HEALTH/2 subscales of Caregiver Reactions Inventory, α= .77, .84.	Impact on schedule correlated with impact on health (r=.55, p<.01) and depression (r=.56, p<.01). Impact on health correlated with depression (r=.56, p<.01).
Given, Wyatt, Given, Sherwood, Gift, DeVoss, et al. (2004)	152 cancer caregivers Prospective, longitudinal design	DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale, α= .80. SOCIAL WELL-BEING/Caregiver Reaction Inventory, α=.87	Overall high to moderate levels of depressive symptoms. Female caregivers had more depressive symptoms than males. Adult children were higher than the cutoff for depression. Caregivers who were employed and those who were looking for work had more depressive symptoms.
Grant, Bartolucci, Elliot, & Giger (2000)	52 cancer caregivers Descriptive, correlational design	DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale. GENERAL HEALTH/ subscale of SF-36, α=.85, .92. SOCIAL SUPPORT/Interpersonal Support Evaluation List, α=.88 total, .61-.83 for subscales. LIFE SATISFACTION/Life Satisfaction Index Z, α=.71, .76.	37% had depressive symptoms. Caregivers with higher levels of depressive symptoms reported significantly less social support, poorer general health, and less life satisfaction than caregivers with low levels of depressive symptoms. Tangible (actual) social support, life satisfaction, physical functioning were best predictors of depressive symptoms. Comments: Used Caregiver Reaction Assessment which measures self-esteem, family support, impact of caregiving on finances, life schedule, and health. Reported findings as total score only, so unable to integrate in ROL.
Grant, Elliot, Giger, & Bartolucci	40 stroke caregivers Correlational,	SOCIAL SUPPORT/Interpersonal Support Evaluation List.	Moderate personal control, social support, life satisfaction, depressive symptoms. Personal control correlated with depressive

Source	Sample and Design	Variables/ Instruments	Findings and Comments
(2001)	cross-sectional design	PERSONAL CONTROL/subscale of Problem-Solving Inventory. LIFE SATISFACTION/Life Satisfaction Index Z. GENERAL HEALTH/ subscale of SF-36. DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale.	symptoms(r=.54, p<.05), general health (r=-.38, p<.05). Social support correlated with life satisfaction (r=.36, p<.05). Multiple regression predicting caregivers depression: 1st model: Social support accounted for 24% of variance. Personal control accounted for another 13%. 2nd model: personal control accounted for 29%. Social support accounted for another 8%. Comments: Used unconventional method to determine 'moderating' and 'mediating' effects. Multiple regression with small sample size. Internal consistency reliability not reported.
Grant, Weaver, Elliott, Bartolucci, & Giger (2004)	74 stroke caregivers Correlational, cross-sectional design	DEPRESSIVE SYMPTOMS /Center for Epidemiological Studies Depression Scale. SOCIAL SUPPORT/Interpersonal Support Evaluation List. GENERAL HEALTH and MENTAL HEALTH/ subscale of SF-36.	38% exceeded 19 on CES-D. No caregiver or patients characteristics were predictive of depressive symptoms. No variables relevant to present study were predictive of depressive symptoms. Comments: Multiple regression with small sample size. Internal consistency reliability not reported.
Hooley, Butler, & Howlett (2005)	50 HF caregivers Correlational, cross-sectional design	ADAPTATIONAL OUTCOMES/ Zarit Caregiver Burden Interview. DEPRESSIVE SYMPTOMS: Modified Beck Depression Inventory II.	Lower income associated with higher burden. 18% scored >10 indicating clinical depression. Correlated with younger age, greater # of patients meds, and higher burden (r=.61, p<.001). Female caregivers of male patients had more depression than male caregivers of female patients (p<.05),
Hughes, Weaver, Giobbie-Hurder, Manheim, Henderson, Kubal, Ulasevich, Cummings, (2000)	1883 HF or COPD caregivers Randomized, controlled trial, experimental design	PHYSICAL, PSYCHOLOGICAL MENTAL HEALTH/8 subscales and mental component and physical component scales of SF-36. PSYCHOLOGICAL WELL-BEING/ Montgomery Burden Scale.	Moderate level of burden at baseline. Caregivers of CHF or COPD (nonterminal) patients in ttreatment group improved significant in 6 SF-36 dimensions: most pronounced were social fx (p<.001), general health (p<.001), and physical functioning (p<.001) - (only 2 without improvement were physical and emotional role function).

Source	Sample and Design	Variables/ Instruments	Findings and Comments
			Significant benefits in physical (p<.01) and mental component scores (p<.01) scores for caregivers of treatment group of nonterminal patients.
			Caregivers of nonterminal treatment group patients reported a significant decline in objective burden as compared to control (p=.008).
			Comments: Very large randomized sample. COPD and HF results reported together as 'nonterminal', experiences may differ. Internal consistency reliability not reported.
Karmilovich (1994)	41 HF caregivers Correlational, cross-sectional design	CAREGIVING TASKS/Physical care scale of the <u>Caregiving Demands Scale</u>. SOCIAL WELL-BEING/Role alterations scale of the <u>Caregiving Demands Scale</u>.. EMOTIONAL RESPONSE: STRESS/General Severity Index from the <u>Derogatis Brief Symptoms Inventory</u>.	Physical care difficulty fairly low. Role alterations has negative changes. Stress level higher than normative population indicating moderate level of stress. Number of tasks and stress correlated (r=.32, p=.04). Difficulty of task and stress correlated (r=.43, p=.01). Women report performing more tasks (p=.005) and increased difficulty (p=.001). African Americans reported greater difficulty than Caucasians (p=.008). Number of tasks, difficulty of tasks, and stress were NOT related to level of NYHA class or EF. Comments: Actual items not consistent with subscale title, some emotions included, limiting usefulness of results. Internal consistency reliability not reported.
Kershaw, Northouse, Kritpracha, Schafen-acker, & Mood (2004)	189 cancer caregivers Descriptive, cross-sectional design using Lazarus theory of stress.	MENTAL HEALTH/subscale of <u>SF-36</u>, α=.93. GENERAL HEALTH/ subscale of <u>SF-36</u>, α=.86.	Physical health and mental health means lower than US population norms.
Kurtz, Kurtz, Given, & Given (1995)	150 cancer caregivers Longitudinal design	DEPRESSIVE SYMPTOMS/<u>Center for Epidemiological Studies Depression Scale</u>, α= .92,	At time 1, impact on schedule was correlated with impact on health(r=.58, p<.001) and depression (r=.49, p<.001). Caregiver depression correlated with impact on health (r=.54, p<.001).

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		.76. PHYSICAL AND SOCIAL HEALTH/ 2 subscales of <u>Caregiver Reactions Inventory</u>, Time 1 α=.78, .56; Time 2 α=.83, .68.	Comments: Low internal consistency at time 2 with Caregiver Reaction Inventory.
Lee, Brennan, & Daly (2001)	140 caregivers of older adults with various illnesses Descriptive, correlational, cross-sectional design using Lazarus theory of stress.	THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=.89. DEPRESSIVE SYMTPOMS/<u>Center for Epidemiological Studies Depression Scale</u>, α = .79. ADAPTATIONAL OUTCOMES: QOL (LIFE SATISFACTION)/<u>Life Satisfaction Index</u>, α = .79. ADAPTATIONAL OUTCOMES: QOL (PHYSICAL WELL-BEING) measured by single item visual analogue scale ranging from 0 (poor) to 100 (excellent).	Moderate threat appraisal. 27% reported depressive symptoms. Moderate life satisfaction. Fairly good physical health Threat appraisal associated with depression (r=.55, p<.001), life satisfaction (r=-.49, p<.001), and physical health (r=-.34, p<.001). Depressive symptoms associated with life satisfaction (r=-.64, p<.001) and physical health (r=-.32, p<.001). Life satisfaction associated with physical health (r=-.34, p<.001) ADLs (tasks), caregivers age, female, and spouse accounted for 15% of variance in depression (p<.001), 10% in life satisfaction (p<.01), and 12% in physical health (p<.05). Total household income and caregiver education related to lower depression. After income, education, and empathy were entered into the model, benefit, general stress, and threat appraisal accounted for 19% of variance in depression (p<.001), 28% in life satisfaction (p<.001), and 10% in physical health (p<.05).
Lu, & Austrom (2005)	97 dementia caregivers Cross-sectional design	DEPRESSION/ <u>Center for Epidemiological Studies Depression Scale</u>, α= .90. TASK DIFFICULTY/<u>Caregiving Hassle Scale</u>, α= .95. PERCEIVED HEALTH STATUS/<u>Self-Assessed Health Scale.</u> PHYSICAL FUNCTION/<u>Physical function subscale of Functional Status Questionnaire</u>, α= .85.	29% reported depressive symptoms. Those reporting depressive symptoms had higher tasks difficulty than those without depressive symptoms (p<.001). Those with depressive symptoms perceived average health status whereas those with no depressive symptoms perceived better health (p<.001). Those with depressive symptoms perceived worsened physical function than those without depressive symptoms (p<.001). Those with depressive symptoms had more symptoms than those without (p<.001).

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Luttik, Blaauwbroek, Dijker, & Jaarsma (2007)	13 HF caregivers Qualitative design	SYMPTOMS/<u>36-Symptoms Initiated Behavior Checklist</u> SOCIAL SUPPORT EMOTIONAL RESPONSES ADAPTATIONAL OUTCOMES	Comments: Size of groups that were compared were significantly unequal. Changes in life: daily life, joint activities, own life, anxiety. Changes in relationship: positive changes and solidarity, communication, sexuality. Coping: passive coping, active coping, problems with coping. Support: social support, support from professionals.
Luttik, Jaarsma, Veeger, & van Veldhuisen (2005)	38 HF caregivers Descriptive, comparative design.	ADAPTATIONAL OUTCOME: QOL/<u>Cantril Ladder of Life</u>.	Caregivers' QOL was pretty stable, 5.9 (now) to 6.1 (past) to 6.4 (future). Compared to healthy, elderly population HF caregivers scored lower. Comments: No information available about caregivers, i.e. health status.
Mahoney (2001)	12 HF caregivers Qualitative, ethnography design	ADAPTATIONAL OUTCOMES/LIFE CHANGES UNCERTAINTY CAREGIVING TASKS	Family members referred to disruptions and interruptions in the normal course of life, causing disorder. Physical change, emotional change, social, economic, spiritual changes. Referred to incoherence, lack of congruence when an experience does not make sense. Similar to uncertainty. Management of complex disease. Referred to 'struggling' to reconcile the disruptions. Strategies employed by family members to control symptoms: spending endless hours observing their sick family member and attempting to meet their physical needs thru elaborate processes of changing dietary habits, testing recipes, or even knitting "stockings without elastic so his legs won't swell so much". Comments: Findings of patients and family members reported together, difficulty to distinguish which results were pertinent to which group. Potential for response bias due to conjoint reporting. No demographic info available about family members.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Markowitz, Gutterman, Sadik, & Papadopou- los (2003)	2477 Alzheimer's caregivers Descriptive design	MENTAL AND PHYSICAL HEALTH/SF12.	Physical health and mental health mean lower than normative population. Comments: Very large sample size.
Martensson, Dracup, & Fridlund, (2001)	23 HF caregivers Qualitative descriptive design with critical incident technique	SOCIAL SUPPORT ADAPTATIONAL OUTCOME: QOL (SOCIAL WELL- BEING).	Practical help from family, friends, HCP, i.e. being available to assist during an emergency situation, encouraging phone calls, transportation, shopping cleaning, were seen as supportive, helpful, and reassuring. Conversations with persons in similar situations helps with coping. Knowledge about HF and management from HF nurse help prepare the caregivers to provide the care. Someone to call concerning uncertainties – formal (heart failure nurse) and informal (children) social support. Spouse feels like an outsider: kept at a distance by spouse, change in patient's personality resulting in change in relationship. Socially isolated: caregivers tasks interfered with usual activities. Loneliness: non-supportive family or friends, don't want to burden them. Not having someone who understands lead to frustration, irritating (because they have the same expectations re: activity level, etc.). Patient becomes the focus of sympathy … "no one cares about me" (insecurity and disappointment). Lack of inclusion in health care planning, not included in explanations showing a "lack of respect".
Martensson, Dracup, Canary, Fridlund, & (2003)	48 HF caregivers Descriptive, cross-sectional, comparative design	DEPRESSIVE SYMPTOMS/Beck Depression Inventory. ADAPTATIONAL OUTCOMES: QOL (MENTAL & PHYSICAL WELL-BEING) as measured by component scores of SF12.	23% had mild to moderate depression. Reported standardized score for physical and mental QOL. Spouse physical QOL lower than normal. Spouse mental QOL not significantly different than patients which suggests that disease affects the social roles and psychological well-being of married couples equally. Predictors of spouse depression were (younger) age of patients and NYHA class (better funct class r/t higher depression (r= -.34, p<.05) Spouse depression was related to husbands functional class and employment and their own mental QOL. Mental component of

Source	Sample and Design	Variables/ Instruments	Findings and Comments
			spouse QOL and age of patients accounted for 33% of variance in spouse depression.

Comments: Small sample for multiple regression. Internal consistency reliability not reported. |
| Meagher-Stewart, & Hart (2002) | 48 HF caregivers, 48 stroke caregivers

Descriptive, comparative design | EMOTIONAL RESPONSE: STRESS/Cantril Ladder.

QOL (LIFE SATISFACTION)/Life Satisfaction Index Z, α=.71, 79.

SOCIAL SUPPORT/Personal Resources Questionnaire, α=.89, .88. | Few statistical differences were found between the 2 groups. HF caregivers perceived more available support than stroke caregivers (p=.002).

HF caregivers: moderate stress, high perceived support, and moderate life satisfaction.

"Right now, what do you find is the most difficult or stressful part of living with your relatives/friends/ health problem".
1. Potential health crisis of ill person. Reports of constant vigilance and fear of sudden death of the care recipient.
2. Dependency/burden.
3. Role changes.
4. Emotional/mental change in ill person.
5. Physical dysfunction of illness.

Comments: Minimal information presented regarding Personal Resources Questionnaire. |
| Miller, Campbell, Farran, Kaufman, & Davis (1995) | 215 dementia caregivers

Descriptive, cross-sectional, descriptive design using Pearlin's and Lawton's conceptual models of caregiver distress | DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale, α=.90.

TASK DIFFICULTY measured by 12 items asking about amount of distress, effort, or difficulty on 5 point scale (1=little or none to 5=a great deal) for 12 tasks. α=.89.

PHYSICAL HEALTH measured by 1 item rating health (1=poor to 4=excellent).

CONTROL | Task difficulty moderate. No to minimal depressive symptoms. Control-approximately 63% felt control over their lives. A low sense of mastery predicted depressive symptoms (p<.01).

African Americans reported less depressive symptoms.

Comments: No description of instrument measuring control. |

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Molloy et al. (2006)	60 HF caregivers Randomized, controlled, experimental design	OUTCOME: Strain (akin to LIFE CHANGES; <u>Care Work Strain Scale</u>. EMOTIONAL RESPONSE: DEPRESSION/<u>Hospital Anxiety and Depression Scale</u> (depression subscale), α= satisfactory.	Strain was significantly higher at 6 months for exercise group. 86% no depression; 12% possible depression; 2% probable depression in total sample. Between 6 and 14% reported depression as compared to 5% in health population sample. Other: Anxiety in caregivers higher than reported in healthy population.
Murray, Boyd, Kendall, Worth, Benton, & Clausen (2002)	20 HF caregivers. Qualitative design	ADAPTATIONAL OUTCOMES: QOL (SOCIAL WELL-BEING) CAREGIVING TASKS DIFFICULTY	Comments from HF caregivers: Social isolation "I feel like I am in prison in here with him and each day is just like the last". Have to cope with variable symptoms and uncertain course of HF. Major task: effort of balancing and monitoring complex and frequently changing medication regimen and their side effects. Other: Limited understanding of cause and prognosis of HF, rare discussion of end of life issues.
Murray, Kendall, Boyd, Worth, & Benton (2004)	20 HF caregivers. *Same sample as Murray et al. (2002)* Qualitative design	ADAPTATIONAL OUTCOMES: QOL (SPIRITUAL WELL-BEING)	Patients and carers spiritual concerns are characterized by hopelessness, isolation, and altered self-image assoc with chronic illness and disability. Carers struggled with managing their own spiritual needs and knowing how to help a loved one in spiritual distress. Illness trajectory was not predictable: gradual physical decline punctuated by episodes of acute deterioration. Death was sudden, usually unexpected with no distinct terminal phase. HF carers talked more about physical needs and practical problems in their daily lives at home and in maintaining a social life (different than Ca who were struggling with 'dying'). Summary: Different disease trajectories led to different patterns of spiritual needs. HF: isolation, hopelessness and loss of confidence predominated throughout. Comments: Did not differentiate between patients and carers, described findings together. Longitudinal: interviewed over 1 year time span.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Nauser (2005)	21 HF caregivers *Same sample as Bakas, Pressler, et al. (2006)*	TASK DIFFICULTY/difficulty subscale of <u>Oberst Caregiving Burden Scale</u>, α=.92.	General Health: 59.52 (US norm: 71.9). 52% below the norm. Mental Health: 71.81 (US norm: 74.7). 43% below the norm. Task difficulty related to threat appraisal (r=.61, p<.01), life changes (r= -.46, p<.05), mental health (r= -.51, p<.05).
		THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=satisfactory. LIFE CHANGES/<u>Bakas Caregiving Outcome Scale</u>, α=.88. MENTAL and GENERAL HEALTH/subscale of <u>SF-36</u>, α=.93, .86.	Threat appraisal related to (r= -.68, p<.001), mental health (r=-.52, p<.05). Life changes related to mental health (r=.66, p<.001). Other variables studied: Optimism related to threat appraisal (r= -.53, p<.05). Vitality from SF36 correlated with threat appraisal, life changes, general health, and mental health.
Nieboer, Schulz, Matthew, Scheier, Ormel, & Lindenberg, (1998)	127 caregivers patients with various illnesses Descriptive, prospective study using Schulz and Heckhausen life span theory of control and Lindenberg's 2 universal goals.	EMOTIONAL RESPONSE: DEPRESSIVE SYMPTOMS/<u>Depression scale of Hospital Anxiety and Depression Scale</u>, α=.71 at time 1; .79 at time 2. CAREGIVING TASKS measured by number of tasks: 18 items, such as eating, dressing, getting in and out of bed, going to bathroom, shopping, household tasks, meals. Higher scores indicative of more tasks. α=.83 at time 1; .82 at time 2. ADAPTATIONAL OUTCOMES: QOL measured by activity restriction: 40 items, such as attending church, visiting, going for a walk, respondents indicated how often they do these life activities (no, every now and then, weekly, or daily). Of the weekly or	In this subsample, most frequently cited most important activities were reading, watching TV, guests, household tasks, biking, shopping, hobbies, radio, visiting. At time 2, depression correlated with # of caregivers tasks (r=.25, p<.01). Depression higher for the 42% spouses that have at least 4 caregivers tasks at time 2 (p<.05). These caregivers average 1.9 activity restrictions compared to 1.1 for the rest of the sample at time 2 (p<.001). Patients level of physical function decreased significantly (p<.01). Regression analysis showed that activity restriction does mediate the effect of caregivers on depression. Caregivers who experience a decrease in physical function have higher levels of depression symptoms. Predictors of depression: increased tasks, inability to do important life activities (appraisal), decreased patients functioning. Mixed sample, acute illnesses as well as chronic. Results associated with physical function scale may be due to caregivers' own chronic illnesses, not caregiver responsibilities.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		daily activities, respondents select 6 most important life activities. QOL: PHYSICAL WELL-BEING/ Physical functioning scale of <u>SF-36</u>, α=.78 time 1; .85 time 2.	Comments: Longitudinal design with use of multiple regression are strength of this study.
Northouse, Mood, Kershaw, Schafen-acker, Mellon, Walker, et al. (2002)	189 cancer caregivers Descriptive, correlational study using Lazarus theory of stress.	MENTAL HEALTH/subscale of <u>SF-36</u>, α=.80. GENERAL HEALTH/ subscale of <u>SF-36</u>, α=.83. SELF-EFFICACY (akin to CONTROL)/<u>Lewis Cancer Self-Efficacy Scale</u>, α=.96. THREAT APPRAISAL/threat subscale of <u>Appraisal of Caregiving Scale</u>, α=.85. UNCERTAINTY/<u>Mishel Uncertainty in Illness Scale</u>, α=.85.	Education positively related to physical health (r=.22, p<.05). Self-efficacy (control-like) related to appraisal (r=-.59, p<.05) and mental health (r=.40, p<.05). Social support related to appraisal (r=-.29, p<.05) and mental health (r=.23, p<.05). Appraisal related to uncertainty (r=.34, p<.05) and mental health (r=.-52, p<.05). Uncertainty related to mental health (r=-.27, p<.05).
Robinson (1989)	78 Alzheimer's caregivers Descriptive, correlational, cross-sectional design using Kahn and Antonucci's goodness of fit model (1980)	ADAPTATIONAL OTUCOMES: PHYSICAL WELL-BEING, GENERAL HEALTH/<u>Louisville Health Scale</u>, α=.78. SOCIAL SUPPORT/<u>Inventory of Socially Supportive Behavior</u>, α=.72-.87 for total and subscales. EMOTIONAL RESPONSE: DEPRESSION/<u>Center for Epidemiological Studies Depression Scale</u>, α= .94.	Total health fairly high, receive support fairly high, depression mean exceeded cut off score. Social support (actual) NOT related to depression. Total health related to depression (r=-.54, p=.001). Multiple regression: Health accounted for 17% of the variance; attitude (toward asking for help) accounted from 10% of the variance. Received social support accounted for no variance in explaining depression. Comments: Social support is measured by actual support received – may be a moderator as opposed to an antecedent in model in present study.
Rohrbaugh, Cranford, Shoham,	174 HF spousal caregivers	EMOTIONAL RESPONSE: ANXIETY AND DEPRESSION/	39.8% spouses qualified for a distress-related psych diagnosis.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
Nicklas, Sonnega, & Coyne, (2002)	Descriptive, comparative design.	<u>Hopkins Symptoms checklist-25</u>, α=.91-.94. EMOTIONAL RESPONSE/<u>Big 5 personality dimension</u>, α=.82.	Male caregivers had lower distress scores than females (p=.01). Patients' NYHA did correlate with patients' emotional distress (r=.33, p<.05) but did NOT correlate with spouses emotional distress. Female spouses report less emotional stability – more neuroticism than male spouses (p=.03). Comments: Anxiety and depression were reported together as distress, so limited value to present study. Big 5 may measure a person factor (antecedent); unable to determine from limited discussion in the study.
Sanford, Johnson, Townsend-Rocchiccioli, & (2005)	63 caregivers of patients with various illnesses in rural communities Descriptive, correlational design	ADAPTATIONAL OUTCOMES/ <u>Zarit Caregiver Burden Interview</u>, α=.88.	Rural caregivers health: 51% reported chronic illness. Arthritis 27%, heart disease (18%), diabetes (14%), hypertension (14%). 81% experience physical symptoms 1-2 times/ month. Sleep disturbance (49%), fatigue (35%), backache (32%), and headache (29%). Fairly low burden. Perceived stress highly correlated with burden (r=.73, p<.01) and moderately correlated with health risks (r=.50, p<.01). Burden moderately correlated with health risks (r=.47, p<.01). Burden and perceived stress account for 27% of the variance of health risks (p<.05). Both variables contributed to variance significantly. Comments: Not enough information about measures to accurately evaluate findings. Caregiver Burden Interview has 2 items that measure appraisal; most items measure emotional, social, physical financial outcomes.
Schulz, & Beach (1999)	392 caregivers of patients with various illnesses and 427 noncaregivers who were living with spouse	OUTCOME of strain: Caregivers were asked about the degree of mental/emotional and physical strain to provide direct care or arrange for care. Responses were no	81% of spouses with disabled spouses were providing care. 56% of these reported strain. After adjusting for sociodemographic factors and physical health status, caregivers who reported strain had 63%

Source	Sample and Design	Variables/ Instruments	Findings and Comments
	strain, some strain, and a lot of strain.		higher 4 year mortality rate than noncaregivers (p<.05). Comments: Sample size, prospective study and control group were strengths of this study. Strain measured with single item, not sure of participants' level of understanding of what constitutes 'strain'.
Schulz, O"Brien, Bookwala, & Fleissner (1995)	41 studies of dementia caregivers	REVIEW ARTICLE. DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale.	A total of 41 manuscripts were reviewed that focused on caregivers of dementia patients. All of the CES-D means published were elevated well beyond the typical population scores of 7.4-9.4.
Schwarz (1999)	100 caregivers of patients with various illnesses Descriptive, comparative design using Lazarus theory of stress.	EMOTIONAL RESPONSE/ burden scale of Philadephia Geriatric Appraisal Scale (PGAS), α =.84. SOCIAL WELL-BEING/ impact scale of PGAS, α=.72. APPRAISAL/satisfaction scale of PGAS, α = .70. DEPRESSIVE SYMPTOMS/Centers for Epidemiological Studies Depression Scale.	All scales at upper limits indicating more positive experiences. Low depressive symptoms. Gender differences: Impact and caregivers satisfaction significantly different. Men had more positive social well-being outcome (p=.05) and more positive appraisal (p<.01). Relationship to care recipient difference: Spouses had more positive caregivers experience in terms of emotions (p<.005), appraisal (p=.02), outcome of social well-being (p<.001) than children. Depression not significantly different (p=.07). 40% of the variance in depressive symptoms was accounted for by burden, impact, mastery, and satisfaction when taken together (p<.0000). Burden (p<.001) and satisfaction (p<.001) were significant predictors of depressive symptoms. Comments: PGAS subscales measure 4 different caregivers' concepts in the present study. Therefore, the total scores are not relevant to the present study. A 4th subscale, mastery, defined as caregivers perceived ability to perform the duties of the caregivers role well is not related to the concepts in the present study, thus are not reported here.
Schwarz (2000)	60 caregivers of chronically ill with various illnesses	SOCIAL SUPPORT/Modified Version of the Inventory of Socially Supportive	Greater depressive symptomology at Time 2 was related to lower emotional support (r=-.28). But not a significant predictor in regression; depression low in this sample

Source	Sample and Design	Variables/ Instruments	Findings and Comments
	Descriptive, correlational, longitudinal design	Behaviors Scale, α=.63-.83 for subscales. DEPRESSIVE SYMPTOMS/Centers for Epidemiological Studies Depression scale, α= .94.	causing low variance. Other: At Time 2, hospital readmission related to depressive symptomology (r=.24, p<.05), lower tangible support (r=-.24, p<.05), and lower emotional support (r=-.25, p<.05).
Schwarz, & Blixen (1997).	Same sample as Schwarz (1999) (secondary analysis). Descriptive, comparative design using Lazarus theory of stress and Wheaton interactive stress-buffering model of social support	Measured 'appraisal' with PGAS which assesses multiple caregiver concepts. EMOTIONAL RESPONSE/ Caregiver Strain Questionnaire, α= .92. DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale, α = .92.	Depressive symptoms was related to caregivers appraisal (r= -.57), and caregivers perceived health (r=.25) and gender (r= -.34), but p value not reported. Compared caregivers of cognitively impaired to caregivers of non-cognitively impaired. Caregivers strain and depressive symptoms were significantly higher at time 1 and 2 (p<.01, .001). Comments: Appraisal results not related to present study, as the scale measures 4 different concepts within the conceptual model.
Schwarz, & Dunphy (2003)	75 HF caregivers Descriptive, cross-sectional, correlational design	EMOTIONAL OUTCOMES/ Perceived stress scale, α=.86. DEPRESSIVE SYMPTOMS/ Center for Epidemiological Studies Depression Scale, α=.87. SOCIAL SUPPORT/Modified Version Of The Inventory Of Socially Supportive Behaviors Scale, α=.90.	Moderate level of stress. Stress did not differ between spousal and children caregivers. Low depressive symptoms. Moderate social support. Stress significant correlated to depressive symptoms (r=.7, p=.01) but not to social support (r= - .22). Comments: Social support did not moderate the negative effects of stress on depressive symptoms, but participants had high perceived social support
Schwarz, & Elman (2003)	128 HF caregivers Prospective, descriptive, predictive design	EMOTIONAL RESPONSE/ Perceived stress scale, α=.83. DEPRESSIVE SYMPTOMS/Center for Epidemiological Studies Depression Scale, α=.90. APPRAISAL/satisfaction scale of Philadelphia Geriatric Center Caregivers Appraisal	Low perceived stress. Depressive symptoms low, 79% scored < 16 (not depressed) with minority 21% reporting depressive symptoms. Appraisal high with mean of 21.5. Informal social support high. Other: Increased caregivers informal social support greatly reduced the risk of hospital admission. Interaction of caregivers stress & depression increased risk for hospital readmission and patients mortality.

Source	Sample and Design	Variables/ Instruments	Findings and Comments
		scale, α=.86. SOCIAL SUPPORT/Modified Version Of The Inventory Of Socially Supportive Behaviors Scale, α=.92.	Comments: Majority (58%) had poorer function (Class III, IV) yet group overall reported low depression, stress, high appraisal.
Scott (2000).	18 HF caregivers (Patients on inotropic infusions for end-stage HF) Descriptive, exploratory, triangulation design using Wilson-Cleary HRQOL model and Smith's model of caregivers effectiveness	UNCERTAINTY/CONTROL RELATED VARIABLE/Caregiver Preparedness Scale, α=.83. SOCIAL SUPPORT, ADAPTATIONAL OUTCOMES/ Caregiver Reaction Assessment, α reported subscale ranges of .56 to .84. MENTAL HEALTH/mental health scale of SF-36, α=.42. QOL/Quality of Life Index, total α=.92; all subscales α>.70 except socioeconomics.	78% reported that daily activities centered on caring for the recipient. 55% reported eliminating things from schedule or interruptions to provide care. 39% reported constant fatigue. 33% financial difficulties. As a result of caregiving, 61% perceived no health status change, 28% health decline. 50% reported anxiety, 45% depression, 39% despondency over the last 4 weeks. 72% had mental health scores below normative values for general population, 89% below normative value for their age norm. Greatest satisfaction from spirituality, friends, family; moderate dissatisfaction with employment status, travel restrictions, lifestyle changes and stress of caregivers. Mental well-being of caregivers, combined with esteem of caregivers, accounted for 49% of variation in caregivers health-related quality of life. Caregivers' preparation accounted for 32% of variance in impact of care provision (impact on finances, health, and schedule), number of caregivers tasks explained an additional 36% of the remaining variation. Comments: Conducted multiple regression with very small sample. Internal consistency reliability for mental health subscale and CRA health subscale unacceptable.

Brief Description of Instruments

36-Symptoms Initiated Behavior Checklist: 36 items that measure physical and
psychological distress symptoms with sum of 36 items with 0 (no) and 1 (yes). Possible

range of 0-36. Few (1-10), moderate (11-20), many (21-36). If present, rated seriousness from 0 (not serious) to 2 (serious). Severity scale summed with less serious (1-16), mod serious (17-39), and more serious (40 and over).

Appraisal of Caregiving Scale: 12 items with 5 point scale (1=strongly disagree to 5=strongly agree) about appraisal of caregiving situation as threatening and potentially harmful to well-being.

Bakas Caregiving Outcomes Scale: 7 point scale (1=changed for the worse to 7=changed for the best) about social functioning, subject well-being, and somatic health.

Beck Depression Inventory: 21 items on 4 point scale (0=absence to 3=severe symptoms) measures somatic (5 items), nonsomatic symptoms (16 items). Possible range 0-63, 0-9: minimal, 10-16: mild, 17-29: mod, 30-63: severe. (Modified) Version; 20 items with yes/no responses. Range of 0-20, score of 10 or higher indicative of clinical depression.

Big 5 Personality Dimension: 20 items on 9 point scale (1=extremely inaccurate to 9=extremely accurate).

Cantril Ladder of Life: assesses global well-being. Respondents rate their sense of well-being on a 10 point scale (0=worse possible life to 10=best possible life) at 3 points in time: now, 1 month prior and 3 years in the future.

Care Work Strain Scale: 13 items with 7 point response scale measures changes in life as a result of caregiving, possible range of 13-91.

Caregiver Preparedness Scale: 8 items on 4 point scale.

Caregiver Reaction Assessment: 24 items to measure 5 dimensions of caregiver esteem (7), impact on schedule (5), lack family support (5), impact on caregiver health (4), and impact on finances (3) on 5 point scale (1=strongly agree to 5=strongly disagree).

Caregiver Reactions Inventory: Health subscale-5 items, measures how caregiving impacts physical health. Schedule subscale-5 items, measures how caregiving impacts usual schedule. All items scored with 5 point response scale (1=strongly disagree to 5=strongly agree). Scored by averaging the 5 items.

Caregiver Strain Questionnaire: 48 items for 3 subscales: exhaustion (30 items), emotional arousal (12 items), and discrepancy with ideal states (6 items). Scores range 16-210.

Caregiving Demands Scale: 31 items (subscales: meals/feeding, intimate care, walking/transfers, treatments, supervision/responsibility). Measures caregivers' actions/behaviors and perceived level of difficulty. Role alterations scale of the Caregiving Demands Scale; 11 items (subscales: work participation, social participation,

interpersonal relationships). Measures caregivers' actions/behaviors and perceived level of difficulty.

Caregiving Hassle Scale: 42 items on a 5 response scale (0=it did not happen to 4=a great deal or much hassle). 5 subscales: assistance in basic ADL (9 items), assistance in IADL (7 items), care-recipient's cognitive status (9 items), care-recipient's behavior (12 items), and caregiver's social network (5 items). Possible range of 0-178; low 1-40, moderate 41-80, high 81-122.

Carer Strain Index: 14 items, positive response to 7 or more items indicates strain.

Center for Epidemiological Studies Depression Scale: 20 items on 4 point scale (0=rarely to 3=most or all of the time). Possible range of 0-60. Cutoff of 16=depression.

Control Attitude Scale: 4 items with 7 point scale (1 = not at all in control to 7 = very much in control).

Cognitive Status Scale: 8 items with 5 point scale (1=can't do at all to 5=not at all difficult) about memory loss, communication deficits, and recognition failures.

Derogatis Brief Symptom Inventory: 53 items, 5 point scale (0=not at all to 4=extremely).

Difficulties managing care: 13 items, number and type of difficulties experienced in managing care.

Family Caregiver Support Scale (modified from Norbeck's social support scale): 16 items with 5 point scale (0=not at all difficult to 4=extremely difficult).

Functional Status Questionnaire (physical function subscale): sum of 7 items with 3 point scale (1=usually did with no difficulty to 3=usually did with much difficulty).

Geriatric Depression Scale: 5 items scale.

Hopkins Symptoms checklist-25: consists of anxiety (10) and depression (15) items from the standard 58 item on a 4 point scale from (1=not at all to 4=extremely). Can be calculated as 2 scores and total score is highly correlated with severe emotional distress; scores > 43 qualify for 'caseness', psychiatric dagnosis.

Hospital Anxiety and Depression Scale (Depression subscale): 7 items and 4 point response scale ranging from 0 to 3. Range 0-21 with higher scores indicating more depression.

Index of Activities of Daily Living: 6 items which assess degree of physical care required by patients. (a=no assistance needed, b=minor, c=major assist needed).

Interpersonal Support Evaluation List: 30 dichotomous items measuring perceived availability of someone to talk to about problems (appraisal), people to do things with (belonging), and material aid (tangible support). Lower scores = greater support.

Inventory of Socially Supportive Behavior: 40 items measuring frequency of receiving socially supportive behaviors on 5 point scale (1=not at all to 5=everyday). 7 items were added to physical help section, factor analysis showed 3 factors: Direct Guidance, 15 items; Physical Help, 10 items; Affection, 3 items.

Inventory of Socially Supportive Behaviors Scale (Modified Version): 9 items that measure tangible benefits that are provided or to be provided by family for friends on a 4 point scale (1=never to 4=very often). Possible range 9-36.

Lewis Cancer Self-Efficacy scale: 17 items that measure confidence in managing the effects of cancer.

LIFE-3: 1 item for global well-being, asked at 2 points in an interview/survey, 7 point scale (1=terrible to 7=delighted).

Life Satisfaction Index Z: 13 items which measure of general well being, zest, self-concept, mood, tone, congruence between desired and achieved goals, and meaning of life on a 5 point scale (1=strongly disagree to 5=strongly agree). Possible range 13-65.

Louisville Health Scale: 5 items measuring physical well-being, overall health and functional health on a 4 point scale (1=never to 4=frequently). Summed to total 'health score'.

Mishel Uncertainty in Illness Scale for family members: 30 items that measures degree of uncertainty over their family member's illness on 5 point scale (1=strongly disagree to 5=strongly agree). Possible range 30-150.

Montgomery Burden Scale: 14 items which examine subjective demand (4 items, overly demanding), subjective stress (4 items, emotional impact) and objective (6 items, infringement on lifestyle) burden. Possible range 14-70.

Oberst Caregiving Burden Scale: 15 items with 5 point scale (1=not difficult to 5=extremely difficult) about direct, instrumental, and interpersonal caregiving tasks.

Perceived Stress Scale: 14 items that assess the degree that situations are appraised stressful (perception of their lives as unpredictable, uncontrollable, and overloading) on a 5 point scale from (0=never to 4= very often). Possible range of 0-56.

Personal Resources Questionnaire: measures situational (estimate of interpersonal support in hypothetical situations, whether the situation occurred, level of satisfaction) and perceived available social support (positive and negative perceptions about functions of social support). Highest possible 7.

Philadelphia Geriatric Center Caregivers Appraisal Scale (PGAS): 11 items measuring worry, anxiety, frustration on 5 point scale (1=never /disagree a lot to 5=nearly always/ agree a lot). Possible range=13-65, higher scores more positive. Satisfaction scale: 5 items measuring benefits of caregivers such as receiving pleasure when the patients is pleased on a 5 point scale (1=never or disagree a lot to 5=nearly always or agree a lot). Possible range 9 to 45, higher scores more positive. Social scale: 6 items measuring infringement on caregivers lifestyles on 5 point scale (1=never or strongly agreed to 5=nearly always or strongly disagreed). Possible range 6 to 30, higher scores more positive.

Piper Fatigue Scale: 22 items measuring behavior or severity (6 items), affective meaning (5 items), sensory (5 items), and cognitive or mood (6 items) on a 10 point scale. Items are summed then divided by 22 with a possible range of 0-10.

Primary Health Questionnaire-9: 9 items with 4 point scale (0=not at all to 3=nearly every day) that correspond with DSM IV depressive criteria. Possible range 0-27, level of severity can be described as none (score 1 to 4), mild (5 to 9), moderate (10-14), moderately severe (15-19), and severe (20-27).

Profile of Mood States Short Form: 30 items on 5 point scale (1=not at all to 5 extremely). 6 subscales of 5 items each: tension/anxiety, depression/ dejection, anger/hostility, vigor/ activity, fatigue/inertia, confusion/ bewilderment.

Psychosocial Adjustment to Illness Scale: 46 questions in 7 domains (# of items): health care orientation (8), vocational environment (6), domestic environment (8), sexual relationships (6), extended family relationships (5), social environment (6), psychological distress (7). 4 point response scale of 0 (no disturbance) to 3 (extreme distress). Total scores and domain scores are calculated.

Quality of Life Index: 36 items, measures satisfaction and importance with 4 domains: health/functioning, family, socioeconomic, psychological/ spiritual (2 items disease specific and were omitted for caregivers).

Response to Caregiving Scale: 21 items with 3 subscales (impact on schedule, negative reaction to caregiving, impact on finances). A 4th subscale, acceptance of caregivers role, maybe antecedent).

Self-Assessed Health Scale: sum of 3 items: assessment of current health in 4 levels (excellent, good, fair, or poor), evaluating health compared to 5 yrs prior (better, about the same, worse), evaluating health compared to what one wants (not at all, a little, or a great deal).

Self-Mastery Scale: 7 items on 5 point scale (1=strongly agree to 5=strongly disagree), assesses the extent to which individuals generally feel they manifest personal mastery over life outcomes.

SF-12 (Mental component summary): 5 items that measure vitality, social functioning, role limitations, and mental health.

SF-36 (General health and mental health subscale): 5 items on a 5 point scale for each.

Social Provisions Scale: 8 items on 4 point scale (1=strongly agree to 4=strongly disagree).

Zarit Burden Interview Scale: 22 items on 5 point scale (0=never to 4=nearly always). Possible range 0-88. Burden defined by authors as "extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative".

APPENDIX B

Institutional Review Board Approvals

DATE: August 23, 2006

TO: Tamilyn Bakas
                  Adult Health
                  NU 417
                  IUPUI

FROM: Tara Bateman
                  Research Compliance Administration

SUBJECT: Final Approval

Study Number: 0606-68
Study Title: Family Caregivers of Heart Failure Patients
Sponsor: N/A

The study listed above has received final approval from the Institutional Review Board (IRB-04). IMPORTANT NOTICE: The Institutional Review Board (IRB) requires that the consent statement given to subjects have the IRB approval stamp on the last page – OR – include information regarding granting of waivers.

Please note that although this study has been granted final approval by the IRB, special requirements apply if the principal investigator becomes aware that an individual enrolled on the study either is a prisoner or has become a prisoner during the course of his/her study participation (and the study has not been previously granted approval for the enrollment of prisoners as a subject population). In such cases, all research interactions and interventions with the prisoner-participant must cease and if it is wished to have the prisoner-participant continue to participate in the research, Research Compliance Administration (RCA) must be notified immediately. In most cases, the IRB will be required to re-review the protocol at a convened meeting before any further research interaction or intervention may continue with the prisoner-participant. Refer to the IUPUI/Clarian Standard Operating Procedure (SOP) on *Involving Prisoners in Research* for further information.

As the principal investigator of this study, you assume the responsibilities as outlined in the SOP on *Responsibilities of Principal Investigators*, some of which include (but are not limited to):

1.   CONTINUING REVIEW - A status report must be filed with the Board. The Research Compliance Administration (RCA) staff will generate these reports for your completion. This study is approved from **August 22, 2006 to August 22, 2007.**

2.   STUDY AMENDMENTS - You are required to report on these forms ANY changes to the research study including protocol design, dosages, timing or type of test performed, population of the study, and informed consent statement. An amendment form can be obtained on our website. See link http://www.iupui.edu/~resgrad/spon/amendment-irb.htm.

3.   UNANTICIPATED PROBLEMS INVOLVING RISKS TO SUBJECTS OR OTHERS AND NONCOMPLIANCE - You must report to the IRB any event that appears on the **List of Events that Require Prompt Reporting to the IRB.** Refer to the SOP on "Unanticipated Problems Involving Risks to Subjects or Others and Noncompliance" for more information and other reporting requirements. The SOP can be found at: http://www.iupui.edu/~respoly/human-sop/human-sop-index.htm. NOTE: If the study involves gene therapy and an adverse event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).

4.   UPDATED INVESTIGATIONAL BROCHURES, PROGRESS REPORTS and FINAL REPORTS - If this is an investigational drug or device study, updated clinical investigational brochures must be submitted as they occur. See link http://www.iupui.edu/%7Eresgrad/spon/cibrequire.htm for requirements. Three copies of progress or final reports must be provided to the Board with your written assessment of the report, briefly summarizing any changes and their significance to the study.

5.   ADVERTISEMENTS - If you will be advertising to recruit study participants for a drug or device study regulated under FDA requirements, i.e., investigational drugs or devices will be used, and the advertisement was not submitted to the Board at the time your study was reviewed, a copy of the information contained in the advertisement and the mode of its communication must be submitted to the reviewing board as an amendment to the study. These advertisements must be reviewed and approved by the Board PRIOR to their use.

6.   STUDY COMPLETION – You are responsible for promptly notifying the IRB when the study has been completed. This is done by contacting RCA staff to request that a continuing review report be generated for your completion within 90 days after termination or completion of the investigation or the investigator's part of the investigation.

7.   LEAVING THE INSTITUTION - If the principal investigator leaves the Institution, the Board must be notified as to the disposition of EACH study.

PLEASE REFER TO THE ASSIGNED STUDY NUMBER AND THE EXACT TITLE IN ANY FUTURE CORRESPONDENCE WITH OUR OFFICE. In addition, SOPs exist which cover a variety of topics that may be relevant to the conduct of your research. See link http://www.iupui.edu/~respoly/human-sop/human-sop-index.htm. All documentation related to this study must be neatly typed and must also be maintained in your files for audit purposes for at least three years after termination of the research; however, please note that research studies subject to HIPAA may have different requirements regarding file storage after termination. If you have any questions, please call RCA at 274-8289.

Enclosures: ☒ Documentation of Review and Approval   ☐ Advertisement(s)
                    ☒ Expedited Review Checklist   ☐ Authorization form(s)
                    ☐ Informed Consent Statement(s)   ☐ Other:

Research
Medical Center™
Your HCA Midwest Hospital

Date: September 5, 2006

To: Julie Nauser, Indiana University School of Nursing Doctoral Student
             Assistant Professor, Research College of Nursing

From: Phyllis Vos, Chairperson
             Institutional Review Committee, Research Medical Center

Study Title: Family Caregivers of Heart Failure Patients

The study listed above has received final approval from the Institutional Review Committee
(IRC) at Research Medical Center in Kansas City, Missouri. The study can be carried out as
approved by the Institutional Review Board at Indiana University Purdue University in
Indianapolis.

You are responsible for promptly notifying the IRC when the study has been completed.

Phyllis Vos, Chairperson

MENORAH MEDICAL CENTER™

Your HCA Midwest Hospital

Date: January 16, 2007

To: Julie Nauser, Indiana University School of Nursing Doctoral Student
              Assistant Professor, Research College of Nursing

From: Julie Iseman, Chairperson
              Institutional Review Committee, Menorah Medical Center

Study Title: Family Caregivers of Heart Failure Patients

The study listed above has received approval from the Institutional Review Committee (IRC) at Menorah Medical Center in Overland Park, Kansas. The registered nurses who have direct contact with patients with chronic heart failure and/or their family caregiver will distribute information about the study. Interested family caregivers will notify the investigator directly to provide their contact information.

The investigator is responsible for promptly notifying the IRC when data collection has ended at Menorah Medical Center.

Julie Iseman, Chairperson

Saint Luke's Hospital of Kansas City

SAINT LUKE'S HEALTH SYSTEM

saintlukeshealthsystem.org
Institutional Review Board – 816-932-3661

Malcolm Baldrige
National
Quality
Award
Saint Luke's Hospital
2003 Award
Recipient

February 16, 2007

Jacqueline Smith, BSN, RN
Department of Cardiovascular Research
Mid America Heart Institute
Saint Luke's Hospital
4401 Wornall Road
Kansas City, MO 64111

RE: Family Caregivers of Heart Failure Patients

Dear Ms. Smith:

I have reviewed the above-referenced research protocol, and in my opinion, your project fulfills requirements of federal regulations which classifies this type of research activity as "EXEMPT" from committee review.

It appears that the only role of MidAmerica Heart Institute/Saint Luke's Hospital personnel will be to distribute recruitment information to potential subjects. No direct contact is to be made with Saint Luke's Hospital patients or their caregivers, and no direct contact information is to be provided to investigators. I have found the recruitment letter and return postcard acceptable for distribution.

Therefore, as long as the protocol is not altered in any way that would involve directly contacting Saint Luke's Hospital patients or bring the work under the provisions that necessitate full review by the Saint Luke's Hospital IRB, I declare this research exempt from review, and you may proceed with distribution of the recruitment letter and postcard to heart failure patients and their caregivers at MidAmerica Heart Institute/Saint Luke's Hospital.

This information will be presented to the Institutional Review Board at the March 9, 2007 meeting.

Sincerely,

Alan Forker, MD, Chair
Institutional Review Board

:M

4401 Wornall Road, Kansas City,   Phone: (816) 932-2000

Saint Luke's Health System is an Equal Opportunity Employer. Services are provided on a nondiscriminatory basis.

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APPENDIX C

Recruitment Letters

A Research Study: Family Caregivers of Heart Failure Patients

Conducted over the Telephone by
Julie Nauser, MSN, RN, Doctoral Student
Indiana University School of Nursing

Dear Caregiver,

Providing care to a family member or friend with chronic heart failure can be difficult. As the cardiologist for your family member or friend, I am writing to tell you about a study for caregivers of persons with heart failure.

The purpose of the study is to learn more about how providing care to your family member or friend affects your life. The study involves a telephone interview scheduled at a time convenient for you. You will be asked a series of questions about your experiences as a caregiver.

What does the study involve?
$\Rightarrow$ About an hour of your time
$\Rightarrow$ A telephone interview
$\Rightarrow$ Answering questions about your experiences as a caregiver
$\Rightarrow$ You will receive a $10 Target gift card as a token of appreciation

In the next few days, a nurse will call you to see if you are interested and eligible to take part in the study. To find out more, you can complete the response card attached to this letter which is already stamped and addressed to Julie Nauser, MSN, RN or call (913) 488-6244. **If you know you do not want to take part in the study, call Julie Nauser and let her know and she will not contact you again.**

Taking part in this study is completely up to you. The care of your family member will not be affected at all by your decision.

Sincerely,

A Research Study: Family Caregivers of Heart Failure Patients

Conducted over the Telephone by
Julie Nauser, MSN, RN, Doctoral Student
Indiana University School of Nursing

Dear Caregiver,

Providing care to a family member or friend with chronic heart failure can be difficult. As the heart failure nurse clinician for your family member or friend, I am writing to tell you about a study for caregivers of persons with heart failure.

The purpose of the study is to learn more about how providing care to your family member or friend affects your life. The study involves a telephone interview scheduled at a time convenient for you. You will be asked a series of questions about your experiences as a caregiver.

What does the study involve?
⇒ About an hour of your time
⇒ A telephone interview
⇒ Answering questions about your experiences as a caregiver
⇒ You will receive a $10 Target gift card as a token of appreciation

In the next few days, a nurse will call you to see if you are interested and eligible to take part in the study. To find out more, you can complete the response card attached to this letter which is already stamped and addressed to Julie Nauser, MSN, RN or call (913) 488-6244. **If you know you do not want to take part in the study, call Julie Nauser and let her know and she will not contact you again.**

Taking part in this study is completely up to you. The care of your family member will not be affected at all by your decision.

Sincerely,

A Research Study: Family Caregivers of Heart Failure Patients

Conducted over the Telephone by
Julie Nauser, MSN, RN, Doctoral Student
Indiana University School of Nursing

Dear Caregiver,

Providing care to a family member or friend with chronic heart failure can be difficult. As a member of the heart failure team for your family member or friend, I am writing to tell you about a study for caregivers of persons with heart failure.

The purpose of the study is to learn more about how providing care to your family member or friend affects your life. The study involves a telephone interview scheduled at a time convenient for you. You will be asked a series of questions about your experiences as a caregiver.

What does the study involve?
⇒ About an hour of your time
⇒ A telephone interview
⇒ Answering questions about your experiences as a caregiver
⇒ You will receive a $10 Target gift card as a token of appreciation

To find out more, you can complete the response card attached to this letter which is already stamped and addressed to Julie Nauser, MSN, RN or call (913) 488-6244. You will be contacted by Julie once she receives your completed response card.

Taking part in this study is completely up to you. The care of your family member will not be affected at all by your decision.

Sincerely,

APPENDIX D

Informed Consent Statement

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Family Caregivers of Heart Failure Patients

More people are living with heart failure than ever before. Many of these people rely on family members or close friends to help them. A family caregiver is someone who helps them at home with their care. Very little is known about how providing care affects the lives of these family caregivers.

STUDY PURPOSE:

The purpose of this study is for research, specifically 1) to test a new survey developed to measure quality of life of heart failure caregivers and 2) to learn about factors that impact caregivers' experiences. The results of this research study will be used to develop programs to support caregivers of patients with heart failure. Since you are involved in the care of a family member or close friend with heart failure, you are invited to take part in this study.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to take part in the study, you will be one of approximately 100 family caregivers who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will be contacted by telephone by the investigator at a time convenient for you. During this telephone call, which will last about 1 hour, you will be asked questions about your quality of life, health and well-being, and about the things you do to help the heart failure patient. Any long distance telephone fees will be paid by the investigator at no cost to you. You will receive a Target gift card for $10.00 for participating in the research study. There is an opportunity to take part in a follow-up telephone interview during which you will be asked questions about your quality of life, which should last about 15 minutes. Should you decide to participate in the follow-up telephone interview, you will receive an additional Target gift card for $10.00.

RISKS OF TAKING PART IN THE STUDY:

There is minimal psychological risk in that some parts of the study may focus on negative emotions or negative experiences while providing care. Participating in the study may remind some caregivers of their own situations that may be stressful or upsetting. You may choose not to answer items or participate in portions of the study that you are uncomfortable with, although all items and portions of the study are important. Choosing not to answer items or participate in portions of the study may result in you being withdrawn from the study by the investigator. You may withdraw from the study yourself at any time since participation in the study is completely voluntary. There are no anticipated physical, social, legal, or other potential risks connected with the study.

In the event of extreme psychological distress, such as severe depression or suicidal thoughts, you will be encouraged to contact the 24-hour Mental Health Crisis Line 888-279-8188, or any resource from where you typically receive care. In the event of suicidal thoughts, the investigator may notify a health care provider on your behalf so he/she can contact you to determine if treatment is necessary.

Subject's Initials _____
ICS August 10, 2006

BENEFITS OF TAKING PART IN THE STUDY:

One benefit to taking part in this study is knowing that you will be helping to provide much needed information that will be used to support family caregivers of heart failure patients.

ALTERNATIVES TO TAKING PART IN THE STUDY:

The only alternative to taking part in this study is to not take part in it. You may decide not to do the telephone interviews with the investigator. The care of you or your family member with heart failure will not be affected in any way by your decision to take part or to not take part in this study.

CONFIDENTIALITY:

Your name or the heart failure patient's name will not be used in the study. Your telephone number, address, and other personal information used to contact you for the interviews and to issue your gift cards will be stored in a separate place from the interview questionnaires. All information from the study will be stored in locked file cabinets, and will only be available to authorized study personnel. Any computer files related to the study will be protected by a password only given to authorized study personnel. No personal information or names will be used to identify you or the heart failure patient when we look at the data. Your name or personal information or the heart failure patient's name or personal information will not be used in the final report, or in any articles or publications from the study. Authorized study personnel will include the investigators and research staff involved in the study. Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or it's designees, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP). All information for the study will be provided by you, the caregiver. No medical records will be accessed or used in the study.

COSTS OF TAKING PART IN THE STUDY:

In the unlikely event of physical or psychological injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled. There will be no research-related costs to you for participation in the study. All long-distance telephone fees, postage, and written materials mailed to you for the study will be paid for by the investigator.

PAYMENT:

Another benefit to taking part in this study is that you will receive a $10 Target gift card for each telephone interview. It is possible to earn a total of $20 in Target gift cards if you participate in both telephone interviews. A $10 Target gift card will be mailed to you right after each telephone interview that you complete with the investigator.

Subject's Initials _____
ICS August 10, 2006

CONTACTS FOR QUESTIONS OR PROBLEMS:

Subjects may call Julie Nauser at 913-488-6244 or Dr. Tamilyn Bakas 317-274-4695 for questions about the study or to report research-related injuries. If you cannot reach the investigators during regular business hours (8:00 AM – 5:00 PM), please call the IUPUI/Clarian Research Compliance Administration office at 317-278-3458 or 800-696-2949. If you experience emotional distress, you may contact the 24-hour Mental Health Crisis Line at 888-279-8188, or any resource from where you typically receive care. For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at 317-278-3458 or 800-696-2949.

VOLUNTARY NATURE OF STUDY:

You don't have to be in this study, and you can say "no" to the interviews at anytime. Your participation is completely voluntary. Your decision about whether or not to be in this study will not affect the quality of health care that you or your family member receives now or in the future.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to participate in this research study.
I acknowledge receipt of a copy of this informed consent statement.

SUBJECT'S SIGNATURE:_____Date:_____

SIGNATURE OF PERSON OBTAINING CONSENT:_____Date:_____
(Person explaining consent over the telephone)

NOTE TO CAREGIVER: PLEASE INITIAL EACH PAGE OF THE INFORMED CONSENT AT THE BOTTOM WHERE IT SAYS, "SUBJECT'S INITIALS."

IRB Approval Date: AUG 22 2006
Continuing Review Date: AUG 22 2007

Subject's Initials_____
ICS August 10, 2006

APPENDIX E

Interview Guide

Heart Failure Family Caregivers
Interview Guide

<u>Caregiver and Patient Characteristics – Demographics Form</u>

This group of questions will provide us with important information about you and the person you provide care for. Please answer the following questions.

1. What is your age? _____

2. What is the heart failure patient's age? _____

3. What is your gender?

    _____ Male
    _____ Female

4. What is the heart failure patient's gender?

    _____ Male
    _____ Female

5. What is your ethnicity and race?
    _____ Hispanic or Latino
    _____ Not Hispanic or Latino

    _____ American Indian or Alaska Native
    _____ Asian
    _____ Black or African American
    _____ Native Hawaiian or other Pacific Islander
    _____ White
    _____ Unknown or Other: Please specify _____

6. What is the heart failure patient's ethnicity and race?

    _____ Hispanic or Latino
    _____ Not Hispanic or Latino

    _____ American Indian or Alaska Native
    _____ Asian
    _____ Black or African American
    _____ Native Hawaiian or other Pacific Islander
    _____ White
    _____ Unknown or Other: Please specify _____

7. How many years of education have you had including grade school, middle school, high school (12 years), technical or business school, or college?

_____ Years

8. How many years of education has the heart failure patient had including grade school, middle school, high school (12 years), technical or business school, or college?

_____ Years

9. What is your relationship with the heart failure patient?

_____ Spouse
_____ Son or Daughter
_____ Son or Daughter Inlaw
_____ Other relative: Please specify _____
_____ Friend
_____ Other: Please specify _____

10. Since they were diagnosed with heart failure, how long have you been providing care for the heart failure patient?

_____ Years   _____ Months   _____ Day

11. On the average how many hours per week do you help the heart failure patient?

_____ Hours per week

12. Do you currently live in the same home as the heart failure patient?

_____ Yes
_____ No

Where is the heart failure patient currently living?

_____ House
_____ Apartment
_____ Assisted living facility
_____ Other: _____

13. Considering your household income from all sources (today), would you say that you are:

          _____ Comfortable
          _____ Just have enough to make ends meet
          _____ Do NOT have enough to make ends meet

14. What is your current employment status?

          _____ Employed full-time
          _____ Employed part-time
          _____ Homemaker
          _____ Retired
          _____ Unemployed
          _____ Other: Please specify _____

15. Did you have to quit a job or take early retirement in order to provide care for the heart failure patient?

          _____ Yes
          _____ No

16. Do you have any of the following health problems? Check all that apply.

    _____ Heart disease
    _____ Myocardial infarction (heart attack)
    _____ Heart failure
    _____ Cerebrovascular Accident (stroke)
    _____ Hemiplegia from CVA or other reason
    _____ Peripherial vascular disease (poor circulation legs)
    _____ Hypertension (high blood pressure)
    _____ Diabetes (high blood sugar)
    _____ Cancer (Leukemia, Lymphoma, skin, breast, prostate, other)
                 _____Specify type of cancer
    _____ Arthritis (osteoarthritis, rhumatoid arthritis)
    _____ Chronic obstructive pulmonary disease (emphysema or lung disease)
    _____ Renal disease (kidney disease)
    _____ Kidney Dialysis
    _____ Ulcer disease (gastric reflux, gastric ulcer)
    _____ Chronic hepatitis or cirrhosis (liver disease)
    _____ Asthma
    _____ Headaches
    _____ Chronic pain
    _____ Alzheimers disease or other form of dementia
    _____ Other: _____

17. Does the heart failure patient have any of the following health problems? Check all that apply.

_____ Heart disease
_____ Myocardial infarction (heart attack)
_____ Cerebrovascular Accident (stroke)
_____ Hemiplegia from CVA or other reason
_____ Peripherial vascular disease (poor circulation legs)
_____ Hypertension (high blood pressure)
_____ Diabetes (high blood sugar)
_____ Cancer (Leukemia, Lymphoma, skin, breast, prostate, other)
_____Specify type of cancer
_____ Arthritis (osteoarthritis, rhumatoid arthritis)
_____ Chronic obstructive pulmonary disease (emphysema or lung disease)
_____ Renal disease (kidney disease)
_____ Kidney Dialysis
_____ Ulcer disease (gastric reflux, gastric ulcer)
_____ Chronic hepatitis or cirrhosis (liver disease)
_____ Asthma
_____ Headaches
_____ Chronic pain
_____ Alzheimers disease or other form of dementia
_____ Other: _____

18. Does the heart failure patient have an implanted ventricular assist device?

_____ Yes
_____ No

19. How would you describe the heart failure patient's symptoms with activities?

_____ No symptoms with activity
_____ Symptoms with moderate activity
_____ Symptoms with minimal activity
_____ Symptoms at rest

Heart Failure Cognitive Status Scale

This group of questions is about the heart failure patient's memory and the difficulty they may have doing some things. Circle the level of difficulty for the patient to do the following:

1.	Remember recent events.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
2.	Know what day of the week it is.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
3.	Remember (his/her) home address.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
4.	Remember words.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
5.	Understand simple instructions.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
6.	Find (his/her) way around the house.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
7.	Speak sentences.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult
8.	Recognize people that (he/she) knows.	Can't do at all	Very difficult	Fairly difficult	Little difficulty	Not at all difficult

<u>Medical Outcomes Study Social Support Survey</u>

People sometimes look to others for companionship, assistance, or other types of support.

About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind?

Write in number of close friends and close relatives: _____

How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
Emotional/informational support					
1. Someone you can count on to listen to you when you need to talk	1	2	3	4	5
2. Someone to give you information to help you understand a situation	1	2	3	4	5
3. Someone to give you good advice about a crisis	1	2	3	4	5
4. Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
5. Someone whose advice you really want	1	2	3	4	5
6. Someone to share your most private worries and fears with	1	2	3	4	5
7. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
8. Someone who understands your problems	1	2	3	4	5
Tangible support					
9. Someone to help you if you were confined to bed	1	2	3	4	5
10. Someone to take you to the doctor if you needed it	1	2	3	4	5

11. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
12. Someone to help with daily chores if you were sick	1	2	3	4	5

Affectionate support

13. Someone who shows you love and affection	1	2	3	4	5
14. Someone to love and make you feel wanted	1	2	3	4	5
15. Someone who hugs you	1	2	3	4	5

Positive social interaction

16. Someone to have a good time with	1	2	3	4	5
17. Someone to get together with for relaxation	1	2	3	4	5
18. Someone to do something enjoyable with	1	2	3	4	5

Additional item

19. Someone to do things with to help you get your mind off things	1	2	3	4	5

Oberst Caregiving Burden Scale – Difficulty Subscale

This group of questions is about the tasks and activities that you do to help the heart failure patient. For each of the following activities, please mark how difficult each activity is for you to do.

		Not Difficult	Slightly Difficult	Moderate Difficult	Very Difficult	Extremely Difficult
1.	Medical or nursing treatments (giving medications, skin care, dressings, etc.).	1	2	3	4	5
2.	Personal care (bathing, toileting, getting dressed, feeding, etc.)	1	2	3	4	5
3.	Assistance with walking, getting in and out of bed, exercises, etc.	1	2	3	4	5
4.	Emotional support, "being there" for the patient.	1	2	3	4	5
5.	Watching for and reporting the patient's symptoms, watching how the patient is doing, monitoring the patient's progress.	1	2	3	4	5
6.	Providing transportation or "company" (driving, riding along with patient, going to appointments, driving patient around for errands, etc.)	1	2	3	4	5
7.	Managing finances, bills, and forms related to the patient's illness.	1	2	3	4	5
8.	Additional household tasks for the patient (laundry, cooking, cleaning, yard work, home repairs, etc.).	1	2	3	4	5
9.	Additional tasks outside the home for the patient (shopping for food and clothes, going to the bank, running errands, etc.)	1	2	3	4	5
10.	Structuring/planning activities for the patient (recreation, rest, meals, things for the patient to do, etc.).	1	2	3	4	5
11.	Managing behavior problems (moodiness, irritability, confusion, memory loss, etc.)	1	2	3	4	5

12. Finding and arranging someone to care for the patient while you are away.	1	2	3	4	5
13. Communication (helping the patient with the phone, writing or reading, explaining things, trying to understand what the patient is trying to say, etc.).	1	2	3	4	5
14. Coordinating, arranging, and managing services and resources for the patient (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help.	1	2	3	4	5
15. Seeking information and talking with doctors, nursing and other professional health care workers about the patient's condition and treatment plans.	1	2	3	4	5

Mishel © Uncertainty in Illness Scale for Family Members

This group of questions is about the level of uncertainty you might feel regarding your family member's illness. Place an X under the column that most closely measures how you are feeling about your family member today.

1. I don't know what is wrong with my family member.

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 family member's 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 family member's pain will be.

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

5. The explanations they give me about my family member seem hazy to me.

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

6. The purpose of each treatment for my family member is clear to me.

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

7. I do not know when to expect things will be done to my family member.

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

8. My family member's symptoms continue to change unpredictably.

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

9. I understand everything explained to me.

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

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

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

11. I can predict how long my family member's illness will last.

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

12. My family member's treatment is too complex to figure out.

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

13. It is difficult to know if the treatments or medications my family member is getting are helping.

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

14. There are so many different types of staff, it's unclear who is responsible for what.

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

15. Because of the unpredictability of my family member's illness, I cannot plan for the future.

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

16. The course of my family member's illness keeps changing. He/she has good and bad days.

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

17. It's vague to me how I will manage the care of my family member after he/she leaves the hospital.

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

18. It is not clear what is going to happen to my family member.

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

19. I usually know if my family member is going to have a good or bad day.

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

20. The results of my family member's tests are inconsistent.

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

21. The effectiveness of the treatment is undetermined.

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

22. It is difficult to determine how long it will be before I can care for my family member by myself.

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

23. I can usually predict the course of my family member's illness.

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

24. Because of the treatment, what my family member can do and cannot do keeps changing.

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

25. I'm certain they will not find anything else wrong with my family member.

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

26. They have not given my family member a specific diagnosis.

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

27. My family member's physical distress is unpredictable; I know when it is going to get better or worse.

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

28. M family member's diagnosis is definite and will not change.

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

29. I can depend on the nurses to be there when I need them.

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

30. The seriousness of my family member's illness has been determined.

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

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

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

Control Attitude Scale

This group of questions is about the level of control you feel over your family member's heart condition. Rate your level of agreement with the statement by circling the number that most closely corresponds to how you feel about your family member's condition.

1. Regarding your family member's heart problems, how much control do you feel?

1	2	3	4	5	6	7
Not at all in control						Very much in control

2. Do you feel that you could take the right steps if your family member were to have an emergency related to his/her heart?

1	2	3	4	5	6	7
Not at all						Very much

3. Regarding your family member's heart problems, how helpless do you feel?

1	2	3	4	5	6	7
Not at all helpless						Very helpless

4. Regarding your family member's heart problems, how helpless do you think he/she feels?

1	2	3	4	5	6	7
Not at all helpless						Very helpless

Appraisal of Caregiving – Threat Subscale

This group of questions represents feelings, beliefs, or attitudes that someone like yourself might have about providing care for a family member with heart failure.

Please think about your own situation in providing care for the heart patient in the future. Circle the number that indicates how much you agree or disagree with each of the statements below.

		Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1.	This situation will be stressful for me in the future.	1	2	3	4	5
2.	I feel things are going to get worse for me.	1	2	3	4	5
3.	I will not be going very well with this situation in the future.	1	2	3	4	5
4.	I worry that I will not be able to meet all my responsibilities.	1	2	3	4	5
5.	I worry that I'll have to give up a lot of things in the future.	1	2	3	4	5
6.	I am afraid that in the future I will not have the energy and endurance I have now.	1	2	3	4	5
7.	This situation will threaten to overwhelm me.	1	2	3	4	5
8.	I am afraid my own physical health will begin to suffer.	1	2	3	4	5
9.	I worry that I will not be able to help the patient in the future.	1	2	3	4	5
10.	I worry that my emotional health will begin to suffer.	1	2	3	4	5
11.	I am concerned that this situation will cause financial hardship for me in the future.	1	2	3	4	5
12.	I am not sure I can handle this situation in the future.	1	2	3	4	5

Primary Health Questionnaire-9

This group of questions asks about various symptoms that you might be experiencing. Circle the number that most closely corresponds with the frequency of these symptoms for you.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed, or the opposite—being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3

Bakas Caregiving Outcomes Scale

This group of questions is about the possible changes in your life from providing care for the heart patient. For each possible change listed, circle one number indicating the degree of change.

As a result of providing care for the heart failure patient:	Changed for the worst			Did not change			Changed for the best
1. My self esteem	-3	-2	-1	0	+1	+2	+3
2. My physical health	-3	-2	-1	0	+1	+2	+3
3. My time for family activities	-3	-2	-1	0	+1	+2	+3
4. My ability to cope with stress	-3	-2	-1	0	+1	+2	+3
5. My relationship with friends	-3	-2	-1	0	+1	+2	+3
6. My future outlook	-3	-2	-1	0	+1	+2	+3
7. My level of energy	-3	-2	-1	0	+1	+2	+3
8. My emotional well-being	-3	-2	-1	0	+1	+2	+3
9. My roles in life	-3	-2	-1	0	+1	+2	+3
10. My time for social activities with friends	-3	-2	-1	0	+1	+2	+3
11. My relationship with my family	-3	-2	-1	0	+1	+2	+3
12. My financial well-being	-3	-2	-1	0	+1	+2	+3
13. My relationship with the heart patient	-3	-2	-1	0	+1	+2	+3
14. My physical functioning	-3	-2	-1	0	+1	+2	+3
15. My general health	-3	-2	-1	0	+1	+2	+3

Heart Failure Family Caregiver-Specific Quality of Life Scale

This group of questions is about how providing care to the heart failure patient has affected your life. Circle the number that most closely corresponds with your level of agreement.

As a caregiver,	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
1. I seem to get sick more often.	1	2	3	4	5
2. I eat healthy foods like I should.	1	2	3	4	5
3. I feel guilty for not providing better care to my family member.	1	2	3	4	5
4. I am able to cope with my family member's health problems.	1	2	3	4	5
5. I am overwhelmed.	1	2	3	4	5
6. I worry about my family member's health.	1	2	3	4	5
7. I feel manipulated by the family member I take care of.	1	2	3	4	5
8. I feel selfish when considering my own needs.	1	2	3	4	5
9. I am supported by health care providers.	1	2	3	4	5
10. My friends are supportive of me.	1	2	3	4	5
11. Other family members are supportive of me.	1	2	3	4	5
12. My spiritual needs are being met.	1	2	3	4	5
13. I have a good relationship with the family member I take care of.	1	2	3	4	5

Because of caregiving,

14. I am tired.	1	2	3	4	5

15. My physical health has suffered.	1	2	3	4	5
16. I am strained physically.	1	2	3	4	5
17. I have body aches and pains.	1	2	3	4	5
18. I feel depressed.	1	2	3	4	5
19. I am more sad than usual.	1	2	3	4	5
20. I feel down in the dumps.	1	2	3	4	5
21. I am stressed.	1	2	3	4	5
22. I am angry.	1	2	3	4	5
23. I am anxious.	1	2	3	4	5
24. I am strained emotionally.	1	2	3	4	5
25. I cry a lot.	1	2	3	4	5
26. I am socially isolated.	1	2	3	4	5
27. I have financial problems.	1	2	3	4	5
28. My life is passing me by.	1	2	3	4	5

Even though I am a caregiver,

29. I am able to take care of my physical needs.	1	2	3	4	5
30. I still have time to take care of my health problems.	1	2	3	4	5
31. I am still able to exercise like I want.	1	2	3	4	5
32. I am able to get to my own checkups with doctors, dentists, and other health care providers.	1	2	3	4	5
33. I get a good night's sleep.	1	2	3	4	5

34. I am in control of my life.	1	2	3	4	5
35. I am able to participate in enjoyable activities.	1	2	3	4	5
36. I am able to spend time with friends.	1	2	3	4	5
37. I am okay financially.	1	2	3	4	5
38. I am able to maintain personal relationships with others.	1	2	3	4	5
39. I am able to practice religious activities if I want to.	1	2	3	4	5
40. I still have time for other family members.	1	2	3	4	5

Caregiving…

41. Adds to my purpose or mission in life.	1	2	3	4	5
42. Adds to my feelings of inner strength.	1	2	3	4	5
43. Gives me a sense of inner peace.	1	2	3	4	5
44. Is a blessing to me.	1	2	3	4	5
45. Makes me happy.	1	2	3	4	5
46. Gives meaning to my life.	1	2	3	4	5

As a caregiver,	Very Poor	Poor	Average	Good	Excellent
47. My physical well-being is	1	2	3	4	5
48. My psychological well-being is	1	2	3	4	5
49. My social well-being is	1	2	3	4	5
50. My spiritual well-being is	1	2	3	4	5
51. My overall quality of life is	1	2	3	4	5

Medical Outcomes Study 36-Item Short Form Health Survey-General Health Scale

This group of questions asks for your views about your health.

1. In general, would you say your health is: (Circle one)

   Excellent ………………………………………………………….. 1
   Very good ………………………………………………………… 2
   Good ……………………………………………………………… 3
   Fair ……………………………………………………………... 4
   Poor ……………………………………………………………... 5

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
2. I seem to get sick a little easier than other people.	1	2	3	4	5
3. I am as healthy as anybody I know.	1	2	3	4	5
4. I expect my health to get worse.	1	2	3	4	5
5. My health is excellent.	1	2	3	4	5

Medical Outcomes Study 36-Item Short Form Health Survey-Mental Health Scale

This group of questions is about how you feel and how things have been with you during the past 4 weeks.

How much of the time in the past 4 weeks:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have you been a very nervous person?	1	2	3	4	5	6
Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
Have you felt calm and peaceful?	1	2	3	4	5	6
Have you felt downhearted and blue?	1	2	3	4	5	6
Have you been a happy person?	1	2	3	4	5	6

APPENDIX F

Suicide Protocol

Family Caregivers of Heart Failure Patients
Suicide Protocol
6/23/06

Suicide guide triggered by caregiver expressing thoughts about being better off dead or of hurting themselves in some way.
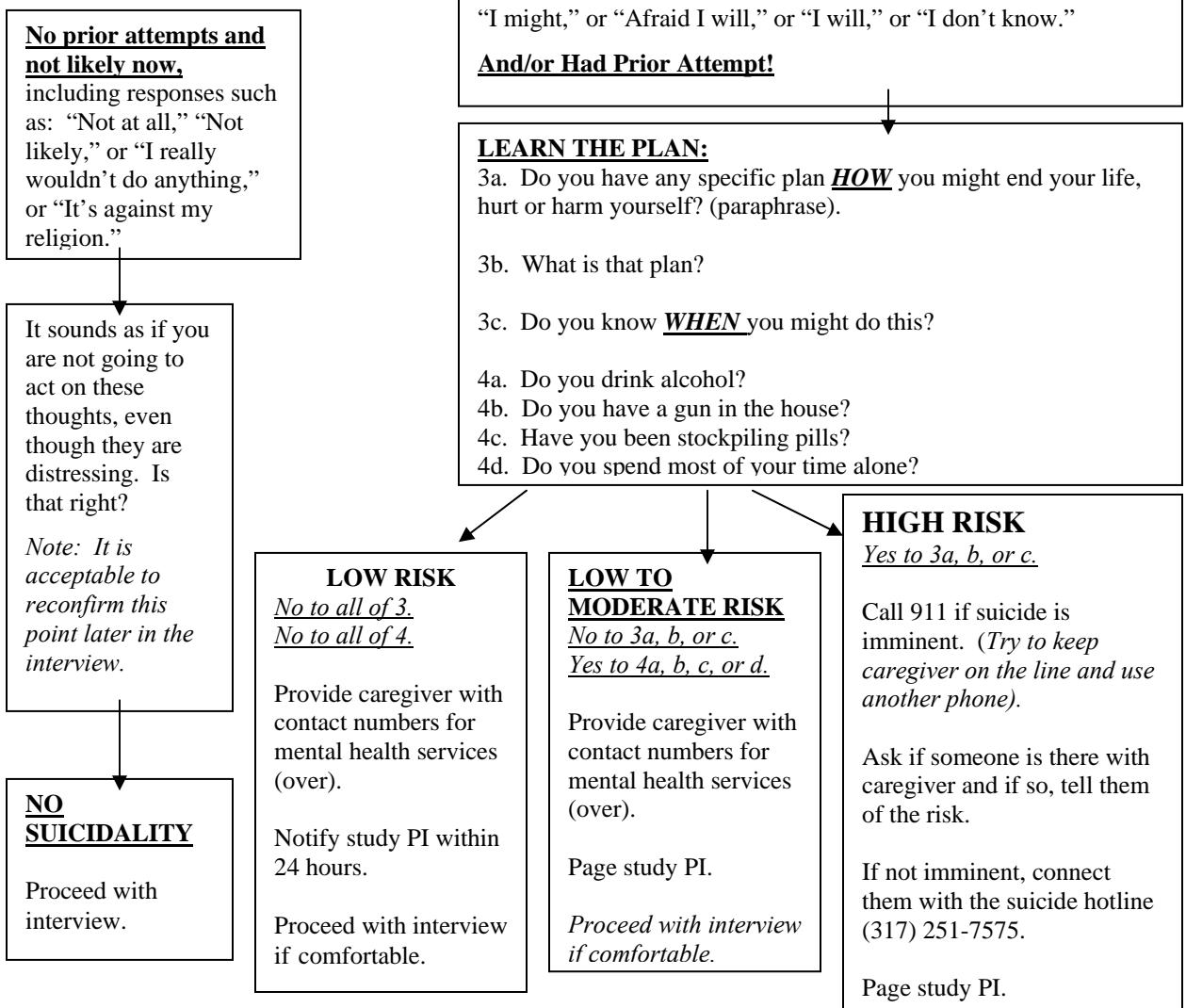
1. You mentioned you… (paraphrase their suidical trigger: "had thoughts about being better off dead," "ending your life," "hurting yourself")… could you tell me more about that? (open ended, regardless of response, proceed to question 2. _____
   _____
   _____

2. How likely is it that you might do something? (to hurt yourself? End your life?) _____

3. Have you ever tried to hurt or harm yourself in the past? (learn when, what, how, hospitalized, enter any details here and on back of form). _____
   _____

NO TO BOTH QUESTIONS 2 & 3   **YES OR UNCLEAR TO QUESTIONS 2 OR 3**

No prior attempts and not likely now, including responses such as: "Not at all," "Not likely," or "I really wouldn't do anything," or "It's against my religion."

It sounds as if you are not going to act on these thoughts, even though they are distressing. Is that right?

Note: It is acceptable to reconfirm this point later in the interview.

NO SUICIDALITY

Proceed with interview.

"I might," or "Afraid I will," or "I will," or "I don't know."

And/or Had Prior Attempt!

LEARN THE PLAN:
3a. Do you have any specific plan **_HOW_** you might end your life, hurt or harm yourself? (paraphrase).

3b. What is that plan?

3c. Do you know **_WHEN_** you might do this?

4a. Do you drink alcohol?
4b. Do you have a gun in the house?
4c. Have you been stockpiling pills?
4d. Do you spend most of your time alone?

LOW RISK
No to all of 3.
No to all of 4.

Provide caregiver with contact numbers for mental health services (over).

Notify study PI within 24 hours.

Proceed with interview if comfortable.

LOW TO MODERATE RISK
No to 3a, b, or c.
Yes to 4a, b, c, or d.

Provide caregiver with contact numbers for mental health services (over).

Page study PI.

Proceed with interview if comfortable.

HIGH RISK
Yes to 3a, b, or c.

Call 911 if suicide is imminent. (*Try to keep caregiver on the line and use another phone*).

Ask if someone is there with caregiver and if so, tell them of the risk.

If not imminent, connect them with the suicide hotline (317) 251-7575.

Page study PI.

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If script triggered by phone call:

1. If plan is specific and imminent, have a colleague call 911. Important in this case to also determine if the caregiver is alone. If not, do ask to talk to the person that is with the patient and make them aware of the risk.

2. If risk is unclear, ask if caregiver would like to talk with a crisis counselor immediately and transfer to Mental Health Crisis Line (888) 279-8188.

3. If not high risk, provide the caregiver with the telephone number for Mental Health Crisis Line (888) 279-8188 or any other resource from where they typically receive care. A list of other mental health resources is below. Determine that continuing with interview is OK with caregiver and switch back to the previous questionnaire.

4. Contact the PI to determine whether contact with a health professional on a caregiver's behalf is necessary.

Johnson County Mental Health Center
      After Hours Emergency (913) 384-3535
      Mission Office (913) 831-2550
      Olathe Office (913) 782-2100
ReDiscover Mental Health and Substance Abuse Services Intake/Crisis – 24 hours (816) 966-0900
Wyandot Mental Health Center
      After Hours Emergency (913) 831-1773
      Central Office (913) 831-0024
Western Missouri Mental Health Center (816) 512-4030
National Hopeline Network 1-800-SUICIDE or 1-800-784-2433 (24 hours/7 days)

Study Number: _____
Date and Time: _____
PI Contacted: _____
911, Suicide Hotline, or Health Professional Contacted: _____
_____
_____

APPENDIX G

Permission to Use Instruments

Permission to use BCOS, ACS, OCBS

Dear Julie,

You have my permission to use the Bakas Caregiving Outcomes Scale in
your research with family caregivers of persons with heart failure.
Attached are the most current background and scoring information for the
scale. I also understand that you want to use the Oberst Caregiving
Burden Scale and the Appraisal of Caregiving Scale as well. Dr. Oberst
has given me permission to distribute her scales to those who wish to
use them for research purposes. A copy of each of these scales is
attached as well. Let me know if you have any questions or comments
related to these scales.

Best wishes on your research,

Tami

Tamilyn Bakas, DNS, RN, FAHA

Associate Professor

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Fax (317) 278-1856

Email tbakas@iupui.edu

Permission to use CAS

From: Moser, Debra [mailto:dmoser@email.uky.edu]
Sent: Wednesday, September 07, 2005 11:48 AM
To: Nauser, Julie
Subject: RE: Questions about Control Attitudes Scale

Hi Julie,

Interesting research area! Of course, you can use that scale. Regarding your question about the 4th item -- we always use all of the items, particularly when there is a definite family member (as there will be in your study). You are right that perceptions may not always match reality or that one member of hte dyad may feel in control while the other feel totally out of control -- however, it is the perception that matters, not the reality....and many people's sense of control begins to be threatened (at least a little) when people around them feel out of control. Our best psychometrics and most reliable performance of the scale comes when it is used in families so I think you will have good results -- I look forward to hearing your outcomes -- Debra

Debra K. Moser, DNSc, RN, FAAN
Professor and Gill Chair of Nursing
Editor, *The Journal of Cardiovascular Nursing*
University of Kentucky, College of Nursing
527 CON Building, 760 Rose Street
Lexington, KY 40536-0232
phone 859-323-6687
fax 859-257-5959
dmoser@uky.edu

Permission to use PHQ-9

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The measure is free to use clinically and for research. Consider this e-mail your
permission

Kurt Kroenke, MD
Professor of Medicine
Indiana University School of Medicine
Research Scientist, Regenstrief Institute
Ph  317-630-7447  (Donna)
Fax 316-630-6611
```

Request Form – PPUS-FM

I request permission to copy the Parents' Perception of Uncertainty in Illness Scale Family Member Form for use in my research entitled,

Family Caregiving in Heart Failure

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study a printout of the uncertainty data on a 3.5 inch disk containing the data with the data dictionary. The data on each subject's response to each item on the *Uncertainty Scale.* This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. Credit will be give to me in any reports referring to my findings.

Julie A. Nauser
October 29, 2005

Position and full address of Investigator

Julie A. Nauser, MSN, RN
Doctoral Nursing Student – IUSON
11403 W. 105 Terrace
Overland Park, KS 66214

Permission is hereby granted to copy the PPUS-FM for use in the research described above.

Merle Mishel
11/2/05

Please send two signed copies of this form to Merle H. Mishel, PhD, FAAN; School of Nursing, CB #7460 Carrington Hall, University of North Carolina, Chapel Hill, NC, 27599-7460

APPENDIX H

16-Item HFCQL Scale

16-Item Heart Failure Family Caregiver-Specific Quality of Life Scale

This group of questions is about how providing care to the heart failure patient has affected your life. Circle the number that most closely corresponds with your level of agreement.

As a caregiver,	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
52. I seem to get sick more often.	1	2	3	4	5
53. I am overwhelmed.	1	2	3	4	5
54. I feel selfish when considering my own needs.	1	2	3	4	5

Because of caregiving,

55. I am tired.	1	2	3	4	5
56. My physical health has suffered.	1	2	3	4	5
57. I am strained emotionally.	1	2	3	4	5
58. I am socially isolated.	1	2	3	4	5

Even though I am a caregiver,

59. I am still able to exercise like I want.	1	2	3	4	5
60. I am able to get to my own checkups with doctors, dentists, and other health care providers.	1	2	3	4	5
61. I am able to participate in enjoyable activities.	1	2	3	4	5
62. I am able to maintain personal relationships with others.	1	2	3	4	5
63. I am able to practice religious activities if I want to.	1	2	3	4	5

Caregiving…

64. Adds to my purpose or mission in life.   1   2   3   4   5

65. Adds to my feelings of inner strength.   1   2   3   4   5

66. Gives me a sense of inner peace.   1   2   3   4   5

67. Gives meaning to my life.   1   2   3   4   5

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Weitzner, M.A., McMillan, S.C., & Jacobsen, P.B. (1999). Family caregiver quality of

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    Stroke, 36, 635-638.

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Yen, M., & Lo, L. (2002). Examining test-retest reliability: An intraclass correlation approach. *Nursing Research, 51*(1), 59-62.

CURRICULUM VITAE
Julie Ann Nauser

Education	Indiana University – Indianapolis Doctor of Philosophy in Nursing Science with Nursing Education Administration minor October 2007
	University of Missouri – Kansas City Master of Science in Nursing August 1993
	Rockhurst University/ Research College of Nursing Kansas City, Missouri Bachelor of Science in Nursing May 1984
Employment Status	Traditional BSN Program Director/ Assistant Professor, Research College of Nursing Kansas City, Missouri

Professional Experience

Traditional BSN Program Director	2007-Present Responsible for managing the operations and providing leadership in the execution of the traditional undergraduate nursing program for approximately 220 students. Facilitate advising and monitor progression and retention of students. Collaborate with faculty across all levels to ensure effective implementation of curriculum.
Assistant Professor of Nursing	1993-Present Provide theory and clinical instruction in sophomore and junior level nursing courses, Pathophysiology, Pharmacology, and Adult Health Nursing.
Cardiac Rehabilitation Nurse Clinician Research Medical Center Kansas City, Missouri	1989-1993 Directed outpatient care of cardiac patients in exercise center

Assistant Head Nurse	1987-1989
Research Medical Center	Coordinated care of inpatient cardiac patients on a 40 bed unit. Responsible for day-to-day activities and staffing.

Staff Nurse	1984-1987
Research Medical Center	Provided direct patient care for cardiac patients.

Presentations and Professional Activities

Presentation "Findings from Heart Failure Family Caregiver Study" at Mid-America Heart Institute Heart Failure Team luncheon meeting. August, 2007; Kansas City, Missouri.

Presentation "Family Caregiving in Heart Failure: Task difficulty, Uncertainty, Depression, and Life Changes" at 42nd Annual Bixby Cardiology Symposium. April 2007; Kansas City, Missouri.

Bakas, T., Pressler, S.J., Johnson, E.A., Nauser, J.A., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research, 55*(3), 180-188.

Presentation "Family Caregiving in Heart Failure" at Annual Research Scholarship Day. April 2005; Kansas City, Missouri.

Presentation "Teaching Thinking: Using Concept Maps for Clinical Instruction". Research College of Nursing Faculty. January 2004.

Research project "Comparing Teaching Strategies for Undergraduate Pharmacology". Poster presentation at AACN National Conference in November 2002. Podium presentation for Research College of Nursing Faculty. August 2002.

Presentation "Teaching the Adult Learner: Discharge Needs of the Cardiac Client". Health Midwest Employees - Baptist Medical Center. April 1999.

Awards and Grants

Chancellor's Scholar at Indiana University-Purdue University Indianapolis. May 2007.

Who's Who among Students in America's Universities and Colleges. May 2007.

Recipient of Graduate Student Nurse Research Grant ($2600) to study family caregiving in heart failure. November 2006.

Research College of Nursing Junior Teacher of the Year in 2005 and Sophomore Teacher of the Year in 2007, 2006, 2002, and 1999.

Recipient of Teaching Excellence Award presented by Research College of Nursing. May 2004.

Nominated to Research College of Nursing Alumni Hall of Fame. November 2003.

Recipient of Presidential Grant ($4000) to study effectiveness of various teaching strategies in undergraduate pharmacology. January 2002.

Service to Research College of Nursing

Admission, Progression, Graduation Committee Member. July 2007 to present.

Rockhurst University Strategic Planning Committee Member. December 2006 to present.

Curriculum Committee Member. August 1998 to present (Chairperson 1999 to 2003).

College Recruitment. 1998 to present.

Scholarly Affairs Committee Member. August 2003 to July 2007.

Service to the Community

Member of Cardiac Arrest Response Team at Church of the Resurrection. November 2005 to present.

Volunteer at Sheffield Place, residential program for homeless women and their children. 2000 to 2003.

Volunteer at Rose Brooks Center, homeless shelter for abused women. 1999 to 2000.

Professional Conferences

AACN Leadership of Academic Nursing Programs. August 2007 to present.
AACN Faculty Development Conference. February 2007.
AHA Scientific Sessions. Fall 2005 and 2006.
NLN Education Summit. September 2004.
MNRS Annual Conference. March 2004.
The Future of Aging. December 2002.
AACN Baccalaureate National Conference. November 2002.

Workforce Challenges and Solutions. June 2001.
Teaching and Learning in Web-Based Courses. January 2001.
AACN Baccalaureate Education Conference. December 2000.
AAHE Conference on Assessment. June 2000.
Exploring Differences in the Workplace. February 2000.

Professional Organizations

American Nurse's Association
Missouri Nurse's Association
American Heart Association – Professional Membership
Midwest Research Nursing Society
Sigma Theta Tau Nursing Society – Lambda Phi Chapter
Research College of Nursing Honor Society