PHYSICAL AND EMOTIONAL HEALTH AMONG CAREGIVERS OF HEART FAILURE PATIENTS

Suzanne D. Chubinski

Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Doctor of Philosophy
in the School of Nursing
Indiana University

August 2007

Accepted by the Faculty of Indiana University, in partial
fulfillment of the requirements for the degree of Doctor of Philosophy.

Susan J. Pressler, DNS, RN

Janet Welch, DNS, RN

Doctoral
Committee

Rebecca Sloan, PhD, RN

June 18,
2007

Silvia Bigatti, PhD

ACKNOWLEDGMENTS

I would like to thank Dr. Susan Pressler, my advisor and committee chairperson for her consistent support, encouragement, generosity, patience, and sense of humor in gently helping me grow as a researcher and scholar.

I would like to thank the members of my dissertation committee, Dr. Janet Welch, Dr. Rebecca Sloan, and Dr. Silvia Bigatti for their support and encouragement of my research ideas, their flexibility, and patience.

I would like to acknowledge Dr. Pizlo, Jim, Kelly, Tina, George, Joan, and the rest of clinic staff that readily embraced and accepted me in the clinic. I would also like to acknowledge Susanne for her dedication, attention to detail, reliability, perseverance, and sense of humor.

I would like to acknowledge Kristie for always being there for me and my phone calls and Dr. Sloan for her support at just the right time in just the right place.

I would like to thank all the caregivers and the HF patients for generously and candidly sharing their lives with me and trusting that I can make a difference for them through this research.

I would also like to thank Bernice, Illiad, all the friends, supporters, exercise buddies, prayer partners, students, and USF family members who have prayed and encouraged me in all different ways for years through this process.

And lastly and most importantly, I would like to thank God for the opportunity to take this journey, my immediate family for their patience, assistance, support, inspirational cards, and repeated sacrifice. I could not have done this without you!

ABSTRACT

Suzanne D. Chubinski

Physical and Emotional Health of Caregivers of Heart Failure Patients

Caregiving has been associated with negative psychological and physical consequences for years (Molloy, Johnston, & Witham, 2005). Some research indicates that caregivers with higher perceived control may experience fewer negative consequences of caregiving (Wallhagen, 1993). Little is known about caregivers of heart failure patients.

The primary purpose of this study was to test a conceptual model of caregiver outcomes among caregivers of heart failure patients. Testing of the model determined which of the demographic and biological factors of the caregiver (age, gender, anxiety, depressive symptoms, and comorbidity), the patient (NYHA class), caregiver burden (task time and task difficulty), and perceived control explained caregiver emotional and physical health. The secondary purpose was to determine the influence of the same caregiver, patient, and burden factors on caregiver perceived control. Perceived control was hypothesized to mediate caregiver burden and caregiver outcomes.

A descriptive design with cross-sectional data collection was used among 63 caregivers of patients with heart failure. The proposed model of caregiving outcomes was partially supported by the data. Stepwise regression analysis indicated caregiver burden (task difficulty), depressive symptoms, and age were significant explanatory variables of emotional health ($R^2 = .43$). Anxiety and caregiver burden (task time) explained 23% of the variance in emotional health. Depressive symptoms, caregiver age, caregiver comorbidity, and patient NYHA class were significant explanatory variables of physical health (R^2 = .35). Caregiver burden-time and depressive symptoms were significant in the regression model for caregiver perceived control (R^2 = .30, F = 4.05, p = .005). The data also suggested that perceived control may have a mediator role between caregiver burden and caregiver emotional health. Further prospective, longitudinal studies with larger more diverse samples are warranted to confirm these results along with the use of reliable valid scales applicable to the caregiver of HF patient population.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

CHAPTER 1
THE NATURE OF THE STUDY

Introduction

Chronic heart failure (HF) is one of the most common chronic progressively debilitating disorders. In the United States, it is estimated to affect over five million people with an estimated additional 550,000 new cases annually (American Heart Association [AHA], 2007). The incidence is estimated to affect 10 persons for every 1,000 over the age of 65 with the lifetime risk of one in five (AHA, 2007). There is no known cure and it is associated with high mortality rates, frequent hospitalizations, and declining quality of life for Americans (AHA, 2006). It is associated with a 12-month mortality rate of 15% and a five-year mortality rate of 50% (AHA, 2003). According to Rich, it is the major reason for acute hospitalization for the elder adult and the most significant cause of disability in older Americans (1997).

As the disease progresses, it is common for the patient to experience diminished physical, psychological, cognitive, and social functioning (Bennett & Sauve, 2003; Freedland & Carney, 2000). As heart failure worsens, home management of HF requires a complex and ever changing program of balancing medications, diet, and implanted devices with activity and symptoms. The goals of reduction of mortality, prevention of unplanned hospitalizations, control of symptoms of dyspnea, fatigue, edema, and anxiety, and maintenance of physical and psychosocial wellbeing can be a daily challenge for the aging patient. As the patient ages and the disease progresses, the patient remains at home and most often relies on family caregivers for increasing assistance.

The patient requires a dynamic medical and self-care regimen of diet, drugs, and exercise that is constantly adjusted according to the patient’s fluctuating symptoms.

Patients usually require the caregiver to gradually take over physically taxing activities such as home maintenance, driving, shopping, and eventually even personal care such as bathing, dressing, toileting and assistance with ambulation due to declining ability and tolerance. Patients may develop cognitive deficits that are difficult for the caregiver. Other common complications of HF can arise such as ventricular or atrial arrhythmias or mood alterations that add complexity. Frequent hospitalizations are common in the later stages which add uncertainty as are implantable devices such as pacemakers, defibrillators or ventricular assist devices which add complexity.

In addition, it is commonplace for the older patient to have other systemic diseases such as hypertension and diabetes. In Mahoney's study (2001), the HF patients averaged 2.7 other cardiac diagnoses and three additional medical diagnoses. This process may occur slowly over decades or rapidly in less than five years and at present has no cure. Caregiving for HF patients thus includes progressively escalating physical care, more vigilant symptom monitoring and management, disease education, increasing household, meal, financial, disease management, constant coordination with health care providers, and potential behavioral management with constant uncertainty and repeated exacerbation of the disease. Caregivers are a critical component to the successful home management of HF patients.

There are an estimated 44.4 million family caregivers of chronically ill patients in the United States (National Alliance for Caregiving, 2004). According to Schulz and Beach (1999), the majority of caregivers are older spouses or adult children. Although their caregiving is vital to their relatives and a substantial cost saving to the health care system, it is not without cost to themselves. In fact, Rohrbaugh and colleagues (2002) characterized caregivers as hidden patients (p.3). The most dramatic impact of caregiving is reported in one of the waves of The Caregiver Health Effects Study (CHES) which reports that caregivers are at greater risk of death than noncaregiving participants, if they report mental or emotional strain (Schulz & Beach). They found that 392 spousal caregivers who reported strain had a 63% higher four-year mortality rate than the 427 age and gender-matched noncaregivers. Although these dramatic results for caregiving in general exist and a great deal is known about other caregivers in other populations such as dementia and cancer, considerably less information is available about caregivers of HF patients in particular. Only 65 studies have been conducted in the HF caregiving population, in spite of the increasing incidence and the greater prevalence of HF than other chronic illnesses.

The general caregiving studies have linked caregiver stress or burden to the number, type, or difficulty of tasks that caregivers perform for the patient. Caregivers caring for a variety of patients have reported many different tasks as stressful. A significant correlation was found between the number of tasks performed and the level of stress of the caregiver of heart patients (Karmilovich, 1994; Scott, 2000; Stolarik, Lindsay, Sherrard, & Woodend, 2000). In fact, Scott (2000) reported the number of tasks explained 36% of the variation in the caregiver's perception of the impact of care in a small sample of HF patients receiving IV inotropic infusion therapy. In a small pilot study of 21 caregivers of HF patients, younger caregivers were more stressed by the difficulty of tasks and had poorer mental health perceptions than older caregivers (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006).

Caregiving burden has been strongly correlated with negative psychological outcomes. In a review, Molloy, Johnston and Witham (2005) noted that most studies have shown that informal caregiving contributes to psychiatric and physical morbidity of the caregiver (p.594). A clear association between caregiving and negative emotional health outcomes was shown in the general caregiving literature (Halm, 2005; Schulz, Visintainer, & Williamson 1990; Biegel, Sales, & Schulz, 1991; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Caregivers were more likely to report depression or anxiety when their burden was greater (Dew et al., 2004). In large prospective longitudinal population studies of caregivers matched with noncaregivers, caregiving was associated with distress, anxiety and depression. Women fared worse than men or the age-matched noncaregivers. In a review of 30 studies of caregivers and psychiatric morbidity, higher levels of depressive symptoms and even clinical depression were seen in women caregivers (Yee & Schulz, 2000).

In the HF literature, caregivers have reported similar rates of psychiatric disorders to other patient populations with chronic illnesses (Pearlin, Mullan, Semple, & Skaff, 1990; Vitaliano, Russo, Young, Teri ,& Maiuro, 1991: Haley et al., 1996; Farran, Loukissa, Perraud, & Paun, 2004; Bookwala & Schulz, 2000; Beach, Schulz, Yee, & Jackson, 2000). Scott reported 50% of caregivers had anxiety, 45% had depression, and 89% had mental health scores below the established age norm. Schwarz and Elman (2003) reported almost one fourth of caregivers experienced depressive symptoms. Up to 40% of spousal caregivers qualified for a psychiatric diagnosis of distress-related disease according to other researchers (Rohrbaugh et al., 2002).

Caregiving has also been associated with negative physical health consequences. Burden was linked to a variety of physical symptoms including sleep deprivation, chronic fatigue, stomach problems, weight changes, and chronic diseases such as hypertension and general health deterioration (Chou, 2000; Clark, 2002; Gaynor 1990; Young & Kahana, 1989; Rankin, 1988; Bull, 1990; Faira, 1998a; Vitaliano et al., 2002; Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997). In several waves of the CHES studies caregivers were compared to noncaregivers with regard to the impact of caregiving burden on four health outcomes; perceived health, health risk behaviors, anxiety, and depression (Beach, Schulz, Yee, & Jackson, 2000). Caregivers consistently had worse health outcomes than noncaregivers. In one of the CHES studies, caregivers were grouped according to increasing level of burden (Burton, Newsom, Schulz, Hirsch, & German, 1997). Those with the greatest burden had the worst health outcomes, regardless of the patient's diagnosis (Burton et al.).

Caregivers also reported that their health had suffered because of caregiving. Caregivers' perception of their general health was lower at 59.5 (on the 0-100 scale of the12-item Short-Form Health Survey, SF-12) than the general United States population rating of 71.9 for noncaregiver adults (Bakas et al., 2006.; Ware, 2004). Similar results were reported in a study comparing HF caregivers (SF-12 score of 40.1) and their HF patients (score of 34.9) with their age matched noncaregivers (score of 50) which was a general population average (Martensson, Dracup, Canary, & Fridlund, 2003). In a small pilot study of 21 caregivers, 48% of the caregivers reported poor physical health, poor general health, and loss of energy as the most negative changes from caregiving after poorer financial well-being (Bakas et al., 2006). Further, 43% of the HF caregivers reported decreased ability to cope with stress as a result of caregiving.

Not only have caregivers reported psychological, social, and physical consequences from caregiving, but there is some indication in the literature that negative outcomes can be improved by perceived control. When caregivers and noncaregivers were compared in a meta-analysis that included 84 studies, noncaregivers had lower stress, depression and higher subjective well-being and higher levels of control than caregivers (Pinquart & Sorensen, 2003). Further, caregiver status explained the small (7.8%) but significant differences in depression, well-being, and control. The effects of caregiver burden were also found to be mediated by caregiver perceived control (Wallhagen, Strawbrige, Kaplan, & Cohen, 1994). In caregivers who had greater control there was a significant and direct impact on life satisfaction and depression and an indirect impact on stress (Wallhagen, 1992). In HF caregivers who reported greater perceived control there was a significant correlation with better emotional-well being compared with those HF caregivers who reported lower perceived control (77.6 versus 65.3, p = .003) (Dracup et al., 2004).

In contrast, caregivers who lacked perceived control consistently had negative outcomes (Dew et al., 2004; Wallhagen, 1993; Bakas et al., 2006). Wallhagen demonstrated burden was mediated by control when studying caregiver adaptation to caregiving. Further, control was directly related to the outcomes of life satisfaction and depression while indirectly related to symptoms of stress. In a study where one set of caregivers had increasing burden and decreased favorite activities compared to a second set of caregivers who had decreasing burden and more time for favorite activities, decreased depression was reported for those with lesser burden. The investigators concluded that the relationship between burden and depression was mediated by control (Nieboer et al., 1998). Wallhagen (1993) pointed out that control may …"indeed mediate aspects of the caregiving situation" (p.231).

Caregiver demographic and health variables have been linked as explanatory variables to increased burden and worse caregiver health-related quality of life. As age increased so did the perception of burden especially after age 75 (Lalonde & Kasprzk, 1993; Young & Kahana, 1992). Wives have consistently reported greater burden in caregiving studies where husbands and wives were compared (Chou, 2000; Bookwala & Schulz, 2000; Pinquart & Sorensen, 2006). Other researchers found a history of depression specifically, was a greater risk of recurrence of depression or other mental health outcomes (Dew et al., 2004). Schulz and Beach's work also supported the link between caregiver comorbid conditions, increased burden and negative outcomes. Caregivers with significant health histories were at greater risk of worse physical outcomes. Since the majority of caregivers are close in age to the patient, the caregiver often has many of the same chronic illnesses of cardiovascular disease, diabetes, osteoarthritis, and sensory changes such as change in vision or hearing as the HF patient. In the CHES studies, 27% of the caregiver sample had a major disease such as myocardial infarction or angina. Another 41% of the same caregivers had evidence of hypertension or carotid stenosis (Schulz & Beach, 1999).

And finally, given that little of the prior research was theoretically guided, future research would be strengthened and focused when theoretically based. Lazarus' theory of stress and coping is a theory that has been utilized in a few caregiving studies. Bakas and

Burgener (2002) tested a model of caregiving outcomes with caregivers of stroke patients based on Lazarus' theory. They postulated that caregiver outcomes were predicted by caregiver burden and distress based on caregiver appraisal. Caregiver and patient characteristics influenced the caregiver's appraisal which mediated the caregiver response and outcomes. Using a sample of 104 family caregivers, they were able to account for 48% of the variance in emotional distress due to self-esteem, burden-difficulty and caregiver appraisal. Twenty-five percent of the variance of general health of the caregivers was predicted in hierarchial multiple regression by whether the caregiver lived with the patient, caregiver income, and threat appraisal. The authors indicated the results supported the theoretical model and that caregiver perceptions of burden and appraisal were significant components to target for interventions and future research. Further testing of the model was conducted with a small sample of HF caregivers with a model that postulated caregiver age, control over heart failure and burden-difficulty were related to caregiver perceived outcomes and mental and general health (Bakas et al., 2006). Most of the relationships in this model were supported especially the relationships between the variables and the caregiver's emotional health. But only emotional health was related to the caregiver's physical health. Given this recent research, a conceptual model that is built on this foundational work and extends the exploration of the relationships of significant variables work would be a useful and appropriate guide in the study of caregivers of HF patients.

In conclusion, the literature provides substantial evidence of negative outcomes of caregiving and links caregiver burden and negative psychological and physical outcomes. Although 65 studies of caregivers or patients with cardiovascular diseases were found in a literature search, thirty studies were of a general caregiving nature, nineteen studies were about patients and only sixteen pertained to caregivers of HF patients. Even fewer studies have focused on the relationship of perceived control, caregiver burden and the outcome of quality of life in the caregiver of HF patients. To date, no published study was found that focused on the relationship of caregiver factors, patient factors and their relationship with caregiver burden, perceived control and caregiver psychosocial and physical outcomes. A gap in knowledge exists concerning the relationship of these variables and specifically the role of control. Further research in this area is warranted. In addition, few studies in HF caregivers have been theoretically based. Using a conceptual framework that has been tested to guide this research provides valuable information about the nature of the relationship of predictors and consequences of caregiving. The framework will also guide future studies. Researchers need to be able to identify predictors of caregiving outcomes and identify caregivers at risk, devise effective interventions, and test interventions to support caregivers.

Problem Statement

There is a lack of knowledge about the ways in which HF caregiving affects caregivers' perceived control and quality of life.

Purposes of the Study

The primary purpose of the proposed study was to test a conceptual model of caregiver outcomes among caregivers of HF patients. Specifically, a descriptive design with cross-sectional data collection was used to determine the influence of explanatory variables of caregiver and patient factors, caregiver burden, and perceived control on caregiver health-related quality of life. The secondary purpose of this study was to determine the influence of those same explanatory variables on perceived control of caregivers of HF patients.

Hypotheses

The following hypotheses were derived from the hypothesized model (Figure 1). The hypotheses are presented according to each purpose.

Primary purpose: to test a conceptual model of caregiver health-related quality of life among caregivers of HF patients.

Hypothesis 1 Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of greater anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty and lower perceived control explain worse emotional health-related quality of life.

Hypothesis 2 Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of greater anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty and lower perceived control explain worse physical health-related quality of life.

Secondary purpose: to test the explanatory variables of caregiver factors, patient factors, and caregiver burden on perceived control.

Hypothesis 3 Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of increased anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty explain perceived control.

Hypothesis 4 Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden and caregiver emotional health-related quality of life.

Hypothesis 5 Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden and caregiver physical health-related quality of life.

Conceptual Framework for the Study

The nature of the study requires a conceptual framework to outline the relationship of the variables. This study's framework was developed from the Bakas' Caregiving Model (2006), Dracup and Moser's (2004) work in perceived control, and the empirical caregiving literature. The Bakas Caregiving Model is derived from Lazarus and Folkman's theory of stress and coping. Lazarus and colleagues (1966, 1991) postulated that personality and situational factors are mediated by cognitive appraisal and coping, which influence emotional responses and outcomes, in specific situations. Bakas and Burgener (2002) created the model from their study of caregivers of stroke patients. The model was adapted and successfully tested with HF caregivers (Bakas et al., 2006). The current study's adaptation includes many of the variables and relationships supported by Bakas and colleagues prior research.

Figure 1 shows the hypothesized Model of Caregiving Outcomes. This model includes five components; caregiver factors, a patient factor, caregiver burden, perceived control, and caregiver health-related quality of life. The caregiver's age and gender have been shown to be related to caregiver burden and negative caregiver outcomes. Most caregivers are older female spouses. Younger and older caregivers have reported excessive stress and burden. Caregiver history of depression has been associated with negative caregiver outcomes in the literature. Caregiver health, such as diabetes, rheumatoid arthritis or sensory and/or mobility changes may make the caregiver role more difficult and may alter the caregiver's sense of control. Caregiver factors may impact control directly or indirectly through burden. Only the caregiver factors of age, gender, anxiety, depression, and comorbidities will be tested in the proposed study.

Terms:
NYHA class= New York Heart Association class

Figure 1. Conceptual Framework of Caregiving Outcomes

The patient factor of NYHA class or illness severity may influence caregiver factors, caregiver burden, and caregiver health-related quality of life. Only the patient factor of NYHA class will be tested in the proposed study.

The work by Dracup et al. (2003, 2004) and Evangelista et al. (2003) with perceived control indicates that control has an inverse relationship with caregiver outcomes. Perceived control may also be influenced by the caregiver burden depending on the amount and difficulty of the tasks involved. The literature on caregiver burden indicates that control mediates or explains the amount of burden and the degree of caregiver outcomes. Greater burden results in worse caregiver health-related quality of life.

Conceptual and Operational Definitions

The conceptual definitions are based on the Model of Caregivng Outcomes and drawn from and consistent with the measured used in the study. In Purpose 1 the dependent variable is caregiver health-related quality of life, specifically, caregiver emotional and physical health. In Purpose 2, the dependent variable is caregiver perceived control.

Conceptual and Operational Definition of Dependent Variables

Health-related quality of life. Caregiver health-related quality of life is defined as caregiver's perception of their well-being including mental status, emotional, vitality, role and social functioning, and physical and general health (Medical Outcomes Trust, 1994,Ware, 2004).

Operational definition

Emotional health-related quality of life is measured by the SF-12 Mental Health Component Summary Scale of the Medical Outcomes Study General Health Survey Short Form 1994).

Physical health-related quality of life is measured by the SF-12 Physical Component Summary Scale of the Medical Outcomes Study General Health Survey Short Form.

Conceptual definition

Perceived control. Perceived control is defined as a belief that one has at their disposal, a response that can influence the adversiveness of an event (Thompson, 1981; Moser and Dracup, 1995). Belief is an important part of control, the control does not need to be exercised or real to be effective for the person (Folkman, 1984). It is also important to recognize that since it is not a personality characteristic, it is therefore amenable to change.

Operational definition

Perceived control is measured by the 4-item Control Attitudes Survey (CAS) (Moser & Dracup, 1995, 2000). The items address how much control or helplessness the individual feels they have over their family member's heart problem.

Conceptual and Operational Definition of Independent Variables

The independent variables include: caregiver demographic factors of age and gender, the caregiver biological factors of anxiety, depressive symptoms, and comorbid conditions, and the patient factor of NYHA class. In purpose 1 caregiver perceived control is also an independent variable. Caregiver demographic factors are descriptors of the caregiver. Age and gender are obtained by self-report from the telephone interview with the caregiver and recorded on a demographics questionnaire.

Conceptual definition

Anxiety. State anxiety is defined as a subjective experience which signals that a threat of some type has stimulated the stress response. It is associated with nervousness, fearfulness, restlessness and tension (Derogatis, 1975).

Operational definition

Caregiver anxiety is measured by the 6-item Anxiety subscale from the Brief Symptom Inventory (BSI) that measures state anxiety not trait anxiety (Derogatis, 1975). It includes questions about nervousness, fearfulness, restlessness and tension.

Conceptual definition

Depressive symptoms. Depressive symptoms are those feelings or behaviors that are indicative of eight mental health disorders (Kroenke, Spitzer, & Williams, 2001).

Operational definition

Depressive symptoms are measured by the eight-question Patient Health Questionnaire (PHQ-8) which includes questions about loss of interest or pleasure, feelings of failure and hopelessness, behaviors such as change in appetite, sleep, concentration or restlessness.

Conceptual definition

Comorbid conditions. Comorbid conditions are defined as those health problems that have been shown to impact length of life (deGrout, Beckerman, Lankhorst , Bouter, 2003; Charlson, Szatrowski, Peterson, & Gold, 1994).

Operational definition

Comorbid conditions are measured by the Charlson Comorbidity questionnaire which includes eleven weighted questions about health conditions such as diabetes, heart failure, chronic obstructive pulmonary disease, connective and cancerous diseases.

Conceptual definition

The patient factor characterizes the patient in terms of severity of heart failure.

Operational definition

The patient NYHA class is obtained from the patient's clinic record.

Conceptual definition

Caregiver burden. Caregiver burden is defined as the number, type, time spent, and difficulty of tasks the caregiver performs for the patient including direct, indirect, monitoring, medical and financial management and mood and behavior management (Oberst, Thomas, Gass, & Ward,1989).

Operational definition

Caregiver burden is measured using the Oberst Caregiving Burden Scale (OCBS), an 18-item questionnaire used to measure the number, time spent and difficulty of tasks. The questionnaire asks about direct and indirect patient care activities, monitoring, medical and financial management, and mood and behavior management.

Assumptions

The following are assumptions underlying this proposed study:

1. Caregivers who agreed to participate did not differ substantially from those who do not participate.
2. Caregivers responded to interview items honestly and accurately.

Limitations of the Study

The following are limitation of the study:

1. Data for the study are gathered from a non-random sample, thereby affecting the external validity of the results.
2. The study is cross-sectional and does not capture the dynamic nature of the variables.
3. The demographic sample may not be generalizeable beyond caregivers whose family member receives care at a university-affiliated multidisciplinary tertiary clinic.
4. The use of single site used for data collection limits the generalizability of results to other types of settings given this is a multidisciplinary specialized clinic.

Significance

There is evidence to support the propositions that caregiver factors, patient factors, and caregiver burden-time and difficulty can influence caregiver health-related quality of life and caregiver perceived control. Prior studies have been limited by the absence of conceptual frameworks. Sampling techniques have been limited by the use of populations that are all older female spousal convenience or volunteer samples. Previous studies are limited by lack of inclusion of caregiver and patient factors and exclusion of physical outcomes. If the relationships of the model variables can be supported, caregivers at risk can be identified and interventions can be designed and tested to improve caregiver health-related quality of life.

Summary

Caregivers of HF patients are an important and understudied population with negative physical and psychosocial outcomes from caregiving. Heart failure continues to increase as does the need for more caregivers to assist these patients. Therefore, research in this area is important and potentially very significant for a large group of caregivers. The relationships among caregiver factors, patient factors, caregiver burden, perceived control, and caregiver health-related quality of life should be examined to identify caregivers at risk and design and test useful interventions. Chapter 1 has provided an overview of the problem of caregiving patients with heart failure, discussed the relationship of the independent and dependent variables, the purposes, hypotheses and conceptual framework for the current study. Chapter 2 provides a more detailed in depth discussion of the current research related to the constructs of the study.

CHAPTER 2

REVIEW OF THE LITERATURE

Chapter 2 provides an overview of theoretical literature about caregiving, caregiving in heart failure, followed by a review of pertinent empirical literature related to the constructs of caregiver burden, perceived control, caregiver outcomes, and the caregiver and patient correlates from the hypothesized model for this study (Figure 1). The aims of the review are to (a) describe the model concepts, (b) identify the state of knowledge with regard to each concept, and (c) identify the gaps in knowledge. Each section includes construct definitions, measures of the construct, empirical research, and implications for the proposed study.

Overview of Caregiving Theoretical Literature

Caregivers and the consequences of caregiving have been of concern to researchers in many disciplines for decades. As a result, there is a vast volume of research by different disciplines in this area. To date the research community has described a variety of caregivers and care receivers, identified caregiver concepts and issues, and created and tested caregiver theories and measurement tools. A variety of psychological, social and community interventions have been tested. Much of this early work was guided by Lazarus and Folkman's stress adaptation theory (1984). Many of the tools that have been developed were also based on Lazarus and Folkman's theory. In its third decade, this young science has common issues of research design, consistent conceptual definition, and instrumentation. It also needs to sample more diverse and representative populations (Farran, 2001). Caregivers of persons with dementia, Alzheimer's disease, cancer, and stroke have been the primary populations that have been described and reported in the literature (Zarit, Reever,& Back-Peterson, 1980; Pinquart & Sorensen, 2003; Han & Haley,1999; Haley, 2003) Caregiving has consistently been identified as stressful in these populations with Alzheimer patients being the most difficult and stress inducing.

More recently researchers have been concerned about the impact of two public health trends on caregiving. The first trend is the large number of retiring baby boomers being added to the already increasing older population. The second trend is the increasing number of persons with chronic heart diseases such as heart failure. Unlike all other major causes of death, which are declining per capita, cardiac diseases are increasing and are the number one killer in the United States (Bull, 1990; Karmilovich,1994; Young & Kahana, 1989; Cossette & Levesque, 1993). Each trend is related to caregiving and to the proposed study.

First, the influence of the increasing numbers of older persons on caregiving is addressed. With the improvements in health care and the advancements in survival, there are more persons living longer but also living with chronic illnesses. In 1991, there were an estimated 31 million persons age 65 and older. Of those persons, between nine and eleven million persons were functionally impaired (US Senate Special Committee on Aging, 1991). An estimated five million of these persons were considered chronically ill adults living in the community and in need of at least minimal assistance (Monk & Cox, 1991). By 2030, it is estimated that 72 million of the US population will be 65 years of age or older. By 2050, it is estimated that will rise to 87 million people (He, Sengupta, Velkoff, & DeBarros, 2005). Although it is assumed that the majority of persons who are in need of assistance are over age 65, when all persons needing assistance are considered, 9.5 million persons in the US were estimated in need of assistance in 2000 and 12.7 million are estimated to be in need of assistance in 2050 (Friedland, 2004). Not only are the numbers of older persons growing, but the number of persons in need of assistance is growing, requiring more caregivers.

There were an estimated 22 million households caring for someone in 1997. In 2004, there were an estimated 44.4 million family caregivers in the United States (National Alliance for Caregiving, 1997, 2004). One in every four households is now affected. Until recently the caregivers were predominantly women, usually the age matched spouse of the care recipient, with adult daughters being the second most common caregiver after the wife (Schulz & Beach, 1999). Caregivers are now also men, with 44% of caregivers being husbands, sons, and nonresidential relatives (National Family Caregiver Association [NFCA], 2000). Most caregivers estimate the length of time they will be caregiving at 2 years, when in fact, the average length of time is 8 years (Metropolitan Life Juggling Act Study, 1999). In the state of Indiana alone, there are an estimated 586,000 caregivers (NFCA). In addition, spousal caregivers typically have chronic diseases themselves. In the CHES studies, 27% of the sample had a major disease such as a myocardial infarction or angina. Another 41% had subclinical diseases with evidence of hypertension or carotid stenosis (Schulz and Beach). It is not uncommon for the caregiver and care recipient to have many of the same diseases. Not only are the numbers of caregivers increasing but the percentage that are caring for persons with HF are increasing. This is where we begin to appreciate the collision of these two trends in caregivers.

Caregiving in Heart Failure Theoretical Literature Review

Like the number of caregivers, the incidence of HF is increasing. It remains at least as malignant as many common cancers in both men and women (Stewart, MacIntyre, Hole, Capewell & McMurray, 2001). Attention to HF also brings attention to the prevalence, incidence, and unique trajectory of HF. Like other chronic illnesses, there are physiological indicators of decline such as declining ejection fraction, increasing NYHA class, declining response to standard medical therapy, and decompensation leading to increasing frequency of acute hospitalization. There are functional indicators of declining mobility or decreasing distance or activity tolerance. But, unlike other chronic illnesses, the trajectory and course of HF are unpredictable.

As Biegel and Schulz (1999) point out, each patient population poses distinct challenges. The initial cause of the HF can impact the length and experience with the disease. The common experience is HF occurs as a result of a myocardial infarction with residual damage to the left ventricle that slowly becomes progressively less effective as a pump. This results in an insufficient supply of blood to the heart muscle, the lungs, the brain, and the kidneys resulting in progressive failure of those systems that alter the patient's mobility, distance in mobility, activity tolerance, cognitive ability, and self-care. The patient requires greater assistance in self-care, mobility, and disease management as the systems fail. The patient requires a dynamic medical and self-care regimen of diet, drugs, and exercise that is constantly adjusted according to the patient's fluctuating symptoms. Other common complications of HF can arise such as ventricular or atrial arrhythmias or mood alterations that add complexity. Frequent hospitalizations are common in the later stages as are implantable devices such as pacemakers, defibrillators or ventricular assist devices. In addition, it is commonplace for the older patient to have other systemic diseases such as hypertension and diabetes. In Mahoney's 2001study, the HF patients averaged 2.7 other cardiac diagnoses and three additional medical diagnoses. This process may occur slowly over decades or rapidly in less than five years and at present has no cure. Caregiving includes progressively escalating physical care, more vigilant symptom monitoring and management, disease education, increasing household, meal, financial, disease management, constant coordination with health care providers, and potential behavioral management with constant uncertainty and repeated exacerbation of the disease.

Given this context, we can begin to appreciate not only the caregiver's individual experience but the significance to nursing. Caregivers can feel strained under the weight of the increasing responsibility. As the number, difficulty, and frequency of caregiving tasks increase, the resulting burden can alter the caregiver's emotional and physical health. Therefore, for this study it is proposed that as caregiver burden increases caregiver's emotional and physical health-related quality of life decline. The next topic, caregiving burden, is discussed in terms of how it is defined, measured, and used in the heart failure literature.

Caregiver Burden

Definition of Caregiver Burden

Caregiver burden has been conceptualized in a variety of ways in the larger caregiving literature. It is also identified as caregiver strain, stress, load, or role overload suggesting something negative, excessive, imposed or unwelcomed (Sales, 2003). Historically, the most common conceptualization of caregiver burden was physical care of another person. More recently, there are three broad approaches to defining caregiver burden: those that define burden according to objective tasks such as direct physical care (Stetz, 1989), and those that define burden from a psychological perspective such as the caregiver's reaction to the tasks, process or experience (Wallhagen, 1992; Schott-Baer, 1989; Brouwer et al., 2004; Cantor, 1983) and those that combine objective and subjective scales, which is common in the heart failure literature (Oberst, et al., 1989).

From the objective burden perspective, there are typically three variations in scope. The most simplistic definition includes only physical care or direct care (Stetz, 1989). A broader definition adds indirect tasks such as laundry, cooking, housecleaning to direct care. And finally the broadest definition adds medical management to indirect and direct care. Within each of these groups are variations such as the frequency of the physical care (Given, Stommel, Given, Osuch, & Kurtz et al., 1993) or the time demands of tasks (Oberst et al., 1989).

From the subjective burden perspective, the caregiver's emotional and/or cognitive reaction to the activities or experience is the focus. It may be framed in terms of caregiver stress (Oberst et al.) or reaction to the process (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) or the degree of difficulty in the tasks (Oberst et al.). Schwarz and Elman (2003) were the only HF researchers that provided a definition. They defined perceived stress as events that threaten available resources (p.91). The most recent variation is studying the positive psychological aspects of caregiving (Kane, Klein, Bernstein, Rothenberg , & Wales, 1985; Kramer, 1997).

The final perspective, the combined burden perspective, measures the objective and subjective burden (Oberst et al.; Montgomery, Gonyea, & Hooyman, 1985). In the broad psychological literature, burden is considered a psychological response to caregiving or the perception of caregiving as burdensome (Vitaliano, Zhang, & Scanlan, 2003). George and Gwyther (1986) who are frequently quoted, define it as physical, psychological, emotional, social and financial problems experienced by families caring for impaired older adults (p.253). In 1989, Oberst and colleagues, interested in family caregivers of cancer patients, created and refined measures to facilitate the study of caregiver burden from a task perspective (Carey, Oberst, McCubbin, & Hughes, 1991). Additional researchers reported the number of tasks and the subjective evaluation of the burden when caring for chronically ill persons at home, was significant and related to negative emotional outcomes (Cossette & Levesque, 1993; Brouwer et al., 2004; Bakas, et al., 2004; vanExel et al., 2005). In studying chronically ill adults, Wallhagen did not provide a definition of burden but adapted items from standardized measures to assess objective and subjective aspects of burden. Molloy, Johnston, Johnston, Morrison, Pollard et al.(2005) did not define demand from the Karasek model of job strain. In the meta-analyses, Pinquart and Sorensen (2003) and Vitaliano and colleagues used the George and Gwyther definition of burden.

In the CHES studies of caregiving, burden was conceptualized as consisting of the task and strain (Schulz & Beach, 1999; Beach, Schulz, Yee, & Jackson, 2000). The objective component was described as caregiver demands and labeled "caregiver involvement" (p.260, Beach et al., 2000). It was operationalized as the degree of care the recipient required. The subjective component was the caregiver's perceived stress which was conceptualized as "…the degree of physical and emotional strain experienced by the caregiver as a result of help provision" (p.260, Beach et al.). Bookwala and Schulz (2000) used two sources of burden, “caregiving assistance” to describe the number of direct and indirect tasks and care recipient behavior problems and their frequency (p.609). Burton and colleagues used the levels of caregiving assistance provided as caregiver burden (1997, 2003).

In the caregiver intervention studies, burden was seldom defined but inferred from the measurement tools. The common measures, Zarit Burden Scale and Montgonery and Borgatta’s Burden Scale, reflect an objective and subjective view of burden.

In the HF literature, as in the larger caregiving literature, the majority of investigators did not define burden regardless of the approach they selected, only three investigators provided definitions. Karmilovich (1994) defined burden or strain as the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults, (p.34). Stolarik, Lindsay, Sherrard and Woodend (2000) used “burden of care” as the effects of the multifaceted stressors associated with providing care for an ill family member (p.1).

Given the pervasive impact of the caregiving experience with HF patients, it is essential to define caregiving burden to include the tasks performed and the caregiver’s emotional and psychological reaction to this growing role. For the proposed study caregiver burden includes the number of tasks, time to complete the task, and caregiver perceived difficulty in completing the task. The tasks include direct personal care such as activities of daily living, assistance with mobility and mental stimulation, emotional support, and indirect tasks such as preparing meals, cleaning, laundry, shopping, household management, financial management, providing transportation and medical management including symptom monitoring and coordination of a changing medical regimen.

Measures of Caregiver Burden

In the general caregiving literature, burden has primarily been measured quantitatively. Some of the common measures which assess burden in a combined fashion are the Burden Interview (Zarit, Reever, & Bach-Peterson,1980), the Caregiver Strain Index (Robinson, 1983), the Subjective and Objective Burden Scale (Montgomery, Gonyea, & Hooyman, 1985), the Caregiver Burden Scale (Oberst et al.,1989) and the Caregiver Demands Scale (Karmilovich, 1994). The Caregiver Reaction Assessment measures five areas of caregiving such as family support, caregiver esteem, and three areas of indirect care (Given et al., 1992). Subjective burden is commonly measured by the Caregiver Appraisal Scale (Lawton, Kleban, Moss, Rovine, & Glicksman,1989), the Appraisal of Caregiving Scale (Oberst et al., 1989) which is based on Lazarus and Folkman. Wallhagen used the Stetz Experience of Caregiving Inventory Part I-Physical Tasks in two studies (1992, 1993) to assess the number and difficulty of tasks and added items to include monitoring and behavioral problems which collected data much like the Oberst Caregiving Burden Scale. Molloy et al. (2005) used the modified Functional Limitation profile which is the United Kingdom version of the Sickness Impact profile.

The CHES studies used three measures to determine caregiver involvement which included the level of patient difficulty in activities of daily living and indirect activities, the number of tasks the caregiver provided, and strain the caregiver experienced. Caregivers were then classified into one of three levels of caregiving such as low, moderate and heavy caregiving responsibility. All the data were collected by in-person interview. Turning to the heart failure literature, the measure of burden can be examined.

In a recent meta-analysis of caregiver intervention studies, Sorenson, Pinquart and Duberstein (2002) noted that of the 57 studies that reported effects for caregiver burden, burden was measured using Zarit Burden Scale (21 studies), Montgomery and Bargatt's Burden Scale (8 studies) and 29 other studies used a variety of measures. Although these studies did not provide definitions for burden, the scales utilized imply a perspective that burden was viewed in the combined broadest sense.

In the HF literature, the majority of the studies approached burden from a combined objective and subjective perspective. Seven of the ten studies that included a measure of caregiver burden, took the combined approach (Bakas et al., 2006; Stolarik et al., 2000; Dew et al., 2004; Nieboer et al.,1998; Scott, 2000; Karmilovich, 1994; Dracup et al., 2004). There were few studies that used the same instruments, premise or assumptions. The researchers did not attempt to contribute to a line of research or create a body of knowledge about one aspect of caregiving. Only two studies used the same measure, the Caregiver Burden Scale, a 15-item scale requiring a response to each direct, indirect and interpersonal caregiving task about the amount of time and difficulty of the task (Bakas; Stolarik). A similar measure, the Caregiver Demands Scale (CDS), a 42-item scale, was used by Karmilovich. The CDS includes five areas of direct and indirect care and difficulty of each task and an 11-item role alterations scale pertaining to changes in relationships due to caregiving. Dracup and colleagues used the burden and impact of role subscales of the by the Caregiver Appraisal Scale. Dew and colleagues created a burden measure that included direct, indirect care, time required, and the caregiver's favorite activities. They also administered the physical subscale of the Sickness Impact Profile. Scott(2000) used the CDS to assess self-esteem, family support, daily schedules, health and finances. Some of HF investigators chose a different approach.

The remaining four studies utilized the subjective approach to caregiver burden testing the caregiver's reaction to caregiving. Schwarz and Elman (2003) used the caregiving subscale of the Philadelphia Geriatric Center Caregiving Appraisal scale to measure factors that influenced the patient's readmission and the Perceived Stress Scale to examine caregiver depression. Having addressed caregiver burden as it is defined, measured, and utilized in the HF literature attention now turns to the relationships of research studies to the proposed study and a review and critique of those studies.

Empirical Literature Review for Caregiver Burden

Previous research supports evidence of burden in HF caregivers and supports the approach of the number and difficulty of tasks as burdensome. Along with general caregiving researchers, investigators in HF literature identified what was burdensome to the HF caregiver and linked burden with the consequences to the caregiver. Six authors reported that the number and/or difficulty of tasks were correlated with caregiver stress (Beach, Schulz, Yee, & Jackson, 2000; Karmilovich, 1994; Scott, 2000; Stolarik et al., 2000; Nieboer et al., 1998.; Dew et al., 2004).

In the general caregiving literature, Beach and colleagues have conducted some important research that should be discussed. Using a sample of 680 caregivers from the first two waves of the CHES study, caregiver strain was examined. Caregiver strain was operationalized as the level of caregiving involvement or the number of caregiver tasks combined with the level of patient difficulty with activities of daily living and independent activities of daily living and the caregiver's perception of the burden. Caregivers were then classified into noncaregiver controls, low caregiving with one independent activity of daily living patient deficit, or moderate caregiving with 2 independent activity of daily living patient deficits, or heavy caregving with more than 2 patient care deficits. Increased caregiver strain was linked to poorer caregiver emotional and physical outcomes. In this population-based longitudinal study with caregiver controls and a large sample size the researchers validated the negative influence of the number and perceived difficulty of tasks on emotional and physical outcomes. It should be noted that the caregivers were in the early stage of caring for someone with declining ability and that the study period was one year which may not have been long enough for many changes to be noted for a patient in the early stage of the illness. It should also be noted that magnitude of the effects was small with changes in burden explaining between 1% and 6% of the variance in the outcomes and like most studies in this field, the data is self-report from the caregiver. The large sample size, reliable measures and longitudinal design are particularly valuable in a field that typically has small samples and cross sectional designs, even though the variance was small the study contributes valuable information in validating the relationship between caregiver burden and caregiver stress or perception of that burden and the negative outcomes. Future studies will hopefully reveal greater variances.

Also in the general caregiver literature are caregiver intervention studies which can be very informative about what impacts caregiver burden. In a meta-analysis of 78 intervention studies in six categories Sorensen et al. (2000) sought to determine the effectiveness of interventions for caregivers of adult patients. Even though there were no studies with HF caregivers found in the literature, interventions of all types are successful in improving objective and subjective caregiver burden for a short period of time (Sorensen et al.). When taking all types of interventions together a significant improvement of 0.14 to 0.41 standard deviation units was noted for the outcomes of interest of burden, depression, well-being, satisfaction, knowledge, and patient symptoms. The authors described this effect as small to moderate. Multicomponent, supportive, psychotherapy, respite/day care, psychoeducation, training of the patient, and miscellaneous categories were effective for burden. Mulitcomponent was the most effective (g = -.62, p <.001) and miscellaneous the least effective (g = -.01, p <.05) for reducing caregiver burden. When examining effects for burden, depression, well-being, uplifts and knowledge, burden experienced a significant improvement (g = -.15, p <.001) that was considered average compared to other outcomes such as knowledge and well-being (g = 0.41, g =.37 respectively). Group interventions were less effective than individual ones for caregiver burden.

The effectiveness of the intervention was moderated by the age of the caregiver (older versus younger), sex of the caregiver (female versus male), caregiver relationship to patient (adult child versus spouse), the length of caregiving (new caregiver versus long term caregiver), the number of hours of care (fewer hours of care versus greater hours of care), subjective burden (greater versus lesser at baseline), and the type of patient (dementia caregivers versus nondementia caregivers) (Sorenson et al.). The older, female, adult child who was a newer caregiver who provided fewer hours of care but felt quite burdened that was caring for a nondementia patient had the greatest reduction of burden with intervention while all caregivers had some improvement in burden.

Sorensen et al. also pointed out that study characteristics had an impact on the size of the effect. When using only randomly assigned studies, there was a significant impact on the size of the effect. When using only randomly assigned studies, psychotherapy was effective for all outcomes. They also pointed out that psychotherapy and psychoeducation were the most consistent for all outcomes. Sorensen and colleagues speculated that these were most effective due to their ability to recognize and address caregiver stressors of feeling overburdened, isolated and having difficulty managing one's own negative feelings.

Intervention studies indicate links between burden and caregiver outcomes and links between burden and caregiver and patient factors. When noting that interventions especially mulitcomponent interventions, psychotherapy, and psychoeducation reduce objective and subjectve caregiver burden, these results link caregiver burden and psychological outcomes. These results also implicate a relationship between control burden and outcome. The results also indicate caregiver factors of age, relationship to the patient, and the duration of caregiving have links to caregiver burden and outcomes.

The researchers noted some limitations in their meta-analysis. When assessing burden, it is typically reported as one score so that a meta-analysis can not unbundled subjective and objective burden. Some categories of intervention could not be studied in more detail due to missing data or only a few studies being available. Delivery characteristics such as group intervention and duration of the intervention are confounding. Not all studies had longer term follow-up. The timing of the intervention could not be controlled. Many studies did not report how long a caregiver had been caring hence control the length and possibly the intensity of burden. Most studies did not report the training or experience of the therapist or social worker that was delivering the intervention. Further, the authors noted that interventions lasted seven months after the intervention and that some had specific domain effects and some had broad nonspecific effects. They suggested better tools for detecting change over time, longitudinal studies with well-controlled randomized interventions with large diverse samples from multiple sites especially for respite/day care in many patient populations.

Caregiver burden in heart failure.

In the first HF caregiver burden study, Karmilovich (1994) reported a correlation between the number and difficulty of tasks and caregiver stress. In a convenience sample of 41 caregivers of NYHA class III or IV patients, the caregivers completed the Caregiver Demands Scale (CDS) and the Brief Symptom Inventory (BSI). The CDS includes five areas of direct and indirect care and difficulty for each task. It also includes an 11-item role alterations scale pertaining to changes in relationships due to caregiving. These measures had acceptable reliability and validity. The caregivers were between 51 and 60 years of age, Caucasian, employed, female spouses. Caregivers of HF patients are often in their sixth or seventh decade and retired or soon to be retired, and caregiving for a longer period of time. This younger sample potentially has the demands of a job and dependent children still living at home. The mean burden scores were higher than mean scores in other studies including advanced cancer patients (Karmilovich). There was a modest positive correlation (r =.32, p = .04) between the number of tasks performed and the level of stress and a significant relationship (r = .43, p =.01) between difficulty in tasks and stress. Women reported doing more caregiving activities and reported a greater sense of burden than males, which is consistent with other studies. Even though a small, nonrandom sample and a descriptive design were used, which limits the generalizability, the results validate the connection between the number and difficulty of tasks and the resulting stress from that burden. The results are consistent with studies in other caregiving populations. These results provide support for the proposed study's link between the number and difficulty of tasks and burden and negative outcomes. The author also used the BSI measure in a sample of HF caregivers with acceptable reliability and validity, as in the proposed study.

In another small descriptive study of 18 pairs of caregivers and inotropically dependent HF patients drawn from five medical centers, the number of tasks explained 36% of the variation in the caregiver's perception of the impact of care ($F[2,15] = 3.57$; $p = .05$) (Scott, 2000). Scott was investigating the patient and caregiver health-related quality of life and the impact of preparation and caregiving tasks on the caregiver's perceptions of caregiving. The 20 caregivers were female, primarily spouses, with a mean age of 63 years. Scott used an 18-item Caregiver Preparedness Scale, the 24-item Caregiver Reaction Assessment (CRA), the Mental Health Inventory-5 (MHI-5), subscale of the SF-36 and the 36-item Quality of life index. Cronbach's alpha was acceptable in all measures except two of the five subscales of the CRA which were 0.56 and the MHI-5 which were 0.42 and 0.44. The majority of the patients and caregivers had mental health scores below the population norm. Fifty percent of the caregivers experienced anxiety in the prior month and 45% of the caregivers reported feelings of depression. The results need to be considered with some caution with the low reliability of 2 subscales of the MHI and the CRA, which may be from sample size. Although Scott's small nonrandomized special subset of end-stage HF patients hampers generalizability and would not be the singular foundation for making decisions, the results lend support to tasks as a significant factor in caregiver burden even in end-of-life HF caregivers.

Using 124 spouses of cardiac bypass patients in a descriptive, comparative longitudinal study, Stolarik et al. (2000) sought to describe and compare caregiver burden of the fast track and nonfast track surgery patients and validate the Cargiver Burden Scale (CBS) in this population. The CBS is a 15-item scale requiring a response to each direct, indirect, and interpersonal caregiving task with regard to the time it takes and the difficulty of the task. Stolarik and colleagues reported patient behaviors, monitoring symptoms, and emotional support were the hardest tasks for caregivers, with each category having a mean score over two (range 1-5). The youngest and oldest caregivers reported the greatest burden. The caregivers were primarily female spouses with the fast track caregivers being younger, ages 41 to 50 year of age and the nonfast track being older and more typical of HF caregivers, 61to70 years of age. The urgency and type of surgery were not factors in caregiver burden. Even though the patients were not HF patients, the study supports the validity of CBS in cardiac surgery caregivers with a Cronbach coefficient of 0.94. This measure is used in the proposed study. The study design, the sample size, and the reliability of the measures give credence to the results in a group of related caregivers. The caregiver's burden impacted by certain tasks, the tasks that are most burdensome, and the influence of age on caregiver perception are results that are supportive of components of the proposed study.

Nieboer and colleagues (1998) studied the effects of increasing and decreasing spousal caregiver demands on depressive symptomology in two different populations. They hypothesized that spousal caregiver activity restriction or loss of access to favorite activities may explain the differences. They assumed that humans desire to maintain control over their environment and themselves and when caregiving demands interfere with the caregiver control including control of enjoyable activities, depression may increase. A total of 127 caregivers of stroke, hip fracture, myocardial infarction, and HF patients (HF *n* = 40) were in the first study taken from a prospective population-based Dutch data base which was compared to 110 USA caregivers of bypass patients. The majority of the Dutch caregivers were female with a mean age of 70 years. Eighteen activities of daily living and independent activities of daily living were measured with Cronbach's alpha of 0.83. Caregivers selected their six most important activities out of a list of forty, such as going to church or going for a walk, that they would miss the most if caregiving were demanding. Depression was measured using the 7-item depression section of the Hospital Anxiety and Depression Scale which had a Cronbach's alpha of 0.71 at time 1 and 0.79 at time 2. From the onset of the health problem at time 1 to time 2, those caregivers with four tasks at time 2 and 1.9 out of six activities lost at time 2 there was an increase in depression from mean of 3.5 to 5.1 ($p <.05$). The caregivers that did not experience such changes had a mean of 3.9 depression at time 1 and 4.2 at time 2 ($p <.001$). These results support the reseachers' hypothesis and validate the relationship between burden and negative psychological outcomes for caregivers.

In the second study, they observed a decrease in caregivng burden for bypass patients in a sample that was primarily female with a mean age 58.3 years. The 10-item Centers for Epidemiologic Studies for Depression Scale was used to measure depression with a Cronbach's alpha of 0.85 at time 1 and 0.82 at time 2. The activity restriction scale was used to indicate which nine areas of activity such as caring for self, were restricted by caregiving. Cronbach's alpha at both times was 0.86. For those caregivers that experienced a decrease of at least 2 tasks (*N* = 27) and a lower activity restriction at time 2, there was significantly lower depression (from 9.2 to 5.9, $p < .001$). Study 2 was important in demonstrating the improved rate of depression with even a partial reduction of tasks and a partial resumption of desirable activities. Study 2 results are important for potential caregiver intervention. When comparing results of study 1 and 2, not all instruments were identical nor were interview intervals nor were the country of the samples or the age of the caregivers. These limitations did not seem to alter the results. It is particularly valuable that Nieboer et al. compared increasing and decreasing burden to demonstrate a linear relationship between burden and depression. Using longitudinal comparative methods, an adequate sample, and established instruments are strengths that validate the link between the number of caregiver tasks, caregiver stress, and caregiver burden.

Dew et al. (2004) also reported on the relationship between caregiver burden and depression and anxiety. Dew and colleagues investigated the predictors of psychiatric disorders post transplant in 190 caregivers from one transplant center. Although their study did not report using a specific theoretical framework, they hypothesized that post-transplant caregivers exposed to chronic stress, like other caregivers of chronically ill persons, would exhibit similar psychiatric disorders in comparable percentages. They used the semi-structured interview process at 2, 12, and 36 months, three indicators of burden, the 52-item physical health subscale of the Sickness Impact Profile, the Mini Mental Status Exam, and a social support and mastery scale. Cronbach's alpha were all in the acceptable range. The investigators totaled the number of direct and indirect care items the caregivers performed and assessed the degree to which their care affected certain domains of their life such as personal affairs and recreation. Dew and colleagues reported …“elements of caregiver burden were among the most critical predictors of risk for both MDD [major depression diagnosis] and anxiety”… (p.1078). The heart transplant caregiver was more likely to report depression or anxiety when their burden was greater, especially if they had high indirect or direct patient care needs during their three year follow up period. The caregiver’s depression and anxiety-related disorders equaled or exceeded other caregiving population rates. The caregivers were primarily female spouses over the age of 50.

Even though the caregivers were drawn from one center, were younger than most heart failure caregivers, and were not randomized, the sample size and repeated time longitudinal design supports the purpose of identifying when psychiatric outcomes can occur and what other factors may correlate with these outcomes. The correlational nature precludes conclusions about causation. The clinical characteristics of the patients were not reported which handicaps the reader in comparing across studies. Many of the patients were likely heart failure patients with cardiomyopathy and like disorders. The patients are likely to be younger than the typical 6th and 7th decade patient. The results support the link between burden and negative caregiver consequences. When looking more closely at what was most burdensome, there is little consensus.

Caregivers generally found the category of indirect care to be the most burdensome, but different indirect activities were cited as the most burdensome by caregivers in different studies. Three authors reported the loss of or the decrease in favorite activities as the most stressful for HF caregivers (Dew et al., 2004; Aldred, Gott,

& Gariballa, 2005; Nieboer et al.,1998). Related to these three studies, Scott found the disruption in the caregiver’s daily schedule was burdensome. Yet in contrast, Scott also found that handling finances and health insurance paperwork was the most burdensome. Similar to Scott, Bakas and colleagues(2006) found among caregivers of veterans, finances and insurance paperwork were in the top four most burdensome tasks with household tasks and patient behavior preceding finances as first and second most burdensome. In contrast, Dew and colleagues found direct care tasks were burdensome which may reflect the greater demands of a transplant recipient.

In a qualitative study, Aldred, Gott and Gariballa(2005) reported that HF affected all aspects of the caregiver’s life. Using focused interviews, with ten adults over age 60 with advanced HF and their caregivers in the United Kingdom, thematic analysis was used to identify themes and sub themes. Eight of the ten patients were male spouses with most in their seventies. The caregiver reported giving up favorite activities, experiencing social isolation. Patients expressed emotional concerns about the added household chores and direct physical care. These changes were compounded by a lack of understanding of HF. The researchers concluded that the HF caregivers had needs not unlike those of patients with terminal diseases (p.116). They also suggested future interviews should be conducted with the patient and caregiver separately, since they had indications from some caregivers and patients that perhaps caregiving was burdensome but the caregiver was reluctant to verbalize it in front of the patient. The influence of English cultural norm of enduring what ever hardship occurs and not complaining, can not be forgotten when interpreting these results and comparing them to results from other countries.

Prior research not only demonstrates the link between the number of tasks and burden but the perceived difficulty of tasks and burden. Two researchers reported the difficulty of the tasks contributed to the caregiver burden (Karmilovich, 1994; Bakas et al., 2006) while other investigators reported the caregivers' stress contributed to their burden. In the Bakas et al. study, a convenience sample of 21 caregivers with a mean age of 59.6 years, who were primarily female were interviewed to describe which caregiving tasks were most difficult and perceived as most negative by caregivers. Based on a caregiving model from prior research, they sought to determine the caregiver's perception of control over heart problems and to determine the relationship between age, control over heart problems, difficulty with tasks and outcomes for the caregivers. They used the 4-item Control Attitude Scale to assess control over heart problems, the difficulty subscale of the Oberst Caregiving Burden Scale to measure caregiver perceptions of difficulty of caregiving tasks, the 15-item Baskas Caregiving Outcomes Scale to evaluate changes in their life from caregiving, two subscales from the SF-36 to measure general and emotional health perceptions.

They found younger age to be significant in the perception of difficulty of tasks and perception of mental health. Greater difficulty with tasks was associated with negative perceptions of caregiver outcomes and worse emotional health. Caregivers reported deterioration in general, emotional, social, and financial health from caregiving. Caregiver control over heart problems was not significantly related to task or outcomes but 43% of the caregivers reported a perceived lack of control. Caregiver mental health scores were comparable to age matched general population scores but only caregiver mental health was moderately correlated with caregiver general health. The convenience sample, the sample size, and the female gender of the sample limit generalizabilty. The measures used had adequate reliability and validity and had been used in prior studies, except the CAS which had a slightly lower Cronbach's alpha at 0.79 in this sample than in the original studies (0.88 and 0.89, Moser & Dracup, 2000). It was suggested that perhaps the difference was due to the chronically ill sample versus the acutely ill original sample (Bakas, 2006). The cross-sectional data collection restricts conclusions about causality but the results are important in identifying what is burdensome and what are the consequences of that burden when perceived as stressful. Their theory was supported. The results support the current study hypotheses that caregiving for HF patients is burdensome, HF caregivers have negative emotional and physical outcomes, and that control may be a significant factor in caregiver outcomes. In addition, many of the same instruments used in the current study are being used in the proposed study.

When caregivers feel burdened by the tasks they have, stress can result and negative consequences can result from that stress which supports the model in the proposed study. Karmilovich also reported a significant relationship between the perceived difficulty and the caregiver's level of stress. The mean burden score (15.27) (*SD* = 11.53) was higher than the mean scores in other caregiver studies. The range was not reported. The mean Brief Symptom Inventory (BSI) stress score was reported as .48 which was higher than non-patient normal score of .30 reported by Derogatis, the author of the BSI, thus indicating a moderate stress level. The range of scores was zero to 1.81 with a standard deviation of 0.48. There was a significant correlation ($r = .43$, $p = .01$) between stress and difficulty in tasks.

Caregiver burden also includes caregiver perception of their burden. Two groups of researchers reported different perceptions of burden linked to negative outcomes (Luttik, Jaarsma, Veeger, & vanVeldhuisen, 2005; Schwarz & Dunphy, 2003). The most significant burden according to Luttik and colleagues was the emotional component. Luttik and colleagues sought to explore the quality of life of 38 Dutch couples where the spouse had heart failure. Using the Cantril Ladder of Life scale both patients and spouses rated their quality of life during hospitalization and recalled and rated it one month prior to hospitalization and projected it three years into the future. Most of the patients were male and spouses female with a mean age of 64 years for spouses. Half of the patients were NYHA class IV and the other half of the patients were class III. The quality of life scores for caregivers were relatively stable at all three time points, at 6.1 prior, 5.9 during, and 6.4 projected in the future while the patient quality of life scores were more variable at 4.9 prior, 6.8 during and 6.7 after, leading to considerable difference between the patient and spouse. The quality of life scores of the HF patients were considered lower when compared to patients in rehabilitation (8.0) and post bypass patients (7.5) (p.13). Caregiver scores were low compared to noncaregivers of similar age (7.9) which is an indication that caregivers feel burdened and stressed. The caregiver's perspective was not altered by the immediate hospitalization. When utilizing these results there are concerns about the small sample size, nonexperimental design, collecting data during hospitalization, the methodology of having participants recall about quality of life in the past and guess in the future, influence of culture on the generalizability, and the possibility of other confounding variables to explain the results. The results are consistent with other studies examining psychological outcomes but the results need to be interpreted cautiously given these limitations. The results support the consistency of caregiver burden regardless of transient events.

Schwarz and Dunphy reported that spousal caregivers experienced moderate stress on the Perceived Stress Scale (PSS) and higher cortisol levels than nonspousal caregivers (2003). They sought to validate the PSS in this convenience sample of 75 caregivers of HF community dwelling patients 65 years of age and older. They also sought to evaluate the moderating effect of social support with the modified Inventory of Socially Supportive Behaviors Scale (ISS) on depressive symptoms measured by the Center for Epidemiologic Study Depression Scale. The majority of the caregivers were white females averaging 63 years of age who reported being in good to excellent health with 65% having no physical limitation who were financially comfortable. They had been caregiving for an average of 6 years (±10 years). The majority of the patients were described as being in good (28%) or fair (41%) health with only 27% being in poor health. No NYHA class was given.

Moderate stress ($M = 16.22$) was reported on the PSS with low stress reported via the salivary cortisol level of 64ug/dl and low depressive symptoms with a mean of 10.89 in a range of 0 to 41on the CES-D and high social support scores with a mean of 24.31 with a range of 9 to 36. The PSS scores were significantly related to the depressive scores ($r = .7$, $p =.01$) but not to the social support. In the regression models, stress and social support accounted for 50% of the variance in the depressive symptoms but caregivers with higher levels of stress did not have higher salivary cortisol levels. The authors suggested age, length of caregiving and the lack of patient deficits may account for the unexpected results or that the measure of global stress may not be the tool to best reflect caregiver stress. They suggested measuring anxiety instead of stress. They also suggested that perhaps a one time check of cortisol may not be as accurate as multiple cortisol levels as in other cortisol studies. They also questioned the self-report measure suggesting there may be mismatches between what caregiver's perceive and what a family or health care professional would perceive. Further, perceptions don't always correlate with physiological levels. In spite of these limitations, the study supported the experience of stress in HF caregivers and the link to negative psychological consequences and raised some important methodological issues about representativeness and the length of caregiving.

As has been shown in this section, HF caregiver burden from the number and/or difficulty of the task or from the caregiver's perception of the experience has been linked to consequences such as stress, poorer quality of life or other negative outcomes. In the next section, caregiver burden is linked to one aspect of caregiver quality of life, emotional health.

Caregiver burden and emotional health-related quality of life

Caregiver burden has been linked with negative emotional health outcomes in a number of general caregiving studies. When caregivers were compared to noncaregivers worse psychological health was typically reported (Vitaliano, Russo, Scanlan, & Greeno, 1996; Bodnar & Kiecolt-Glaser, 1994; Pinquart & Sorensen, 2003). In large prospective longitudinal population studies of caregivers matched with noncaregivers, caregiving was associated with distress, anxiety and depression. Women fared worse than men or the age-matched noncaregivers. In a review of 30 studies of caregivers and psychiatric morbidity, higher levels of depressive symptoms and even clinical depression were seen in women caregivers (Yee & Schulz, 2000). The women's mean Center for Epidemiologic Study Depression Scale (CES-D) scores for studies using this measure were at or above the cutoff of 16 which is used for clinical depression, while men were below 16. In another two-year longitudinal study, women's scores rose rapidly and remained high while men's depression scores rose over two years to equal women's. When comparing women caregivers with age-matched female noncaregivers, caregiver's CES-D scores were 13.98 to 18.87 which were elevated compared to the noncaregiver's CES-D score of 6.72 (Schulz & Williamson, 1991). Women also had higher anxiety scores than men (Yee & Schulz, 2000). In a review, Molloy and colleagues noted that most studies have shown that informal caregiving… "contributes to psychiatric and physical morbidity" …of the caregiver (p.594, 2005). A clear association between caregiving and negative mental health outcomes was shown in the general caregiving literature (Schulz, Visintainer, & Williamson 1990; Biegel, Sales, & Schulz,1991; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Halm, 2005; Beach et al., 2000).

In the HF literature, caregivers have reported similar rates of psychiatric disorders to other patient populations with chronic illnesses (Pearlin, Mullan, Semple, & Skaff, 1990; Vitaliano, Russo, Young, Teri, & Maiuro, 1991; Haley et al., 1996; Farran, Loukissa, Perraud, Paun, 2004; Bookwala & Schulz, 2000). Scott reported 50% of the 20 caregivers had anxiety, 45% had depression, and 89% had mental health scores below the established age norm. Scott (2000) also reported mental health and caregiving esteem explained 49% of the variance in caregiver health-related quality of life. Dew et al. (2004) reported that caregiver's depression and anxiety-related disorders equaled or exceeded other caregiving population rates. Rohrbaugh and colleagues (2002) reported that 40% of 128 spousal caregivers qualified for a psychiatric diagnosis of distress-related disease. Fifty percent of the patients and 56% of the spouses were above the norm for anxiety and 57% of the patients and 67% of the spouses were above the norm for depression (Moser & Dracup, 2004). Schwarz and Elman reported that 21% of the sample of family caregivers of HF patients (*N* = 156) scored greater than 16 on the CES-D with a mean of 11.4 (*SD* = 8.8) which is comparable to Pinquart and Sorensen's 2003 meta-analysis results of caregivers of chronic illnesses who measured 11.5 (*SD* = 2.9). This would suggest that HF caregivers experience comparable or worse emotional outcomes than caregivers of other chronic illnesses such as Alzheimer's disease or Parkinson's. Alzheimer's patients are considered some of the most difficult to care for especially if they have behavioral problems.

In the HF literature, caregiver burden and emotional health outcomes are the most extensively studied relationship. Five investigators who examined emotional outcomes related to caregiver burden associated with care of HF patients, consistently found that perceived difficulty was associated with negative caregiver outcomes (Bakas et al., 2006; Karmilovich, 1994; Dracup et al., 2004; Nieboer et al.,1998; Wallhagen, 1992). Bakas et al. reported that 57% of the caregiver's negative emotional well-being was associated with caregiving. Karmilovich reported the mean stress of 0.48 (*SD* = 0.48) for caregivers was greater than non patient population's score of .30. Dracup and colleagues reported results similar to Scott (*N* = 69) with caregivers scoring below their age norm in depression (2004). As difficulty increased so did the depression in Wallhagen's study*(r* =.38, *p* = .01). Dew and colleagues reported similar results as did Nieboer and colleagues who demonstrated a link between caregiving and depression that was mediated by the lack of favorite activities. Depression increased or decreased with caregiving demands and favorite activities (Nieboer et al.).

Five HF researchers also reported a significant relationship between caregiver stress/burden and depression in spousal caregivers (Martensson, Dracup, Canary, & Fridlund. 2003; Schwarz & Dunphy, 2003; Rohrbaugh et al., 2002; Schwarz & Elman, 2003; Moser & Dracup, 2004). Martensson et al. reported 33% of the variance in spousal depression was accounted for by the spousal mental quality of life and the age of the patient ($p = .003$). Spousal depression was impacted by patient function, patient employment, and their own mental quality of life. Schwarz and Dunphy reported moderate stress for caregivers but stress and social support explained 50% of caregiver depression.

As an essential concept of the proposed study, caregiver burden is linked to negative emotional health in the general and HF literature. This link supports the model for the proposed study. A more extensive discussion about burden and psychosocial outcomes occurs in a later section on caregiver outcomes. The other component of caregiver quality of life is physical health.

Caregiver burden and physical health-related quality of life

Relationships between caregiver burden and poorer caregiver health are reported in a few HF studies but more effectively in the general caregiving literature. Burden has been related to poor physical health when caregivers report less time for self-care such as lack of rest, lack of time to exercise or for preventative health behaviors (Burton et al., 1997; Schulz et al., 1997). In several waves of the CHES studies caregivers and noncaregivers were compared in regard to caregiving burden as it relates to four health outcomes; perceived health, health risk behaviors, anxiety, and depression (Beach et al., 2000). Caregivers were consistently found to have worse health than noncaregivers with those caregivers with the greatest burden and strain having the worst health outcomes. More extensive discussion will follow in the latter section about caregiver quality of life.

Caregiver burden and perceived control

Relationships between caregiver burden and perceived control have been reported in the general and in the HF caregiving literature. Seventy-two percent of the variance in patient's mental health was explained by loss of control and feelings of powerlessness from worry and depression (Scott, 2000). While among caregivers, the impact of caregiver burden on adaptation was buffered by control (Wallhagen et al., 1994). Control has been reported as an important variable in caregiver anxiety and depression (Molloy et al., 2005; Sistler & Blanchard-Fields, 1993) often statistically significant (Pinquart & Sorensen, 2003; Burton et al., 2003; Wallhagen, 1992). Caregiver control acts as a mediator in the relationship between caregiver burden and caregiver psychosocial health. A more extensive discussion about control and burden follows in a later section on perceived control.

Caregiver burden and caregiver factors

Relationships between caregiver burden and caregiver demographic variables (age and gender) were reported in a number of studies. Age was repeatedly found to correlate with burden, generally the older the caregiver, especially after age 75, the greater the burden (Lalonde & Kasprzyk, 1993; Young & Kahana, 1992). Older caregivers with prevalent disease and the greatest burden who reported strain were at the greatest risk of higher 4-year mortality (Schulz & Beach, 1999). Spouses, especially wives, have consistently reported the greater burden in caregiving when samples of husbands and wives were compared (Chou, 2000; Gaynor, 1990; Robinson, 1990; Bookwala & Schulz, 2000; Pinquart & Sorensen, 2006). Husbands have been studies less often than wives.

Schulz and Beach's work also offers support for links between caregiver burden and some of the caregiver biological factors (anxiety, depressive symptoms and comorbidity). They indicated that caregivers with significant comorbid conditions are at greater risk of negative physical outcomes (1999). Dew et al. (2004) also offers support for a history of depressive symptoms. They found that caregivers with a prior history of depression were at greatest risk of recurrence of depression when caregiving a post transplant patient. In contrast, the youngest and the oldest caregivers reported the greatest burden in caregiving (Stolarik et al., 2000). Long-term caregivers tend to report poorer health (Gaynor, 1990; Schulz et al., 1997; McCann et al., 2004). Role, gender and marital quality were critical findings, with marital quality mediating the relationship between gender and caregiver distress (Rohrbaugh, et al., 2002; Bookwala & Schulz, 2000).

Caregiver burden and patient factors

Relationships between caregiver burden and patient NYHA class were reported in a few studies. The level and type of demands, and the trajectory of an illness appeared to impact caregiver distress across a broad range of chronic illnesses (Biegel & Schulz, 1999). Caregivers of physically frail elder adults had higher stress, lower well being, and poorer health than noncaregivers (Pinquart & Sorensen, 2003). Male patients created higher level of objective and subjective burden for the caregiver (Lalonde & Kasprzyk, 1993). A more extensive discussion of this relationship occurs in a later section of patient factors.

Conclusions

Caregiver burden has been widely studied in the general literature in a large variety of patient populations but only more recently and on a limited basis in HF. Caregivers report caregiving as difficult in terms of the number and type of tasks with certain types of tasks as the most difficult. Wives found caregivng the most stressful. Older and younger caregivers report the greatest difficulty and stress with caregiving. Even with the limited number of studies focused on HF caregivers, they consistently have negative consequences similar to other caregivers in other patient populations. Caregivers who have some control experience less of those negative consequences. Caregiving burden is correlated with some caregiver and patient demographic factors.

The relationships between caregiver burden, perceived control, caregiver quality of life, caregiver factors, and patient factors as hypothesized in the present study are supported by the literature. Gaps in knowledge identified from the literature support the need to (a) explore what is burdensome for HF caregivers with a larger sample than the Bakas et al. pilot, (b) test the hypothesized relationships from the proposed model in a larger sample of caregivers, (c) create a better understanding of the relationship of burden, control and outcomes, and (d) understand the impact of caregiver and patient factors infrequently included in the literature.

From a methodological standpoint, there are limitations in the literature, most studies are atheoretical so that measures are the only indication of a theory or framework. Only a few studies have tested models or theories of caregiving. Burden is most often undefined and when defined, it is operationalized in a variety of ways making comparisons more cumbersome and accumulation of a body of data more difficult.

The majority of studies are quantitative cross-sectional studies which provide information in an understudied area of caregiving. Many samples are small such as 18 participants (Scott, 2000), 41 participants (Karmilovich,1994), and 48 participants (Matensson et al., 2003), with the range from 18 to 190 (Dew et al., 2004) raising question about their ability to answer research questions. Participants were often self-selected raising questions of representativeness. The samples in the studies most often suffer from being primarily Caucasian educated middle-class female spousal convenience samples. The ages of the participants vary widely as do the patient's NYHA class which is roughly a proxy for their severity of illness. The severity of the patient's health is described in a variety of ways from self-reported global health assessment to caregiver assessment to NYHA class so that comparisons are difficult. There are only a few prospective longitudinal studies and no randomly controlled or experimental studies evaluating interventions. Caregiver intervention studies support links between caregiver factors and burden and between burden and negative psychosocial outcomes. There were a wide variety of measures, many not well tested and with lower than accepted reliability or modified measures without reported reliability on the modified form. Many of the measures are self-report.

The proposed study can make a significant contribution to the HF caregiving literature, working from a research based conceptual framework that had been tested with well defined conceptual terms and measures, to identify which tasks are burdensome and difficult for the HF caregiver and identify relationships between burden and other study variables.

Caregiver Health-Related Quality of Life

Caregiver burden has been linked to a variety of negative psychosocial and physical consequences. The literature supports the hypothesis that increased caregiver demands have a negative impact on the caregiver's emotional health. Caregiver health-related quality of life will be discussed first as perceived emotional health status followed by a section on perceived physical health status. In the emotional health section, quality of life, caregiver intervention, and studies examining stress or distress are included.

Definitions of Health-Related Quality of Life

The majority of outcomes related to caregiver burden in the general and in the HF literature are emotional, psychological, and social outcomes, all of which are components of emotional health, in a quality of life view. A few studies specifically utilized quality of life or health-related quality of life as an outcome. Most researchers did not discuss the conceptualization of the psychological outcomes in their studies. Information about the use of quality of life comes largely from the HF literature so that will be addressed first followed by studies on stress and distress in the HF and general literature.

In the HF literature, six studies examined quality of life of some type, such as global or emotional, two of whom provided a definition of quality of life. Scott used health-related quality of life based on Wilson and Cleary's theory. Scott's definition included an overall effect and outcome of an illness and its treatment on an individual's physical, psychological and social well-being (Schipper, 1990). Evangelista and colleagues (2002) studied quality of life in patients using the Minnesota Living with Heart Failure Questionnaire. Evangelista defined quality of life as "the degree to which aspects of patients' physical, social, functional, and emotional well-being are impacted by health" (p.362, 2002). The remaining researchers did not provide definitions but indicated their concept of quality of life by the tools they used. Luttik and colleagues (2005) studied quality of life using a measure that reported global well-being in terms of psychosocial adjustment. Dracup et al. (2004) operationalized emotional well-being as the results of the mental and physical health subscales of the SF-12. Bakas and colleagues (2006) examined caregivers'mental health using the SF-12 also.

Eight authors examined stress and distress, two in the general caregiving literature (Wallhagen, 1993 and Molloy et al., 2005) and six in the HF literature (Rohrbaugh et al., 2002; Moser & Dracup, 2004; Schwarz & Elman, 2003; Schwarz & Dunphy, 2003; Evangelista et al., 2002; Karmilovich, 1994). Few of the eight researchers provided definitions of their emotional health outcome. Some stated the outcome of interest was operationalized by the instrument in use. Wallhagen examined stress in two studies, while Molloy et al. looked at distress. Wallhagen also investigated life satisfaction or social changes. Three of the HF investigators did not provide definitions (Rohrbaugh et al., Karmilovich, and Moser & Dracup). Rohrbaugh et al. studied distress of patients and caregivers to determine if their role in the relationship or their gender was significant in determining their level of distress. Moser and Dracup looked at emotional distress of patient and spouse and their adaptation to a cardiac event. In two different but related studies, the two remaining HF investigators that provided definitions were teams with Schwarz in two different investigations. Schwarz and colleagues defined stress and utilized the Perceived Stress Scale. Schwarz and Dunphy (2003) defined stress as an "emotionally, disruptive response resulting from problems that threaten available resources" (p. 222). They suggested that a person's appraisal of a situation as stressful is the best indicator of the experience of stress. They stated that stress, strain and burden can be used interchange-ably to describe the caregiver's response to care. Evangelista and colleagues reported psychological well-being which was operationalized as low levels of depression and high levels of perceived control and used the Beck's Depression Inventory to measure depression (2002). Anxiety and depression studies will be examined in a later section about caregiver biological factors.

Noting the variety of instruments for emotional health outcomes and the rarity of definitions for outcomes, caregiver quality of life is defined as the caregiver's perception of their well-being including mental, emotional, vitality, role and social functioning, and physical ability and functioning and general health (Medical Outcomes Trust, 1994, Gandek, Ware, Aaronson, & Apolone, 1998).

Measures of Emotional Health-Related Quality of Life

There is no consensus about which instruments to use to measure emotional health in the general or HF literature. In the general caregiving literature, Wallhagen used the Life Satisfaction Index A to assess psychological well-being while Molloy and colleagues used the 14-item Hospital Anxiety and Depression Scale to assess caregiver distress. In the HF literature, quality of life was measured in three studies (Evangelista et al., Dracup et al., Bakas et al.) with the SF-12, while the longer SF-36 was used in all three of Bull's studies (1990). Scott used the six-point Quality of Life Index that measures perceived satisfaction and the importance of different domains in life. Luttik et al. used the Cantril Ladder of Life for global quality of life with embedded adjustment questions. Evangelista et al. and Bakas et al. used the mental health subscale of the SF-12 which measures vitality, social functioning, and role limitations due to emotional problems. Evangelista et al. (2002) defined mental health in terms of distress and well-being.

Since quality of life includes perceived emotional health status, some quality of life studies used stress and distress measures when examining emotional health are mentioned. The Hopkins Symptom Checklist (HSCL) was used by Rohrbaugh et al. (2002). The HSCL identifies persons with high levels of anxiety and depressive distress. The Center for Epidemiologic Study Depression Scale and the Perceived Stress Scale were used in two studies (Schwarz & Elman, 2003; Schwarz & Dunphy, 2003). The Perceived Stress Scale was developed based on Lazarus and Folkman's theory to determine the degree to which a person appraises their life as unpredictable, uncontrollable and overloaded (Schwarz & Dunphy). This is intended to be a global stress tool. Karmilovich used the Brief Symptom Inventory. Moser and Dracup used the Multiple Affect Adjective Checklist to measure emotions in patients and spouses in three studied (2003, 2004, 1995) and the Psychological Adjustment to Illness Scale only with patients in two of those studies (2004, 1995).

Empirical Literature Review for Emotional Health-Related Quality of Life

As discussed in a prior section, a significant relationship between caregiver burden and a variety of negative quality of life outcomes is supported by research. Caregiver burden has a significant negative relationship with caregiver emotional health outcomes, such as, quality of life and stress and distress. Caregiver burden and/or stress have also been linked to distress in caregiving spouses. Caregiver burden has been linked to social outcomes such as changes in social relationships future outlook, or finances.

Patient factors such as age, severity of illness, and patient relationship with the caregiver have been associated with negative caregiver emotional health outcomes.

As previously discussed, the general caregiving literature shows a clear association between caregiving and negative emotional health outcomes (Biegel & Schulz, 1999; Beach et al., 2000). This was also reported in studies comparing caregivers and noncaregivers (Vitaliano et al., 1996; Pinquart & Sorensen, 2003). Women caregivers typically fared worse with anxiety and depression than male caregivers or age-matched noncaregivers (Yee & Schulz, 2000; Schulz & Williamson, 1991). Caregiver scores were low compared to noncaregivers of similar age (7.9) which is an indication that caregivers feel burdened and stressed. In the CHES study, where caregivers were caring for patients early in their disease process with only one or two patient deficits, increased caregiver strain was linked to poorer caregiver mental and physical outcomes (Beach et al., 2000). Schwarz and Dunphy (2003) reported that spousal caregivers experienced moderate stress on the Perceived Stress Scale and higher cortisol levels than nonspousal caregivers.

In the general caregiving literature, caregiver intervention studies were effective in reducing caregiver depression and improving subjective well-being with psychoeducation, psychotherapy, respite care, and training of the patient (Sorenson et al., 2002). Multi-component interventions were not effective for depression. As Sorensen et al. noted when examining multi-component interventions, many researchers did not provide enough information to determine what was included in the therapy. The longer the intervention was, the larger the effect in changing depression. Age, adult child status, and greater subjective burden at baseline were positively associated with intervention effectiveness for depression and well-being while gender had no association. Random assignment significantly predicted the size of the effect for depression and well-being, when randomly assigned, the effect was smaller.

Some of the limitations Sorensen et al. noted were differences of effectiveness according to which measurement tool was used. Beck's Depression Inventory has the largest effect (g = -0.43) while Zarit's Burden Inventory had a lower effect (g = -0.04) and the Geriatric Depression Scale had the lowest effect size (g = -0.03). They also noted the timing of the intervention in the disease process was significant, as in, was the intervention at the beginning

As previously discussed, HF researchers reported a significant relationship between caregiver burden and emotional outcomes. Some brief references to those results are included here followed by more extensive review of results not previously discussed. Karmilovich found a correlation between the number of tasks and stress and the difficulty of tasks and stress (1994). Scott reported mental health and caregiving esteem explained 49% of the variance in caregiver health-related quality of life (2000). Dracup and colleagues (2004) reported results similar to Scott (N = 69) with caregivers scoring below their age norm in depression. Bakas et al. (2006) also reported a correlation of difficulty of tasks with worse mental health scores. Further, they reported that 57% of the caregiver's negative emotional well-being was associated with caregiving. Scott reported that majority of the patients and caregivers had mental health scores below the population norm. In Aldred and colleagues (2005) qualitative study, they reported that HF affected all aspects of the caregiver's life. The caregiver reported giving up favorite activities, experiencing social isolation. Lastly, Luttik et al.(2005) reported lower quality of life scores for caregivers versus noncaregivers indicating burden or stress.

A number of researchers examined stress or distress as an outcome. Rohrbaugh et al.(2002) examined distress and marital quality with 167 HF patients and their spouses. In a cross-sectional design, they sought to investigate the levels and correlates of distress in married HF patients focusing on gender and role as the source of variation in distress. The patients were recruited from the University of Michigan HF clinic with a requirement of EF of 35% or lower. Caregivers were primarily Caucasian, married an average of 25 years with a mean age of 52 years. Interviews were conducted in the participants' homes conjointly and separately using self-report Hopkins Symptom Checklist-25 for anxiety and depression, the modified Family Time and Routines scale for marital routines, a single subjective rating of relationship change since the diagnosis of HF, a modified Ways of Coping scale and the 20-item marker of the Big Five looking for the five major psychiatric disorders. The Hopkins Symptom Checklist-25 identifies which persons have high levels of anxiety and depressive distress. Cronbach's alpha for all measures were acceptable.

Female patients reported the highest levels of distress with male spouses reporting the lowest via ANOVA (F 1,169 = 24.38, $p < .01$). A significant role-gender interaction indicated that patient-spouse differences in distress varied with their gender. Female patients reported better relationships than male patients. The patient's NYHA class correlated with his distress but not the spouses' distress. The most impaired patients also had the highest distress. Also, if one partner was distressed, the other partner tended to be also. The authors suggested it was also feasible that both partners were reacting to the same situation by being upset. Forty percent of the spouses were in the distressed range. Distress for both partners correlated negatively with ratings of marital quality. Better marital quality also correlated with higher income.

From a limitation perspective, Rohrbaugh and colleagues' results are cross-sectional and self-report which limits their generalizing to like populations and raises other plausible explanations for their results. Same sex interviewers could have created biased gender reports and other variables like caregiver loss of favorite activities, spousal style of coping, or changes in the relationship due to illness were not included. Regardless of the limitations, the results confirm that caregivers are distressed in significant numbers which is supportive of the proposed study hypothesis that stressed caregivers experience greater burden and with greater burden comes negative psychological outcomes. The results also confirm that patient distress is proportional to their disease which would also imply that caregivers of worse patients would potentially have higher distress than caregivers of less ill patients. It is also important that their relationship with the patient is a significant factor in their distress level especially when noting the length of marriage averaged 25 years in this sample which offers support for the hypothesis that years married is significant variable in the caregiver's burden.

Moser and Dracup (2004) also examined the relationship between patient distress and spousal distress and the responses and perceptions of control of each to a new myocardial infarction or bypass surgery. In a comparative design, 417 pairs of patient-spouses from six hospitals were assessed for emotional responses using the Multiple Affect Adjective Checklist (MAACL), control via the Cardiac Attitudes Scale, patient adjustment via the Psychological Adjustment to Illness Scale, and the marital quality via the Spanier Dyadic Adjustment Scale. Spouses were female, age 59 (+/- 11years) with college education. Patients were slightly older with the majority NYHA class I with mean ejection fraction of 51%.

Unlike Rohrbaugh et al., spouses had higher anxiety (*p* <.001) and depression (*p* <.001) than patients. Compared to published norms for the MAACL 50% of the patients and 56% of the spouses were above the norm for anxiety and 57% of the patients and 67% of the spouses were above the norm for depression. Spousal anxiety and depression that was greater than the patient's negatively impacted patient adjustment to their illness. Patients who were more anxious than their spouses or similar to their spouses adjusted better to their illness. In regard to control, spouses had lower control and higher anxiety and depression than the patients which differs from prior research on patient populations. Even though the design was cross sectional, the large multisite sample of 417 pairs of spouse-patients is a strength of this study. The NYHA class and ejection fraction of the patients indicate a healthier patient population than those in the proposed study. Spouses were negatively impacted by the patients' change in health demonstrating the link between patient health and caregiver outcomes and the reciprocal nature of the patient-spouse relationship.

Evangelista, Dracup, et al. (2002) sought to describe and compare the emotional well-being of HF patients and their caregivers, to determine if gender is a significant factor in the emotional well-being, and to identify factors associated with the emotional well-being of the patients. In their prospective comparative design they used 103 pairs of patient-caregivers from a single medical center that completed the SF-12 to assess physical and mental health. Caregivers were mainly Caucasian female spouses with a mean age of 59.5 years (± 17.6 years). Patients were mainly Caucasian, unemployed males with a mean age 57.6 with an ejection fraction of 25.5% and 23 % in class II and 40% in class III and 21% in class IV.

Similar to Rohrbaugh et al, and Scott, Evangelista, Dracup et al. found patients had significantly poorer emotional well-being than caregivers. Female patients and caregivers had poorer emotional well-being than males but the difference was only significant for patients (p =.018). This finding is similar to Karmilovich (1994). Age and gender were associated with the patient's results, as in younger male patients had better results than older female patients (p <.05). The patient's age, gender and the caregiver's emotional well-being accounted for 54% of the variance of the patient's emotional health. Scott found similar results in regard to caregiver mental health predicting the patient mental health. As has been shown in prior studies, the relationship between the patient and caregiver, especially the spouse, is a reciprocal one. The comparative design and the sample size are strengths of this study while the convenience sample limits conclusions and the descriptive cross-sectional data collection preclude causality. The unmonitored administration of the SF-12 did not prevent couples from completing the forms together. As with other similar studies, potentially confounding variables were not included in the analysis such as comorbidities, perceptions of social support, marital quality, or patient function level.

Dracup and Evangelista et al. (2004) described the emotional well-being of spouses of HF patients, identified factors associated with spouses emotional well-being, and compared emotional well-being of spouses with high versus those with low perceived control. Using a cross-sectional correlational design a convenience sample of 69 spouses, (mainly females with mean age of 54 years) completed two subscales of the SF-36 for mental and physical health, the Control Attitudes Scale (CAS) and two subscales of the Caregiver Appraisal Tool (CAT) to assess burden and impact of caregiving. Cronbach's alpha ranged from 0.70 for the CAT to 0.90 for the CAS.

Spouses reported significantly lower mental health and health perception than age-adjusted norms for the general population. Greater distress was associated with age (younger age), higher burden, and lower control (*p* =.001). Spouses that had higher control reported significantly higher emotional well-being (77.6 versus 65.3, *p* =.003). The results reinforce the proposed study in terms of caregivers with greater burden have worse mental health. And as will be discussed in a later section, the result of caregivers control may mediate burden's impact on caregiver emotional health also supports the proposed study. As with prior studies, the caregivers were younger, still employed and potentially responsible for dependent children or elder parents which may confound the results. As in prior studies, the cross-sectional design, the small sample size and the homogeneous nature of the caregivers are limitations to generalization.

And lastly, caregiver burden has been negatively related to social outcomes in previous research. Both Nieboer et al. and Dew et al. found that a reduction in favorite activities for caregivers due to increasing caregiver demands resulted in increased depression. Other general outcomes were affected negatively as reported by Bakas et al. About 48% of caregivers (*N* =21) reported their lives changed for the worse as a result of caregiving a HF patient in regard to their outlook on the future, their level of energy, time for socializing and their financial well-being (Bakas, et al., 2006). Also, 29% of caregivers reported managing finances and providing transportation for the patients was moderately to extremely difficult.

Similar results were found by a qualitative researcher who reported a process of disruptions, incoherence, and reconciling for HF patients and their caregivers (Mahoney, 2001). Disruptions in the normal course of life cause disorder in emotional, social, economic and spiritual levels. Incoherence follows when the experience such as a hospitalization or a new symptom was unexpected which taxes the patient and caregiver to struggle to make sense of the event. New burdens, changes and uncertainty result. Weller (2002) reported that burden was a series of ongoing losses for the wives of husbands with heart failure. These results support the negative impact of burden on the social outcomes for caregivers.

Emotional Health-Related Quality of Life and Patient Factors

Previous research supports the relationship of patient factors of severity of illness and negative caregiver psychological outcomes. The caregving and HF literature indicates a declining patient health has a negative impact on caregivers. Couples research suggests that the patient's declining emotional or physical state can be a stressor for the caregiver. Molloy and colleagues report that HF has been consistently associated with higher levels of emotional distress in patients (Molloy et al., 2005; Freedland et al., 2003; Faris, Purcell, Henein, & Coats, 2002; Biegel & Schulz, 1999). If the patient is distressed, it is common for the caregiver to be distressed also (Bookwala & Schulz, 1998). Similar results were reported with HF patients and post myocardial infarction or bypass patients and their caregivers (Evangelista et al., 2003, 2002; Scott, 2000; Moser & Dracup,1995, 2004). Martensson et al. (2003) found that as patient dysfunction level increased so did the spousal depression. In contrast, an increased risk of readmission for HF patients occurred when the caregiver was stressed or depressed (du Fort, Kovess, & Boiven,1994; Schwarz & Elman, 2003). Moser and Dracup (2004) reported that the caregiver's anxiety, depression and perceived control correlated with the patient's adjustment to illness, which was worse if the caregiver was more depressed or anxious than the patient. These results support the proposed study's focus on the relationship of patient factors that may negatively impact the caregiver and caregiver outcomes. Although caregivers may be more anxious or depressed than patients, among spouses, gender altered how caregivers provide care and perceive the stress of that care. Further discussion of relationships between patient factors and caregiver outcomes follows in the Patient Factors section.

Emotional Health-Related Quality of Life and Caregiver Factors

Previous research supports relationships between caregiver factors (age and gender) and psychological outcomes. Wives reported more negative psychological and social consequences of caregiving than husbands. As caregivers, husbands reported fewer behavioral issues with their wives as care recipients, less restrictions on their personal time, and less change in their relationship with the patient's spouse, compared to wives. This is believed to explain greater secondary stressors for wives in greater depression and depressive symptoms (Bookwala & Schulz, 2000). Three HF researchers used spousal caregivers and reported a significant relationship between caregiver stress/burden and depression (Martensson et al, 2003; Schwarz & Dunphy, 2003; Rohrbaugh et al, 2002). For Schwarz and Dunphy, 50% of the variance in depressive symptoms was accounted for by stress and social support. They reported significantly higher stress for spousal caregiver than non spousal caregiver via salivary cortisol levels (2003). Martensson et al.

and Rohrbaugh et al. reported relatively high levels of distress and poor mental health. While Rohrbaugh et al. found that 40% of the spouses (*N* =128) were in the distressed range. Further discussion of caregiver factors and their relationship to caregiver outcomes occurs in the later Caregiver Factors section.

Molloy and colleagues (2005) point out that despite the increasing incidence and prevalence of HF there are few comprehensive studies on caregivers of HF patients. However, the number of studies is limited that have examined relationships between caregiver emotional outcomes and this study's variables (eg. caregiver burden-time and difficulty, perceived control, caregiver factors and patient factors).

Conclusions

Negative psychological outcomes have been consistently associated with caregiving in a wide variety of patient populations in the general caregiving literature and recently in the HF literature. Burden conceptualized as the number and difficulty of tasks has been associated with distress, anxiety, depression and depressive symptoms in HF caregiving. Social outcomes have been negatively impacted by caregiving burden. Control has consistently played a significant role in the relationship between burden and negative psychosocial outcomes, as a buffer or mediator or in some a direct or indirect relationship. Some caregiver and patient factors have been linked to negative psychosocial outcomes. Female gender, spousal relationships, and worse patient health with greater demands have been associated with negative psychological outcomes. The remaining caregiver and patient factors have been inconsistent in their relationships to outcomes or underexplored.

From a methodological standpoint, the general caregiving literature offers studies with stronger designs than those found in the HF literature. The general caregiving literature includes longitudinal, population based comparative studies such as the CHES studies with controls, large samples from multiple sites (Beach et al., 2000; Yee & Schulz, 2000). It also includes several meta-analyses (Vitaliano et al, 2003; Pinquart & Sorenson, 2003) with samples in the thousands and comparisons of caregivers and noncaregivers. Even in this literature, there are limitations such as limited use of theories, models or definitions of terms. There is no consistency in the use of measures although they are well recognized measure such as the Center for Epidemiologic Studies Depression Scale or Beck's Depression Inventory with established reliability and validity. Many of the measures are self-report.

In the HF literature, there are some studies examining outcomes that are stronger methodologically than the rest of the HF literature. The use of (Schwarz & Elman, 2003; Rohrbaugh et al., 2002; Moser & Dracup, 2004; Evangelista, Dracup et al., 2002) larger samples between 103 and 417 and the use of comparative designs (Moser & Dracup; Evangelista & Dracup et al.) and populations drawn from multiple sites provided stronger results and the opportunity to draw conclusions about causality. Few studies used samples other than white, female spouses as the caregivers. The severity of the patient's health is described in a variety of ways from self-reported global health assessment to caregiver assessment to NYHA class so that comparisons are difficult. Most of the measures were well recognized measures with acceptable reliability and validity. Many of the measures were self-report.

The literature supports the hypothesized proposal’s relationships of burden and outcomes mediated by control. There is little research utilizing the instruments proposed for this study on these variables. Gaps in knowledge identified from the literature support the need to (a) test the model in a larger sample of caregivers than Bakas’ pilot, (b) explore the social outcomes in a larger sample, (c) better understand the relationship of burden, control and outcomes, and (d) understand the impact of caregiver and patient factors infrequently explored in the literature. The next section addressed not only the measures of physical health but the current literature related to physical health.

Measures of Physical Health-Related Quality of Life

In the general caregiving literature, physical health is measured a variety of ways with few researchers offering a definition. In the CHES series, physical health was measured by the presence of clinical disease and disease indicators strongly associated with morbidity or mortality. Participants were divided into three categories, those with prevalent disease such as myocardial infarction, stroke or HF, those with subclinical disease with indicators of electrocardiographic changes, claudication, and those with no disease or indicators. In wave 1 and 2 Beach, Schulz, Yee and Jackson (2000) and Burton et al. (2003) measured general health by a single item on a 5-point scale from poor to excellent and by a count of seven health risk behaviors such as eating less than three meals a day and not getting enough rest. Beach et al. did provide a conceptual model based on Lazarus’s theory of how caregiver demands can increase health problems via perceived stress. In the meta-analyses by Vitaliano et al. (2003) and Pinquart and Sorensen (2000), similar results regarding health were reported, but health was measured many different ways. Of the 45 studies reviewed by Vitaliano et al. health was measured by one of five categories; global self-report which may have been a single item, the number of chronic conditions, the number of symptoms, the number of medications used, or health services used such as, doctor or hospital visits. The studies were fairly equally distributed in each category. Pinquart and Sorensen found similar results. Vitaliano et al. also reported that about half of the studies also measured objective physiological health by measuring antibodies, immune function, stress hormones, cardiovascular measures or metabolic measures. There were four to six studies for each of these categories.

And finally McCann et al. (2004) followed over 4,000 community residents from a large Chicago population study for a three-year period with particular interest in identifying when caregiving began and correlating health consequences with caregiving. McCann used a combination of self-report health, objective function measures of the Katz Activities of Daily Living scale and the Rosow-Breslau Functional Health scale, a 4-item health-related quality of life measure, and blood pressure.

Five HF researchers included physical or general health as an outcome for caregivers (Bakas et al., 2006; Scott, 2000; Evangelista & Dracup et al., 2002; Nieboer et al., 1998; Martensson et al., 2003). Few defined or discussed their conceptualization of health. Scott (2000) defined health-related quality of life as the "overall effect and outcome of an illness and its treatment on an individual's physical, psychological, and social well-being as perceived by the individual" (p.83). Scott also utilized the Caregiver Reaction Assessment which included some general health questions. Another investigator inferred a broad concept of health by use of a quality of life measure (Luttik et al., 2005) while two others used the SF-12 as their proxy for caregiver general health (Bakas et al., Nieboer et al.). All of the health measures were self-report measures. For the proposed study, physical health-related quality of life includes the caregiver's perceived health status including self-reported morbidity status (Lyons, 1988).

Empirical Literature Review for Physical Health-Related Quality of Life

In a review of the HF literature, Molloy and colleagues (2005) noted that most studies have shown that informal caregiving… "contributes to psychiatric and physical morbidity"… (p. 594). Previous research supports the relationship between burden and negative health outcomes for caregivers. The most valuable source of information about caregiving and health are the four large longitudinal prospective population studies that compare caregivers to noncaregivers. In wave 1 and 2 of the CHES studies, the relationship of caregiving burden was examined with four health outcomes; perceived health, health risk behaviors, anxiety and depression (Beach et al., 2000; Burton et al. 1997; Burton et al., 2003; Schulz & Beach, 1999). It was assumed that exposure to chronic stress or strain may be a significant factor of duration or intensity of burden.

In Beach et al., the purpose was to examine the direct effects of caregiving demands and perceived caregiver stress on caregiver health outcomes. Caregiver demands were operationalized as the degree of patient disability and the care required of the caregiver. Caregiver stress is the degree of physical and emotional strain reported by the caregiver. Outcomes of interest were perceived health, health-risk behaviors, anxiety, and depression. The sample of 680 persons was divided into four groups, noncaregiver controls and three caregiving groups organized according to the level of care for a disabled spouse and the strain on the caregiver, such as group 2 with at least one patient disability and no caregiving, group 3 two or more disabilities and care for one disability but no strain, and group 4 with multiple disabilities and care and reported strain either physical or emotional. Information was collected at baseline and at the end of each year with this report covering two time points.

Trained interviewers conducted structured interview in the participant's home lasting between 60 to 90 minute using the Stressful Life Events list resulting in a simple count of negative life events during the prior 6 months, using six activities of daily living and six independent activities of daily living questions to assess function, the Quality of Marital Relationships was used, the 14-item dyadic relationship component of the Family Assessment Measure was used, caregiver strain was calculated as the mean level of emotional and physical strain, a single 5-point scale item was used to assess their general health from poor to excellent, health behaviors were assessed by asking about seven behaviors such as eating less than three meals a day, and the DIS-III-R was used for anxiety and depression. The study was based on a conceptual model from Lazarus's theory assuming demands increase health problems via perceived stress.

Approximately 381 participants or 56% were noncaregivers while 35% reported the patient had one disability, 35% reported between two to four disabilities, and 30% reported five or more disabilities. The participants were (M = 71.5 years) almost all White race, 42% college educated and equally distributed between male and female. The patients had diagnoses such as stroke, arthritis, heart disease, and dementia. There was little change from year 1 to year 2, where the average caregiver was helping the patient with 70% of the tasks that he could not perform and reporting low levels of physical and emotional strain (M = 0.3 with range of 0-2). Beach et al. reported that the caregivers were less healthy than the controls (p <.01), with the largest effect for those with the most caregiving as evidenced by moderate to high correlations. Beach and colleagues reported that caregivers with a consistently high burden and those with an acutely high burden reported poorer health. Fifteen percent of the variance in health was attributed to caregiver strain. Increased burden and increased strain were related to increased anxiety. Increased patient impairment and increased caregiver burden were associated with all poorer outcomes in all four health outcomes over the 2-year study period. The magnitude of these effects is small with changes in caregiving accounting for 1 to 6% of the variance in health outcomes.

The authors suggest this effect size may be due to the small amount of change, the stable period of observation for the patient, and/or the early stage of disability for the patient. The authors also suggest that changes in caregiver health lead to changes in caregiving, as an alternate explanation for the results. Even though the study has the strength of longitudinal design with a large sample and controls, the results are limited by the self-report measures and possibly some sampling bias due to the differences between the enrollees and the refusals in the initial enrollment in the parent study, the Cardiovascular Health Study. The enrollees are younger and better educated than those that refused with less disabled spouses with less caregiver strain at baseline. The link between caregiving burden and health demonstrated by Beach et al. supports the same link in the proposed study.

Burton and colleagues (2003) also used data from the CHES study and studied 818 spousal caregivers versus noncaregivers over a 5-year period. The caregiver transitions into and out of caregiving and the amount of caregiving were examined as were the changes in mental and physical health, specifically depression, health, preventative health behavior and self-mastery. The caregivers were interviewed four times over five years. The participants were classified into one of four groups, noncaregiving control if they remained in that status for five years, moderate caregiver if they began caregiving to provide at least 1indirect activity of daily living and stayed at that level and heavy caregiver if they provided at least 1 direct activity of daily living at any one of the follow-up points. There were 209 noncaregivers and 136 moderate and 83 heavy caregivers at the end of the 5-year study. The moderate and heavy caregivers were typically older at 78 to 80 yrs of age. They used the Center for Epidemiologic Studies Depression Scale for depression, Pearlin's Self-Mastery for a sense of control, health via 5-point self-rated single question, health risk behaviors as described above in Beach et al.

Eighty-three caregivers became heavy caregivers who then had greater depression, worse health risks and "health outcomes that became progressively worse over time" (Burton et al., p.236) than noncaregivers or moderate caregivers ($F = 6.88$, $p<.001$) based on an interaction of transition and time ($F=2.74$, $p<.05$). Noncaregivers were younger, had higher income, with the highest control and lowest health risk and lowest depression.

Participants more likely to become caregivers were older with lower income, lower control and a greater number of health risk behaviors prior to becoming a caregiver.

The results support the relationship between burden and negative consequences for the caregiver's health. The sample is older than most samples in the HF literature. The criteria for qualifying in the moderate or heavy caregiving were minimal such that caregivers who are providing higher levels of care would theoretically have worse outcomes (such as Schulz & Beach's 1999 study). The criteria did not increase over time which would be highly likely in a 5-year span for HF patients in their seventies or eighties. The strengths of the study are the longitudinal design with controls, the large random sample from multiple sites, and the multiple time points to show change but the health data is based on self-report. In addition, the transition group sized at 83 was not large and certainly warrants additional study to replicate the results. The authors suggested a limitation was also the loss (via death or admission to a nursing home) of caregivers who may be experiencing the greatest stress may cause an underestimation of the effects of caregiving.

The third CHES report by Schulz & Beach (1999), examined the relationship between caregiving demands and 4-year all cause mortality. Using the prospective population based cohort design caregivers were followed for an average of 4.5 years from four different communities. A sample of 392 caregivers and 427 noncaregivers living with a spouse were enrolled in the study. Using the same four groups as Beach et al., physical health status was measures as the presence of prevalent clinical diseases and subclinical disease indicators strongly associated with mortality. Three categories of health were created, 1= prevalent disease with one of six disease indicators, 2= subclinical disease with no disease but one of 5 indicators, 3= no prevalent or subclinical disease. About 27% of the participants had at least one prevalent disease such as angina, while 41% had one subclinical disease and 32% had neither. After adjusting for sociodemographic factors and physical health status, caregivers who reported strain had a 63% higher 4-year mortality rate compared to age and gender matched persons who were not caregivers. Caregiving was an independent risk factor for mortality. They also found elevated mortality rates for all participants that had prevalent disease (22.5%) but stated a larger sample would be required to state that disease plus strain is conclusively associated with mortality. The strained caregivers had higher levels of depression, anxiety and lower perceived health and higher health risk. These data support the relationship between caregiver burden and worse health outcomes in the proposed study.

Burton, et al. (1997) examined how the burden of caregiving impacted preventative health behavior of the caregiver. They hypothesized that caregivers with strong sense of control will be more likely to engage in preventative health than caregivers with a weak sense of control. They also hypothesized that a strong sense of control will moderate the risk of caregivers failing to use preventative health. Using the baseline and 1-year data from the CHES study, 619 caregivers and age and gender matched controls were enrolled in the current study. Caregivers were stratified into high level or moderate level as used in the 2003 Burton et al. study described above.

They measured sense of control using 7-item Pearlin's Self-Mastery. About half of the participants were in the moderate and half in the high caregiver category. There is a significant linear relationship between the level of caregiving, age, health of caregiver and social support. Health behaviors of lack of exercise, lack of rest, allow rest when sick, forgetting to take medications ($p <.001$) and not making doctor appointments and the level of caregiving ($p <.000$). The remaining health behaviors were more frequent in high caregivers but not statistically significant. At each level of caregiving, caregivers with a strong sense of control there were fewer incidences of unhealthy behaviors while those with weak sense of control had higher incidences of unhealthy behaviors. Hence, caregiving is more strongly associated with poor health behaviors if the caregiver also has a weak sense of control, for example, for not getting enough rest (OR = 2.33). The Odds-ratio for a strong sense of control and not getting enough rest were 0.32. The results indicate that the greater the burden, the more likely the caregiver is to fail to take care of themselves. In the presence of a strong sense of control, the caregiver is more likely to carry out preventative behaviors than with a weak sense of control.

The longitudinal comparative control design along with the sample size and composition are the strengths of the study while the self-report measures are the weak link. The results support the proposed study's link between burden and the negative impact of burden on health behaviors of the caregiver. Further, it supports the moderating role of perceived control in the relationship between burden and health outcomes.

McCann et al. (2004) utilized a longitudinal prospective database of 4,000 elders in the city of Chicago. They were interested in identifying predictors of who would become and persist in caregiving. They used a combination of blood pressure, self-report health questions, objective function measures from the Katz Activities of Daily Living scale and the Rosow-Breslau Functional Health scale, which is a 4-item health-related quality of life measure. They found that healthier persons were significantly more likely to become caregivers and to continue caregiving. Marital status, age, and gender were significant predictors of beginning caregiving. Spouses were two time more likely to become caregivers and 70% of those who became caregivers, cared for a spouse. Further young, white and healthy spouses were most likely to become a caregiver. Age and physical function influenced beginning caregiving. Married healthy females were more likely to begin and continue caregiving. But with each loss of function the likelihood of beginning caregiving was cut in half. Ending continuing caregiving was most often due to physical health decline, disability or patient or caregiver death. Declining mental health or stress did not significantly impact continuing caregiving. McCann et al. provide support for the importance of caregiver health to continue caregiving. Compromised mental health or increased stress did not prevent caregiver continuation, which may be evidence that caregivers continue even when their own health is threatened. McCann et al. provide support for the link between the negative health consequences and caregiving.

The general caregiving literature has other substantial links between burden and poor health. Prior researchers have found increased rates of illness in addition to a link between chronic stress and reduced immunity in caregivers (Cantor, 1983; Kiecolt-Glaser et al., 1987; George & Gwyther, 1986; S. Cohen, Kessler, & Underwood-Gordon, 1997; Greenwood, Muir, Packham, & Madeley, 1996). Burden was linked to a variety of symptoms including sleep deprivation, chronic fatigue, stomach problems, weight changes, and chronic diseases such as hypertension and general health deterioration (Chou, 2000; Clark, 2002; Gaynor 1990; Young & Kahana, 1989; Rankin, 1988; Bull, 1990; Faira, 1998a; Vitaliano et al., 2002; Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997).

Three researchers using meta-analysis reported four studies with significant links between burden and poor physical health for caregivers (Vitaliano et al., 2003; Pinquart & Sorensen, 2003; Schulz et al. 1990,1995). As evidence of the recent interest in caregiver health, in a 1990 meta-analysis only 11 of 34 studies examined physical health and only one included objective measures (Schulz et al., 1990). Five years later, Schulz reviewed 40 new studies and reported caregivers had more chronic illnesses and medication use than noncaregivers.

Vitaliano et al. compared 1,594 caregivers of persons with dementia to 1,478 age and demographically matched noncaregivers. Based on the literature reviewed, chronic stress which is associated with illness and individual differences, and gender was suggested as a key element of a model explaining why caregivers are at greater risk of health problems. In the meta-analysis, they found that health was measured by one of five categories they created, global self-report which may have been as little as one item, the number of chronic conditions, the number of symptoms, the number of medications used, or health services used such as a doctor or clinic. The number of studies were fairly equally distributed in each of the five categories. About one-half of the studies also provided an objective physiological measure of health such as antibodies. There were between four to six studies for each of these objective categories. Comparing 23 samples totaling 3,072 subjects with roughly one-half being caregivers and one-half being noncaregivers from 3 continents, the average age of the caregiver was 65 years with 65% being female and the majority being Caucasian. Caregivers had 23% higher stress hormones than noncaregivers and 15% poorer antibody production. Caregivers exhibited slightly greater risk for health problems; however sex and the category moderated this relationship. The authors suggested further study pre- and post- caregiving to determine what factors related to the onset of caregiving relate to health and which factors covary with the person or caregiving. Vitaliano et al.result offers more support for the proposed study's relationship between caregiving and negative health outcomes. Similar results were found in another meta-analysis, the results were small ($g = 0.18$) (Pinquart & Sorensen, 2003).

Physical health-related quality of life and caregiver burden

Studies reporting physical health outcomes for caregivers in the HF literature are limited (Bakas et al, 2006; Scott, 2000; Martensson et al., 2003; Evangelista, Dracup, et al., 2002). Molloy et al. noted in their review of HF literature that only six studies included self-reported health measured by the SF-12 or the SF-36 and of those six, four studies did not address physical health (Bull, Hansen, & Gross, 2000a, 2000b, 2000c; Schwarz & Elman, 2003). Caregiver's perceptions of their general health were rated lower at 59.5 (0-100 scale) than the general United States population rating of 71.9 (Bakas et al.; Ware, 2004). When examining the physical component of quality of life for both patient and spousal caregiver, similar results were found. Quality of life scores were reported as lower by caregivers (40.1) and patients (34.9) than their age matched persons at 50 (an average of in the general population) (Martensson et al., 2003). About 48% of the caregivers (*N* =21) reported physical health, general health, and level of energy as the most negative changes from caregiving after financial well-being. And about 43% of the caregivers reported decreased ability to cope with stress as a result of caregiving (Bakas, et al). In contrast, Scott reported the majority of caregivers reported they were in good to excellent health (89%). Eleven of the 18 caregivers did not perceive that their health had changed while five (28%) reported their health had declined. But 39% of the caregivers reported constant fatigue. The caregivers also reported higher health-related quality of life (*M* =20.11; *SD* = 7.64) than the patients (*M* = 9.34; *SD* = 8.08). It should be noted that the reliability coefficient with the caregiving health subscale of the CRA was reported at 0.56 while the health-related quality of life scale was 0.92 so decisions can not be made on this evidence or an error in measurement need to be considered.

Physical health-related quality of life and perceived control

Previous research supports links between burden, control, and negative health outcomes. Four general caregiving studies provide important information about burden, control, and health outcomes (Burton et al., 1997; Burton et al,. 2003; Schulz et al., 1997; Wallhagen, 1993). In Burton et al.'s 1997 study, the caregivers who had high sense of control used more preventative health behaviors than those with weak control. Control moderated the relationship between the caregiver and getting enough sleep as a preventative behavior but not the rest of the preventative health behaviors. Those caregivers with the highest burden were also at the greatest risk of not using preventive health behaviors (Burton et al., 1997). In the 2003 study, noncaregivers had the highest level of control consistently over the 5-year study. Among caregivers, control was inversely related to burden, caregivers with the greatest burden had the least control and this remained consistent at each follow-up point (Burton et al.). When caregivers report less time for self-care, they report lack of enough rest, lack of time to exercise or to carry out preventative health behaviors (Burton, et al., 1997; Schulz et al., 1997).

Wallhagen et al.(1994) examined the relationship between baseline internal health locus of control and the change in physical functioning six years later in a group of 365 older men and women. Internal health locus of control was measured by two questions from the 6-item Multidimensional Health Locus of Control Scale and the change in function was measured by an 18-item self-report scale including seven activities of daily living, three independent activities of daily living, two mobility measures and five physical performance items and one item about getting to places. Each was scored on a 0-4 scale. The results were summed with a maximum total of 72 which indicated higher functioning. Women were a mean age of 72.5 years, mostly white, and married. Women were older than men at the follow up and had lower income, less education and poorer perceived health than men. Women had more chronic illnesses, were more impaired in mobility, had lower functioning scores at baseline and at follow up. In sum, women had declined more in the six-year study period (60% versus 50%). The importance of good health was strongly associated with internal health locus of control for men but weaker in association for women. Control had a strong direct effect on the health outcomes and physical functioning for women but for men only with lower functioning at baseline. The authors suggested men and women have different orientations to control even though they had similar mean scores for internal health locus of control. Further they suggested that both men and women are more influenced on a daily basis by control than on the basis of long term behaviors and that control mediates many daily health behaviors such as eating differently when ill. They suggested that limitations like the self-report nature of measures and the use of only two items for internal health locus of control may have been too narrow a measure. They were able to demonstrate the importance of control and health behaviors longitudinally in a large sample of men and women. These results support the link in the proposed study between control and health outcomes.

Physical health-related quality of life and caregiver factors

Previous research supports links between caregiver demographic factors and negative physical health outcomes. Previous discussions have addressed older and female caregivers and the link to negative outcomes. Previous discussion have addressed education and income and years married and those links to negative outcomes. Caregiver biological factors of duration of caregiving may be associated with poorer health. Long term caregivers tend to report poorer health (Gaynor, 1990; Schulz et al., 1997; McCann et al., 2004). Long-term caregivers had more illness episodes with hypertension and arthritis being the most common. Compared to noncaregivers, strained caregivers report more anxiety, depression and are more likely to use unhealthy coping such as smoking (Schulz et al., 1997). Schulz and Beach suggested that a combination of factors such as loss, prolonged exposure to stress, caregiver burden, and biological vulnerability of older caregivers may compromise their physiological functioning and put them at greater risk for health problems. Similarly, Epel et al., (2004) and Everson et al., (1997) reported that chronic stress associated with caregiving may promote earlier onset of age-related disease by as much as a decade. Vitaliano et al. pointed out that in the general population over age 65, 40% have HTN, 25% have heart disease and 18% have diabetes (Centers for Disease Control and Prevention, 1998) so when comorbidites are combined with the stress of caregiving, spousal caregivers are at greater risk for additional health problems. Vitaliano et al. found similar results in sample of male caregivers who had a greater prevalence of heart disease than noncaregiver men 27 to 30 months after the study entry.

Physical health-related quality of life and patient factors

Prior research supports relationships between patient factors and negative physical health outcomes for caregivers. Revisiting couples research, patient's emotional or physical state can be a stressor for the caregiver resulting in at least distress. If the patient is distressed, it is common for the caregiver to be distressed also (Bookwala & Schulz, 1998). Similar results were reported with HF patients and post MI or bypass patients and their caregivers (Evangelista et al., 2003, 2002; Scott, 2000; Moser & Dracup, 1995). Martensson et al. (2003) found that as patient dysfunction level increased so did the spousal depression. In Parkinson's patients control over disease progression has a significant association with patient and caregiver well-being and lessened caregiver burden (Wallhagen & Brod, 1997). The literature supports links between most caregiver factors and negative physical outcomes and between the patient factors and negative physical outcomes.

Conclusions

The model variables of caregiver burden, perceived control, caregiver factors, patient factors and physical health outcomes have been insufficiently examined in the HF literature. As Molloy and colleagues (2005) observed, this relative neglect of HF informal caregivers is in stark contrast to other leading cases of morbidity and mortality such as stroke and cancer. There are few conceptualizations of physical health in any of the caregiver literature and few theoretically based studies. Physical health or lack of good health is measured primarily by presence of self-reported comorbidites or self-reported single questions about general health or questions about health behaviors. Some studies have measured health with a wide and varied number of objective tests. Comparisons and accumulation of a body of knowledge is difficult in this present mixture of measures.

The longitudinal studies have consistently indicated that caregiving can result in poorer health for the caregiver especially one that feels stressed. Long term heavy caregiving can shorten life, accelerate age-related illnesses, and limit use of health maintenance behaviors. Perceived control may mediate some of the effects of long term heavy caregiving especially with preventative health behaviors. Our knowledge of the impact of caregiving on HF caregivers' health is very limited given the research available. The gaps in the literature support the need to, (a) test the hypothesized model in the HF caregiving population to discern if HF caregivers mirror the larger caregiver population with regard to poor health outcomes, (b) examine if HF caregivers with the greatest burden also have the poorest health outcomes, and (c) examine if perceived control mediates the relationship between burden and health outcomes.

Perceived Control

Definitions of Perceived Control

Control has been evolving in conceptualization for nearly four decades with most of the work being done by different schools of thought within the disciplines of psychology, sociology, and nursing. A Medline search readily reveals hundreds of terms for perceived control such as personal control, sense of control, locus of control, mastery, self-determination, and autonomy just to name a few. It is evident from the literature though that the construct of control is still under debate. The history of the concept of control is reflected in the typologies, first Averill (1973) who divided control into behavioral, cognitive and decisional. Miller (1979) followed with the addition of instrumental and potential control while Thompson added retrospective and informational control (1981). Rothbaum, Weisz and Snyder (1982) sorted control by levels starting with primary and secondary and within that level added general and situation specific, and vicarious, illusory, predictive and interpretative. Heckhausen and Schulz (1995) added functional and dysfunctional while Fiske and Taylor (1991) expanded Averill's work to six categories by adding retrospective and secondary and most recently Skinner (1996) who classified control not by categories as in the prior work but by a framework of agent who exercises the control, means how was it used, and ends, with categories and which dimension of control under each heading.

There are some important dimensions of the concept of perceived control to highlight from the literature that are applicable to the current study of caregivers in HF.

The five dimensions of perceived control, self as the agent of control, belief about control, experiences of control, situation specific scope of control, and the motivation of control are dimensions worthy of comment. Self, as in subjective control, is the realm of perceived control as opposed to controlling others. The critical element of belief that one has and can exercise control if desired is an essential dimension of perceived control. Control is associated with action, but it does not have to be real or exercised to be an effective belief. Perception of control is "critical to the argument" that a person's control influences their behavior or emotions according to Skinner (1996, p.551). She continues with "many theorists are convinced that perceived control is a more powerful predictor of functioning than actual control" (p. 551).

The experiences of control refer to the feeling of control or feeling of efficacy (White, 1959) which confirm that the condition can be improved with control or has been improved with control in the past. Experiences of control and cognitive control have a uniformly positive psychological and physiological effect (Skinner; Thompson, 1981). Knowing that one has a cognitive strategy lessens anticipatory anxiety, and reduces the impact of the stimulus and adds an element of predictability (Thompson, 1981). Lefcourt, Hogg, Struthers, and Holmes (1975) suggested the advantage of considering domain specific control versus general control, is that the more specific a concept is to a particular domain and behavior, the stronger the magnitude of the relationship between the belief and the behaviors in that domain. And finally, the motivation for control is defined as the person seeks ways to gain and maintain control whenever possible. It is considered innate in all humans to engage in effective interaction with the environment (White, 1959; Harter, 1978). These dimensions are considered the necessary theoretical elements of perceived control which may or may not be present when operationalized or incorporated in a research study.

In the general and the HF caregiving literature, nine authors used a measure of perceived control and eight authors provided a definition of control and/or a theoretical framework for control. Those that provided definitions were remarkably similar. Beginning with the general caregiving researchers, perceived control has been implicated in the adaptation and well being of older adults (Wallhagen, 1992). It is considered critically important to successful coping with stress and management of challenges (Lefcourt et al., 1976). Perceived control was defined as the perception that salient or valued aspects of one's life are manageable (p. 220, Wallhagen, 1992). Wallhagen elaborates that this definition corresponds to Lazarus and Folkman's secondary appraisal process so she adds that for caregivers, the concept of control is important to understanding the balance between demands and resources. Continuing the same theme and consistent with Lazarus and Folkman's social cognition theory, Sistler and Blanchard-Fields (1993) defined perceived control as the individual's belief that they have direct internal control over a situation (p.537). Dracup and Evangelista, et al.(2004) borrowed from Folkman's definition of perceived control as the self-generated belief that one has at one's disposal a response that can influence the adversiveness of an event (p.355).

In two different studies, Burton and colleagues (1997) referred to "sense of control" that was defined as the extent to which people see themselves as being in control of the forces that importantly affect their lives. Hence conceptually Burton's definition of control is consistent with perceived control but it was labeled mastery (p.163) in the

CHES study and in the Transition study (p.232, 2003). Nieboer and colleagues (1998) and Bakas and colleagues (2006) did not provide definitions for control but provided theoretical frameworks which are consistent with the definitions of perceived control in the caregiving literature. Bakas and colleagues narrowed the focus of perceived control to control over the patient's heart disease. Molloy and colleagues (2005) choose an interesting application of an occupational psychology model, Karasek's model of job strain, which posits that control balances the physical and psychological demands of the job. The model is consistent with the literature that reports caregivers who feel burdened/strained experience greater negative physical and psychological outcomes. The remainder of the studies did not provided definitions or theoretical frameworks for the concept of control in their studies but provided descriptions of their instruments. For the proposed study, the use of perceived control, defined as a belief that one has at their disposal, a response that can influence the adversiveness of an event (Moser & Dracup, 1995) is reflective of the definitions used in the caregiving literature.

Measures of Perceived Control

In the general caregiving literature, researchers created tools or utilized a version of Pearlin's mastery scale. Walhagen, Sistler and Blanchard-Fields, and Molloy and colleagues created tools to measure control while Burton and colleagues and Bosma et al. (2005) used the Pearlin Mastery Scale. Wallhagen created the Perceived Control Questionnaire, a 20-item tool, with a 1-5 Likert response format from strongly agree to strongly disagree to assess caregiver's perception of the manageability of their situation. A Cronbach's alpha of 0.93 was reported. Two published tools were adapted to assess object and subjective demands, caregiver competence (equivalent to self- efficacy), resources, and housing (1992). Molloy and colleagues used the Perceived Control over Recovery Scale, an eight-item scale, with 1-5 Likert scale, with 1 being not at all difficult and 5 being extremely difficult. It asked about control over the patient's stroke recovery via questions about difficulty. It had a satisfactory internal reliability and test-retest (*r* =.69) (1987). Sistler and Blanchard-Fields used two questions when asking caregivers about their Alzheimer spouses' behavior, one about control of patient's upsetting behavior and control over self in the same situation. Using a 4-point scale 0-3, (0 being no control and 3 being a great deal) they focused on very specific behavior. No reliability data were provided. Burton and colleagues used the seven-item mastery scale of Pearlin and Schooler (1997, 2003). Reliability for the Burton and Newsom et al .study was Cronbach's alpha of 0.75 while the Burton et al. study was 0.69. And Szabo and Strang (1997) conducted a qualitative study using secondary analysis with caregivers of dementia patients.

In the HF caregiving literature, six researchers used a measure of perceived control. Three researchers used the same measure and the remaining studies used different measures of control. A version of the Control Attitudes Scale was used by Moser and Dracup (2004), Bakas et al. (2006), and Dracup et al. (2004). Moser and Dracup developed the Control Attitudes Scale and initial reliability was reported as Cronbach's alpha of 0.89 (1995). The Control Attitudes Scale is a 4-item scaled used to measure the degree of control a spouse feels related to the patient's HF. Questions such as, "Regarding your family member's heart problem, how much control do you feel" are used. Responses are scored on a 1-5 Likert scale, with 1 being no control at all to 5 being very much control. Cronbach's alpha for Dracup et al.'s study was reported as 0.90 and for Bakas et al. was 0.75. Bakas et al. also used a 1-7 Likert scale with the CAS. Dew and colleagues (2004) used the 7-item Sense of Mastery Scale to assess the degree of control the caregiver of heart transplant patients felt when things happened to them. Questions such as "I often feel helpless in dealing with the problems of life" were included. Cronbach's alpha was reported as 0.79.

Nieboer et al.used a list of 40 favorite activities such as bike riding, reading, or attending church from which each caregiver selected the most important six activities. Activity restriction of these six activities was conceptualized a as a threat to primary control, so that the greater the activity restriction, the greater the threat to control or the loss of control. Scott (2000) utilized the Caregiver Reaction Assessment to measure the effects of caregiving in five areas: caregiver esteem, daily schedule, family support, caregiver health, and finances. Reliability ranged from 0 .56 to 0.84 (for finances).

Given the definition of perceived control being used in my proposed study and the conceptualization of control in the proposed study, the Control Attitudes Scale will be the instrument to measure caregiver control.

Empirical Literature Review for Perceived Control

Control has been positively linked with adult adaptation to normal and stressful life events. A sense of control has been linked to successful aging, reduced stress response, and improved mental health (Seeman & Lewis, 1995; Partridge & Johnson, 1989; Breier, Albus, Pickar, Zahn, & Wolkowitz 1987; Leavitt, Clark, Rotton, & Finley 1987). Seven general caregiving studies were found that examined the relationship of control, burden, and psychological outcomes. Lack of control was generally associated with negative psychological outcomes such as stress, depression or poorer emotional well-being but results are not consistent. (Sistler & Blanchard-Fields, 1993; Wallhagen, 1993; Wallhagen & Brod, 1997; Pinquart & Sorensen, 2003; Burton et al., 2003; Szabo & Strang, 1999). In contrast, Molloy et al. found lower control with higher demands resulted in lower distress (2005).

Perceived control, burden and emotional health-related quality of life

In the general caregiving literature, less control was linked with negative psychological outcomes. In a meta-analysis including 84 studies with primarily dementia caregivers, the researchers found that caregivers had higher levels of stress, depression, lower subjective well-being, and lower levels of control and self-efficacy than noncaregivers (Pinquart & Sorensen, 2003) The authors sought to determine if caregivers and noncaregivers differ in psychological and physical health especially stress, depression, well-being, and control. They also sought to identify which aspects of health showed the largest differences between the two groups and if those differences were influenced by moderator variables. Sixty-three percent of the caregivers were caring for demented elders. The participants were almost all women spouses averaging 62.5 years and living with the patient and providing care for 55 months at an average of 42.9 hours per week (*SD* = 24.3).

Caregiver status explained 7.8% of the variance in depression regressions and 8% variance in the dependent variables. Differences between caregivers and noncaregivers for depression (g = -.58), stress (g = -.55), well-being and control were medium except for physical health (g =.18) which was statistically significant but small. The differences were attributed to lack of control for the caregiver. Female caregivers were more impaired on all outcomes than noncaregivers, except stress. Older caregivers reported more depression and lower control than younger caregivers, who were more stressed than older caregivers. Differences were larger for dementia caregivers than samples that had demented and nondemented patients. Differences in stress, depression and burden among caregivers were greater for spouses than adult children. The results support that greater control in caregiving results in less stress, depression and better well-being. The results support the proposed study's link between control and negative outcomes. The authors suggest there may be other outcome variables to consider such as level of anxiety, social integration, and leisure time but there were not enough studies to evaluate those variables. They also suggested social economic status and duration of caregiving as possible variables.

Burton and colleagues (2003) found in their 5-year longitudinal study that as caregiving burden increased, self-mastery declined and depression and health risk behaviors increased. Only continuous noncaregiviers reported a consistently high level of control over the 5-year study period.

Previous general caregiving research supports relationships between caregiver burden, control, and negative psychosocial outcomes. Lack of control was consistently associated with negative outcomes. When studying caregiver adaptation to caregiving, the effect of burden was buffered by control (Wallhagen et al.,1994). Wallhagen et al. (1992) also used two published measures of objective and subjective demands, caregiver competence (self-efficacy), resources, and housing. The 60 women were age 69.4 (M) who cared for a spouse or close relative with a chronic illness such as stroke, dementia or Parkinson's disease. Control was directly related to the outcomes of life satisfaction and depression while indirectly related to symptoms of stress. In elderly caregivers greater control had a significant and direct relationship with the outcome variables of life satisfaction, depression and indirect relationship with symptoms of stress explaining a significant amount of the variance in each regression equation (Wallhagen, 1992). The investigator states that control may "indeed mediate aspects of the caregiving situation…"(p.231). For the caregivers, a lack of control, in the presence of high burden was correlated with depression (Sistler & Blanchard-Fields, 1993).

General caregiving researchers also found control over patient behavior or symptoms was linked to burden and psychological outcomes. The caregiver's lack of control over the demented patient's behavior and their own behavior in this stressful situation was correlated with caregiver depression. Caregivers and noncaregivers were similar in their lack of control over their spouse's behavior, but noncaregivers did not experience the depression that caregiver did (Sistler & Blandard-Fields). Even in qualitative research with caregivers of persons with dementia, maintaining control required continual attention and caregiver felt they moved between being in control and "regaining control" depending on the demands of caregiving. The patients changing physical condition most often triggered loss of control (Szabo & Strang, 1999).

The patient's control over symptoms, not disease progression, improved caregiver burden and patient and caregiver well-being. The researcher noted that control over symptoms was more valuable than control over disease progression ($r = .22$, $p =.026$, Wallhagen & Brod, 1997). The purpose of the Wallhagen and Brod study was to identify the relationship of patient perceived control over symptoms and perceived control over disease progression and the impact on the patient well-being and the caregiver well-being. One hundred-one patients with Parkinson's disease were recruited from support groups, doctor offices and via newsletters along with 45 of their caregivers. The baseline interview was compared to the one year interview. At the baseline, two questions were used to assess control beliefs, one question was used to assess control over disease progression, and one question was used to assess control over symptoms. Each question was rated on a 1-5 scale. Well-being was assessed using the SF-36 with a Cronbach's alpha of 0.98. Caregivers received a mailed set of questions which included the SF-36, The Caregiver Burden Interview, a 22-item scale by Zarit, Reeever, and Bach-Peterson (1980) to evaluate four areas commonly affected by caregiving.

The participants were predominantly white, well educated, married, middle class with patients being male with mean age of 72 years with Parkinson's disease for an average of seven years with mild to moderate Parkinson's disease. The patients reported a moderate control over symptoms and disease progression. Patient well-being had a mean of 72 (range of 17-99) indicating a wide variance of impact of the disease. The caregivers were women, average age 69 years, educated with burden mean of 27 (range of 3 to 67) indicating the experience varied widely. Well-being of caregivers had a mean of 74, slightly higher than the patients. No association between the patient and caregiver well-being was found. Patient control over symptoms was statistically significant when associated with less caregiver burden ($B = -.29$, $p = .03$) and accounted for 9% of the variance. These results support the notion that control can have a significant impact on caregiver burden. In this case when its patient control it reinforces the importance of the caregiver-patient relationship in caregiver burden and caregiver outcomes.

In contrast to the prior studies, Molloy and colleagues (2005) found that lower control with higher demands resulted in reduced distress. Using the Perceived Control over Recovery Scale, an 8-item scale with a 1-5 Likert scale, with acceptable internal reliability and test-retest reliability of *r* =.69 (1987) they found results contrary to their predictions and different from the prior literature. In their regressions, control accounted for 27% of the variance; high demand and low control were associated with higher depression. The investigators speculated that these results may have been explained as the caregiver adapting to what can not be controlled in a patient's recovery.

Perceived control in heart failure

In the HF caregiver research, six investigators whose studies were discussed in prior sections found that lower levels of control were associated with worse emotional outcomes and increased burden (Nieboer, et al.,1998; Dew et al, 2004; Dracup et al., 2004; Karmilovich,1994; Bakas, et al.,, 2006; Mahoney, 2001). Loss of control over one's life has a direct negative effect on the caregiver (Donaldson et al., 1998; Kinney, Stephens, Franks, & Norris, 1995**)**. As an example of loss of control, Neiboer and colleagues reported a threat to primary control explained caregiver depression when the caregiver's favorite activities are limited due to caregiving tasks. Nieboer et al. reported results for two groups of caregivers, one with increasing burden and one with decreasing burden. Those with increasing tasks and decreasing favorite activities or control had increased depression while those with decreasing tasks and increasing favorite activities had decreased depression, leading to the conclusion that the relationship between burden and depression was mediated by control. Dew and colleagues also found that restriction of favorite activities due to demands of caregiving resulting in restricted control which was associated with greater depression, anxiety and stress. Dew et al. also found other factors that increased the risk for caregiver anxiety.

In addition, some researcher reported greater caregiver control was associated with better emotional well-being in other studies (Dracup et al.). Spouses with higher control reported significantly greater emotional well-being than spouses with low control (77.6 versus 65.3, $p = .003$). Further, forty percent of the variance in emotional health was explained by age, burden and control ($p = .001$). Other caregivers reported one of the most difficult tasks was watching their spouse become ill and having no control over the progression of the disease (Karmilovich). Three HF researchers (Moser & Dracup, 2004; Bakas et al., 2006; Dracup et al., 2004) used a version of the Control Attitudes Scale (CAS) which was developed by Moser and Dracup. An initial reliability was reported as Cronbach's alpha of 0.89 (1995). The CAS is a 4-item scale used to measure the degree of control a spouse feels related to the patient's HF. Questions such as, "Regarding your family member's heart problem, how much control do you feel", are used. Responses are scored on a 1-5 Likert scale, with 1 being no control at all to 5 being very much control. Cronbach alpha for Dracup et al.'s study was reported as 0.90 and for Bakas et al. was 0.75. Bakas et al. also used a 1-7 Likert scale with the CAS. Reconciling or struggling to make sense and gain control over symptoms was the process to regain balance for caregiver in a qualitative study (Mahoney, 2001).

Perceived control, burden, and physical health-related quality of life

Control, burden and physical health outcomes have been linked in prior research. Four general caregiving studies and three adult studies offer important information about caregiver control (Burton, et al.,.2003,1997; Pinquart & Sorensen, 2003; Vitaliano et al. 2003; Wallhagen et al.,1994; Bosma et al., 2004; Endler et al., 2001). Comparing caregivers and noncaregiver, Burton and colleagues examined the impact of control on specific health outcomes in two different studies. The caregivers in the 1997 study who had high control used more preventative health behaviors than those with weak control. Control moderated the relationship between the caregiver and getting enough sleep as a preventative behavior but not the rest of the preventative behaviors. Those caregivers with the highest burden were also at the greatest risk of not using preventive health behaviors. In the 2003 study, noncaregivers had the highest level of control consistently over the 5-year study. Among caregivers, control was inversely related to burden, caregivers with the greatest burden had the least control and this remained consistent at each follow-up point. Both meta-analyses found caregivers had lower physical health and self-efficacy than noncaregivers but the differences were small to moderate compared to the differences for negative psychological outcomes (Pinquart and Sorensen; Vitaliano et al.). These authors were able to demonstrate the relationship between control and physical health in caregivers, which supports the proposed study hypothesis that higher caregiver control is related to better physical health outcomes.

In three adult studies, control can account for health behaviors (Wallhagen et al, 1994; Endler, Kocovski, & Macrodimitris 2001; Bosma, Van Jaarsveld, Tuinstra, Sanderman et al., 2005). In a 6-year longitudinal study of 365 men and women about control, health behaviors and health outcomes, control had a strong direct effect on the health outcomes and physical functioning. (Wallhagen et al.,1994). Control had an independent and significant relationship in physical functioning for the women and their importance on good health. This was not true for the men. Control decreased with age for women but increased for men with age.

Along a similar line, control explained short and long-term behaviors related to illness in Endler et al.'s study (2001). Endler et al. compared the control of persons with acute versus chronic illness in a convenience sample of 274 adults enrolled during a museum visit. The majority of the sample was middle aged females. Both groups reported about the same level of control, except for the most seriously ill who had lower control. Persons with short term acute illnesses focused on symptom management and reported greater self-efficacy in managing their illness, while those with chronic illnesses focused on adapting to their illness.

Control again accounted for health related behaviors in Bosma et al's study (2005). Using the Pearlin Mastery Scale, 30% of the variance in cardiovascular risk in 5-year longitudinal study of almost 4,000 Dutch adults versus 4% variance was attributed to genetics. When researching who is most likely to become a caregiver, spouses when older with lower income and lower sense of control and higher health risks prior to beginning caregiving were most likely to become a caregiver (McCann et al., 2004). The three adult studies provide additional information that supports the relationship between control and health behaviors.

Perceived control in heart failure

Additional support for the role of perceived control with quality of life can be found in the HF patient studies. Greater control has been positively associated with better psychological and physical well-being for HF patients. Functional status, depression, and perceived control were significantly related to quality of life with female heart transplant patients and accounted for 49% of the variance in overall quality of life (Evangelista et al., 2003). These same investigators reported "perceived control was a strong predictor of

QOL" (p.365). Evangelista et al. sought to describe and compare the quality of life and psychological well-being of transplant women and their controls and to identify correlates of quality of life in female transplant patients. Using a convenience sample of 50 transplant patients with mean age of 54.7 years and age, gender and disease matched candidates for transplant, they administered the Beck Depression Inventory, the Control Attitude Scale, and the Minnesota Living with HF Questionnaire. They reported Cronbach alpha of .93. The transplanted patients were interviewed at 5.2 years (±- 4.4 months) post transplant while the candidates were interviewed 4.2 years before (range of 1-12 years).

The quality of life for the transplanted patients was twice that of the candidates (*p* <.01) while the physical health for the transplanted patients was 11.3 compared to 19.9 (*p* <.01) for the candidates. The emotional health for the transplanted patients was 7.5 compared to 12.8, (*p* <.001) for the candidates. The lower scores indicate better results. Depression scores were lower by almost one-half for the transplanted patients and control was higher. But 35% of the transplanted patients reported moderate to severe depression which was the same as candidates. Twenty-six percent of the transplanted patients also reported low control. The authors suggested these initially contradictory results with depression and control for transplanted patients were consistent with prior researchers (Dew, Switzer, Goycoolea, DiMartini, & Kormos et al., 1997) who reported there were gains in physical function with transplant but there "were no gains in …psychological health…" (p.365). Evangelista et al. speculated that ongoing uncertainty, unpredictability and feelings of lack of control over their life may account for this minority in the transplanted patients.

Some of the limitations of the study are a convenience sample that may or may not be the same as those who chose not to participate, the use of Minnesota Living with HF Questionnaire in a transplant population where reliability and validity if the measure has not been established, the small sample from a single source which limits generalizabilty. The authors also suggest that other variables not included in the study may account for some of the variance, such as, social support, compliance, hormones and other chemicals and their impact, personality and coping styles. Unlike Dew et al. (2004) who examined the caregivers in the first three years post transplant and found high incidence and prevalence of psychiatric diagnoses, Evangelista et al. examined patients five years post transplant and still found a minority of patients who had depression and lower control. Given these limits, these results support the importance of control in quality of life, psychological and physical health and demonstrate the use of the CAS measure.

HF patients with higher perceived control had greater 6-minute walk distances and less emotional distress that patients with low perceived control (Dracup, Westlake, Erickson, Doering, Moser et al., 2003). Dracup et al. assessed control with the Control Attitudes Scale (CAS) and anxiety, depression and hostility with the Multiple Affect Adjective Checklist and function with a 6-minute walk test in a sample of 222 HF patients from one medical center. Cronbach's alpha was 0.77 for the CAS. Most of the patients were male, white with NYHA class of 2.57 and EF of 26.1%. Patients had a moderate level of control, anxiety and high levels of depression. Those patients with greater control had a longer 6-minute walk distance ($t = 4.77$, $p = .001$) and lower NYHA class, less anxiety, and depression than patients with low control. The authors reported the relationship between function and control was new and speculated about its direction since this was a cross-sectional correlational study. They suggested it may be bidirectional or function may drive control. Further research in a larger sample with a randomly controlled design may uncover the answers. Dracup et al. were able to demonstrate a link between control and function in patients that may also be mirrored in the general population or in caregivers. They also used the CAS which is one of the measures used in the proposed study.

Loss of control, feelings of powerlessness from worry and depression explained 72% of the variance in the patient's mental health (Scott, 2000). Moser and Dracup (1998) also found that perceived control was a strong predictor of quality of life for myocardial infarction patients. Similarly, patients with high perceived control were less anxious, less depressed and had better adjustment (Moser & Dracup, 1995). This was also true in patients in their 2004 study of 417 patient-spouse pairs post myocardial infarction or post coronary artery bypass, where spouses were more anxious, depressed and had less control than patients. Spousal emotional state was significantly correlated to patient anxiety, depression and psychological adjustment to illness or health (Moser & Dracup, 2004; Scott, 2000).

Perceived control and caregiver factors

Previous research supports relationships between some caregiver factors and perceived control. Age and gender have been the primary demographic variables that have been associated with control.

Age and perceived control explained 49% of the variance in the caregiver's emotional well-being, so that older spouses reported better emotional well-being than younger spouses (Dracup et al., 2004). Molloy et al. (2005) also found older caregivers and spouses had higher control. But the results on age and control are not consistent. Two studies reported older female caregivers have a lower sense of control (Burton et al., 1997; Wallhagen et al., 1994). Vitaliano et al. (2003) also found that older caregiver had lower control. The authors speculated that older females may have different expectations about what they can control especially related to health of a partner. They further speculated that females and males are socialized differently and take on different social roles which are tied to perceived control.

Younger caregivers had greater stress and greater burden which was linked to the notion of the additive affect of caregiving to their busy lives. Control increased for men with age (Wallhagen et al.).The investigators reported this data was conflicting, while some data suggest that older adults have less desire for control over their health care (Degner & Sloan, 1992). It is uncertain at present to know if control actually changes with age (Rodin, Timko, & Harris, 1985). Age was also described as having a moderating effect on differences between caregivers and noncaregivers in Vitaliano and colleagues' study. Age, burden, less personal time and poorer relationship with the patient were the variables that explained caregiver anxiety (Dew et al., 2003). Molloy et al. reported similar results with control and caregiver demands being predictive of emotional outcomes.

Gender was a significant variable with caregivers and control. Females sought more supportive coping styles so when explaining control only accounted for 8% of variance (Wallhagen, 1993). Wallhagen (1994) also found women had worse function over 5 years as a caregiver and that men and women had different orientations toward control. Control had an independent and important effect on change in function for women and an interactive effect at baseline for men. Control decreased with age for women but increased for men with age. Females benefited more from the reduction of burden and the increase in favorite activities when looking at depression than men (Neiboer et al., 1998). Dew et al. (2003) reported similar results of more personal time, lower burden and higher control reduced anxiety in older caregivers. Women had more health problems but no greater health risk (Vitaliano et al., 2003). When reporting on gender and preventative health behaviors, men were more likely to have time to exercise, to rest when sick and to see a doctor but more likely to skip meals (Burton et al., 1997).

Perceived control and patient factors

Previous research supports relationships for some patient factors and control. Patient health, function and severity of illness have been variables associated with patient perceived control. Perceived control was associated with longer 6-min walking distance and lower NYHA class for patients. Twenty-three percent of the variance in patient anxiety was explained by perceived control and 19% of the variance in depression (Dracup et al., 2003). Patient function and control explained patient quality of life so that older patients with lower function and poorer health had worse quality of life (Evangelista et al.,2003). Severity of illness and control explained 42% of the variance in patient's well-being. Control mediated the effect of severity on adjustment, which seemed to work better for women than men even though men had higher levels of control (Barlow, Macey, & Struthers, 1993).

Conclusions

Given the research on perceived control in caregivers of HF patients, further research in this area is warranted. The previous research generally supports the positive impact of perceived control on caregiver burden and emotional and psychological outcomes such as anxiety and depression. The strongest studies in this area are the longitudinal population studies. No randomly controlled studies were found in the review of the literature. The general patient and caregiver literature on control support the significant relationship of control to health behaviors but no research in HF caregiving was found to support this relationship. The literature has reported a variety of roles for control from a corollary with negative outcomes such as depression and poorer health to a mediator or moderator but it has not been consistent. Given the increasing number of persons with HF and the number of persons living later with later stage HF, it is important for researchers to have a full understanding of the influence of control on the lives of the HF caregivers. Therefore, it is proposed that perceived control is a mediator between caregiver burden and caregiver outcomes. It is further proposed that the patient factor of NYHA class and caregiver factors of age, gender and health are associated directly with perceived control.

Caregiver Factors

Definition of Caregiver Factors

Caregiver factors are defined as the self-reported demographic characteristics of the caregiver that provide the age, gender, education, income, years married to the HF patient, biological factors of anxiety, depressive symptoms and comorbid conditions, and caregiver experience factors of duration and prior caregiving. Only age, gender, anxiety, depressive symptoms and comorbid conditions are being tested in the proposed study.

In the previous reported studies, the caregivers were almost all female spouses, only a few studies included other family members (McCann, et al., 2004;Vitaliano et al., 2003). Almost all caregivers were living with the patient. About half of the samples of caregivers were over 65 years of age and about half were 64 and under, with those under 64 being primarily 50 to 64 years of age.

Empirical Literature Review for Caregiver Factors

Age

Since most of the caregivers have traditionally been older female spouses, most of the studies reported have used age as a sample characteristic of these caregivers. There are six general caregiving studies that included caregiver age as a variable and reported a relationship to one of the proposed study variables of burden, psychological outcomes, physical health, or perceived control (Pinquart & Sorensen, 2003; McCann et al., 2004; Rohrbaugh, et al., 2002; Burton et al., 2003; Schulz & Beach, 1999; Wallhagen et al., 1994).

Age and current health influenced caregiver burden. Older caregivers with prevalent disease and the greatest burden who reported strain were at the greatest risk of higher 4-year mortality (Schulz & Beach, 1999). Even becoming a caregiver was related to age. McCann et al. reported that marital status, age, and gender were significantly associated with beginning caregiving (age, $p = .0001$). As age beyond 65 years increased, it was less likely for a spouse to become a caregiver and over age 85 there was only a 2%

chance. Molloy and colleagues (2005) stated that caregiver's age was one of the "well-established demographic predictors of caregiver outcomes"(p. 595).

Within the HF literature, significant relationships between caregiver age and caregiver burden were reported in some of the reviewed studies (Stolarik et al., 2000; Bakas et al., 2006; Dracup et al., 2004). The youngest and the oldest caregivers reported the greatest burden in caregiving (p =.03, Stolarik et al., 2000). Significant relationships were reported for younger caregivers who found tasks more difficult and stressful (r = -.60, p <.01, Bakas et al.), (B = -.01, p <.05, Pinquart & Sorensen), (B = .5, p = .001, Dracup et al.). Younger, employed, better educated, non-spouses experienced greater strain and their care recipients were hospitalized more frequently (Naylor, 2000).

Relationships between caregiver age and psychosocial outcomes were reported in eleven caregiving studies. The reported relationships were not consistent. Five authors previously reviewed reported younger caregiver had worse emotional outcomes such as anxiety and depression (Bakas et al., 2006; Dracup et al., 2004; Dew et al., 2004) while three investigators reported older caregivers had worse emotional outcomes (Evanglista et al., 2002; Pinquart & Sorensen, 2003; Schwarz & Dunphy, 2003).

Bakas et al. reported a modest correlation of perceived mental health and younger age (r = -.43, p <.05) with a convenience sample of 21 caregivers of veterans. The mean age was 59.6 with the range 45 to76 years with most of the caregivers in the 53 to 66 age range. According to Dracup et al. 49% of the variance in emotional well-being was explained by age (younger), burden (higher), and control (lower) (R^2 =.49, p =.000). Using a larger convenience sample of 69 HF spouses than Bakas et al., the caregivers averaged 54 years of age (range of 30 to77 years) and younger age was associated with greater distress. With a larger sample Dew et al. enrolled 190 caregivers in a three year prospective study to determine the onset of depression and anxiety for caregivers of transplant patients. Dew et al. reported the risk for anxiety disorder was increased by younger age (RR 3.73, $p < .05$) along with other factors. They also reported the risk factors were additive for anxiety.

Evangelista et al. (2002) studied 103 pairs of patient-caregivers where caregivers were 59.5 years of age. Both gender and age were associated with the patients' emotional well-being ($p < .05$). In their 2003 meta-analysis where approximately 6,000 caregivers were compared with 24,000 noncaregivers in 84 studies, age was the moderator of emotional outcomes for depression and control with larger differences for older participants (Pinquart & Sorensen, 2003). Age, duration of caregiving, and the patient's functioning were the combination of factors that impacted caregiver stress and depression (Schwarz & Dunphy, 2003). Schwarz and Dunphy studied 75 caregivers who averaged 63 years.

Older caregivers and spouses reported more depression than nonspousal caregivers (Molloy et al., 2005). When caregiver emotional health was compared with their partner, caregivers had better health than the patients (Rohrbaugh et al., 2002 ; Scott, 2000). In contrast, coronary artery bypass patient spouses' distress was still higher than the patient's distress at 6 weeks post operatively (Miller et al.,1994).

Relationships between caregiver age and physical outcomes were reported in five studies (Burton et al., 2003; Burton et al., 1997; Schulz & Beach, 1999; Pinquart & Sorensen, 2003, Wallhagen, 1994). Increasing age, disease, and demand were correlated with poor caregiver health outcomes. The “trajectory of health outcomes with caregiving was generally downward” (p.230, Burton et al. , 2003).

Few studies reported a relationship between age and control and those that did, did not show any consistency. As previously discussed in the section on perceived control, there is not enough data as to whether control actually changes with age (Rodin, Timko, & Harris, 1985).

Previous data supports a significant relationship with older age, greater burden, and negative caregiver outcomes. In addition, in the HF literature, there is also support for a significant relationship between younger age and increased anxiety or greater burden and negative caregiver outcomes. The data supporting a relationship between age and perceived control is more limited and inconsistent which warrants further investigation.

Gender

Spouses are the most common population sampled in the caregiving literature and most often those spouses are female. Nine caregiver studies examined gender as a main variable (Bookwala & Schulz, 2000; McCann et al., 2004; Rohrbaugh et al., 2002; Schulz & Beach, 1999; Wallhagen et al., 1994; Pinquart & Sorensen, 2003, 2006; Evangelista, Dracup et al., 2002; Yee & Schulz, 2000). Female gender was associated with lower emotional well-being even in large population studies (Rohrbaugh et al., 2002; Evangelista et al., 2003; Schulz et al., 1997; Yee et al., 2000).

Examining the most recent meta-analysis first, Pinquart and Sorensen (2006) sought to answer the question are gender differences in burden, depression, well-being and physical health in caregivers in individual studies statistically and practically significant when averaged across a large number of studies. They also sought to quantify how large these differences were, are they of practical meaning, and are they different from the general population. According to Cohen, to meet the criteria for practical significance, a variable should explain at least a1% change in a dependent variable and at least 55% of women should be in the above median level group of the dependent variable (Pinquart & Sorensen, 2006, p.34). In a meta-analysis a small change across a large sample is considered reliable.

As has been reported in many other individual studies, they found women reported greater burden, depression, worse well-being, and worse health. Gender explained 2.7% of the variance for burden, 2.8% for depression, 1% in tasks, and less than 1% for well-being and health. In terms of differences, results equal to or less than .50 were considered small and results equal to or less than .20 were considered very small (burden [d = .34], depression [d =.34], tasks [d =.20]). They suggested that gender differences were of practical significance in the amount of care provided, burden, and depression in the caregiving literature (Pinquart & Sorensen, 2006, p.38) but that they were statistically small.

In their 2003 meta-analysis in examining differences between caregivers and noncaregivers, Pinquart and Sorensen found a significant effect of caregiver gender in univariate and multivariate analysis. They commented that samples with higher percentages of female spouses, differences were greater. They reported female caregivers reported greater stress than noncaregivers (B = -.09, p =.002). In multivariate analysis, they found gender acted as a moderator but commented it may not be statistically independent due to the caregiver samples being primarily spouses.

McCann et al.(2004) cited gender as one of the significant variables in who would be likely to become a caregiver (*p* = .001). McCann et al. followed 3, 756 noncaregivers participants in a larger study for three years to determine who would become caregivers. They began with 100 initial male caregivers compared to 122 initial female caregivers who remained caregivers through the three years. They reported married participants were twice as likely as unmarried participants to become caregivers. They found a strong interaction of age and gender in their regressions.

Relationships between caregiver gender and burden were reported in a number of studies. Spouses, especially wives, have consistently reported greater burden in caregiving (Chou, 2000: Gaynor, 1990; Robinson, 1990; Lalonde & Kasprzyk, 1993 ; National Family Caregiver's Association/Fortis long term Care, 1998; Yee & Schulz, 2000; Bookwala & Schulz, 2000; Pinquart & Sorensen, 2003; Karmilovich, 1994). Yee & Schulz reported 17 of the 30 studies reviewed used a measure of strain or burden and the "vast majority" reported women experienced higher burden than men (p.158). Women's burden was found in spouses and adult daughters.

Schulz and Beach also used the CHES data when they compared 392 caregivers to 427 noncaregivers. The caregivers and noncaregivers were approximately half female and half male. They reported gender was a significant factor for older, male, black participants with at least 1 prevalent disease which resulted in higher 4-year mortality. Their primary focus was to evaluate the relationship between caregiver demands and all cause mortality.

Men and women may experience the burden in different ways. Care delivered by men is "quantitatively and qualitatively different" from women (p.607, Bookwala &

Schulz, 2000). In studying a CHES first wave sample of 283 caregivers that were about half male and half female, men are less likely to perform housework and meals and assist with personal care especially bathing, dressing, and incontinence. As a result, husbands and wives differ in their caregiver stressors. Husbands report fewer behavioral issues, less restrictions on the personal time, and less change in their relationship with the patient spouse, compared to wives (behavior, $p < .05$; activity, $p < .001$; relationship, $p < .01$). This is believed to explain greater secondary stressors for wives. Men report spending significantly less time doing the constant type of caring tasks so that they contribute only 21% of the "constant/40 hours per week" caregiving (National Alliance for Caregiving, 1997).

Gender and emotional health-related quality of life. Relationships between caregiver gender and negative psychological outcomes especially anxiety, depressive symptoms, and depression were reported in numerous studies with five larger studies using gender and psychological outcomes as variables (Pinquart & Sorensen, 2003, 2006; Bookwala & Schulz, 2000; Rohrbaugh et al. , 2002; Yee & Schulz, 2000). In their latest meta-analysis of 84 studies with approximately 6,000 caregivers compared to 14,000 noncaregivers, Pinquart and Sorensen (2006) found that gender differences were larger for caregivers with depression (d =.34) but the caregiver's well-being did not differ from that of the general population (caregiver d = -.09, general population d = -.08). When looking at depression, health and well-being, two of the three were larger than the general population. And as the authors concluded after multiple regressions, gender differences for all caregiving outcomes remained statistically significant (p.38). In a meta-analysis, Molloy and colleagues (2005) listed gender as one of the predictors of HF caregiver well-being.

In a review of 30 caregiving articles, Yee and Schulz reported 11 studies examined gender differences in psychiatric symptoms. Nine of the eleven studies found gender differences in depression and three found differences in general psychiatric symptoms. Yee and Schulz point out that seven of nine report higher levels of depressive symptoms for women. In all the reviewed studies that used the Center for Epidemiological Studies Depression Scale (CES-D), women's scores were very close to or above the cutoff score of 16 for clinical depression while men's scores fell below the cutoff score. Gender differences were also found for anxiety. When compared to noncaregiving age-matched community samples, the women's CES-D means were 8.82 compared to the caregiver scores of 13.98 to 18.87. Pinquart and Sorensen (2003) found similar results as Yee and Schulz, in that female caregivers experienced greater stress, subjective well-being, and depression than noncaregivers (SWB- B =.002, *p* <.001, depression-B =.002, p <.05).

Using CHES data, Bookwala and Schulz compared 145 women and 138 men based on the impact of primary and secondary stressors on depressive symptoms. Primary stressors would include behavior problems of the patient and the amount of caregivng they needed. Secondary stressors would include activity restrictions for the caregiver and the caregiver and patient relationship. They assessed the behavior problems of the patient, the sum of the ADL and IADL provided to the patient, the quality of the relationship, the caregiver's activity restriction and depression via the CES-D. Consistent with prior research, caregiver husbands and wives experienced caregiving differently and reported different levels of stressors. Caregiving wives reported more activity restriction (*r* =.45, p<.001)and less close relationship with the patient *(r* = -.54, *p* < .001) than husbands so that they experienced more primary stressors which lead to more secondary stressors than caregiving husbands which resulted in more depression in caregiving wives than husbands. The authors noted that the caregivers were only older caregivers, the data was cross-sectional and that longitudinal data may uncover other variables or associations.

Female caregivers and female patients generally had worse outcomes than males. Females had greater risk of depression or anxiety and worse emotional outcomes than male patients and male caregivers. (Yee & Schulz, 2000; Pinquart & Sorensen, 2003, 2006; Bookwala & Schulz, 2000; Molloy, et al. , 2005; McCann et al. , 2004; Rohrbaugh et al., 2002; Karmilovich, 1994; Evangelista et al., 2003, 2002; Dew et al. , 2003; Scott, 2000; Moser & Dracup, 2004). Female spousal caregivers are more likely to show higher levels of distress than other caregivers, due to age-related illness, providing four times more care than nonspousal caregivers, (Pinquart & Sorensen, 2003; Tennstedt, McKinlay, & Sullivan,1988) and having fewer buffering activities (Rohrbaugh, et al.).

Male patients create higher level of objective and subjective burden (Lalonde & Kasprzyk,1993). But female patients were more distressed than their caregiver husbands. Patients were more distressed than their spouses. Sicker patients were more distressed than healthier ones. Female spouses were more distressed than male spouses (Rohrbaugh et al.). When caregivers had a decrease in their demands, men reported a smaller reduction in depression than females (Nieboer et al.). Older females had worse emotional outcomes than younger (Evangelista et al.).Younger caregivers and females were at greater risk of depression or anxiety (Dew et al.).

Rohrbaugh and colleagues enrolled 128 male patients and 49 female patients and their spouses. Female patients reported the highest level of stress and the male spouses reported the lowest via an ANOVA with a main effect for role resulting, F (1,169) = 24.38, *p* <.01. Consistent with prior research, Rohrbaugh et al. found that wives of male HF patients were more distressed than husbands of female HF patients.

Evangelista and colleagues (2002) reported female patients and caregivers have worse emotional well-being compared to males but the difference was only statistically significant for patients (*p* = .018). They also reported that patient age, gender and caregiver emotional well-being accounted for 54% of the variance in the patient's emotional well-being. Dew et al. reported that female caregivers equaled or exceeded the rate of other caregiving populations with depression and anxiety while Moser and Dracup (2004) found similar results. Fifty-six percent of the female spouses were above the norm for anxiety and 67% were above the norm for depression. Moser and Dracup compared 417 pairs of patient-spouses. The spouses were 86% female with a mean age of 59 years. They also reported that spouses had significantly higher levels of anxiety (*p* <.001) and depression (*p* <.001)

<u>Gender and physical health-related quality of life.</u> There were few reported relationships between gender and caregiver physical health. Many studies that used gender as a variable also used age or caregiver versus noncaregiver status. Women reported more health problems than men (Schulz et al., 1995; Kessler et al., 1994; Rahman et al., 1994; Pinquart & Sorensen, 2006). Pinquart and Sorensen (2003) reported female caregivers versus noncaregivers had significantly poorer physical health (B=0.002, *p* <.001). In comparison to other variables in the study, the difference between

the caregivers (N = 6,716) and noncaregivers (*N* = 24,597) was considered small (*g* =.18, *k* = 66). Gender differences in caregiving physical health exceeded those in general adult population (Pinquart & Sorensen, 2006). Even though they found gender differences, when averaged over 229 studies, Pinquart and Sorensen concluded that they are small in magnitude. Women report caregivng is more stressful than men. Sex may moderate the relationship between stress and health with caregivers having higher level of stress hormones, poorer antibody production and higher levels of metabolic syndrome (Vitaliano et al., 2003). Physical health samples were not large enough to draw conclusions (Vitaliano et al.). Male caregivers had a greater prevalence of heart disease than noncaregiving men 27 to 30 months after the study entry (Vitaliano et al., 2002).

Gender and perceived control. Gender was a significant variable with caregivers and control. Pinquart and Sorensen reported a significant relationship between control and female caregivers versus noncaregivers (B =.003, *p* <.05). Females with higher control used more useful coping styles in the face of greater objective caregiving demands (Wallhagen, 1993) and men and women had different orientations to control (Wallhagen, 1994). When Wallhagen noted the variance in wishful thinking, control, and subjective and objective demands accounted for 24% of the variance. Only females used support seeking behavior so that this behavior was associated only with gender (B= -0.32, *p* =.01) (Wallhagen, 1993). Control had an independent and important effect on change in function for women and an interactive effect at baseline for men but women had worse function over the 5 years of the study (Wallhagen, 1994). Control decreased with age for women but increased for men with age. Females benefited more from the reduction of burden and the increase in favorite activities when looking at depression than men

(Nieboer et al.) while Dew et al. reported similar results but for older caregivers. With preventative health behaviors, men were more likely to carry out common behaviors than women (Burton et al., 1997) but females had no greater health risk even though they reported more health problems (Vitaliano et al.).

Yee and Schulz, who reviewed 30 research articles on caregivers and psychiatric outcomes, reported that personality or coping was a moderator in many of the studies. Coping included control and women reported low control in many studies and less effective coping strategies and greater depression, raising low control as a possible explanation for greater depression in women.

Caregiver gender especially female gender has a significant link to burden, control, and caregiver outcomes in the HF literature. The data supports the relationship in the proposed study for gender and the outcomes of interest.

Caregiver Biological Factors

Anxiety, depressive symptoms, and depression are considered biological or chemical brain imbalance issues for the caregiver along with other health problems such as diabetes or hypertension. Current medical management of these health issues is chemical or chemical in combination with behavioral modification therapy. Prior research has identified negative relationships between anxiety and/or depressive symptoms and burden.

Anxiety and Depressive Symptoms. Few of the researchers provided definitions of anxiety or depressive symptoms. Schwarz and Elman (2003) defined depressive symptomatology as a state of sadness or inadequacy in response to stress with feelings of hopelessness (p.91) while Dracup et al.(2004) defined psychological morbidity as emotional distress specifically anxiety, depression and hostility. There were numerous authors that investigated depression or depressive symptoms (Wallhagen, 1992, 1993; Molloy et al., 2005.; Bookwala & Schulz, 2000; Beach et al., .2000; Burton et al., 2003; Evangelista et al., 2002, 2004; Martensson et al., 2003; Dew et al., 2004; Nieboer et al., 1998; Schwartz & Elman, 2003; Scott, 2000; Moser & Dracup, 2004) and three authors (Karmilovich, 1994; Scott, 2000; Moser and Dracup, 2000) also examined anxiety. The measures used to study anxiety and depressive symptoms have been discussed in prior sections.

Previous research supports the relationship between a history of anxiety or depressive symptoms and greater caregiver burden. Prior research also supports the relationship between a history of anxiety or depressive symptoms and worse emotional health outcomes in caregivers. When studying the impact of burden on a small sample of caregivers, Scott reported 50% of the caregivers had anxiety, 45% had depression, and 89% had mental health scores below the established age norm while Moser and Dracup (2004) reported fifty percent of the patients and 56% of the spouses were above the norm for anxiety and 57% of the patients and 67% of the spouses were above the norm for depression, Dew and colleagues(2004) reported that the mental health scores of the transplant caregivers were below the population norm and that half of the sample reported anxiety and almost half reported depressive symptoms. Further, caregivers with prior psychiatric history had major depression diagnosis sooner post-transplant and a greater rate (57%) than those without a prior history (15%). They also investigated other predictors of psychiatric disorders such as nature and level of burden, caregiver characteristics, caregiver mental history, and caregiver psychiatric exam at the outset of the study. They were surprised to find post traumatic stress disorder at 22.5% primarily in the first year post-transplant. Those with prior psychiatric history or a poorer relationship with the patient also had a greater number of disorders. Schwarz and Elman (2003) reported almost one fourth of 128 caregivers experienced depressive symptoms. The researchers sought to determine if severity of cardiac illness, cognitive functioning and functional health of patients with HF and psychosocial factors of their caregivers were predictive hospital readmission for patients with HF. The interaction of the caregivers stress and depression increased the risk of patient readmission (p <.05). Even in a group of caregivers that appeared to have high social support, financial stability, and lower stress, caregivers experienced negative consequences from caregiving.

Martensson et al.(2002) examined 48 HF patient-spouse pairs to compare their levels of depression and health-related quality of life and to identify factors that contribute to their depression and health-related quality of life. Using a 2-group comparative design they used the Beck Depression Inventory, the SF-12, and the 6-minutes walk test. The spouses were white females with a mean age of 57 (± 10 years). Similar to Rohrbaugh et al., the patients were more depressed and had worse physical quality of life than their spouses. Patient depression correlated with their function level and their mental quality of life and accounted for 51 % of the variance in patient depression. Spousal depression was impacted by patient function, patient employment, and their mental quality of life. Thirty-three percent of the variance in spousal depression was accounted for by the spousal mental quality of life and the age of the patient (p = .003). The depression of the patient did not impact the spouse nor vice versa which surprised the researchers. Even though the study is cross-sectional and all the patients were male and from a single source, Martensson et al.'s (2003) results support the impact of patient health or function on the caregiver's psychological outcome of depression. The results also support the impact of caregiver perceptions on psychological outcomes. Pinquart and Sorensen reported that age-related illnesses especially for female caregivers may be linked to greater levels of distress than other caregivers.

Comorbid conditions. Relationships between the caregiver health and burden have been presented in previously reviewed research. The results from the CHES studies (Burton et al., 1997, 2003; Schulz & Beach, 1999; Beach et al., 2000) such as older caregivers with any level of prior disease and strain had a higher mortality rate versus noncaregivers. This provides strong evidence of a relationship in large prospective population studies. Beach and colleagues (2000) suggested that besides caregiving affecting caregiver health that it is also "possible that change in health lead to changes in caregiving" and suggest it be explored (p.267). Older caregivers health was a significant factor in whether a spouse would begin caregiving, so if a caregiver had more than one disability, it halved the likelihood of starting caregiving and an increase in the number of days of poor health also decreased the likelihood of beginning caregiving (McCann et al., 2004).

There were reports of some relationships between caregiver health and psychological outcomes. Caregiver physical and psychological health were studied and analyzed separately. A lifetime history of psychiatric disorder was one of the strongest risk factors for depression with caregivers of heart transplant patients (Dew et al., 2004). In the couples' research, the caregiver was influenced by the health of the patient and some studies reported the patient was influenced by the caregiver's health. Some researchers also reported that the caregiver and patient may in fact have shared perspectives that affect both persons (Evangelista et al..; Burton et al.; Bookwala & Schulz). The emotional well being of the caregiver was associated with the patient well-being (Evangelista et al.). Caregiver's mental health influences the patient's health and well-being (Dew et al.; Biegel et al.,1991; Williamson & Shaffer, 2001; Burgener & Twigg, 2002). Female spousal caregivers are more likely to show higher levels of distress than other caregivers due to age related illness, providing four times more care than nonspousal caregivers, (Pinquart & Sorensen, 2003; Tennstedt, et al, 1988) and having fewer buffering activities (Rohrbaugh et al.).

Empirical Literature Review for Patient factors

Patient NYHA class

NYHA Class and EF of HF have been used in the literature to objectively quantify and describe the severity of HF disease in study patients and thereby estimate caregiver burden. The typical HF patient does not have just HF but a number of cardiac diagnoses and increasing severity of HF typically exacerbates other cardiac diseases. Since each population of chronically ill patients has distinct or unique caregiving challenges "researcher should attempt to separate the disease specific from the general aspects of caregiving" (p.345, Biegel & Schulz, 1999). Nine studies examined HF severity as a variable, most used specific stage and EF and required a duration of symptoms of at least six months, while some used a cut-off criteria like EF less than 40% and minimum NYHA class like class III. Others added current symptoms and a functional measure like a 6-minute walk and/or comorbidities to describe the patient sample (Evangelista et al., 2002, Karmilovich, 1994; Schwarz & Elman, 2003; Martensson et al., 2003).

Negative relationships between the severity of the patient's HF and caregiver burden were reported in the previous literature. Severity of illness is related to strain in caregiving and caregiver well-being (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). As severity of HF increased, functional status decreased and the number or difficulty of tasks increased and caregiver burden increased (Schulz & Beach, 1999; McCann et al., 2004; Burton et al., 2003; Burton et al.,1997; Beach et al., 2000; Lalonde & Kasprzyk, 1993; Dew et al., 2003; Scott, 2000; Pinquart & Sorensen, 2003). When caregiver burden increased the literature consistently reported that caregiver well-being declined. Severity of illness, NYHA class, and function were three of the significant factors that accounted for hospital readmissions for HF patients (Schwarz & Elman, 2003).

Relationships between patient severity of illness and negative caregiver psychological outcomes were reported in the previous research (Pinquart & Sorensen, 2003; Moser & Dracup, 2003; Schwarz & Dunphy, 2003; Dew et al., 2003). Age, duration of caregiving, and the patient's functioning were the combination of factors that impacted the caregiver stress and depression (Schwarz & Dunphy). The lack of employment, greater caregiving burden, and a poor relationship with the patient were the risk factors for depression (Dew et al.). Older caregivers who reported strain were at greater risk of higher mortality, accelerated illness and exacerbation of illness and worse health maintenance behaviors (Schulz & Beach; 1999; Burton et al., 1997; Burton et al., 2003; Beach et al., 2000). NYHA class was correlated with patient distress but not spouse's distress (Rohrbaugh et al., 2002) and Martensson et al. also found patient function was related to patient NYHA class, as 6-minute walk distance decreased, NYHA class increased. Further, caregiver emotional well-being was affected by patient function level.

Relationships between severity of illness and control have been reported in the prior research. Severity of patient illness was negatively related to control (Endler et al., 2001). Control was significant in caregiver's global well being. Further, severity of illness and control explained 42% of variance in patients' well-being (Barlow, Macey, & Struthers, 1993). Control mediated the effect of severity on adjustment, which seemed to work better for women than men even though men had higher levels of control (Bookwala & Schulz, 2000). These resources indicate a link between patient severity of illness and negative caregiver psychological outcomes which supports the link between patient factors and caregiver outcomes in the proposed study.

Conclusions

Few studies examined caregiver demographic variables and their relationship to caregiver burden, perceived control, and psychological and physical outcomes. Those studies that did examine these variables reported differing results. Most of the studies in the HF literature are cross-sectional and use small samples so that causal relations are cautionary. The strongest results are from the longitudinal population studies and the meta-analyses. No randomly controlled studies were found in the literature for caregivers of HF patients. Findings from the literature support some of the caregiver factors, such as age, gender, the relationship to the patient, and duration of caregiving. Caregiver age had a significant relationship to caregiver burden and negative caregiver outcomes for both younger and older caregivers. Caregiver age was inconsistently related to perceived control, even though greater perceived control was positively related to lower burden and better outcomes. The literature provides contradictory results for caregiver education and income and no results for prior caregiving, which warrants further investigation.

Younger caregivers are stressed with caregiving in addition to the other demand of their lives and older caregivers are less able to care for the increasing demands of a spouse when their own health is declining. Older caregivers are at greater risk of worse health outcomes and greater mortality when strained with greater burden. Older caregivers have worse mental health outcomes when their health declines and/or their burden increases.

Females in the general population report worse emotional and physical health outcomes. Pinquart and Sorensen reported that caregivers had worse outcomes than noncaregivers and female caregivers had worse outcomes than caregivers but a question remains if it is due to caregiving or due to gender. Some studies reported that males and females experience caregiving differently and may complete tasks in different proportions and report reactions to different aspects of caregiving that differ by gender.

Caregiver health was linked with worse burden and negative outcomes. In order for the caregiver to continue caregiving they needed to have a minimum level of health. McCann et al. demonstrated that caregiver disability would prevent a potential caregiver from beginning or continuing caregiving. Caregiver health was negatively impacted by long term caregiving via exposure to chronic stress and negatively impacted mortality as Beach and Schulz (1999) reported.

Patient NYHA class was a significant variable in the literature. Worsening HF and disability were linked to increasing burden for the caregiver. The severity of illness was linked with increased risk of hospital readmission for the patient and increasing burden for the caregiver. The literature also supports increasing patient disability with negative caregiver outcomes via caregiver strain and increasing burden.

It is important for researchers to have a clearer understanding of the relationship of caregiver variables with caregiver burden and outcomes. Therefore, it is proposed that caregiver factors have a reciprocal relationship with patient NHYA class and have a significant impact on caregiver burden and caregiver outcomes. It is further proposed that patient NHYA class and caregiver factors (such as age, gender, health, anxiety, and depressive symptoms) can impact perceived control directly.

Summary

The literature findings support the conceptual model as theoretically plausible. Even though caregiver burden has been conceptualized and operationalized in a wide variety of ways, it has been widely researched in the caregiving literature. Caregiver burden, conceptualized as the number and difficulty of tasks, is supported in the general and HF literature. Hypothesized relationships between caregiver burden and caregiver psychosocial and physical outcomes are supported by the literature reviewed.

Perceived control has a demonstrated relationship with caregiver burden and caregiver outcomes. The mediation role of control to reduce the level of negative caregiver outcomes has been demonstrated in the general caregiving literature in other patient populations and in a limited number of HF patient and caregiver studies. The role of perceived control needs to be better understood in this population especially with the potential it holds for caregiver intervention.

Physical health outcomes have been studied in large populations studies and those studies strongly indicate the negative impact of caregiving burden but as Biegel and Schulz (1999) point out, each disease has its unique characteristics that should be pursued. The health consequences for HF caregivers need to be examined further.

The findings from the literature support a number of relationships with the study variables and caregiver factors of age, gender, anxiety, depressive symptoms and health. Lastly, findings supported relationships with the study variables and patient NYHA class.

In conclusion, no studies have focused on the combined variables in the hypothesized model in caregivers of HF patients. Nor have any published studies tested this theoretical model. As caregivers of HF patients have only recently become a population of interest in spite of the increasing prevalence and incidence of heart failure, the proposed study can fill in the gaps in research on caregivers of HF patients. Chapter 2 has provided an overview of caregiving, caregiving in heart failure and a review of the pertinent research related to the constructs of the study. Chapter 3 provides a description of the research design and methods utilized to collect and analyze data for the current study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

Chapter 3 describes the research methods for the study. This includes information about the design of the study, sampling and recruitment, setting, human subject protection, definitions of the variables and instruments, data collection procedures, and data analysis.

Study Design

This study was a secondary analysis of the baseline data of a larger study carried out in the Clarian Advanced Heart Care Program affiliated with Indiana University School of Medicine, Indianapolis. That project, entitled "Family Caregiving Outcomes Study in Heart Failure" (FAMOUS-HF), involved interviewing 63 caregivers to learn about the impact of caregiving on general, emotional, and physical caregiver outcomes. The FAMOUS-HF study used a repeated measures design with three time points (baseline, 4 months and 8 months) for data collection. The principal investigator in the FAMOUS-HF study, Dr. Susan Pressler, granted permission for the present study to use baseline data from the FAMOUS-HF study.

The current study used a descriptive design with cross-sectional data collection to test the conceptual model of caregiver outcomes among caregivers of HF patients. The primary aim of the current study was to describe the relationships among variables rather than infer cause-and-effect relationships. The cross-sectional data collection allows the collection of a large number of variables in a single study, identifying associations, and studying multiple outcomes (Brink & Wood, 1998).

Sample

The target population for this study was adult caregivers at least 21 years of age, who are routinely caring for someone with HF. The proposed sample for this study was a convenience sample of 110 caregivers who were recruited for the FAMOUS-HF study (see Inclusion and Exclusion Criteria).

Sample Size

The final sample size was controlled by the sample recruited for the FAMOUS-HF study. Initially a total of 110 caregivers were to be recruited for the FAMOUS-HF study but recruitment was closed at 63. Using a practical rule of thumb of Tabachnick and Fidell (1996) of ten cases for each independent variable the regression analyses were limited to six independent variables to maintain predictive power and decrease the risk of a type II error in some analysis**.** Based on a power analysis using multiple correlation parameters, a sample of 63 subjects results in a power of 0.90 with an alpha of 0.05 if the change in the dependent variable is 0.42 for one standard deviation change in the independent variable (Schoenfeld, 2007).

Setting

The setting for the study was the Clarian Advanced Heart Failure Clinic associated with Methodist Hospital, which provides comprehensive multidisciplinary diagnostic and therapeutic services such as social workers, advanced practice nurses and cardiologists specializing in the care of HF patients. Patients range from those initially diagnosed with NYHA Class I HF to those with advanced NYHA Class IV HF including implantation of ventricular assist devices (VAD) and heart transplantation. Patients may be drawn from the immediate metropolitan community or the larger state referral base. The caregivers tend to be well-educated and have some type of health care coverage.

Inclusion Criteria

The inclusion criteria for the FAMOUS-HF study were also used for the current study, which are:

1. a family member or friend who provides care to a patient with HF, NYHA class II-IV enrolled in the Clarian Advanced Heart Care Program;
2. age 21 years or older;
3. able to speak English;
4. has access to a working phone;
5. able to hear and speak audibly for telephone interview;
6. willing to complete required questionnaires; and
7. agreed to participate in study and has signed the informed consent statements.

NYHA Class II-IV patients would potentially require caregiving while NYHA Class I are unlikely to require caregiving.

Exclusion Criteria

The exclusion criteria for FAMOUS-HF study were also used for the current study, which are:

1. evidence of dementia or other communication disorder; or
2. caregiving a patient with HF who also has a recent VAD or heart transplant.

The caregiver of a HF patient who recently received a VAD or a transplanted heart has unique caregiving demands not typical of the rest of the HF population.

Instrumentation

Eight instruments are being used in this study (see Appendix A). The instruments are congruent with the conceptual definitions of the variables and were selected to yield high quality data. The conceptual and operational definitions are found in Chapter 1. Caregiver demographic factors (age and gender) were measured using an adapted demographic collection instrument revised based on previous studies. Caregiver biological factors (anxiety, depressive symptoms, and comorbid conditions) were measured with three different instruments. Caregiver anxiety was measured using the Anxiety subscale of the Brief Symptom Inventory (BSI). Caregiver depressive symptoms were measured by the PHQ-8. Caregiver comorbid conditions were measured using the Charlson Cormorbidity Index. The patient's NYHA class was measured using a chart review form to collect this data from the patient's medical record (see Appendix B). Caregiver burden was measured using the Oberst Caregiver Burden Scale (OCBS). Caregiver perceived control was measured using the Control Attitudes Scale (CAS). Caregiver health-related quality of life was measured using the physical and mental health component summary scales of the SF-12. In the following section, operational definitions for each variable in the conceptual model are presented. The validity and reliability of the measures are presented. Conceptual definitions of each variable were presented in Chapter 1.

Caregiver Factors

Caregiver factors are operationalized by self-reported age in years and gender. Caregiver biological factors are operationalized as the Anxiety Subscale of the BSI, the depression module from the PHQ-8 and the total score from the Charlson Comorbidity Index (CCI).

Brief Symptom Inventory

State anxiety is defined as a subjective experience which signals that a threat of some type has stimulated the stress response. It is associated with nervousness, fearfulness, restlessness and tension (Derogatis, 1975).

Caregiver anxiety was measured by the 6-item Anxiety subscale of the Brief Symptom Inventory (BSI). The BSI is a 53-item self-report questionnaire that measures nine primary symptoms including somatization, obsessessive-compulsive thoughts, interpersonal sensitivity, depression, anxiety, hostility, phobic, anxiety, paranoid ideation, and psychoticism. It was developed by Derogatis and Melisaratos (1983, 1977) from the longer parent Symptom Checklist 90 (SCL-90-R) that they also developed. The SCL-90-R was created to evaluate a broad range of psychological and psychopathological symptoms in adult and teens and psychiatric adult patients.

The BSI used three normed populations, two of which were psychiatric patient populations and one was a nonpatient population. The nonpatient population is 344 males and 341 females randomly stratified from a large eastern state. Internal consistency was established with 1,002 psychiatric out patients with Cronbach's alpha in a range of 0.71to 0.85 for each section of the scale. Test-retest was established with 60 non patients who were tested at 2 week intervals with Cronbach's alpha of 0.68 to 0.91. Correlations between the SCL-90-R and the BS1 with 565 out patients were .92 to .99. Convergent validity with the MMPI was reported at .30 to .72. Construct validity was determined with factor loading of the 1,002 out patient scores with… "seven of the nine constructs being reproduced with little to no disjuncture of items”…(p.603, 1983). Derogatis and Melisaratos also report other published reports show high sensitivity for the BSI (Marshal & Lewinsohn, 1981; Peterson et al., 1981).

The BSI has been used in a variety of patient populations including patients with new myocardial infarctions and caregivers of HF patients with internal consistency reported as .71 to .95 and Cronbach’s alpha of 0.84 in 243 post myocardial infarction patients (Derogatis & Melisaratos,1983; Moser & Dracup, 1996; DeJong, McKinley, Garvin, Hall, & Moser, 2005; Karmilovich, 1994). Normative values for the Anxiety Subscale have been reported for healthy adults (.35 ± .45) and psychiatric outpatients (1.70 ± 1.15) and psychiatric inpatients (1.70 ± 1.0) (DeJong et al., 2005; Derogatis, 1993). The Anxiety Subscale was strongly correlated with the Spielberger Anxiety Index ($r = .56$) (DeJong et al.).

The Anxiety subscale consists of six items with a 5-point response (0-4) of distress ranging from “Not at All” to “Extremely” intended to measure state anxiety not trait anxiety. Six symptoms of anxiety are included such as nervousness, fearfulness, restlessness, and tension. To score the anxiety level, the values for the items are summed and the sum is then divided by 6 in order to obtain a mean summary score that reflects the participant’s overall level of anxiety. Scores range from 0 to 4, with a higher score indicating a higher level of anxiety.

Patient Health Questionnaire

Depressive symptoms are defined as those feelings or behaviors that are indicative of eight mental health disorders (Kroenke, Spitzer Williams, 2001).

Depressive symptoms were measured by the 9-item Patient Health Questionnaire (PHQ). The parent PHQ is a 3-page, self-administered version of the PRIME-MD diagnostic instrument that screens for nine common mental disorders. The scale was developed by Spitzer, Williams, and Kroenke (2001). The PHQ-9 is a 4-point module for detecting depression which scores each of the 9 DSM-IV criteria. The measure asks about loss of interest or pleasure, felling down or depressed, trouble sleeping, felling tired, appetite, feeling bad about yourself, concentration and change in rate of speech or mobility. The responses range from 0 to 3 or “Not at all” to “Nearly every day” with the total score summed. Scores range from 0 to 24. Scores of 10 or greater are indicative of possible need for clinical treatment. Scores equal to or greater than 15 are indicative of high likelihood of depressive symptoms.

Strong criterion and construct validity were reported along with external validity with primary care and obstetric-gynecological patients during instrument development (Kroenke, Spitzer, & Williams, 2001; Spitzer, Williams & Kroenke, 2000). Internal reliability was reported as Cronbach alpha of 0.89 and 0.86 with test-retest reliability at 2 weeks reported as .84 with specificity and sensitivity in primary care populations (Kroenke et al., 2001). Construct validity was reported in 1,003 general hospital patient sample and a 2,066 general population sample (Diez-Quevedo, Rangil, Sanchez-Planell, Kroenke & Spitzer, 2001; Martin, Rief, Klaiberg, & Braehler, 2006). Martin and colleagues reported strong associations between the PHQ-9 depression scale and the BDI (r =.73, p <.0001) and the General Health Questionnaire (GHQ-12) (r = .59, p <.0001) with the general populations sample. The PHQ-9 has been used in stroke patients and caregivers of stroke patients with reported Cronbach alpha of 0.80 to 0.86 (Bakas, Champion, et al., 2006; Bakas, Kroenke, et al., 2006). For the current study the PHQ-9 was modified by excluding one question about suicide which the authors have recommended in nonpsychiatric populations (Kroenke & Spitzer, 2001).

Charlson Comorbidity Index

Comorbid conditions are defined as those health problems that have been shown to impact length of life (deGrout, Beckerman, Lankhorst & Bouter, 2003; Charlson, Szatrowski, Peterson, & Gold, 1994). The Charlson Comorbidity Index (CCI) was used to measure caregiver health. The index includes 19 medical conditions which are weighted based on their association with mortality. For example, moderate or severe liver disease is assigned a weight of 3 while a metastatic solid tumor and AIDS are assigned a weight of 6, the highest weight assigned. (Charlson, Szatrowski, Peterson, & Gold,1987). The total is summed and ranges from 0 to 35 with the higher scores indicating a greater number of significant diseases or severity of comorbid conditions (Charlson et al., 1987). The weights are categorized and assigned such as scores of 1 to 2 are assigned a 1, scores of 3 to 4 are assigned a 3 and scores of 5 or more are assigned a 5.

The CCI was developed from 1 year follow-up data of 604 hospitalized patients. These patients were followed for ten years to test the predictability of the measure. Further testing was conducted with 685 breast cancer patients in another hospital during which the CCI was compared to the Kaplan and Feinstein method (Charlson et al., 1987). Both methods were significant predictors of death from disease and yielded similar survival results (Charleson et al., 1994). The Charlson Index is the most extensively studied cormorbidity index (p. 225, deGroot et al., 2003). Concurrent validity was reported by deGroot et al. (2003) when comparing with six comorbidity indices with a correlation coefficient greater than .40. Predictive and constructive validity were reported when comparing the CCI to other critierion outcomes such as mortality and disability (deGroot et al., 2003). Test-retest and interrater reliability were reported as good to moderate (Extermann et al.,1998; Katz et al.,1996; Liu, Domen, & Chino, 1997).

The CCI has been used in patients with stroke, heart disease and surgery (Liu et al., 1997; Librero, Peiro, & Ordinana, 1999; Rochon et al., 1996). The CCI has been reported in studies of patients with dementia and patients with falls where the CCI is utilized to assess patient mortality and among caregivers and their use of preventive health services (Shega et al., 2005; Kuzuya et al., 2006; Kim, Kabeto, Wallace, & Langa, 2004).

Patient Factors

The patient factor of severity of heart failure is operationalized as NYHA class, which is obtained from the patient's clinic record.

Oberst Caregiver Burden Scale

Caregiver burden is defined as the number, type, time spent, and difficulty of tasks the caregiver performs for the patient including direct, indirect, monitoring, medical and financial management and mood and behavior management (Oberst, Thomas, Bass , & Ward, 1989). Caregiver burden was measured using the Oberst Caregiving Burden Scale (OCBS), a 15-item questionnaire used to measure 15 common caregiving tasks in personal, direct, indirect, interpersonal and support care (Oberst et al., 1989; Carey, Oberst, McCubbin, & Hughes, 1991). The measure was developed by Oberst from the Caregiving Load Scale (Oberst et al., 1989). The OCBS has two responses to each task category; time on the task and difficulty associated with the task. Participants select a response to time on task from a 5-point scale from “none” to “a great amount” and a similar 5-point scale for the difficulty associated with the task from “not difficult” to “extremely difficult”. The time and difficulty subscales can be summed. Each subscale ranges from 18-90. Higher scores indicate greater time on task or task difficulty.

Content and construct validity and internal consistency and reliability have been reported in cancer, stroke, pediatric renal transplant, and cardiac surgery caregivers (Bakas & Burgener, 2002; Bakas & Champion, 1999; Fedewa & Oberst, 1996; Stolarik et al., 2000; Carey et al., 1991; Oberst, 1990). Oberst and colleagues (1989) reported Cronbach’s alpha for burden-time total (0.88) and burden-difficulty total (0.91) indicating high internal consistency. Criterion validity was reported as .85 ($p < .001$) (Oberst et al., 1989). Convergent validity ($r = .72$, $p <.001$) was reported between the caregiver burden-difficulty scale and negative life changes of the Bakas Caregiver Outcomes Scale which were strongly correlated (Bakas et al., 2001). Cronbach’s alpha was reported as 0.84 for both the time and difficulty subscale by Bakas and Burgener (2002) while Stolarik and colleagues (2000) reported Cronbach’s alpha for coronary artery bypass patients for both time (0.92) and difficulty (0.94). In the 2006 study, Bakas et al. reported Cronbach’s alpha of 092 with difficulty in a sample of 21 heart failure caregivers.

Three additional questions about common behaviors were added for the FAMOUS-HF study raising the total number of questions to eighteen. This expanded version was utilized in a pilot study of adult caregivers of HF patients (Bakas et al., 2006).

Control Attitude Survey

Perceived control is defined as a belief that one has at their disposal, a response that can influence the adversiveness of an event (Thompson, 1981, Moser and Dracup, 1995). Perceived control was measured by the 4-item Control Attitude Survey (CAS) developed by Moser and Dracup (1995). The scale was developed to measure the degree of control patients feel they have over their cardiac disease. Moser and Dracup wanted a measure that asked questions that were more relevant to the patient's current health problem and performed better in predicting health outcomes (p.274, 1995). Initial reliability and validity testing was conducted with a sample of 325 cardiac patients with diagnoses of myocardial infarction or coronary artery bypass surgery from multiple centers on the west coast. Internal consistency was reported by Cronbach's alpha of 0.89. For the 1995 study Cronbach's alpha was 0.77 with test-retest reliability at 2 weeks of r = .62 (p = .001). Construct validity was reported as moderate (r =. 58, p =.01) when correlated with the Psychosocial Adjustment to Illness Scale health care orientation subscales.

The survey addresses how much control or helplessness the individual feels they have over their family member's heart problem. Participants select the degree of control from a 7-point scale with 1 as "not at all in control" and 7 as "very much in control". The scores range from 4-28 with higher scores indicating greater control. The questionnaire has been used in patients with cardiovascular disorders and their spouses, transplant patients, HF patients, and caregivers of HF patients (Moser & Dracup, 1995, 2000,2004; Evangelista, Moser, Dracup, Doering , & Kobashigawa, 2003; Dracup, Westlake et al., 2003; Dracup, Evangelista et al., 2004; Bakas et al., 2006). Dracup, Westlake et al.

reported Cronbach's alpha of 0.77 in their study of 222 heart failure patients, while Moser and Dracup (2000) reported a Cronbach's alpha of 0.88 with 196 caregivers of cardiac patients and Evangelista et al. reported Cronbach's alpha of 0.93 for their 50 transplant and 50 caregiver of transplant study while Bakas and colleagues reported a Cronbach's alpha of 0.75 for their 21 caregivers of HF patients.

Medical Outcomes Study Short Form Health Survey, SF-12

Caregiver health-related quality of life is defined as caregiver's perception of their well-being including mental status, emotional, vitality, role and social functioning, and physical and general health (Medical Outcomes Trust, 1994, Ware, 2004). The SF-12 was used to measure the caregiver's perception of their general physical and mental health (Medical Outcomes Trust, 1994; McHorney, Ware, Lu, & Sherbourne, 1994; Ware, 2004). It was developed in 1996 as a downsized version of the SF-36 including only 1 to 2 items to measure the same eight concepts of the SF-36 (Ware, Kosinski, & Keller). Items that represented the eight health items were selected based on forward regression analysis of R^2 of .90 or greater between the selected items and the original items of the longer form. The SF-12 measures physical functioning, role-physical, role-emotional, mental health, bodily pain, general health, vitality, and social functioning. It can produce two summary scales-a physical component sum (PCS) and a mental component sum (MCS) which are weighted and range from 0 to 100, with 100 being the best quality of life score.

The SF-12 was tested in a general population sample (N = 2,333). The short form achieved R of .911 and .918 with multiple regressions in predicting the physical and mental component of the SF-36, respectively (p.220, 1996). Strong test-retest reliability was reported for the physical and mental subscales (.89 and .76) as was empirical validity as .43 to .93 (median = .67) (Ware et al., 1996). The SF-12 has been cross-validated with the SF-36 in nine countries with over 9,000 participants reporting correlations of .94 to .96 for the physical and mental summary measures (Gandek, Ware, Aaronson, & Apolone, 1998). Face, content, criterion, and construct validity of the SF-12 have been reported (Brazier et al., 1992; Jenkinson, Wright, & Coulter, 1994; Ware et al., 1998). It has been widely used in large outpatient samples and stroke and heart failure caregivers with acceptable reliability and validity (McHorney et al., 1994; Bakas & Burgener, 2002; Bakas & Champion, 1999; Evangelista et al., 2002; Bakas et al., 2006). In other studies of caregivers of HF patients, Cronbach's alpha has ranged from 0.78 to 0.83 for physical subscale and 0.93 for the mental subscale (Bakas et al., 2006; Nieboer et al., 1998).

Procedures

Caregiver and Patient Enrollment

The sample of caregivers was obtained from the caregivers who are enrolled in the FAMOUS-HF study. The current study did not require the addition or modification of procedures in the FAMOUS-HF study. The procedures for the FAMOUS-HF study are as follows:

1. Institutional Review Board approval from Indiana University was obtained
2. Caregivers of patients who received care in the Clarian Advanced Heart Failure Clinic were invited to participate in the study by the staff of the clinic. A brief explanation of the study was provided along with the study brochure. Caregivers were asked to verbally agree to participate. Once they agreed, the

investigator contacted them in person or by telephone to explain the study more fully and obtain written informed consent (See Appendix C).

3. The investigator assisted the caregiver and patient with the completion of informed consent forms in person or by telephone (when the consent forms were mailed to the caregiver).

   a. If the caregiver requested the consent forms by mail, a cover letter explaining which forms are to be completed by the caregiver and patient was sent in addition to another copy of the study brochure, a postage paid preaddressed return envelope, and copies of the consent forms for the participants to retain.

4. Once all the required consent forms were completed by the caregiver, a telephone call was scheduled to complete the baseline interview. The baseline interview took between 60 and 90 minutes to complete.
5. Once the patient has completed their consent forms, information to confirm the severity of their HF was collected from the patient's medical record in the Clinic.

Protection of Human Subjects

The procedures for informed consent and protection of human subjects for the FAMOUS-HF study were followed for the current study. Informed consent was obtained in writing prior to data collection. The nature, purpose procedures, risks and safeguards used were explained in understandable wording for the population. Confidentiality of records identifying the participant and the protection of the participant's identity was addressed as were the participant's rights and who to contact about questions about participants rights. The voluntary nature of participation and the right to withdraw without penalty were addressed. All caregiver and patient records were assigned anonymous study identification numbers (ID) and all data from questionnaires and chart reviews were assigned study ID numbers. Master files of study data were kept in a locked file cabinet in the research office with access limited to investigators.

All data was kept confidential. The data was entered into an Access database on a password protected computer. Only study ID numbers were included in the database, no personal identifiers were entered into the database. The data was backed up weekly. The data was reported as group data and individuals were not identified.

Data Analysis

The data analysis plan included data screening, cleaning, assessment of scale reliability, description of the sample and instruments, and examination of the research hypotheses. Questionnaires were coded and data were entered into SPSS-PC for Windows, version 14.0 (SPSS, Inc., 2006). The data file included responses to all individual items; total scores were calculated from individual items. All scores were computed, and all data were analyzed using SPSS 14.0. Data were analyzed using both descriptive and inferential statistics. Appropriate analyses will be conducted for specific aims as described below. The hypotheses were tested using the general linear model. The significance level was set at .05. Data from the FAMOUS-HF study had been coded, entered and screened for error by FAMOUS-HF researchers and statisticians prior to their release for this study. Prior to analysis, data were screened for the assumptions of independence of error, normality, homogeneity of variance, linearity, the presence of outliers, and multicollinearity.

Independence of Error

Linear regression assumes that the error is independent and that there are no serial correlations. Use of the Durbin-Watson statistic was used to test for the presence of serial correlations.

Normality of Dependent Variables

Procedures to screen for normality among the dependent variables (caregiver emotional and physical health-related quality of life and perceived control) were conducted by the FAMOUS-HF statisticians using descriptive statistics to check for skewness, kurtosis and outliers. Visual inspection of box plots, q-q plots and histograms revealed scales produced acceptable normality with no outliers. There was no substantial skewness or kurtosis in the data and no transformations were necessary.

Tests of Independent Variables

Each independent variable was tested separately. It is assumed that they are nultivariate normal if they are individually normal. The same graphical and statistical methods described above were utilized.

Homogeneity of variance was evaluated for pairs of variables (caregiver emotional and physical health and one independent variable each time) using boxplots and Levene methods. Linearity was tested using scatter plots and diagnostic hypothesis testing for linearity was used.

Presence of Outliers

Univariate outliers will be examined using standard scores with the dependent variable. Multivariate outliers will be examined using the minimum and maximum Mahalanobis distance values (Tabachnick & Fidell, 1996). In all multivariate analyses, residuals and scatter plots were constructed to further screen for outliers. No significant outliers were noted in any data screening.

Multicollinearity

Multicollinearity was examined using the tolerance for each independent variable and collinearity diagnosis. It was assessed using the criteria, if the bivariate correlation is greater than .60 and squared multiple correlations greater than .60 (Nunnally & Bernstein, 1994). The tolerance values for all of the independent variables were larger than 0.20, multicollinearity was not a problem in the regression analyses.

Preliminary Analysis

Descriptive statistics were calculated for each measure to obtain the frequencies, overall mean, median, standard deviation, minimum, maximum, range, and central tendencies for the sample of caregivers and HF patients. The internal consistency reliability, Cronbach's alpha, was estimated for all multiple-item scales including the Oberst Caregiving Burden Scale (OCBS), Control Attitudes Scale (CAS), PHQ-8, Brief Symptom Inventory (BSI) and the SF-12. Cronbach's alpha can not be calculated to scales with weighted scores such as the Charlson Comorbidity Index. Internal consistency was supported in all the scales with Cronbach's alphas ranging from 0.75 for the Brief Symptom Inventory (BSI) to 0.82 for the Difficulty subscale of the Oberst Caregiver Burden. Only the total Perceived Control scale had a lower than expected Cronbach's alpha of 0.44. Cronbach's alpha was improved to a 0.54 by utilizing only two of the scale's questions, question 1 and 3 (CAS2mean) (Table 3). Question 1 inquired about general control over the patient's heart problems and question 3 inquired about general helplessness over the patient's heart problems.

In order to detect the presence, strength, and direction of relationships of continuous caregiver factors on the dependent variables of caregiver emotional and physical health-related quality of life and perceived control, Pearson product-moment correlation coefficients were examined. Independent variables that had significant (p <.05) correlations with any of the dependent variables were entered into the regression analyses to test the study hypotheses. Discrete variables such as caregiver gender and patient NYHA class were evaluated using analysis of variance (ANOVA) and variables with significant (p <.05) univariate F's were entered into regression analyses to test the study's hypotheses.

Statistical Analysis of Hypotheses

All of the hypotheses were examined using general linear regression models and multiple regression models. For each hypothesis the standard regression models were calculated. The most significant independent variables were entered into the regression equation simultaneously. This allowed the evaluation of each variable's contribution to the prediction of the dependent variable. Additionally, groupwise step regressions were calculated to evaluate the contribution of independent variables of greatest interest to the study for Purpose 1 and 2.

Primary Purpose: to test a conceptual model of caregiver health-related quality of life among caregivers of HF patients.

Hypothesis 1

Among caregivers of HF patients, demographic factors such as, older age and female gender and biological factors such as, greater anxiety, more depressive symptoms, and more comorbid conditions along with patient HF severity (worse NYHA class) and greater caregiver burden-time and difficulty and lower caregiver perceived control explain worse emotional health-related quality of life.

To test Hypothesis 1, multiple linear regression models were computed to identify the relationship of caregiver demographic factors (age and gender), caregiver biological factors (anxiety (BSI), depressive symptoms (PHQ-8), comorbid conditions (Charlson Comorbidity Index), patient factors (NYHA class), caregiver burden (OCBS), and perceived control (CAS) on caregiver health-related quality of life (mental health [SF-12]). A group-wise stepwise regression model was computed with caregiver emotional health-related quality of life as the dependent variable with the independent variables entered as caregiver factors, patient factors and caregiver burden followed by perceived control. The change in the R^2 from the first to the last stage was used to evaluate the importance of the variables and their contribution to the variance of the dependent variable.

<u>Hypothesis 2</u>

Among caregivers of HF patients, demographic factors such as, older age and female gender and biological factors such as, greater anxiety, more depressive symptoms, and more comorbid conditions along with the patient HF severity (worse NYHA class) and greater caregiver burden-time and difficulty and lower caregiver perceived control explain worse physical health-related quality of life.

The same computations that were described for Hypothesis 1 were calculated to test Hypothesis 2, using (physical health (SF-12)) as the dependent variable.

Secondary Purpose: to test the explanatory variables of caregiver factors, patient factors, and caregiver burden on perceived control.

Hypothesis 3

Among caregivers of HF patients, demographic factors such as older age and female gender and biological factors such as greater anxiety, more depressive symptoms and more comorbid conditions along with the patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty explain perceived control.

To test Hypothesis 3, multiple linear regression models were computed to identify the relationship of caregiver demographic factors, caregiver biological factors, caregiver comorbidity, patient NYHA class and caregiver burden on perceived control. A group-wise stepwise regression model was computed with perceived control as the dependent variable with the independent variables entered as all caregiver factors, patient factors, and caregiver burden. The change in the R^2 from the first to the last stage was used to evaluate which variables explained the variance in perceived control.

Hypothesis 4

Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden and caregiver emotional health-related quality of life.

To test Hypothesis 4, the MacKinnon approach (2002) was utilized where three regressions are conducted and evidence of mediation is determined based on a reduction in the regression beta and significance that included perceived control.

Hypothesis 5

Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden and caregiver physical health-related quality of life.

To test Hypothesis 5, the same calculations were computed as in Hypothesis 4 but using physical health as the dependent variable.

Summary of Methods

This current study investigated explanatory variables of caregiver outcomes in a convenience sample of caregivers of persons with heart failure. A cross sectional design was used to examine the hypotheses. The sample selection, instruments, and procedures for conducting the study and protecting human subjects were described. The instruments have demonstrated validity and reliability. The plan for data analysis organized around the specific aims was described. Linear regression models and correlations were computed to test the hypotheses. By testing the relationships among the independent and dependent variables, new knowledge was gained that may be foundational in the development of caregiver interventions. Chapter 4 provides specific results related to the procedures used.

CHAPTER 4

RESULTS

In this chapter, the results of data analyses are presented in three sections. The first section describes the caregiver sample and the care recipients in terms of demographics, comorbid conditions, and dependent and independent variables. In the second section, the relationships among the independent variables are examined for multicollinearity and results of zero-order correlations are reported. In the third section the results of hypotheses testing are presented.

Description of the Sample

The sample for the current study was drawn from the FAMOUS-HF study. It consisted of 63 caregivers of HF patients who met the inclusion criteria of the FAMOUS-HF study and completed the baseline interview. The sample was described in terms of age, gender, ethnicity, education, employment, income, and relationship to the patient. These results are in Table 1. The sample consisted of 48 females and 15 males with a mean age of 59.7 years (*SD* = 14.9 years, range 24-86 years), and 53 (84.1%) were self-identified as White and 10 (15.9%) as African American. Thirty-six percent completed high school while 22% attended college and another 28% completed college or graduate school. Eighteen (28.6%) caregivers worked full-time while 28 (44.4%) were retired. Forty-three percent said they had a comfortable income while 36% said they had just enough to make ends meet. Seventeen (25.8%) caregivers had changed employment to be caregivers. Forty-three (68%) were spouses while 13 (20.6%) were sons or daughters.

Table 1

Frequencies and Percentages for Demographic Characteristics of Caregivers

Characteristic	Frequency	Percent	Mean	SD	Range
Age	63		59.7	14.9	24-86
20-50	17	27.4			
51-65	21	33.9			
over 65	24	38.7			
missing	1				
Gender					
Male	15	23.8			
Female	48	76.1			
Race					
White	53	84.1			
African American	10	15.9			
Education					
Grade school or less	4	6.3	13.4	2.98	2-19
Some high school	4	6.3			
Completed high school	23	36.5			
Some college	14	22.2			
Completed college	8	12.7			
Graduate school	10	15.9			

Table 1 (continued).

Characteristic	Frequency	Percent	Mean	SD	Range
Income					
Comfortable	29	43.9			
Just enough	24	36.4			
Not enough	10	15.2			
Relationship to patient					
Spouse	43	68.3			
Son or daughter	13	20.6			
Other relative	3	4.8			
Friend/Other	4	7.4			

The Care Recipients

The care recipients were described in terms of age, gender, ethnicity, and health. The results are in Table 2. There were 34 men (54%) and 29 women (46%) self-identified as White (81%) with a mean age of 68.97 years (*SD* = 12.6 years, range 30-91 years). The patients were primarily NYHA class III, stage C with a mean ejection fraction of 42% (*SD* = 15.68; range 15-72%) who had HF for five years or less (58.6%). They took a mean of 12.6 medications (*SD* = 4.1; range 5-23).Over twelve percent had some type of pacemaker, while 22% had implantable cardioverter defibrillators (ICD). Almost 13% had a stroke while 30% had chronic obstructive pulmonary disease and 46% had diabetes (requiring medication). Slightly more than 71% had a Charlson Comorbidity Index of 3

Table 2

Frequencies and Percentages of Demographic Characteristics of HF Patients

Characteristic	Frequency	Percent	Mean	SD	Range
Age	63		68.97	12.6	30-91
20-50	17	27.4			
51-65	21	33.9			
over 65	24	38.7			
missing	1				
Gender					
Male	34	46			
Female	29	54			
Race					
White	51	81			
African American	12	19			
Employment					
Full time	3	4.8			
Part time	2	3.2			
Homemaker	6	9.5			
Retired	38	60.3			
On Disability	10	15.9			
Unemployed/Other	2	3.2			
Missing	2	3.2			

Characteristics	Frequency	Percent	Mean	SD	Range
Quit/Retired due to HF	23	34.8			
NYHA Class					
I	4	6.5			
II	15	24.2			
III	33	53.2			
IV	10	16.1			
Stage of HF					
A	0	0			
B	1	4.8			
C	54	85.7			
D	5	7.9			
Duration of HF					
1-5 years	34	58.6			
6-10 years	14	24.2			
11 or more	10	17.2			
Missing	5	7. 9			

out of a possible 5, indicating multiple chronic diseases that are associated with greater mortality. This is in addition to their diagnosis of HF.

Study Variables

Caregiver Biological Factors

Anxiety. Caregiver anxiety was measured by the Brief Symptom Inventory (BSI), a six question scale with a possible range of 0-24 that is summed and divided by six. The mean score was 0.50 (*SD* = 0.54, actual range .25-1.02, with a range in each question of 0 [Not at All] to 4 [Extremely]). The majority of caregivers reported feeling no fear, panic, nervousness, or restlessness in answer to five of the six questions. But 39% of the caregivers did report feeling moderate or quite a bit of nervousness and 14.3% reported a moderate amount of fear. In response to the sixth question about feeling tense, only 35% reported none at all while 35% reported feeling a little bit and 29% reported feeling a moderate to an extreme amount. Five of the caregivers reported total scores above 2.5. The descriptive statistics for study independent variables are found in Table 3.

Depressive symptoms. Caregiver depressive symptoms were measured by the Patient Health Questionnaire (PHQ-8), an eight question scale with a possible range of 0-24. The mean score was 4.57 (*SD* = 4.098, actual range of 0-18 with a range in each question of 0 [Not at all] to 3 [Nearly every day]) indicating a low level of symptoms among the caregivers. The majority of caregivers indicated no problem or low level with four of the eight questions. Forty-one caregivers reported some level of trouble falling or staying asleep while 45 reported feeling some level of being tired or having little energy. Thirty-one of 63 caregivers reported feeling down or depressed some days to nearly every day. Eighteen (29%) caregivers reported trouble concentrating several to more than half the days. Nine (14%) caregivers said more than half to almost every day they experienced loss of pleasure in doing things. Although most of the caregivers indicated

Table 3

Descriptive Statistics for Study Variables

Variable (Measure)	Items	Mean	SD	Median	(Possible) Actual Range	Cronbach's alpha
Anxiety (BSI)[a]	6	0.5	0.54	0.17	(0-4) .25-1.02	0.75
Depression (PHQ-8)[b]	8	4.57	4.09	3.94	(0-24) 0-18	0.79
Comorbidity Score (CCI)[c]	11	1.43	2.52	NA	(0-40) 0-13	weighted 0-5
Caregiver burden-time (OCBS)[d]	18	40.05	8.97	39.18	(18-90) 25-60	0.815
Caregiver burden-difficulty (OCBS)	18	29.7	8.99	28	(18-90) 18-54	0.819
Perceived Control Total (CAS)[e]	4	16.13	4.3	16.0	(4-28) 7-26	0.44
CAS2mean (Q 1 and 2)	2	9.22	2.60	9.0	(2-14)	0.54
Caregiver emotional health (SF-12)	12	48.7	10.48	51.9	(0-100) 19-65	weighted
Caregiver physical health (SF-12)	12	47.39	10.84	51.09	(0-100) 16-61	weighted

a = BSI =Brief Symptom Inventory
b = PHQ-8 = Patient Health Questionnaire
c = CCI =Charlson Comorbidity Index
d = Oberst Caregiving Burden Scale
e = Control Attitudes Scale

few problems, six caregivers reported scores at or above 10 (7.5%), which is considered in need of clinical treatment. Two (3%) caregivers reported scores above 15, which is considered highly indicative of depressive symptoms.

Comorbidity. Comorbidity among the caregivers was measured by the Charlson Comorbidity Index (CCI) which is scored by summed and weighted answers. The mean score was 1.43 on a weighted scale with a range of 0 to 5 (*SD* = 2.52). Fifty-three of the 63 caregivers had a weighted score of 1 indicating the majority of the caregivers had few chronic illnesses associated with a greater risk of death. A score of one may indicate the caregiver may have a history of a myocardial infarction or have one chronic illness. Twenty-two percent had asthma or diabetes that requires medication. But a few caregivers had much higher scores. Four caregivers had scores of 3. Six caregivers had scores of 5. Several required routine medication. Almost 18% had diabetes requiring oral or injectable medication. Almost ten percent had rheumatoid arthritis. Eight percent had gastric or peptic ulcers.

Caregiver Burden. Caregiver burden was measured by the Oberst Caregiving Burden Scale (OCBS), an 18-question measure with a possible range of 18-90. Two scores are reported for burden, the time the task requires and the difficulty of the task. The mean score for time for the task was 40.05 (*SD* = 8.96, range for each question 1 [None] to 5 [A great amount]). The mean score for the difficulty was 29.7 (*SD* = 8.99, possible range 18 to 90, range for each question 1 [Not difficult] to 5 [Extremely difficult]). Both scores indicate a moderate time for caregiving and a lower perception of difficulty.

The top five tasks that were most time consuming for the caregiver were (in order); providing emotional support to the patient (*M* = 3.48), monitoring the patient's symptoms (*M* = 3.41), providing transportation (*M* = 3.08), doing additional household tasks (*M* =3.0), and managing the patient's special diet (*M* = 2.78). Some of the most time consuming tasks were also some of the most difficult tasks. The top five tasks that were the most difficult were; managing pt moodiness or irritability (*M* = 2.41), providing emotional support (*M* = 2.19), managing the patient's special diet (*M* = 2.17), monitoring the patient's symptoms (*M* = 1.95), and seeking information from health care providers (*M* = 1.81).

When examining only the extremely high scores for time, there were between 4 and 15 caregivers who scored very or extremely high on the top five most time consuming tasks. When examining only the extremely high score for difficulty, there were between 3 and 14 caregivers who scored very or extremely high in the top five most difficult tasks. When combining extremely high responses to time and difficulty, there were between one and four caregivers who responded with high scores to15 of the 18 questions. Hence, a few caregivers were managing not only the top five issues in time and difficulty but also patients with high physical, mobility, comprehension, and cognitive needs in addition to finances and additional outside duties.

Perceived Control. The four-question Control Attitudes Scale (CAS) was used for perceived control with a possible range of 4-28 and a mean of 16.13 (*SD* = 4.32, range for each question 1 [not at all in control] to 7 [very much in control]). In evaluating the reliability of the scale, a Cronbach's alpha of 0.44 was obtained when all four questions were retained while an alpha of 0.54 was obtained when only two questions (Questions one and two) were retained. Using questions one and two, caregivers report a mean of 9.22 (*SD* = 2.60, possible range 2 to 14) when asked about how much control they felt over the patient's HF and when asked if they could take the right steps in an emergency related to the patient's heart. The mean indicates the caregivers felt they had control over the patient's HF and heart emergencies.

SF-12 Mental Component Summary Scale. The SF-12 is a shorter version of the SF-36 that was used to measure emotional and physical health-related quality of life of the caregiver. It has a possible range of 0 to100. The mean caregiver score was 48.71 (*SD* =10.48, range for each question 1 [all of the time] to 5[none of the time]) with a 12-question scale where a larger number is indicative of better health. In comparison to the general US population mean of 50.04 (*SD* = 9.59, *n* = 2,329) (Ware, Kosinski, & Keller, 1995) however, caregivers had a lower mean of 48.7. The caregivers also had a lower mean when compared to their age groups' mean of 50.57 (*SD* = 9.82, *n* = 250) (Ware et al., 1995). The comparison is more dramatic when comparing the caregiver means to Ware's 2004 population norm of 74.7 (*n* = 2,474) (Ware, 2004).

The majority of caregivers reported their perception of their health as good to excellent and they had no limitation of activity, accomplishment, kind of work or carefulness in work due to emotional problems. The majority also reported emotional problems do not interfere with social activities. In contrast, two questions about feeling calm and peaceful and one question about having a lot of energy drew a wider variance in answers. Fifty-six percent of the caregivers said they felt calm and peaceful all or most of the time while 19% said they were calm only a little to none of the time. When asked about having a lot of energy about 43% said they did all or most of the time but 33% said they had little or no energy. When examining high scores, 8% of caregivers said emotional problems affected what they wanted to accomplish and that they worked less carefully all or most of the time and almost 10% said they were depressed/down most of the time. And 14% said emotional problems interfere with social activities.

SF-12 Physical Component Summary Scale. The mean score was 47.39 (*SD* =10.84, possible range 0 to 100, range for each question 1 to 5) with 12 questions where a larger score is a better result. Compared to the general US population mean of 50.12 (*SD* = 9.45) caregivers mean of 47.39 was lower and therefore less healthy but compared to adults age 55 to 64 with a mean of 46.55 (*SD* = 10.63) the caregivers were slightly healthier that their age mates (Ware et al., 1995). The majority of caregivers reported no limitations with moderate activities (such as moving a piece of furniture), no limitations with physical accomplishments or types of physical activities or pain. In contrast, the majority had either a little or a lot of limitations in climbing several flights of stairs while 11% were limited a lot in moderate activities, 12% were limited all or most of the time in physical accomplishments and the kind of work and 13% had pain that interfered with normal activities quite a bit or extremely. Twenty-one percent report fair to poor health.

Assessment of Multicollinearity

To detect the presence of multicollinearity among the independent variables, Pearson's product moment correlation coefficients were calculated. These results are in Table 4. Correlations ranged from .07 to .74. Since multicollinearity is only a problem when correlations are greater than .80, none of the correlations were problematic (Nunnally & Bernstein,1994). All the independent variables were considered acceptable for entry into the regression equations. See Table 5.

Table 4

Correlations Among Caregiver Study Variables

Variable (n=63)	Age	Anxiety	Depressive Symptoms	Comorbid	Burden-time	Burden-difficulty	Control	Emotional Health
Age								
Anxiety	$-.25^{*}$							
Depressive Symptoms	-.16	$.69^{**}$						
Comorbid	.23	-.05	.06					
Burden-time	-.19	.13	.22	.13				
Burden-difficulty	-.23	.20	$.46^{**}$	.07	$.74^{***}$			
Control	.01	$-.28^{*}$	$-.40^{**}$	-.09	$-.32^{**}$	$-.36^{**}$		
Emotional Health	-.25**	-.39**	-.54***	-.09	-.33**	-.54***	.37**	
Physical Health	-.30**	-.22	-.31*	-.44**	-.14	-.17	.23	.09

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

Zero-Order Correlations

The examination of the correlations in Table 4 between the independent variables and emotional health-related quality of life reveals, age (*r*= -.25, *p* <.01), anxiety *(r* = -.39, *p* <.01), depressive symptoms *(r* = -.54, *p* <.001), caregiver burden-time (r=-.33, p<.01), and caregiver burden-difficulty (*r* = -.54, *p* <.001) were negatively related to emotional health-related quality of life. Perceived control was also moderately correlated with emotional health-related quality of life (*r* =.37, *p* <.01) and negatively correlated with caregiver burden-time (*r* = -.32, *p* <.01) and caregiver burden-difficulty *(r* = -.36, *p* <.01). Age and caregiver anxiety (*r* = -.25, *p* <.05) were associated. Older caregivers had worse emotional and physical health-related quality of life and younger caregivers had greater anxiety. The correlation for comorbidity did not reach significance.

When examining the correlations between the independent variables and physical health-related quality of life, age (*r* = -.30, *p* <.01), depressive symptoms (*r* = -.31, *p* <.05), and comorbidity (*r* = -.44, *p* <.01) were negatively correlated with physical health-related quality of life. Anxiety, caregiver burden-time and difficulty, and perceived control did not reach significance.

T-tests were conducted for differences between female and male caregivers related to emotional health-related quality of life (Table 5) and physical health-related

Table 5

T-tests for Differences in Gender for Emotional Health-Related Quality of Life

Variable	n	M	Lower CL	Upper CL	*SD*
Male	14	52.7	47.49	57.9	9.09
Female	48	47.5	44.44	50.6	10.7
difference		5.2			

Test of Equality	df	t	p-value	Critical t
Pooled	60	1.66	.10	-2, +2

Table 6

T-tests for Differences in Gender for Physical Health-Related Quality of Life

Variable	n	M	Lower CL	Upper CL	SD
Male	14	46.8	40.8	52.8	10.46
Female	48	47.56	44.3	50.8	11.05
difference		-0.71			
Test of Equality	df	t	p-value	Critical t	
Pooled	60	-.21	.84	-2, +2	

quality of life (Table 6). There was no significant difference between the means of each group indicating gender was not a significant factor with emotional or physical health-related quality of life. In addition, gender was regressed with emotional health-related quality of life but it was not found to be significant (Table 7).

Examination of the correlations between the independent variables and perceived control revealed, anxiety ($r = -.28$, $p <.05$), depressive symptoms ($r = -.40$, $p <.01$), caregiver burden-time ($r = -.32$, $p <01$) and difficulty ($r = -.36$, $p < .01$) were negatively related to perceived control. Age and comorbidity did not reach significance.

Hypotheses Testing

In the next section, the hypotheses are restated, followed by a discussion of the results from the analyses. As described in Chapter 3, hypotheses were tested using multiple and stepwise regression modeling.

Results for hypothesis 1

Hypothesis 1. Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of greater anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty and lower perceived control explain worse emotional health-related quality of life.

Hypothesis 1 was partially supported. Individual regressions with emotional health-related quality of life were conducted using the variables that had significant correlations. As a result, age, anxiety, depressive symptoms, caregiver burden-time, caregiver burden-difficulty, and perceived control were found to be related to emotional health-related quality of life (Table 7). Next, the independent variables with the largest *F* value were tested in combination.

A stepwise regression was conducted to determine which variables or combination of variables had the greatest influence on emotional health-related quality of life (Table 8). Caregiver burden-difficulty was entered in step 1 ($F = 25.27$, $p < .0001$, *df* 1,60 $F \approx 4.0$) with R^2 of .30. In step 2 depressive symptoms was added to caregiver burden-difficulty ($F = 19.7$, $p < .0001$) with an R^2 of .40. In step 3 age was added to caregiver burden-difficulty and depressive symptoms ($F = 14.75$, $p < .0001$) with an R^2 of .43. In the presence of caregiver burden-difficulty and depressive symptoms, age made a small improvement in the model explaining caregiver emotional health-related quality of life. Greater caregiver burden-difficulty, more depressive symptoms, and older age explained 43% of the variance in caregiver emotional health-related quality of life.

Table 7

Regressions for Dependent Variable Emotional Health-Related Quality of Life

Variable	R^2	F value	P	β	SE	t	p-value
Age	.10	7.14	.0097	.22	.08	2.67	.0097
Gender	.04	2.75	.103	-5.2 F	3.14	-1.66	.103
				M	not	estimable	
Anxiety	.16	11.03	.0015	-1.26	.38	-3.32	.0015
Depressive Symptoms	.29	24.50	<.0001	-1.39	.28	-4.95	<.0001
Caregiver Burden-difficulty	.30	25.27	<.0001	-0.63	.13	-5.03	<.0001
Caregiver Burden-time	.11	7.35	.0087	-.39	.14	-2.71	.0087
Perceived Control	.14	9.40	.0033	2.54	.83	3.07	.003

Table 8

Stepwise Regression for Dependent Variable Emotional Health-Related Quality of Life

Model	R^2	F value	df	P	β	SE	t	p-value
Step 1								
(Constant)					67.43	3.89	300.3	<.001
Caregiver Burden-difficulty	.296	25.27	1,60	<.0001	-.63	.125	25.27	<.0001
Step 2								
(Constant)					66.06	3.65	327.8	<.0001
Caregiver Burden-Difficulty					-0.43	0.13	10.9	.0017
Depressive Symptoms	.40	19.7	2,59	<.0001	-0.94	0.29	10.23	.002

Table 8 (continued).

Model	R^2	F value	df	P	β	SE	t	p-value
Step 3 (Constant)					56.88	6.18	84.7	<.0001
Caregiver					-0.39	0.13	8.9	.004
Burden-					-0.90	0.29	9.7	.003
Difficulty								
Depressive Symptoms								
Age	.43	14.75	3,58	<.0001	0.13	0.07	3.32	.073

Additional regression models were conducted to test the influence of rest of the significant variables in Hypothesis 1 on emotional health-related quality of life (perceived control, anxiety, caregiver burden-time and patient NYHA class) (Table 9). The combination of anxiety and perceived control was significant (*F* = 8.59, *p* <.001) with an R^2 of 23%. The next combination of perceived control, anxiety and NYHA class was significant (*F* = 4.52, *p* <.01) with R^2 of 29% but the variable NYHA did not reach significance. The third combination included the significant variables of the prior stepwise regression (caregiver burden-difficulty and depressive symptoms) with anxiety and perceived control. NYHA was removed. The third combination was significant (*F* = 10.2, *p* <.001) with an R^2 of .417. This model accounted for 42% of the variance in emotional health-related quality of life. In the presence of perceived control and anxiety, only the variable, caregiver burden-difficulty, was still significant in explaining

Table 9

Regression Models for Dependent Variable Emotional Health-Related Quality of Life

Variable	R^2	F value	P	β	SE	t	p-value
Model 1 Perceived Control Anxiety	.23	8.59	.0005				
(constant)				45.09	3.61	12.50	<.0001
Perceived Control				1.91	.82	2.31	.024
Anxiety				-0.99	.38	-2.62	.011
Model 2 Perceived Control Anxiety NYHA Class	.29	4.52	.0016				
(constant)							
Perceived Control						9.27	.004
Anxiety						6.83	.011
NYHA Class						2.16	.103
Model 3 Caregiver Burden-difficulty Depressive Symptoms Perceived Control	.417	10.2	<.0001				

Variable	R^2	F value	P	β	SE	t	p-value
Anxiety							
(constant)				63.02	5.58	11.29	<.0001
Caregiver Burden-difficulty				-0.42	0.14	-3.05	.0034
Depressive Symptoms				-0.64	0.41	-1.55	.127
Perceived Control				0.71	0.78	.91	.37

emotional health-related quality of life.

Further regressions were conducted to test perceived control and anxiety with caregiver burden-time on emotional health-related quality of life (Table 10). The first combination of all three variables was significant ($F = 6.04$, $p = .001$) with an R^2 of 24% but the variable perceived control did not reach significance. Perceived control was removed in the next step and the combination of anxiety and caregiver burden-time was significant ($F = 8.99$, $p = .000$) with an R^2 of 23%. Hypothesis 1 was partially supported by these data.

Results for hypothesis 2

Hypothesis 2. Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of greater anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty and lower perceived control explain worse physical health-related quality of life.

Hypothesis 2 was partially supported. Individual regressions were conducted with

Table 10

Stepwise Regression for Dependent Variable Emotional Health-Related Quality of Life

Model	R^2	F	df	P	β	SE	t	p-value
Step 1								
(Constant)					63.12	6.80	9.30	.000
Anxiety					-.36	-.357	-3.09	.003
Perceived Control	.24	6.04	3,58	.001	.07	.067	.58	.563
Caregiver burden-time					-.29	.135	-2.47	.016
Step 2								
(Constant)	.16	11.03	1,60	.002	-.394	2.27	-3.32	.002
Anxiety								
Step 3								
(Constant)					-.356	2.20	-3.1	.003
Anxiety								
Caregiver burden-time	.23	8.99	2,59	.000	-.283	0.13	-2.5	.017

age, depressive symptoms, comorbidity, and physical health-related quality of life (Table 11). The regression results showed that age, depressive symptoms, and comorbidity were related to physical health-related quality of life. A stepwise regression was conducted to determine which of these variables or combination of variables had the greatest influence on physical health-related quality of life (Table 12). The independent variable with the largest F value was entered first followed by variables with the next largest F values. Comorbidity was entered in step 1 ($F = 14.44$, $p = .003$, df 1, 60 $F = 4.0$) with R^2 of 19%.

Table 11

Regressions for Dependent Variable Physical Health-Related Quality of Life

Variable	R^2	F value	P	β	SE	t	p-value
Age	.08	5.81	.02	-.21	.09	-2.41	.019
Depressive Symptoms	.096	6.38	.014	-.83	.328	-2.53	.014
Comorbidity	.19	14.44	.0003	-1.89	.496	-3.8	.0003
Gender	.0007	.05	.83	not	estimable		

Table 12

Stepwise Regression for Dependent Variable Physical Health-Related Quality of Life

Model	R^2	F value	df	P	β	SE	t	p-value
1. (Constant)					50.04	1.42	1228	<.0001
Comorbidity	.19	14.44	1,60	.0003	-1.89	.496	14.44	.0003
2. (Constant)					53.62	1.93	772.7	<.0001
Comorbidity					-1.83	.47	14.9	.0003
Depressive Symptoms	.28	11.36	2,59	<.0001	-0.78	.30	6.9	.01
3. (Constant)					65.67	5.21	158.9	<.0001
Comorbidity					-1.55	.47	10.9	.002
Depressive Symptoms					-0.91	.29	9.93	.003
Age	.35	10.27	3,58	<.0001	-0.91	.08	6.12	.02

Depressive symptoms was added to comorbidity in step 2 (F = 11.36, p <.0001) with an R^2 of 28% while age was added to comorbidity and depressive symptoms in step 3 (F =10.27, p <.0001) with an R^2 of 35%. More caregiver comorbidity, greater depressive symptoms, and older age significantly explained 35% of the variance in physical health-related quality of life. Gender was also regressed with physical health-related quality of life and the model was not significant (F =.05, p =.84) nor was either gender in the model (Table 11). Hypothesis 2 was partially supported by the data.

Results for hypothesis 3

Hypothesis 3. Among caregivers of HF patients, demographic factors of older age and female gender, and biological factors of increased anxiety, more depressive symptoms, and more comorbid conditions, patient HF severity (worse NYHA class), greater caregiver burden-time and difficulty explain perceived control.

Hypothesis 3 was partially supported. To test hypothesis 3, the variables that reached significance were tested in regressions (Table 13). Caregiver burden-time and depression were the first set of independent variables that were tested with a R^2 of 22%.The model was significant (F = .27, p = .0007, df 2, 60, $F = 3.15$) as were the two variables. Caregiver burden-difficulty and anxiety were added to caregiver burden-time and depression. The model was significant (F = 4.05, p = .006) but with a lower F and the same R^2 of 22% but none of the variables were significant. Next, NYHA class was added to caregiver burden-time and difficulty, anxiety, and depressive symptoms. This model had a lower F but an R^2 of 8 30%. The model was significant (F = 3.28, p = .006, df 7, 54, $F = 2.17$) but only caregiver burden-time and depressive symptoms were significant in the presence of anxiety, caregiver burden-difficulty, and NYHA class.

Greater caregiver burden-time and more depressive symptoms explained 30% of the variance in perceived control. Hypothesis 3 was partially supported by the data.

Table 13

Regression for Dependent Variable Perceived Control

Variable	R^2	F value	P	β	SE	t	p-value
Model 1							
Caregiver Burden- time	.22	8.27	.0007				
Depressive Symptoms							
(constant)				5.77	.81	7.16	<.0001
Caregiver Burden- time				-.042	.02	-2.11	.040
Depressive Symptoms				-.13	.04	-2.93	.005
Model 2							
Caregiver Burden- time	.22	4.05	.006				
Depressive Symptoms							
Caregiver Burden- difficulty							
Anxiety							
(constant)				5.8	.82	7.05	<.0001
Caregiver Burden-time				-.03	.03	-.12	. 27
Depressive Symptoms				-.11	.07	-1.6	.12
Caregiver Burden- difficulty				-.01	.03	-.38	.71
Anxiety				-.02	.08	-.25	.81

Model 3 Caregiver Burden-time Depressive Symptoms Caregiver Burden- difficulty Anxiety NYHA class	.30	3.28	.006				
(constant) Caregiver Burden-time Depressive Symptoms Caregiver Burden- difficulty Anxiety NYHA class				-	-	-	-

Results for hypothesis 4

Hypothesis 4. Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden-time and difficulty and caregiver emotional health-related quality of life.

Hypothesis 4 was partially supported. To test for mediation, the MacKinnon approach (2002) was utilized, where the result of the regression of the caregiver burden and caregiver emotional health-related quality of life is compared to the regression of caregiver burden with perceived control on emotional health-related quality of life. According to the MacKinnon method, a reduction of the significance of the model when perceived control is present, is considered evidence of the presence of mediation (MacKinnon, Lockwood, Hoffman, West & Sheets, 2002). Caregiver burden-time and caregiver emotional health-related quality of life had been regressed with a significant F of 7.35 (beta = -.385, *p* = .009, R^2 = 11%) (Table14). The regression for perceived control and emotional health-related quality of life resulted in a significant F of 9.40 (beta = 2.53, *p* = .003, *R* = 13.5%). The regression for the combination of caregiver burden-time and perceived control with emotional health-related quality of life resulted in a significant F of 6.52 with a beta of -0.266, (*p* = .003, *R* = 18%). The F and beta were reduced with the presence of perceived control. The caregiver burden-time was not significant (*p* =.07) in the third regression yet perceived control was (*p* = .026) These results suggest that perceived control may have a mediation role.

Regressions were then conducted with caregiver burden-difficulty with emotional health-related quality of life. The regression of caregiver burden-difficulty and emotional health-related quality of life revealed a significant F of 25.27 (beta = -.629, *p* <.0001, R^2 of 30%) (Table 14). The next regression of perceived control and emotional health-related quality of life was also significant (*F* = 9.40, *p* =.003, R^2 =13.5%) as was the final regression combining caregiver burden-difficulty and perceived control with emotional health-related quality of life (*F*= 14.38, beta = -.547, *p* <.001, R^2 = 33%). In this final computation, the F and beta were reduced and caregiver burden-difficulty remained significant while control did not and the R^2 again increased slightly. This set of regressions also suggests that perceived control may have a mediation role.

Results for hypothesis 5

Hypothesis 5. Among caregivers of HF patients, perceived control mediates the relationship between caregiver burden and caregiver physical health-related quality of life.

Hypothesis 5 was not supported. The same methodology was utilized to test for mediation as in Hypothesis 4. Regressions with caregiver burden-time and caregiver burden-difficulty with physical health were conducted followed by regressions with each caregiver burden variable combined with perceived control and physical health-related quality of life (Table 15). The regressions with caregiver burden-time were not significant (F = 1.05, p = .31, R^2 = 1.7%) nor were perceived control and physical health-related quality of life (F = 3.3, p = .074, R^2 = 5.2%) or caregiver burden-time and perceived control (F = 1.72, p = .19, R^2 = 5.5%). These data do not support perceived control as a mediator for caregiver burden and caregiver physical health-related quality of life. Regressions were also computed for caregiver burden-difficulty and physical health-

Table 14

Regressions for Mediation of Perceived Control with Emotional Health-Related Quality of Life

Variable	R^2	F value	P	β	SE	t	p-value
Caregiver Burden-time	.11	7.35	.009	-0.385	.14	-2.71	.009
Perceived Control	.135	9.40	.003	2.535	.83	3.07	.003
Caregiver Burden-time and Perceived Control	.18	6.52	.003	-0.27 1.98	.15 .87	-1.81 2.28	.074 .03
Caregiver Burden-difficulty	.30	25.27	<.0001	-0.63	.125	-5.03	<.0001
Caregiver Burden-difficulty and Perceived Control	.33	14.38	<.0001	-0.55 1.31	.13 .79	-4.11 1.66	.0001 .10

related quality of life. Similar results were noted, none of the regressions were significant and there was no evidence for mediation by perceived control with physical health-related quality of life.

Table 15

Regressions for Mediation of Perceived Control with Physical Health-Related Quality of Life

Variable	R^2	F value	P	β	SE	t	p-value
Caregiver Burden-time	.017	1.05	.30	-0.16	.15	-1.02	.31
Perceived Control	.05	3.30	.07	1.63	.895	1.82	.07
Caregiver Burden-time and Perceived Control	.05	1.72	.19	-0.07 1.48	.16 .96	-0.42 1.54	.67 .13
Caregiver Burden-difficulty	.03	1.76	.19	-0.20	.15	-1.33	.19
Caregiver Burden-Difficulty and Perceived Control	.06	1.89	.16	-0.11 1.37	.16 .97	-0.71 1.41	.48 .16

Summary of Findings

In Chapter 4, the caregiver and care recipient samples were described and data pertaining to each hypothesis were presented. Caregivers were primarily older, white female spouses who were well-educated and retired. The care recipients were about half male and half female, white, older with NYHA class IIIC heart failure for 5 years or less who were taking about 13 medications a day with a Charlson Comorbidity score of three out of possible five. The majority of the caregivers reported no problems with most of the questions on the BSI related to anxiety, or the PHQ-8 related to depressive symptoms. There were about one-third of the caregivers who were moderately to quite nervous or tense. A majority of the caregivers were tired and about one-half were depressed some to over half of the time. With both anxiety and depressive symptoms, there were a small number of caregivers with high scores indicative of clinical illness. The caregivers averaged a low Charlson comorbidity score but again a few had multiple chronic illnesses with high scores.

The caregivers reported lower average burden difficulty and moderate burden time with specific tasks that were the most difficulty and time consuming such as, managing patient mood and symptoms, providing emotional support and seeking information from health care providers. Caregivers reported control over the patient's heart failure. The caregivers also reported few limitations on the SF-12 related to emotional health-related quality of life but less than half reported feeling energetic and a small number of the caregivers were very affected by emotional problems. The caregivers had a substantially lower mean on the SF-12 mental scale than the general population or their age group. They also reported few physical limitations on the SF-12 except climbing stairs but had a lower mean that the general population but a higher mean than their age mates.

Hypothesis Testing

When examining the results of the hypotheses testing, Hypothesis 1 that suggests that emotional health-related quality of life is explained by caregiver factors, patient NYHA class, caregiver burden-time and difficulty and perceived control was partially supported. The caregiver factors of age, anxiety, and depressive symptoms and caregiver burden-time and difficulty and perceived control were the most significant variables in explaining the variance in the emotional health-related quality of life of the caregiver. Caregiver gender, comorbidity, and patient NYHA class were not supported by this data as significant variables that explained emotional health-related quality of life. The data did support the hypothesized relationship of older age, more depressive symptoms, greater caregiver burden-difficulty as explanatory variables of worse emotional health-related quality of life. The data also supported the hypothesized relationship of more anxiety and higher caregiver burden-time as explanatory variables of worse emotional health-related quality of life.

The second hypothesis that postulated caregiver factors, patient NYHA class, caregiver burden-time and difficulty and perceived control explain physical health-related quality of life was partially supported. Although perceived control was significant in some of the regressions, it did not remain so in the final model. Gender, caregiver burden-time and difficulty were not significant variables in explaining caregiver physical health-related quality of life. Only age, depressive symptoms, and comorbidity remained in Model 3, which explained 35% of the variance in caregiver physical health-related quality of life. Hypothesis 2 was partially supported by the data. The data did support the hypothesized relationship of an older caregiver with more depressive symptoms explains caregiver physical health-related quality of life.

The third hypothesis regarding caregiver factors, patient NYHA class and caregiver burden-time and difficulty explaining perceived control was partially supported also. When regressions were completed, only caregiver burden-time and depressive symptoms remained significant and explained 30% of the variance in caregiver perceived control. NYHA class, anxiety, and caregiver burden-difficulty were not significant in the final model.

Hypothesis 4 postulated that perceived control mediates the relationship between caregiver burden-time and difficulty and emotional health-related quality of life. Regressions between caregiver burden-time and difficulty and emotional health-related quality of life with and without perceived control were compared looking for a reduction in the F and the beta. In the regression with caregiver burden-difficulty and perceived control, the model and caregiver burden-difficulty remained significant but control did not. In the regression with caregiver burden-time the model and only perceived control remained a significant variable but caregiver burden-time did not. Even though there was a reduction in the F and the beta indicating a mediation role when perceived control was included, the data need to be interpreted conservatively given the alpha of perceived control.

Hypothesis 5 postulated that perceived control mediates the relationship between caregiver burden-time and difficulty and physical health-related quality of life. Regressions between caregiver burden-time and difficulty and physical health-related quality of life with and without perceived control were compared with the goal of finding a reduction of the F and beta when perceived control was included. None of the regressions were significant so the data did not support perceived control as a mediator between caregiver burden and physical health-related quality of life.

In sum, the data partially support four of the five hypotheses. The variances in the multiple regression models explain a moderate amount of caregiver emotional and physical health-related quality of life. Depressive symptoms appear to play an important and consistent role in the emotional and physical health-related quality of life of the caregiver. Age plays an important role in several of the hypotheses. The data support most of relationships of the hypothesized independent variables and the caregiver outcomes in the conceptual model of caregiving outcomes. The findings are discussed further in Chapter 5 along with the limitations of the study and recommendations for further research.

CHAPTER 5

DISCUSSION

This chapter provides a discussion of the empirical findings, including their support for the conceptual model (Figure 1), their relationship to the prior literature, the limitations of the study, and recommendations for future research.

Discussion of Findings

First briefly examining the sample, the caregivers were primarily older white female spouses who were well-educated and retired with a mean age of 59.7 years. This sample was similar in age, race, and health to caregivers in eight other studies in the HF literature (Bakas et al.,2006; Karmilovich,1994; Dracup and Evangelista et al.,2004; Martensson et al., 2002 ; Scott, 2000; Evangelista et al, 2002; Dew et al., 2004) Some samples had a larger percentage of caregivers who were still working (Scott; Evangelista et al.) and some were less well-educated (Martensson et al.; Karmilovich).

The patients were also primarily older (*M* = 68.97) white retired males, better educated, with better ejection fractions (*M* = 42%) than the patient samples in the HF literature. The patient samples in the HF literature were younger 56, 51 to 60, 61, 62.7 respectively (Evangelista et al., Karmilovich, Martensson et al., Bakas et al) and had lower reported ejection fractions (average of 26%)(Evangelista et al., Martensson et al., Karmilovich) than the current study sample. The lower ejection fraction may be an indicator of worse heart health. Most patient samples including the current study sample were also primarily NYHA class III, when it was reported. The results of the hypotheses testing will be discussed next.

Caregiver health-related quality of life

The primary purpose of the current study was to test a model of caregiver outcomes with caregivers of HF patients. The model (Figure 1) is based on the Bakas Caregving Model developed from prior research with caregivers of stroke patients (Bakas and Burgener, 2002) and Dracup and Moser's work with perceived control (2004). Although some of the model relationships have been tested in a small convenience sample of HF caregivers, this is the first test of this model (Bakas et al., 2006). The model was partially supported by the results of the current study as were many of the most important relationships within the model. It was hypothesized that caregiver factors of age and gender, biological factors of caregiver anxiety, depressive symptoms and comorbidity and the patient factor of worse severity of disease (NYHA class), worse caregiver burden-difficulty and burden-time would explain caregiver health-related quality of life (emotional and physical health). The relationship of caregiver age, depressive symptoms and caregiver burden-difficulty with emotional health-related quality of life was supported with a modest R^2 of .43. Caregiver burden-difficulty explained the largest part of the variance (30%) with depression explaining about 10% and age contributing about 3%. Higher caregiver burden-time and worse anxiety explained 23% of the variance in emotional health-related quality of life.

These results are consistent with prior research with HF caregivers who reported caregiver emotional well-being was related to perceived difficulty with burden (Bakas et al., 2006; Martensson et al., 2002; Bakas & Burgener, 2002; Scott, 2000; Evangelista et al., 2002; Karmilovich, 1994). Scott reported 45% of the caregivers had depression and 89% had mental health scores below their age norm. Martensson and colleagues found that 26% of the mental health variance for the caregiver was due to depression unlike the current study which was lower. This was echoed by Scott with mental health and caregiver esteem accounting for 49% of the variance in caregiver health-related quality of life.

These results are also consistent with the general caregiving literature linking burden with negative emotional health-related quality of life (Nieboer et al.,1998; Wallhagen, 1992; Dew et al., 2004; Rohrbaugh et al., 2002; Moser & Dracup, 2004). The literature comparing caregivers to noncaregivers consistently reported depression with caregiving (Vitaliano, Russo et al., 1996; Pinquart & Sorensen, 2003; Molloy et al., 2005). Dew and colleagues found that caregivers with a history of depressive symptoms were at higher risk of recurrence and greater frequency as a caregiver of a transplant patient (2004). Wallhagen reported the greater the difficulty with caregiving the lower life satisfaction and the greater the depressive symptoms for the caregiver.

The relationship between older age and worse emotional health-related quality of life is also supported by previous research (Martensson et al., 2003; Stolarik et al., 1999; Evangelista et al., 2002; Lalonde & Kasprzyk, 1993; Young & Kahana, 1992). Evangelista et al. reported that the patient's age and gender were associated with the patient's emotional health-related quality of life and that older patients had worse emotional health-related quality of life scores (2002). However, Bakas and colleagues found that younger caregivers had higher burden-difficulty and perceived their emotional health-related quality of life to be worse than older caregivers (2006).

The variables that did not help explain emotional health-related quality of life were gender, NYHA class, comorbidity, and perceived control. Although gender, comorbidity, and perceived control were correlated with emotional health-related quality of life in the Pearson product correlations, the correlations at the .01 level (except age) did not remain significant variables in the regression analyses. First the issue of gender, in previously reviewed research, female caregivers reported feeling more stress or burden and reporting worse emotional health-related quality of life (Yee & Schulz, 2000; Schulz & Williams, 1991). Female spouses also reported greater burden when females and males were compared (Chou, 2000; Bookwala & Schulz, 2000; Pinquart & Sorensen, 2006). In this study, the sample of male caregivers may have been too small or too homogeneous to detect gender differences. It is also possible that the age range was too narrow to have enough variability to detect differences. It may be plausible that because most of the male and female caregivers were retired and their social and work roles were now more similar, that difference by gender was diminished in this sample. A larger, randomized sample more representative of the general population may support the role of gender in the model.

Comorbid conditions were a significant part of Schulz and Beach's CHES publications. Older caregivers with prevalent disease and higher burden who felt stressed by caregiving had higher risk of mortality (1999). Comorbidity did not reach significance with emotional health-related quality of life although it is significant with physical health-related quality of life. This sample of caregivers did have a low mean with comorbidity indicating a healthy sample. Perhaps there was not enough variability in comorbidity to reach significance. Perhaps a different measure may produce results that mirror the prior research and support this variable in the model. Perhaps the significant role for comorbidity is in its relationship with physical health-related quality of life and not emotional health-related quality of life and the model needs to be tailored for each outcome.

NYHA class was intended to act as a proxy for the patient's severity of illness in this study. The literature indicated this was a common practice and that as a patient's severity increased, the caregiver's burden and stress increased thereby influencing the caregiver's emotional health-related quality of life (Martensson et al., 2002; Rohrbaugh et al., 1999; Tennstedt & Schulz, 1999; Schulz & Beach, 1999). NYHA class did not seem to function as expected. It is possible that more variance in NYHA class or a larger sample was required for this variable to be influential. Fifty-three percent of the patients were class III in this sample. In a future study, a larger sample and more patients in all four classes may allow this variable to be more influential.

And finally, perceived control which had a moderate zero-order correlation with emotional health-related quality of life did not help explain emotional health-related quality of life in the regressions in the presence of other variables such as caregiver burden-difficulty. Questions about the validity and reliability of the measure arise especially when a four-item scale is further reduced to a 2-item scale. The scale was effective in prior studies with acceptable Cronbach's alpha of 0.75 to 0.93 (Bakas, et al., 2006; Evangelista et al., 2003; Moser & Dracup, 1995). Further development or expansion of this scale with higher reliability would be warranted.

Issues arise for consideration for future research, such as, the use of a different perceived control measure that had been utilized extensively with caregivers with acceptable reliability and the impact on the results. The use of a larger sample or a ramdomly assigned sample may reveal support for perceived control. The use of a more diverse sample, especially in regard to the percentage of retired caregivers, who may have a different expectation for control in this situation compared to younger caregivers. Since emotional health-related quality of life has a large perceptual component as does burden-difficulty, it seems as though perceived control should have been an important variable in explaining emotional health-related quality of life. Further testing with larger more diverse randomized sample may support the model as hypothesized. Failing further support, substitution of an alternate scale for perceived control may be necessary.

In addition to questions about the function of the variables included in the model, questions arise regarding variables that are not included in the model. The study model explained 43% of the variance in emotional health-related quality of life-related quality of life, but future research may reveal what may account for the rest of the variance. Issues such as caregiver personality, such as hardiness as proposed by Kobasa (1984), optimism, religious beliefs, or other adaptation/appraisal variables as proposed by Lazarus and Folkman (1984) may account for some of the variance. The meaning of the caregiving such as caregiver satisfaction as proposed by family systems proponents may explain some of the variance. Caregiver competence and preparation may account for some of the remaining variance. Social support or caregiver networks have been researched and may account for some of the variance in caregiver emotional health-related quality of life. The model may need to include some of these variables to improve it’s explanatory ability. Further testing would be required to determine if any of these variables improve the model. Turning next to physical health-related quality of life, depression and age again are significant variables.

Thirty-five percent of the variance in physical health-related quality of life was explained by age, depression, and caregiver comorbidity when testing Hypothesis 2. Caregiver comorbidity explained 19% of that variance. The largest percentage of the variance was explained by the caregiver's health history. These results are consistent with the research particularly that of the CHES series that linked disease with risk of mortality. Even caregivers with the lowest level of risk in the CHES series (those with disease indicators, but no disease present) were at greater risk of mortality (Beach & Schulz, 1999). McCann et al. reported caregivers' health worsened over time as a caregiver and even prevented caregivers from continuing or resuming caregiving (2004). Pinquart and Sorensen's meta-analysis reported worse physical health-related quality of life and depression for caregivers when compared to noncaregivers (2003). Other researchers have linked the worsening physical health-related quality of life of the caregiver with increased depressive symptoms (Nieboer et al., 1998). The relationship of depressive symptoms explaining caregiver physical health-related quality of life is supported by many of the comparative studies of caregiver and noncaregivers. Researchers report caregivers are more likely to report anxiety and depression and to use unhealthy coping such as smoking, all of which impact health negatively (Schulz et al., 1997; Burton et al., 1997; Burton et al., 2003).

Even though anxiety, caregiving burden-time and difficulty were inversely related in the correlations to physical health-related quality of life, they did not reach significance in the correlations or play a significant role in explaining the variance in physical health-related quality of life. Perceived control was not significant in the correlations or in explaining physical health-related quality of life nor was gender.

Although the literature that has compared male and female caregivers suggests that female caregivers perform more tasks when caregiving and feel more emotional stress when caregiving and have more negative physical consequences when caregiving, that was not supported by the data in this study. It was most surprising that caregiver burden-time was not explanatory in physical health-related quality of life. Even though the correlation was low and not significant in this study, there was an inverse zero-order relationship as expected.

The literature suggests when comparing caregivers and noncaregivers that strained caregivers report more anxiety, depression and suffer more illness (Schulz et al, 1997). Caregiving status (in this study caregiver burden) accounted for most of the variance in well-being in Pinquart and Sorensen's meta-analysis when comparing caregivers and noncaregivers (2003). A longitudinal study may support this relationship especially if the patient disease worsens and caregiver demands escalate. The relationship between anxiety and physical health-related quality of life was nonsignificant. It may be more relevant to emotional health-related quality of life than physical health-related quality of life. The results indicate that physical and emotional health-related quality of life have different sets of variables that are significant in explaining each with some variables in common. Even though some of the variables were not explanatory in physical health-related quality of life, it was of interest that both age and depressive symptoms were explanatory in both emotional and physical health-related quality of life. It is especially important for testing of interventions or screening of caregivers to note the pervasive influence of depressive symptoms for the caregiver.

Perceived control may have been linked to burden such that if burden was not influential, neither was control. (Burton et al.,1997, 2003). Pinquart and Sorensen's meta-analysis found medium differences between caregivers and noncaregivers for control. Control had a strong direct effect on the health and functioning of 365 men and women (Wallhagen et al., 1994). A comparison of HF caregivers with high control versus those with low control on the outcome of physical health-related quality of life may be supportive of the hypothesized relationship. It may be significant when measured over time as in a longitudinal study. The relationship of perceived control and burden may have suffered as a result of the reliability of the control scale or the relationship may be influenced by more factors than those identified in this study. How long a caregiver has been providing care may bear on perceived control. It may be more pertinent to emotional health-related quality of life in HF caregivers.

The model was successful in accounting for 35% of the variance in physical health-related quality of life, but questions arise about the remaining variance. Questions regarding the tools and variables included in this study arise first, such as, is the Charlson Comorbidity Index the best tool to assess physical health-related quality of life. Further, even though the Charlson and the SF-12 include questions about health and function, perhaps the construct of health and function status explain more than 19% of the variance in physical health-related quality of life when using other tools or using multiple tools. Questions about other variables not included in the model arise also. Perhaps other important variables impact physical health-related quality of life such as personality, family health history, nutrition or activity level. Perhaps objective measures of physical health-related quality of life such as fitness test, cortisol levels in addition to the subjective measures used in this study explain a greater percentage of variance in physical health-related quality of life. Further research could supply answers to these questions, which may include the expansion of the model to include additional variables and/or tailoring of the model variables for physical health-related quality of life. Perceived control is examined next.

In the current study, perceived control had a significant inverse correlation with caregiver anxiety, depressive symptoms, caregiver burden-time and burden-difficulty. These results are consistent with Hypothesis 3. These relationships are supported by the reviewed literature (Schulz et al., 1997; Pinquart & Sorensen, 2003; Evangelista et al., 2003; Moser & Dracup. 1995). But only caregiver depressive symptoms and caregiver burden-time explained perceived control with a small *F* of 3.28. Patients with higher control were less anxious, depressed and had better adjustment (Moser & Dracup, 1995, 2004). These results are consistent with the literature that links lower control with more depression and higher burden (Wallhagen, 1993: Wallhagen & Brod, 1997; Pinquart & Sorensen, 2003).

Age and gender were hypothesized to influence perceived control as supported by the literature but the literature was not consistent about these relationships. Gender has not been a predictive variable in the model in any of the relationship although age has. Comorbidity has only been predictive in caregiver physical health-related quality of life. It is surprising again that caregiver burden did not explain perceived control as it did emotional health-related quality of life. Given the consistent relationship in the literature of burden and negative psychological outcomes, it is surprising that burden did not explain control. Perhaps if the caregivers with higher burden were compared to those with lower burden on perceived control there would be different results. It is also surprising that anxiety did not help explain perceived control given the association in the literature of higher anxiety and burden. Testing of these variables in a longitudinal study with a different scale or this scale with higher alpha may reveal different results. It is also of note, that depressive symptoms were a significant variable as it had been in physical and emotional health-related quality of life-related quality of life.

In Hypothesis 4 and 5, perceived control was also hypothesized as a mediator for caregiver burden-time and difficulty and emotional and physical health-related quality of life. The correlations indicated that perceived control and physical health-related quality of life were not related. There was a modest but significant relationship between perceived control and emotional health-related quality of life and between perceived control and caregiver burden-time and difficulty. In the regressions to test mediation with physical health-related quality of life and caregiver burden, the regressions were not significant so the role of perceived control as a mediator could not be confirmed. On the other hand, there was a suggestion that perceived control may play a mediation role with caregiver burden-difficulty and emotional health-related quality of life and caregiver burden-time and emotional health-related quality of life. Given the lower than expected Cronbach's alpha and the reduction of the perceived control scale to two questions, these results need reported cautiously.

Limitations

Limitations that may influence the outcomes of the study are discussed next. The first two limitations were identified in Chapter 1 and the latter ones were identified during the course of the study. The first two limitations are issues related to generalizability and external validity.

1. Data for the study were obtained from a non-random sample from one site so that the results may not be generalizable beyond caregivers who received care at a multidisciplinary specialized clinic affiliated with a tertiary care hospital and university.

The results can not be generalized to more diverse populations due to the sampling methodology, sample characteristics and site characteristics. Sample selection bias may influence the results and needs to be taken into account when interpreting the results. The caregivers in this study were primarily white, female spouses who were retired and well-educated. The patients were being treated in an urban university-affiliated clinic with specialized practitioners.

2. The study is cross-sectional and does not capture the dynamic nature of the variables.

The cross-sectional design captures caregivers at different points in the caregiving experience and with differing degrees of expertise. An attempt was made to capture the dynamic nature of the variables in the conceptual model. In the current study, some caregivers were providing care at the end of the patient's life and other caregivers were just beginning the process. The cross-sectional design does not permit determination of causality. While longitudinal designs such as the parent study, the FAMOUS-HF study, can capture caregiving over time, this study helps inform and guide subsequent research especially the design and testing of interventions. The next limitation is related to instrument reliability and methodology.

3. The instruments utilized were not developed for heart failure caregiver but were adapted to this population and the 4-item Control Attitude Survey (CAS) used to measure perceived control produced a Cronbach's alpha of .44.

Three instruments with limited application in the caregiver of HF patient population were utilized in the current study. The Brief Symptom Inventory (BSI) has been used in a variety of community populations and in one study of caregivers of HF patients but no Cronbach's alpha was reported in that study (Karmilovich, 1994) so the measure's use in the caregiver of HF patients is limited. The second measure, the Oberst Caregiver Burden Scale (OCBS) has been used with stroke, cardiac surgery caregivers and caregivers of HF patients with Cronbach's alpha of 0.84, 0.91 and 0.92 respectively (Bakas and Burgener, 2002; Stolarik et al., 2000; Bakas et al., 2006). So although the Cronbach alphas that have been reported are quite high, the measure's use in the HF caregiver population is limited. Additional studies with both of these measures in this population would be useful comparisons for the current study results.

The Control Attitude Survey (CAS) was developed with patients with cardiovascular diseases. It has a reported Cronbach's alpha of 0.89 and test-retest reliability of r = 0.62 (Moser & Dracup, 1995, 2000). It has been used in patients with heart failure and their spouses with Cronbach alpha of 0.75, 0.77 and 0.90 respectively (Bakas, et al, 2006;Dracup, Westlake,et al, 2003; Dracup, Evangelista et al, 2004). It is a shorter and relatively new scale that has not been widely used and adapted. Communication with the author indicated a longer version was in development (D. Moser, personal communication, Novermber, 2006). In the current study, the Cronbach's alpha was improved by utilizing only questions 1 and 2 which resulted in an alpha of

0.54. As a result of this lower than expected alpha, results involving perceived control need to be interpreted cautiously. An internal validity issue such as this may threaten external validity and generalizability. The last limitation is related to methodology.

4. The mediation methodology.

The traditional method of evaluating mediation between variables tests four relationships between the independent variable, the mediator, and the dependent variable (Baron and Kenny, 1986). This method has been challenged with alternative methods such as the MacKinnon method or the MacArthur approach that test for mediation by evaluating the indirect effects of the independent variable on the caregiver outcomes through perceived control in regression modeling (MacKinnon, Lockwood, Hoffman, West & Sheets, 2002; Kraemer, Wilson, Fairburn & Agras, 2002). The mediation methodology was selected based on the literature.

Conclusions and Recommendations

The primary purpose of the study was to test a model of caregiver outcomes in the population of caregivers of HF patients. This study confirmed many of the relationships in the proposed model and the data partially supported the model. Specifically, older caregivers with more or more severe depressive symptoms and greater burden-difficulty have worse emotional health-related quality of life. The regression testing of these variables accounted for 43% of the variance in emotional health-related quality of life, the majority of which was explained by greater burden-difficulty. The regression testing also revealed that caregiver anxiety and higher burden-time can explain 23% of the variance in emotional health-related quality of life. Related to this result, the younger caregivers were more anxious and all the caregivers had higher levels of anxiety than noncaregivers and most other caregiver samples. The level of caregiver burden-difficulty was surprisingly high when compared to other studies.

Almost half of the variance in physical health-related quality of life was explained by older age, greater depressive symptoms, and higher comorbidity. Age and greater depressive symptoms were two of the variables that had an important role in the caregiver outcomes of emotional and physical health-related quality of life as well as perceived control. When revising the caregiver model, it would be important to retain these relationships between these variables.

The variance in perceived control was explained by caregiver burden-time and depressive symptoms. It was surprising that burden-difficulty did not influence perceived control given the strong influence it had on the emotional health-related quality of life. It was also hypothesized that perceived control mediated the relationship between caregiver burden and emotional health-related quality of life. Caregivers with greater perceived control would have better emotional health-related quality of life and the regressions indicate that may be accurate. Given the perceptual nature of these variables relationships, it seems perceived control could have a strong role in mediating emotional health-related quality of life. Perceived control did not mediate the relationship between caregiver burden and physical health-related quality of life, hence this part of the model would need to be tested further or revised.

The data partially supported four of the five hypotheses, with the strongest support for the relationships between the independent variables and emotional health-related quality of life and the independent variables and physical health-related quality of life. It may be warranted to revise and tailor the relationships of the model.

Since there is a limited amount of knowledge about caregivers of HF patients, this study contributes theoretically based information to an area in need of answers. Further, since few studies have examined both emotional and physical health-related quality of life in caregivers of HF patients and even fewer that have done so from a theory base that incorporated the role of perceived control, the results of this study are important in advancing our knowledge about caregivers of HF patients. It is important to continue to build a model that can be used by multiple researchers to advance our knowledge about this group of caregivers. This study offers confirmation of some of the relationships of the current model and some insights about the caregivers of HF patients and how they are similar and different than other caregiver populations. Continued study of HF caregivers based on this model will facilitate confirmation of these results, refinement of the model relationships, predictors of caregiver outcomes and creation of interventions to improve outcomes in this growing population of caregivers of HF patients.

For future studies of this model, the most immediate need is a valid and reliable measure for perceived control so that meaningful results can be generated. Refinement of the model with different sets of variables for physical and emotional health-related quality of life and further testing of the revised model would be appropriate. Testing the model in a larger more diverse group of caregivers longitudinally would allow for the measure of perceived control at different time points and the retesting of the model relationships over time. It is also recommended in the caregiving research, the use of valid and reliable measures so that results can be compared and a body of knowledge can be created. The replication of studies with prospective, longitudinal designs and larger more diverse samples is necessary to confirm what has been discovered. The use of diverse samples and age-matched nonspousal caregivers would be another recommendation in future studies. There is a need for prospective longitudinal studies that enroll caregivers at the outset of their caregiving to study the evolution of caregiving and allow a comparison of pre caregiving and post caregiving. Studies of single caregivers compared to families of caregivers are warranted to learn if caregiver outcomes are altered with a group of caregivers. The use of interdisciplinary research teams who can merge their different perspectives for the benefit of the caregiver. It is also recommended that theoretically based caregiver interventions be designed and studied to test their feasible in altering the known negative outcomes of caregiving.

In conclusion, as the number HF patients grow and the number of caregivers taking care of them grows, it is essential to grow our knowledge of this understudied population and create tested interventions to improve their emotional and physical health-related quality of life.

REFERENCES

Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing, 49*(2), 116-124.

American Heart Association (2004). *Heart disease and stroke statistics-2003 update.* Dallas, TX: American Heart Association.

American Heart Association (2005). *Heart disease and stroke statistics-2004 update.* Dallas, TX: American Heart Association. Retrieved January 19, 2005 from http://www.americanheart.org/downloadable/heart/1072969766940HSStats2004Update.pdf

American Heart Association (2006). *Heart disease and stroke statistics 2005 update-at-a-glance.* Dallas, TX: American Heart Association. Retrieved March 15, 2007 from http://www.americanheart.org

American Heart Association (2007). *Heart disease and stroke statistics 2007 update-at-a-glance.* Dallas, TX: American Heart Association. Retrieved May 1, 2007 from http://www.americanheart.org

Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M.(1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*(3), 245-248.

Averill, J. R. (1973). Personal control over aversive stimuli and its relationship to stress. *Psychological Bulletin, 80,* 286-303.

Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., & Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing, 36*(2), 95-106.

Bakas, T., & Burgener, S. C. (2002). Predictors of emotional distress, general health and caregiving outcomes in family caregivers of stroke survivors. *Topics in Stroke Rehabilitation, 9*(1), 34-35.

Bakas, T., & Champion, V. (1999). Development and psychometric testing of the Bakas Caregiving Outcomes Scale. *Nursing Research, 48,* 250-259.

Bakas, T., Champion, V., Perkins, S. M., Farran, C. J., & Williams, L. S. (2006). Psychometric testing of the revised 15-item Bakas caregiving outcome scale. *Nursing Research, 55*(5), 346-355.

Bakas, T., Kroenke, K., Plue, L. D., Perkins, S. M., & Williams, L. S. (2006). Outcomes among family caregivers of aphasic versus nonaphasic stroke survivors. *Rehabilitation Nursing, 31*(1), 33-42.

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.

Barlow, J. H., Macey, S.J., & Struthers, G.R. (1993). Health locus of control, self-help and treatment adherence in relation to ankylosing spondylitis patients. *Patient Education Counseling 20* (2-3), 153-166.

Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging 15*(2), 259-271.

Bennett, S. J., & Sauve, M. J. (2003). Cognitive deficits in patients with heart failure: A review of the literature. *Journal of Cardiovascular Nursing, 18,* 219-242.

Biegel, D. E., Sales, E., & Schulz, R. (1991). *Family caregiving in chronic illness.* Newbury Park, CA: Sage.

Biegel, D. E., & Schulz, R. (1999). Caregiving and caregiver interventions in aging and mental illness. *Family Relations 48,* 345-352.

Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic stress isn't over when it's over. *Psychology and Aging, 9,* 372-380.

Bookwala, J., & Schulz, R. (1998). The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. *Journal of Gerontology: Psychological Sciences, 53*B*,* 155-164.

Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The Caregiver Health Effects Study. *Psychology and Aging, 15*(4), 607-616.

Bosma, H., Van Jaarsveld, C. H. M., Tuinstra, J., Sanderman, R., Ranchor, A. V., Van Eijk, J. Th. M., et al. (2005). Low control beliefs, classical coronary risk factors, and socio-economic differences in heart disease in older persons. *Social Science & Medicine, 60*, 737-745.

Brazier, J. E., Harper, R., & Jones, N. M. B., O'Cathain, A., Thomas, K. J., Usherwood, T., et al. (1992). Validating the SF-36 Health Survey Questionnaire: New outcome measure for primary care. *British Medical Journal, 305*, 160-164.

Breier, A., Albus, M., Pickar, D., Zahn, T. P., & Wolkowitz, O. M. (1987). Controllable and uncontrollable stress in humans: Alterations in mood and neuroendocrine and psychophysiological function. *American Journal of Psychiatry, 144,* 1419-1425.

Brink, D. P., & Wood, M. J. (1998). *Advanced design in nursing research*. Newbury Park: Sage Publications.

Brouwer, W. B. F., van Exel, N. J. A., van de Berg, B., Dinant, H. J., Kiipmanschap, M. A., & van den bos, G. A. M. (2004). Burden of caregiving: Evidence of objective burden, and quality of life impacts on informal caregivers of patients with RA. *Arthritis and Rheumatism, 51*(4), 570-577.

Bull, M. J. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research, 12,* 758-770.

Bull, M. J., Hansen, H.E., & Gross, C. R. (2000a). Predictors of elder and family caregiver satisfaction with discharge planning. *Journal of Cardiovascular Nursing, 14*, 76-87.

Bull, M. J., Hansen, H.E., & Gross, C. R. (2000b). Differences in family caregiver outcomes by their level of involvement in discharge planning. *Applied Nursing Research, 13,* 76-82.

Bull, M. J., Hansen, H.E., & Gross, C. R. (2000c). A professional-patient parternship model of discharge planning with elders hospitalized with heart failure. *Applied Nursing Research 13*, 19-28.

Burgener, S., & Twigg, P. (2002). Relationships among caregiver factors and quality of life in care recipients with irreversible dementia. *Alzheimer Disease & Associated Disorders, 16,* 88-102.

Burton, L. C., Newsom, J. T., Schulz, R., Hirsch, C. H., & German, P. S. (1997). Preventative health behaviors among spousal caregivers. *Preventative Medicine, 26,* 162-169.

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *Gerontologist, 43*(2), 230-241.

Canam, C., & Acorn, S. (1999). Quality of life for family caregivers of people with chronic health problems. *Rehabilitation Nursing, 24,* 192-196.

Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Geronologist, 23,* 597-604.

Carey, P. J., Oberst, M. T., McCubbin, M. A., et al. (1991). Appaisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum, 18,* 1341-1348.

Centers for Disease Control and Prevention. (1998). *National estimates and general information on diabetes in the United States* (DHHS Publication No. 98-1118). Washington, DC: U.S. Government Printing Office.

Chang, B. L. (2004). Internet intervention for community elders process and feasibility. *Western Journal of Nursing Research, 26*(4), 461-466.

Charlson, M. AE., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases, 40*(5), 373-383.

Charlson, M., Szatrowski, T. P., Peterson, J., & Gold, J. (1994). Validation of a combined comorbidity index. *Journal of Clinical Epidemiology, 47*(11), 1245-1251.

Chou, K. (2000). Caregiver burden: a concept analysis. *Journal of Pediatric Nursing, 15(*6), 398-407.

Clark, P. (2002). Effects of individual and family hardiness on caregiver depression and fatigue. *Research in Nursing and Health, 25*, 37-48.

Clark, P. C., & King, K. B. (2003). Comparison of family caregivers: Stroke survivors vs. person with Alzheimer's disease. *Journal of Gerontological Nursing, 29(*2), 45-53.

Cohen, S., Kessler, R. C., & Underwood-Gordon, L. (1997). *Measuring stress: A guide for health and social scientists.* New York, NY: Oxford University Press.

Cossett, S., & Levesque, L. (1993). Caregiving tasks as predictors of mental health of wife caregivers of men with chronic obstructive pulmonary disease. *Research in Nursing and Health, 16*, 251-263.

Cowie, M. R., Mosterd, A., Wood, D. A., Deckers, J. W., Poole-Wilson, P. A., Sutton, G. C., et al. (1997). The epidemiology of heart failure. *European Heart Journal, 18*(2), 208-225.

Coyne, J. C., & Fiske, V. (1992). Couples coping with chronic illness. In T. J. Akamatsu, J. C. Crowther, S. C., & Hobfoll, M. A. P. Stevens (Eds.). *Family health psychology 129-149.* Washington, DC: Hemisphere.

Coyle, J. C., & Smith, D. A. (1991). Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *Journal of Personality and Social Psychology, 61,* 404-412.

Degner, L. F., & Sloan, J. A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology, 45*(9), 941-950.

de Groot, V., Beckerman, H., Lankhorst, G. J., & Bouter, L. M. (2003). How to measure comorbidity. A critical review of available methods. *Journal of Clinical Epidemiology, 56*(3), 221-229.

Derogatis, L. R. (1975). *Brief symptom inventory.* Baltimore, Clinical Psychometric Research.

Derogatis, L. R. (1982). Self report measures of stress, in Goldberger, L., & Breznitz, S. (eds). *Handbook of stress*. New York, Free Press.

Derogatis, L. R., & Melisaratos, N. (1983). The brief symptom inventory: an introductory report. *Psychological Medicine, 13,* 595-605.

Derogatis, L. R. (1993). *BSI, Brief Symptom Inventory: Administration, scoring and procedure manual.* Minneapolis: National Computer Systems.

Dew, M. A., Myaskovsky, L., Dimartini, A.F., Switzer, G.E., Schulberg, H.C., & Kormos, R.L. (2004). Onset, timing and risk for depression and anxiety in family caregivers to heart transplant recipients. *Psychological Medicine, 34*, 1065-1082.

Dew, M. A., Switzer, G.E., Goycoolea, J. M., Allen, A. S., DiMartini, A., Kormos, R. I., et al. (1997). Does transplantation produce quality of life benefits? A quantitative analysis of the literature. *Transplantation, 64,* 1261-1273.

Diez-Quevedo, C., Rangil, T., Sanchez-Planell, L., Kroenke, K., & Spitzer, R. (2001). Validation and utility of patient health questionnaire in diagnosing mental disorders in 1003 general hospital Spanish inpatients. *Psychosomatic Medicine, 63,* 679-686.

Donaldson, C., Tarrier, N., & Burns, A. (1998). Determinants of carer stress in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 13*, 248-256.

Dracup, K., Evangelista, L. S., Doering, L., Tullman, D., Moser, D. K., & Hamilton, M. (2004). Emotional well-being in spouses of patients with advanced heart failure. *Heart & Lung, 33,* 354-361.

Dracup, K., Westlake, C., Erickson, V. S., Doering, L. V., Moser, D. K., & Hamilton, M. A. (2003). Perceived control reduces emotional distress in patients with heart failure. *Journal of Heart and Lung Transplantation, 22,* 90-93.

du Fort, G. G., Kovess, V., & Boiven, J. F. (1994). Spouse similarity for psychological distress and well-being: A population study. *Psychological Medicine, 24,* 431-447.

Endler, N. S., Kocovski, N. L., & Macrodimitris, S. D. (2000). Coding efficacy, and Perceived control in acute vs. chronic illnesses. *Personality and Individual Differences, 30*, 617-625.

Endler, N. S., Kocovski, N. L., & Macrodimitris, S. D. (2001). Coping, efficacy, and perceived control in acute vs. chonic illness. *Personality and Individual Differences, 30,* 617-625.

Epel, E., Blackburn, E., Lin, J., Dhabhar, F., Adler, N., Morrow, J., et al. (2004). Accelerated telomere shortening in response to life stress. *Proceedings of the National Academy of Sciences, 101*(49), 17312-17315.

Evangelista, L.S., Dracup, K., Doering, L., Westlake, C., Fonarow, G.C., & Hamilton, M. (2002). Emotional well-being of heart failure patients and their caregivers. *Journal of Cardiac Failure, 8*(5), 300-305.

Evangelista, L. S., Moser, D. K., Dracup, K., Doering, L., & Kobashigawa, J. (2003). Functional status and perceived control influence quality of life in female heart transplant recipients. *Journal of Heart and Lung Transplantation, 23*(3), 360-367.

Everson. S. A., Lynch, J. W., Chesney, M. A., Kaplan, G. A., Goldberg, D. E., Shade, S. B., et al. (1997). Interaction of work place demands and cardiovascular reactivity in progression of carotid atherosclerosis: population based study. *British Medical Journal, 314*, 553-558.

Extermann, M., Overcash, J., Lyman, G. H., Parr, J., & Balducci, L. (1998). Comorbidity and functional status are independent in older cancer patients. *Journal of Clinical Oncology, 16*(4), 1582-1587.

Faira, S. (1998a). Through the eyes of a family caregiver: perceived problems. *Home Care Provider, 3*, 221-225.

Faira, S. (1998b). Through the eyes of a family caregiver: strategies to manage caregiver problems. *Home Care Provider, 3*, 271-275.

Faris, R., Purcell, H., Henein, M. Y., & Coats, A. J. S. (2002). Clinical depression is common and significantly associated with reduced survival in patients with non-ischaemic heart failure. *European Journal of Heart Failure 4,* 541-551.

Farran, C. J. (2001). Family caregiver intervention research: Where have we been? Where are we going? *Journal of Gerontological Nursing, 27*(7), 38-45.

Farran, C. J., Loukissa, D., Perraud, S., & Paun, O. (2004). Alzheimer's disease caregiving information and skills. Part II family caregiver issues and concerns. *Research in Nursing and Health, 27*, 40-51.

Fiske, S. T., & Taylor, S.E. (1991). *Social cognition.* New York: McGraw-Hill.

Fedewa, M. M. , & Oberst, M. T. (1996). Family caregiving in a pediatric renal transplant population. *Pediatric Nursing, 22(*5), 402-410.

Folkman, S. (1984). Personal control and stress and coping processes: a theoretical analysis. *Journal Personality and Social Psychology, 40*, 839-852.

Freedland, K. E., Rich, M. W., Skala, J. A., Carney, R. M., Davila-Roman, V.G., & Jaffe, A. S. (2003). Prevalence of depression in hospitalized patients with congestive heart failure. *Psychosomatic Medicine, 65,* 119-128.

Freedland, K. E., & Carney, R. M. (2000). Psychological considerations in elderly patients with heart failure. *Clinics in Geriatric Medicine, 16*(3), 649-661.

Friedland, R.B. (2004). Caregivers and long-term care needs in the 21st century: Will public policy meet the challenge? Washington DC, USA: Georgetown University, Center on an Aging Society at the Health Policy Institute.

Fuller-Jonap, F., & Haley, W. W. (1995). Mental and physical health of male caregivers of a spouse with Alzheimer's disease. *Journal of Aging and Health, 7*, 99-118.

Gallant, M. P., & Connell, C. M. (1997). Predictors of decreased self-care among spouse caregivers of older adults with dementing illness. *Journal of Aging and Health, 9*, 373-395.

Gandek, B., Ware, J. E., Aaronson, N. K., & Apolone, G. (1998). Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: International quality of life assessment. *Journal of Clinical Epidemiology, 51*(11), 1171-1178.

Gaynor, S. (1990). The long haul: The effects of home care on caregivers. *Journal of Nursing Scholarship, 22,* 208-212.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented elders. *The Gerontologist, 26,* 253-259.

Given, C. W., Given, B., Strommel, M., Collins, C., King, S., & Franklin, S. (1992). Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health, 15,* 271-283.

Given, C., Strommel, M., Given, M., Osuch, J., Kurtz, M., & Kurtz, J. (1993). The influence of cancer patients, symptoms, and functional states on patients, depression, and family caregivers' reaction and depression. *Health Psychology, 12*, 277-285.

Greenberg, J. S., Boyd, M. D., & Hale, J. F. (1992). *The Caregiver's guide: For caregivers and the elderly.* Chicago: Nelson-Hall.

Greenwood, D. C., Muir, K. R., Packham, C. J., & Madeley, R. J. (1996). Coronary heart disease: a review of the role of psychosocial stress and social support. *Journal of Public Health Medicine, 18*(2), 221-231.

Haley, W.E., Roth, D.I., Coleton, M.I., Ford, G.R., West, C.A.C., Collins, R. P., et al. (1996). Appraisal, coping and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology, 64,* 121-129.

Haley, W. E. (2003). The costs of family caregiving: implications for geriatric oncology. *Critical Reviews in Oncology/Hematology, 48,* 151-158.

Halm, M. A. (2005). Caregiver burden and its relationship to health-related quality of life of spouses of coronary artery bypass patients. *Doctoral dissertation, University of Minnesota.* (UMI No. 3167683).

Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke. Review and analysis. *Stroke, 30,* 1478-1485.

Harter, S. (1978). Effectance motivation reconsidered: Toward a developmental model. *Human Development,* 21, (1), 34-64.

He, W., Sengupta, M., Velkoff, V.A., & DeBarros, K. A. (2005). *65+ in the United States.* Washington, DC: U.S. Government Printing Office. (U.S. Census Bureau, Current population reports, P23-209)

Heckhausen, J., & Schulz, R.(1995). A life-span theory of control. *Psychological Review, 102,* 284-304.

Intrieri, R. C., & Rapp, S. R. (1994). Self-control skillfulness and caregiver burden among help-seeking elders. *Journal of Gerontology, 49*(1), 19-23.

Jenkinson, C., Wright, L., & Coulter, A. (1994). Criterion validity and reliability of the SF-36 in a population sample. *Quality of Life Research, 3*(1), 7-12.

Juenger, J., Schellberg, D., Kraemer, S., Haunstetter, A., Zugck, C., Herzog, W., et al. (2002). Health related quality of life in patients with congestive heart failure: Comparison with other chronic diseases and relation to functional variables. *Heart, 87*, 235-241.

Kane, R, Klein, S., Bernstein, L., Rothenberg, R., & Wales, J.(1985). Hospice's role in alleviating the emotional stress of terminal patients and their families. *Medical Care, 23* (3), 189-197.

Karmilovich, S. E. (1994). Burden and stress associated with spousal caregiving for individuals with heart failure. *Progress in Cardiovascular Nursing, 9(*1), 33-38.

Katz, J. N., Chang, L. C., Sangha, O., Fossel, A. H., Bates, D. W. (1996). Can comorbidity be measures by questionnaire rather than medical record review? *Medical Care, 34(*1), 73-84.

Kessler, R.C., McGonagle, K. A., Zhao, S., Nelson, C. B., Hughes, M., Eshlemen, S. et al. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. *Archives of General Psychiatry, 51*, 8-19.

Kessler, R. C., McGonagle, K. A., Nelson, C. B., Hughes, M., Swartz, M., & Blazer, D. G. (1994). Sex and depression in the National Comorbidity Survey II: Cohort affects. *Journal of Affective Disorders, 30,* 15-26.

Kiecolt-Glaser, G. K., Glaser, R., Dyer, C., Shuttleworth, E., Ogocki, P., & Speicher, C.E. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosomatic Medicine, 49,* 523-535.

Kim, C., Kabeto, M.S., Wallace, R. B., & Langa, K. (2004). Quality of preventative clinical services among caregivers in the Health and Retirement Study. *Journal of General Internal Medicine, 19,* 875-878.

Kinney, J. M., Stephens, M. P., Franks, M. M., & Norris, V. K. (1995). Stress and satisfaction of family caregivers to older stroke patients. *Journal of Applied Gerontology, 14*, 3-21.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist, 37,* 218-232.

Kraemer H.C., & Kiernan, M. (2006, March). *Moderators and mediators: Comparing the Baron and Kenny and MacArthur approaches.* Master lecture presented at the 27th Annual Meeting of the Society of Behavioral Medicine, San Francisco, CA .

Kraemer, H.C., Wilson, T. G., Fairburn, C.G., McPhil, D.M., Psych, F.R.C., & Agras, W.S. (2002). Mediators and moderators of treatment effects in randomized clinical trials. *Archives of General Psychiatry, 59*, 877-883.

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9, validity of a brief depression severity measure. *Journal of General Internal Medicine, 16,* 606-613.

Kroenke, K., & Spitzer, R. L. (2002). The PHQ-9: A new depression diagnostic and severity measure. *Psychiatric Annals 32*(9), 1-7.

Kuzuya, M., Masuda, Y., Hirakawa, Y., Iwata, M., Enoki, H., & Hasegawa, J. et al. (2006). Falls of the elderly are associated with burden of caregivers in the community. *International Journal of Geriatric Psychiatry, 21* (8), 740-745.

Lalonde, B., & Kasprzyk, D. (1993). Correlates of caregiver strain in home health care. *Home Health Care Services Quarterly, 14*, 97-110.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology, 44*, 61-71.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer.

Leavitt, M. J., Clark, M. C., Rotton, J., & Finley, G.E. (1987). Social support, perceived control and well-being: a study of an environmentally stressed population. *International Journal of Aging and Human Development, 25*(4), 247-58.

Lefcourt, H. M., Hogg, E., Struthers, S., & Holmes. C. (1975). Casual attributions as a function of locus of control, initial confidence, and performance outcomes. *Journal of Personality & Social Psychology, 32(*3), 391-397.

Librero, J., Peiro, S., & Ordinana, R. (1996). Chronic comorbidity and outcomes of hospital care: Length of stay, mortality, and readmission at 30 and 365 days. *Journal of Clinical Epidemiology, 52,* 171-179.

Lim, J., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes, 2*(1), 50-59.

Liu, M., Domen, K., & Chino, N. (1997). Comorbidity measures for stroke outcome research: A preliminary study. *Archives of Physical Medicine & Rehabilitation, 78*(2), 166-172.

Luttik, M. L., Jaarsma, T., Moser, D., & Sanderman, R. P. D. (2005). The importance and impact of social support on outcomes in patients with heart failure: An overview. *Journal of Cardiovascular Nursing, 20*(3), 162-167.

Luttik, M. L., Jaarsma, T., Veeger, N. J. G. M., & van Veldhuisen, D.J. (2005). For better and for worse: Quality of life impaired HF patients as well as in their partners. *European Journal of Cardiovascular Nursing, 4,* 11-14.

Lyons, B. (1988, December). *Diagnostic reasoning: Coming of age.* Paper presented at The 5th INDA Conference.

MacKinnon, D. P., Lockwood, C. M., Hoffman, J. M., West, S. G., & Sheets, V. A. (2002). Comparison of methods to test mediation and other intervening variable effects. *Psychoogical Methods, 7*, 83-104.

Mahoney, J. S. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart Lung, 30(*6), 429-436.

Marshal, P.S., & Boughsty, T. (1981). Social/psychological problems in an energy-impacted community. In J.A. Davenport and J. Davenport's (Eds.), *Proceedings of the first international symposium on the human side of energy* (pp. 55-66). University of Wyoming: Laramie, Wyoming.

Martensson, J., Dracup, K., Canary, C., & Fridlund, B. (2003). Living with heart failure: Depression and quality of life in patients and spouses. *Journal of Heart Transplantation, 22(*4), 460-467.

Martin, A., Rief, W., Klaiberg, A., & Braehler, E. (2006). Validity of the brief patient health questionnaire mood scale (PHQ-9) in the general population. *General Hospital Psychiatry, 28,* 71-77.

McCann, J. J., Hebert, L. E., Bienias, J. L., Morris, M. C., & Evans, D. A. (2004). Predictors of beginning and ending caregiving during a 3-year period in a biracial community population of older adults. *American Journal of Public Health, 94(10)* 1800-1806.

McHorney, C. A., Ware, J. E., Lu, J. F., & Sherbourne, C. D. (1994). The MOS 36-item Short Form Health Survey (SF-36)III: Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care, 32*(1), 40-66.

Medical Outcomes Trust. (1994). *How to score the SF-36 health survey.* Boston: Medical Outcomes Trust.

MetLife Juggling Act Study, (1999). Balancing caregiving with work and costs involved. Mature Market Institute, Metropolitan Life Insurance Company: Westport CT.

Miller, S. M. (1979). Controllability and human stress: method, evidence, and theory. *Behavior Research and Therapy, 17*, 287-304.

Miller, B., McFall, R.T., & Campbell, J., (1994). Changes in sources of community long-term care among African American and white frail older persons. *Journal of Gerontology: Social Sciences 49*, S14-S24.

Molloy, G. J., Johnston, D. W., Johnston, M., Morrison, V., Pollard, B., Bonetti, D., et al. (2005). Extending the demand-control model to informal caregiving. *Journal of Psychosomatic Research, 58,* 243-251.

Molloy, G. J., Johnston, D. W., & Witham, M. D.(2005). Family caregiving and congestive heart failure. Review and analysis. *The European Journal of Heart Failure, 7,* 592-603.

Monk, A., & Cox, C. (1991). *Home care for the elderly: An international perspective.* New York: Greenwood Publishing Group.

Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations, 34,* 19-36.

Moore, S. M. (1994). Psychologic distress of patients and their spouses after coronary artery bypass surgery. *AACN Clinical Issues, 5,* 59-65.

Moser, D. K., & Dracup, K. (2004). Role of spousal anxiety and depression in patients' psychosocial recovery after a cardiac event. *Psychosomatic Medicine, 66(4),* 527-532.

Moser, D. K., & Dracup, K. (2000). Impact of cardiopulmonary resuscitation training on perceived control in spouses of recovering cardiac patients. *Research in Nursing & Health, 23,* 270-278.

Moser, D. K., & Dracup, K. (1995). Psychosocial recovery from a cardiac event: The influence of perceived control. *Heart Lung, 24,* 273-280.

Moser, D. K., Dracup, K., & Doering, L. V. (1998). Emotional distress after cardiac events is worse among spouses than patients. *Circulation, 98*, 323.

Moser, D. K., & Worster, P. L. (2000). Effect of psychosocial factors on physiologic outcomes in patients with heart failure. *Journal of Cardiovascular Nursing, 14(4),* 106-115.

National Alliance on Caregiving and the American Association for Retired Persons. (2004). Caregiving in the U.S.: 2004 Final Report. Retrieved January 29, 2005 from http://www.caregiving.org/04finalreport.pdf

National Alliance for Caregiving and the American Association for Retired Persons. (1997). *Family caregiving in the U.S.: Findings from a national survey, Final report.* Bethesda, MD: National Alliance for Caregiving.

Naylor, M. D. (2000). A decade of transitional care research with vulnerable elders. *Journal of Cardiovascular Nursing, 14(3), 1-14.*

Nieboer, A. P., Schulz, R., Matthews, K. A., Scheier, M. F., Ormel, I., & Lindenberg, S. M. (1998). Spousal caregivers' activity restriction and depression: a model for changes over time. *Social Science and Medicine, 47,* 1361-1371.

Nolan, M., & Nolan, J. (1998). Cardiac rehabilitation following myocardial infarction. *British Journal of Nursing, 7(4),* 219-225.

Nunnally, J.C., & Bernstein, I.H. (1994). *Psychometric theory (3rd ed.).* New York: McGraw-Hill.

Oberst, M. T., Thomas, S. E., Gass, K. A., & Ward, S. E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing, 12,* 209-215.

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *The Gerontologist, 39*, 177-185.

Partridge, C., & Johnson, M. (1989). Perceived control of recovery from physical disability, measurement and prediction. *British Journal of Clinical Psychology, 28,* 53-59.

Pearlin, L. L., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-594.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19,* 2-21.

Peterson, R.L., Hodge, E.A., Kafer, L. G., Matthews, S. R., Pfeife, H. H., & Van Heuse, C. L. (1981). A group counseling emphasis at a university counseling service. *Psychotherapy Theory and Practice, 18,* 525-536.

Pinquart, M., & Duberstein, P. (2006). Optimism, pessimism, and depressive symptoms in spouses of lung cancer patients. *Psychology and Health, 20*(5), 565-578.

Pinquart, M., & Sorensen, S. (2003). Predictors of caregiving burden and depressive mood: a meta-analysis. *Journal of Gerontology: Psychological Sciences, 58B,* 112-128.

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *Journal of Gerontology: Psychological Sciences, 61(*1), 33-45.

Premen, A. J. (1996). Research recommendations for cardiovascular aging research. *Journal of the American Geriatrics Society, 44*(9)*,* 1114-1117.

Rahman, O., Strauss, J., Gertler, P., Ashley, D., & Fox, K. (1994). Gender differences in adult health: an international comparison. *Gerontologist, 34,* 463-469.

Rankin, S. (1988). *Gender, age, and caregiving as mediators of cardiovascular illness and recovery.* Unpublished doctoral dissertation, University of California, San Francisco.

Remme, W. J. (2001). Guidelines for the diagnosis and treatment of chronic heart failure. *European Heart Journal, 22(17),* 1527-1560.

Riegel, B., Moser, D. K., Glaser, D., Carlson, B., Deaton, C., Armola, R., et al. (2002). The Minnestota Living with Heart Failure Questionnaire: Sensitivity to differences and responsiveness to intervention intensity in a clinical population. *Nursing Research, 51*(4)*,* 209-218.

Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., et al. (2005). Predictors of high level of burden and stress in caregivers of demented patients: Results of an Italian multicenter study. *International Journal of Geriatric Psychiatry, 20(*2), 168-174.

Robinson, B. C. (1983). Validation of caregiver strain index. *Journal of Gerontology, 38,* 344-348.

Robinson, K. M. (1990). Predictors of burden among wife caregivers. *Scholarly Inquiry for Nursing Practice, 4(*3), 189-203.

Rochon, P.a., Katz, J. N., Morrow, L.A., McGlinchey-Berroth, R, Ahlquist, M.M., Sarkarati, M. et al. (1996). Comorbid illness is associated with survival and length of hospital stay in patients with chronic disability. *Medical Care, 34,* 1093-1101.

Rodin, J., Timko, C., & Harris, S. (1985). The construct of control: biological and psychosocial correlates, in *Annual Review of Gerontology and Geriatrics,* Vol.5, Eisdorfer, C. (ed.), New York: Springer Publishing.

Rohrbaugh, M.J., Cranford, J.A., Shoham, V., Nicklas, J.M., Sonnega, J.S., & Coyne, J.C. (2002). Couples coping with congestive heart failure: role and gender Differences in psychological distress. *Journal of Family Psychology, 16*(1), 3-13.

Ross, C. E., Sastry, J. (1999). The sense of personal control: Social-Structure causes and emotional consequences, in C. S. Aneshensel, & J. C. Phelan (Eds.), *Handbook of the Sociology of Mental Health*, (pp. 369-394). Springer US.

Rothbaum, F., Weisz, J., & Snyder, S. (1982). Changing the world and changing the self: A two process model perceived control. *Journal of Personality and Social Psychology, 42*, 5-37.

Russo, J., Vitaliano, P. P., Brewer, D., Katon, W., & Becker, J. (1995). Psychiatric disorders in spouse caregivers of care recipients with Alzheimer's disease and matched controls: a diathesis-stress model of psychopathology. *Journal of Abnormal Psychology, 104,* 197-204.

Sale, E. (2003). Family burden and quality of life. *Quality of Life Research, 12(1),* 33-41.

Saunders, M. M. (2003). Family caregivers need support with heart failure patients. *Holistic Nursing Practice, 17(*3), 136-142.

Shega, J. W., Hougham, G.W., Stocking, C.B., Cox-Haley, D,.& Sach, G.A. (2005). Factors associated with self- and caregiver report of pain among community-dwelling persons with dementia. *Journal of Palliative Medicine, 8*(3), 567-575.

Schipper, H. (1990). Guidelines and caveats for quality of life measurement in clinical practice and research. *Oncology, 4(*5), 51-57.

Schoenfeld, D.A. (2007). Statistical considerations for clinical trials and scientific experiments. Retrieved January 05, 2007 from http;//hedwig.mgh.hardvard.edu/ sample_size/size.html

Schott-Baer, D. (1989). *Family culture, family resources, dependent care, caregiver burden, and self-care agency in spouses of cancer patients.* Unpublished doctoral dissertation, Wayne State University, Detroit, Michigan.

Schulz, R. (2001). Some critical issues in caregiver intervention research. *Aging & Health, 5* (Supplement 1), 112-115.

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association, 282(*23), 2215-2219.

Schulz, R., Newsom, J., Mittlemark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: The Caregiver Health Effects Study: An ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine, 19,* 110-116.

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35,* 771-791.

Schulz, R., Beach, S. R., Ives, D.G., Martire, L. M., Ariyo, A. A., & Kop, W. J. (2000). Association between depression and mortality in older adults. *Archives of Internal Medicine, 160,* 1761-1768.

Schulz, R., Visintainer, P., & Williamson, G. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology: Psychological Sciences, 45,* 181-191.

Schulz, R., & Williamson, G. M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6,* 569-578.

Schwarz, K. A., & Dunphy, G. (2003). An examination of perceived stress in family caregivers of older adults with heart failure. *Experimental Aging Research, 29,* 221-235.

Schwarz, K. A., & Elman, C. S. (2003). Identification of factors predictive of hospital readmissions for patients with heart failure. *Heart & Lung, 32(*2), 88-99.

Scott, L. (2000). Caregiving and care receiving among a technologically dependent heart failure program. *Advances in Nursing Science, 23,* 82-97.

Seeman, M., & Lewis, S. (1995). Powerlessness, health and mortality: A longitudinal study of older men and mature women. *Social Science & Medicine, 41(*4), 517-525.

Sistler, A. B., & Blanchard-Fields, F. (1993). Being in control: A note on differences between caregiving and noncaregiving spouses. *Journal of Psychology, 127,* 537-542.

Skinner, E. A. (1996). A guide to constructs of control. *Journal of Personality and Social Psychology, 71,* 549-570.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42, 356-372.*

Spitzer, R. L., Williams, J. B. W., & Kroenke, K. (2000). Validity and utility of the Patient Health Questionnaire in the assessment on 3000 obstetric-gynecologic patients: The PRIME-MD Patient Health Questionnaire obstetrics-gynecology study. *American Journal of Obstetrics and Gynecology, 183,* 759-769.

Stetz, K. M. (1989). The relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. *Scholarly Inquiry for Nursing Practice, 3,* 133-153.

Stewart, S., MacIntyre K., Hole, D. J., Capewell, S., & McMurray, J. J. (2001). More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European Journal* of *Heart Failure, 3*(3), 315-322.

Stolarik, A.,Lindsay, P., Sherrard, H., & Woodend, K. (2000). Determination of the burden of care in families of cardiac surgery patients. *Progress in Cardiovascular Nursing, Winter 2000*, 4-10.

Szabo, V., & Strang, V. R. (1997). Secondary analysis of qualitative data. *Advances in Nursing Science, 20(*2), 66-74.

Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics* (3rd ed.). New York: Harper Collins College Publishers.

Tennstedt, S. L., McKinlay, J. B., & Sullivan, L. M. (1988). *Informal care for frail elders: the role of secondary characteristics.* Paper presented at the annual scientific meeting of the Gerontological Society of America, San Francisco.

Thompson, S. C. (1981). Will it hurt less if I can control it? A complex answer to a simple question. *Psychological Bulletin, 90(*1), 89-101.

U. S. Senate Special Committee on Aging. (1991). *Aging America: Trends and Projections (1990-1991 Edition).* Washington D. C. Government printing office.

van Exel, N. J. A., Koopmanschap, M. A., van den Berg, B., Brouwer, W. B. F., & van den Bos, G. A. M. (2005). Burden of informal caregiving for stroke patients. *Cerebovascular Diseases 19,* 11-17.

Vitaliano, P. P. (1997). Physiological and physical concomitants of caregiving: introduction to a special issue. *Annals of Behavioral Medicine, 19*, 75-77.

Vitaliano, P. P., Russo, J., Scanlon, J. M., & Greeno, C. G. (1996). Weight changes in caregivers of Alzheimer's care recipients: psychobehavioral predictors. *Psychology and Aging, 11,*155-163.

Vitaliano, P. P., Russo, J., Young, H. M., Teri, L., & Maiuro, R. D. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's Disease. *Psychology and Aging, 6,* 392-402.

Vitaliano, P. P., Scanlon, J. M., Zhang, J., Savage, M. V., Hirsch, J. B., & Siegler, C. (2002). A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic Medicine, 64,* 418-435.

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129(*6), 946-972.

Wallhagen, M. I. (1992-1993). Perceived control and adaptation in elder caregivers: development of an explanatory model. *International Journal of Aging and Human Development, 36,* 219-237.

Wallhagen, M. I. (1992). Caregiving demands: Their difficulty and effects on the well-being of elderly caregivers. *Scholarly Inquiry for Nursing Practice: An International Journal, 6*(2), 111-127.

Wallhagen, M. I., & Brod, M. (1997). Perceived control and well-being in Parkinson's disease. *Western Journal of Nursing Research, 19(*1), 11-31.

Wallhagen, M. I., Strawbridge, W. J., Kaplan, G. A., & Cohen, R. D. (1994). Impact of internal health locus of control on health outcomes for older men and women: a longitudinal perspective. *The Gerontologist, 34(*3), 299-306.

Ware, J. E., Kosinski, M., & Keller, S. D. (1995). *SF-12: How to score the SF-12 Physical and Mental Health Summary Scales*. Boston, MA: The Health Institute, New England Medical Center.

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey. *Medical Care, 34,* 220-233.

Ware, J. E. (2004). SF-36 Health Survey Update. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment (3rd ed.).* (pp. 693-718). Mahwah NJ: Lawrence Erlbaum Associates.

Weller, E. (2002). Early childhood risk factors differentiated juvenile onset from adult onset major depressive disorder. *Evidence-Based Mental Health*, *5*(4),125.

White, R.W. (1959). Motivation reconsidered: the concept of competence. *Psychological Review, 66* (5), 297-331.

Williamson, G. M., & Shaffer, D. R. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now.The family relationships in late life project. *Psychology and Aging, 61,* 217-226.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among caregivers: A review and analysis. *The Gerontologist, 40(*2), 147-164.

Young, R. F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *Gerontologist, 29,* 660-666.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist, 20,* 649-655.

Appendix A: Instruments

Brief Symptom Inventory – Anxiety Subscale

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes how much the problem has distressed or bothered you recently, including today. Circle only one number for each problem. Your responses will remain completely confidential.

How much were you distressed by:	**Not at All**	**A Little Bit**	**Moder-ately**	**Quite a bit**	**Extre-mely**
1.Nervousness or shakiness inside	0	1	2	3	4
2. Suddenly scared for no reason	0	1	2	3	4
3.Feeling fearful	0	1	2	3	4
4. Feeling tense or keyed up	0	1	2	3	4
5. Spells of terror or panic	0	1	2	3	4
6. Feeling so restless you couldn't sit still	0	1	2	3	4

PHQ-8 for Depressive Symptoms

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 being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

TOTAL SCORE ___________

If equal to or greater than 15, advise participant to contact their physician that they are having some symptoms of sadness that the physician may want to discuss.

Control Attitudes Scale

Instructions: Please read each statement, taking your time to think about what each statement says. Then 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. Please respond to every statement.

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

OBERST CAREGIVING BURDEN SCALE

This group of questions is about the tasks and activities that you do to help the patient at home. For each of the following activities, please mark how much **time you spend** and **how difficult** each activity is for you to do.

1. Medical or nursing treatments (giving medications, skin care, dressings, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

2. Personal care (bathing, toileting, getting dressed, feeding, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

3. Managing dietary needs of the patient (planning and cooking meals, monitoring salt intake, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

4. Assistance with walking, getting in and out of bed, exercises, etc.:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

5. Emotional support, “being there” for the patient:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

6. Watching for and reporting the patient’s symptoms, watching how the patient is doing, monitoring the patient’s progress:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

7. Providing transportation or “company” (driving, riding along with patient, going to appointments, driving patient around for errands, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

8. Managing finances, bills, and forms related to the patient’s illness:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

9. Additional household tasks for the patient (laundry, cooking, cleaning, yard work, home repairs, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

10. Additional tasks outside the home for the patient (shopping for food and clothes, going to the bank, running errands, etc.):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

11. Structuring/planning activities for the patient (recreation, rest, meals, things for the patient to do, etc.):

Time you spend:	How difficult:
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

12. Managing behavior problems in terms of the patient's moodiness and irritability:

Time you spend:	How difficult:
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

13. Managing behavior problems in terms of the patient's memory loss, concentration, and attention:

Time you spend:	How difficult:
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

14. Managing behavior problems in terms of the patient's confusion, disorientation, or dementia:

Time you spend:	How difficult:
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

15. Finding and arranging someone to care for the patient while you are away:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

16. Communication (helping the patient with the phone, writing or reading, explaining things, etc):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

17. Coordinating, arranging, and managing services and resources for the patient (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help):

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

18. Seeking information and talking with doctors, nurses, and other professional health care workers about the patient's condition and treatment plans:

Time you spend:	**How difficult:**
___ A great amount (5)	___ Extremely difficult (5)
___ A large amount (4)	___ Very difficult (4)
___ A moderate amount (3)	___ Moderately difficult (3)
___ A small amount (2)	___ Slightly difficult (2)
___ None (1)	___ Not difficult (1)

___About how many hours/day
___About how many hours/week

SCORING INSTRUCTIONS FOR THE CAREGIVING BURDEN SCALE

Code the responses to each of the 15 items into the computer using the format below, then add the scores for TIME for a time subscale score and add the scores for DIFFICULT for a difficulty subscale score. If less than 50% of the responses are missing for each subscale, imputing the scale mean for missing data is acceptable to preserve sample size if desired.

TIME	DIFFICULT
5=A great amount	5=Extremely difficult
4=A large amount	4=Very difficult
3=A moderate amount	3=Moderately difficult
2=A small amount	2=Slightly difficult
1=None	1=Not difficult

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Thank you for completing this survey!

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐1	☐2	☐3	☐4	☐5

2. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a <u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐1	☐2	☐3
b Climbing <u>several</u> flights of stairs	☐1	☐2	☐3

3. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a <u>Accomplished less</u> than you would like	☐1	☐2	☐3	☐4	☐5
b Were limited in the <u>kind</u> of work or other activities	☐1	☐2	☐3	☐4	☐5

4. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a <u>Accomplished less</u> than you would like	☐1	☐2	☐3	☐4	☐5
b Did work or other activities <u>less carefully than usual</u>	☐1	☐2	☐3	☐4	☐5

5. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐1	☐2	☐3	☐4	☐5

6. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u>...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Have you felt calm and peaceful?	☐1	☐2	☐3	☐4	☐5
b Did you have a lot of energy?	☐1	☐2	☐3	☐4	☐5
c Have you felt downhearted and depressed?	☐1	☐2	☐3	☐4	☐5

7. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐1	☐2	☐3	☐4	☐5

Thank you for completing these questions!

Comorbidity

Myocardial Infarction (total score possible: 1)

1. Have you ever had a heart attack?

☐ No ☐ Yes (Score 1)

Congestive Heart Failure (total score possible: 1)

2. Have you ever been treated for heart failure? (You may have been short of breath and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.)

☐ No ☐ Yes (Score 1)

Peripheral Vascular Disease (total score possible: 1)

3. Have you had an operation to unclog or bypass the arteries in your legs?

☐ No ☐ Yes (Score 1)

Cerebrovascular Accident (total score possible: 1)

4. Have you had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack (TIA)?

☐ No ☐ Yes (Score 1)

Hemiplegia (total score possible: 2)

4a. Do you have difficulty moving an arm or leg as a result of the stroke or CVA?

☐ No ☐ Yes (Score 2)

Chronic Obstructive Pulmonary Disease (total score possible: 1)

5. Do you have asthma? ☐ No ☐ Yes

If yes, do you take medicines for your asthma?

a. Yes, with flare-ups of asthma only ☐ No ☐ Yes

b. Yes, I take medicines regularly, even when I'm not having a flare-up. ☐ No ☐ Yes

6. Do you have emphysema, chronic bronchitis, or chronic obstructive lung disease?

☐ No ☐ Yes

If yes, do you take medicines for your lung disease?

c. Yes, only with flare-ups ☐ No ☐ Yes

d. Yes, I take medicines regularly, even when I'm not having a flare-up.

☐ No ☐ Yes

Any Yes to a., b., c., or d: (Score 1)

Ulcer Disease (total score possible: 1)

7. Do you have stomach ulcers or peptic ulcer disease?
☐ No ☐ Yes

If yes, has this condition been diagnosed by endoscopy (where a doctor looks into your stomach through a scope) or an upper GI or barium swallow study (where you swallow chalky dye and then x-rays are taken?
☐ No ☐ Yes
(Score 1)

Diabetes (total score possible: 2)

8. Do you have diabetes (high blood sugar)? ☐ No ☐ Yes
   a. Is it treated by medications taken by mouth? ☐ No ☐ Yes
   b. Is it treated by insulin injections? ☐ No ☐ Yes

Any Yes to a. or b. (Score 1)

   c. Has the diabetes caused:
      1) Problems with your kidneys? ☐ No ☐ Yes
      2) Problems with your eyes; treated by an ophthalmologist? ☐ No ☐ Yes

Any Yes to a. or b. (Score 1)

Renal (total score possible: 2)

9. Have you ever had the following problems with your kidneys?
   Poor kidney function (blood tests show high creatinine)? ☐ No ☐ Yes
   Have used hemodialysis or peritoneal dialysis? ☐ No ☐ Yes
   Have received kidney transplantation? ☐ No ☐ Yes

Any Yes (Score 2)

Connective Tissue Disease (total score possible: 1)

10. Do you have rheumatoid arthritis that you take medications for regularly?
☐ No ☐ Yes
   Do you have Lupus (systemic lupus erythematosus)? ☐ No ☐ Yes
   Do you have Polymyalgia rheumatica? ☐ No ☐ Yes

Any Yes (Score 1)

Dementia, liver disease, leukemia, lymphoma, tumor, metastases, AIDS:

11. Do you have:

Alzheimer's Disease or another form of dementia?	☐ No	☐ Yes	(Score 1)
Cirrhosis or serious liver damage?	☐ No	☐ Yes	(Score 2)
AIDS?	☐ No	☐ Yes	(Score 6)
Leukemia or polycythemia vera?	☐ No	☐ Yes	(Score 2)
Lymphoma?	☐ No	☐ Yes	(Score 2)
Cancer, other than skin cancer, leukemia, or lymphoma?	☐ No	☐ Yes	
If yes, has the cancer spread or metastasized to other parts of your body?	☐ No	☐ Yes	(Score 6)
If the cancer has NOT metastasized, was the cancer first treated less than 5 years ago?	☐ No	☐ Yes	(Score 2)

TOTAL SCORE __________

Comorbidity CATEGORY _________
Score of 1-2 = 1
Score of 3-4 = 3
Score of 5 or more = 5

Family Caregiver Demographic

This group of questions will provide us with important information about you and the care that you provide. Please answer the following questions.

1. What is your age? __________

2. What is your gender?

   __________Male
   __________Female

3. What is your race? Check all that apply

   __________American Indian or Alaskan Native
   __________African American or Black
   __________Asian
   __________Native Hawaiian or Other Pacific Islander
   __________White
   __________Other: Please specify
   ____

4. Do you consider yourself Hispanic or Latino? ___Yes ___No

5. What is your relationship with the patient?

   __________Spouse
   __________Son or Daughter
   __________Son or Daughter In-law
   __________Other relative: Please specify
   ____
   __________Friend
   __________Other: Please specify
   ____

6. Where is the patient currently living?

   __________house
   __________apartment
   __________assisted living facility
   __________nursing home
   __________inpatient rehabilitation facility

7. Do you currently live in the same home as the patient?

   __________Yes
   __________No

8. How many days per week do you help the patient?

__________daily, 7 days per week
__________5-6 days per week
__________3-4 days per week
__________1-2 days per week
__________less than one day per week

9. Are there other family members living at home with you that also need your help (for example: children, spouse, parents, others)?

__________Yes (Who?)________________________
__________No

10. If you are not the spouse, are you single or married?
____

10a. How many years have you been married?
____

11. How many years of formal education have you had including grade school, middle school, high school (12 years), technical or business school, or college?

__________Years

12. What is your current employment status?

__________Employed full-time
__________Employed part-time
__________Homemaker
__________Retired
__________Unemployed
__________Other: Please specify
____

13. (*If employed*) Did you have to change your employment to be a caregiver?
__________Yes
__________No

a. If yes, what was the change?
__________Shift
__________Hours
__________Employer
__________Other: Please specify__________________

14. (*If unemployed*) Did you have to quit a job or take early retirement in order to provide care for the patient?
__________Yes
__________No

15. What is (Mr./Mrs./Ms.)_____________current employment status?

__________Employed full-time
__________Employed part-time
__________Homemaker
__________Retired
__________Unemployed
__________Disability (receiving)
__________Pending Disability
__________Other: Please specify

____

16. Did (Mr./Mrs./Ms.)_______________ have to quit a job or take early retirement because of their heart failure?

__________Yes
__________No

17. 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

Appendix B: Patient Chart Review Form

FAMILY CAREGIVER STUDY
Patient Data Collection Form for HF Patient Record

1. Patient Name:____

2. DOB: _________________________ 3. Study ID: ________________

4. Gender: ☐M ☐F 5. Marital Status: ☐Single ☐Married

6. Ethnicity: ___American Indian or Alaskan Native
___African American or Black
___Asian
___Native Hawaiian or Other Pacific Islander
___White
___Other: Please specify________________________________
Any documentation of Hispanic or Latino? ___Yes ___No

7. Number of medications:				
8. Duration of HF *(per physician's HX)*:				
9. NYHA Class: *(circle one)*	I	II	III	IV
10. Stage HF: *(circle one)*	A	B	C	D

ECHO RESULTS

11. Date of Echo: ________________ (mm/dd/yy) Value:

12. LV diameter diastolic >= 5.5 ☐ Yes ☐ No___________

13. Fraction of systolic shortening <=0.18 ☐ Yes ☐ No___________

14. LV dysfunction systolic ☐ Yes ☐ No___________

15. Generalized abnormal ventricular wall motion ☐ Yes ☐ No___________

16. Echo – LVEF <= 40% ☐ Yes ☐ No___________

DEVICES

17. Regular Pacemaker ☐ Yes ☐ No___________

18. Biventricular Pacemaker ☐ Yes ☐ No___________

19. ICD ☐ Yes ☐ No___________

20. LVAD ☐ Yes ☐ No___________

21. Transplant ☐ Yes ☐ No
☐ Pre ☐ Post

22. Other

____

Comorbidity Questionnaire – CHARLSON FORMAT (Chart)

1. Myocardial Infarction: (total score possible:1)
One or more instances of definite or probable MI (enzymes):……………

No_____Yes_____→score ❶_____

2. Congestive Heart Failure: (total score possible:1)
History of exertional or paroxysmal nocturnal dyspnea with symptomatic response to dig, diuretics or afterload reducers: ……………………………

No_____ Yes_____→score ❶____

3. Peripheral Vascular Disease: (total score possible:1)
Current: intermittent claudication, gangrene, acute arterial insufficiency, or untreated thoracic or abdominal aneurysm (6cm or more) or history of arterial bypass: ……...

No_____ Yes_____→score ❶_____

4. Cerebrovascular Accident: (total score possible:1)
CVA with minor or no residual or transient ischemic attack (TIA): …………

No_____ Yes_____→score ❶_____

5. Hemiplegia: (total score possible:2)
Hemiplegia or paraplegia as a result of CVA or other condition:……….

No_____ Yes_____→score ❷_____

6. Chronic Obstructive Pulmonary Disease: (total score possible:1)
Asthma, emphysema, chronic bronchitis, or chronic obstructive lung disease (dyspneic at rest or with activity) ………………………………….

No_____ Yes_____→score ❶_____

7. Ulcer Disease: (total score possible:1)
Peptic ulcer disease requiring treatment (including hx of bleed): …………….

No_____ Yes_____→score ❶_____

8. Diabetes: (total score possible: 2)
Diabetes requiring medication (oral or insulin), not treated by diet alone:…

No_____ Yes_____→score ❶_____

Diabetes with end-organ damage: retinopathy, neuropathy or nephropathy:.

No_____ Yes_____→score ❶_____

9. Renal: (total score possible:2)
Moderate or severe renal disease (serum creatinine >3 mg%, with uremia, on dialysis, or history of transplant: …………………….…………………

No_____ Yes_____→score ❷_____

10. Connective tissue disease: (total score possible:1)
Systemic lupus erythematosus, polymyositis, mixed connective tissue disease,

Polymyalgia rheumatica, or moderate to severe Rheumatoid Arthritis:…...

No_____ Yes_____→score ❶_____

11. Dementia, liver disease, leukemia, lymphoma, tumor, metastases, AIDS:

Alzheimer's Disease, or another form of dementia: ……………………..

No_____ Yes_____→score ❶_____

Chronic hepatitis or Cirrhosis with<u>out</u> history of portal HTN or variceal bleeding …………………..…………………..…………

No_____ Yes_____→score ❶_____

Cirrhosis <u>with</u> history of portal HTN or variceal bleeding? ………………

No_____ Yes_____→score ❸_____

AIDS:………………….. …………………..………………………

No_____ Yes_____→score ❻_____

Leukemia or polycythemia vera: …………………..…………………..

No_____ Yes_____→score ❷_____

Lymphoma: …………………..…………………..…………………

No_____ Yes_____→score ❷_____

Cancer, other than skin cancer, leukemia, or lymphoma (Solid Tumor):

With metastasis: …………………..…………………..…………

No_____ Yes_____→score ❻_____

With<u>out</u> metastasis, but first treated less than 5 years ago: …………..

No_____ Yes_____→score ❷_____

TOTAL SCORE _______

Comorbidity **CATEGORY** (Score of 1-2 = 1; 3-4=3; 5 or more = 5) _______

Appendix C: Informed Consent Statements

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Family Caregiving Outcomes Study in Heart Failure (Caregivers)

STUDY PURPOSE:

You are invited to take part in a research study about being a caregiver of a person with heart failure. The purpose of this study is to learn more about how your caregiving role affects you and your health. We want to learn about your health, family functioning, the tasks you need to perform and your idea of how difficult or stressful these tasks are. We will ask caregivers and heart failure patients to be in the study.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to take part, you will be one of about 110 caregivers who will be in this study. In addition, you may also be invited to take part in a longer audiotape-recorded interview.

PROCEDURE FOR THE STUDY:

If you agree to be in the study, you will do the following things:

1. Take part in 3 interviews lasting about 60 minutes each. The interviews will be done at the time you enroll in the study or shortly thereafter and at 4 months and 8 months after the first interview. Trained research team members from the Methodist Heart Failure Clinic or the Indiana University School of Nursing will conduct these interviews. In the interviews, we will ask you about how caregiving has affected you and your family, how much time and effort it takes to be a caregiver, and how it has affected your health.
2. These interviews will be conducted in the clinic or at home by telephone. You may choose where you can be interviewed.
3. In addition to the three interviews, you may be invited to take part in extended conversations lasting 60 to 90 minutes. You will be asked to relate stories about what it is like to be a caregiver for someone with heart failure. You may choose when and where the conversations will take place. We will audiotape record these interviews if you agree. The audiotape and other research materials will be kept in a secure area with limited access to help protect your confidentiality. These audiotapes will be destroyed after analysis.

RISKS OF TAKING PART IN THE STUDY:

The study involves low risk. The risks of taking part in the interviews include the possible loss of confidentiality or being uncomfortable answering the questions that may arise. The risk of getting tired may occur as a result of taking part in the three one-hour interviews.

Loss of confidentiality is a possibility. Many measures will be taken to prevent this from happening such as storing information in a locked office. Only researchers will have access to audiotape recordings and other study materials.

It is also possible that during the interview and remembering about your health, painful memories or thoughts could happen. The interviewer is a nurse or social worker and has had discussions like this with many people. You are free to not answer any questions that may be uncomfortable.

While completing the interview, you can tell the researcher that you feel uncomfortable or do not care to answer a particular question. You may stop the interview at any time without penalty of any kind to you. If you wish, the interviewer will help you find a counselor to help with any uncomfortable feelings.

If you take part in the extended conversations, in addition to the risks already listed, you may experience some psychological or social risk associated with personal experience of caring for someone with heart failure. In the event that you share information that indicates a serious health risk to you, the research team will help you identify the appropriate health care provider.

BENEFITS OF TAKING PART IN THE STUDY:

The benefits to being in the study are having the opportunity to share your experiences with heart failure with an interested interviewer. There may be a benefit to learning more about the experience of being a caregiver to a person with heart failure. This may help patients and caregivers in the future.

CONFIDENTIALITY:

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. Your identity will be held in confidence in reports in which the study may be published.

If you take part in the tape-recorded interviews, the investigators will destroy the tape-recorded material that has been de-identified once the accuracy of the transcription is determined. Typed transcripts will be kept in a locked file cabinet with access limited to members of the research team. Records for documenting access to these files will be maintained.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the investigator and her research associates and the IUPUI/Clarian Institutional Review Board or its designees.

COSTS/COMPENSATION:

You will receive payment for taking part in this study. You will receive $10 for each interview completed. In the event of physical 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.

CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study, contact the researchers, Susan Bennett DNS, RN at (317) 274-4432, or George Smith, ACSW, LCSW, at (317) 962-9706.

For questions about your rights as a research participant, you may contact the Subject's Rights Representative, IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

PARTICIPANT'S CONSENT:

In consideration of all of the above, I give my consent to take part in this research study.

I acknowledge receipt of a copy of this informed consent statement.

Participant's Signature: ______________________________ Date: ____________
(must be dated by participant)

Signature of Person
Obtaining Consent: ______________________________ Date: ____________

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Family Caregiving Outcomes Study in Heart Failure (Patients)

STUDY PURPOSE:

You are invited to take part in a research study about caregiving for a person with heart failure. The purpose of this study is to learn more about how your caregiver's role affects them and their health. We want to learn about their health, family functioning, the tasks they need to perform and how difficult or stressful these tasks are. We will ask caregivers and patients to be in the study.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to take part, you will be one of 110 heart failure subjects who will be in this study.

PROCEDURE FOR THE STUDY:

If you agree to be in the study, you will do the following thing:

Allow the research team members from the Indiana University school of Nursing to examine your medical records. The medical records will be examined for demographic information, number of medications, duration of heart failure, New York Heart Association classification of heart failure, echocardiographic results and any mechanical devices that support the heart such as pacemakers.

RISKS OF TAKING PART IN THE STUDY:

The study involves low risk. Loss of confidentiality is a possibility. Many measures will be taken to prevent this from occurring such as storing information in a locked office. Only researchers will have access to study materials.

BENEFITS OF TAKING PART IN THE STUDY:

The benefits to being in the study may be learning more about patients with heart failure. This may help patients in the future.

CONFIDENTIALITY:

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. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the investigator and her research associates and the IUPUI/Clarian Institutional Review Board or its designees.

COSTS/COMPENSATION:

There is no direct compensation for participating in the study. There are no costs associated with participating in this study as we are only asking to review your medical records.

CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study, contact the researchers, Susan Bennett DNS, RN at (317) 274-4432, or George Smith, ACSW, LCSW, (317) 962-9706.

For questions about your rights as a research participant, you may contact the Subject's Rights Representative, IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Refusing to take part in the study or deciding to leave the study will not jeopardize the investigators' interest in you or affect the treatment or care you receive.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to take part in this research study. I acknowledge receipt of a copy of this informed consent statement.

Participant's Signature: ______________________________ Date: __________
(must be dated by participant)

Signature of Person
Obtaining Consent: ______________________________ Date: __________

Appendix D: Institutional Review Board Approval

(don’t print this page!!!!!
Or the next 2 pages-Use 3 faxed pages)

(don’t print this, useFAX copies)

(Last page of 3 pages – use fax copies)

CURRICULUM VITA

Suzanne D. Chubinski

Education:

2007	PhD. - Doctorate of Philosophy: Nursing Indiana University, Indianapolis
1983	M.A. - Ball State University, Muncie, Indiana
1974	B.S.N. - Loyola University, Chicago, Illinois

Honors, Awards, Fellowships:

Grants and Funding

CAES- School of Health Sciences Funding for completion of PhD
(competitive review) Fall, 2006

Midwest Alliance for Health Education Nursing Research Fellowship
The Impact of Caregiving on Caregivers of Persons with Heart Failure
(competitive review) Summer, 2006

CAES- School of Health Sciences Funding for completion of PhD
(competitive review) Spring, 2006

Graduate End-of-Life Nursing Education Consortium (ELNEC) from American Association of Colleges of Nursing (AACN) for 3-day ELNEC course
(competitive) Summer, 2004

Midwest Medical Research Foundation Nursing Research Fellowship
Quality of Life in Patients with Implantable Cardioverter Defibrillator
(competitive review) 1994-95, Academic Year

Indiana University-Purdue University Faculty Summer Grant
Pilot Study: *Quality of Life in Patients with Automatic Implantable Cardioverter Defibrillators*
(competitive review) Spring, 1994

Alpha Chapter of Sigma Theta Tau
Pilot Study: *Quality of Life in Patients with Automatic Implantable Cardioverter Defibrillators*
(competitive review) Spring, 1994

University of Saint Francis-Lilly Grant
Indiana High School Guidance Counselors'Attitudes about an Ideal Career versus a Nursing Career
(competitive review) Fall, 1993

Saint Francis College Faculty Development Research Grant
High School Students' Attitudes about an Ideal Career versus a Nursing Career
(competitive review) March, 1993

Honors and Distinctions

Values in Action Award, USF, 2002

Awarded tenure, USF, 2001

Pinning Ceremony speaker for ASN students at IPFW in 1990, 1992, 1996 and 1997 (selection by students)

Most Inspiring Teacher, IPFW, 1997 (selection by students)

Research and Training Experience:

Research

Physical and Mental Health Among Caregivers of Heart Failure Patients, 2007

End-of-Life Care for Patients with Chronic Heart Failure, 2002

Impact of the Nurse Practitioner on End-of-Life Care, 2001

Quality of Life in Patients with Implantable Cardioverter Defibrillator, 1994-1995

Quality of Life in Patients with Automatic Implantable Cardioverter Defibrillator- A pilot study, 1994

Indiana High School Guidance Counselors' Attitudes about an Ideal Career versus a Nursing Career, 1993

Pilot Study -*High School Students' Attitudes about an Ideal Career versus a Nursing Career*, May 1993

Pilot Study- *Allen County High School Guidance Counselors' Attitudes about an Ideal Career versus a Nursing Career,* March 1993

Cooperative study with National League for Nursing- *A Comparison of Computer*

Adaptive Testing and Paper and Pencil Testing in Measuring Nursing Students' Achievement in Pharmacology, April 1991

Master's Project- *Criterion Based Performance Evaluation for Critical Care Nurses* 1983

Professional Experience:

Academic Appointments

2006 - Associate Professor, Nursing, University of Saint Francis (USF), Fort Wayne, Indiana

1998-2006 - Assistant Professor, Nursing, University of Saint Francis, Fort Wayne, Indiana

1990-1996 - Assistant Professor, Department of Nursing, Indiana University-Purdue University at Fort Wayne (IPFW), Fort Wayne, Indiana

1985-1990 - Associate Faculty, IPFW, Fort Wayne, Indiana

Clinical Practice

1998-present - Case Manager, Critical Care, prn Parkview Hospital, Fort Wayne, IN

1996-1998 - Case Manager, Cardiovascular, Parkview Hospital, Fort Wayne, IN

1996-1999 - Staff Nurse, HeartWatch, SpectraCare Home Health Care, Fort Wayne, IN

1987-1996 - Staff Nurse in Cardiovascular (CCU, Telemetry), Parkview Hospital, Fort Wayne, IN

1983-1987 - Director of CCU, Parkview Hospital, Fort Wayne, IN

Licenses, Registrations, and Certifications

Professional License: RN, State of Indiana Health Professions Bureau/State Board of Nursing

Publications:

Refereed Journals

Chubinski, S. (1996). Creative critical thinking strategies. *Nurse Educator, 21* (6), 23-27.

Burns, C., Chubinski, S., & Freiburger, O. (1983, Spring). A Criteria-Based performance appraisal for the critical care nurse. *Nursing Administration Quarterly,* 46-58.

Textbooks

Chubinski, S. (1999). Case studies for each chapter. In Townsend, R. and Roth, R. (Eds.), *Nutrition and Diet Therapy*. Albany: Delmar.

Chubinski, S. (2002) revision of case studies for Townsend, R and Roth, R. *Nutrition and Diet Therapy.* Albany: Delmar.

Chubinski, S. revision of case studies for 2002 print and creation of Blackboard and WebCT version of Townsend, R and Roth, R. *Nutrition and Diet Therapy*. Albany: Delmar. publication expected 2007.

Book Reviews

Jaffe, M.S., & McVan, B.F. (1997). *Davis's Laboratory and Diagnostic Test Handbook.*

Other

Chubinski, S. (2006). The impact of caregiving on caregivers of persons with heart failure. *Student Research Fellowship Program Abstract,* 7.

Chubinski, S. (2004). The nature of pain in late stage heart failure patients. *Student Research Fellowship Program and Clinical Case Studies Program-Abstracts, 8.*

Chubinski, S. (2002). End-of-life care for patients with chronic heart failure. *Program and Abstracts from the 6th Annual Scientific Meeting of Heart Failure Society of America,* HFSA Boca Raton, FL.

Chubinski, S., & Mueller, C. (1995, Summer). Research Report: Quality of life in patients with implantable cardioverter defibrillators. *Nursing Research Consortium Newsletter. 2* (5), 2.

Chubinski, S., & Mueller, C. (1995, Summer). Quality of life in patients with implantable cardioverter defibrillators. *Midwest Medical Research Foundation Research Fellowship Program Proceedings.* 34.

Chubinski, S., & Mueller, C. (1994, Winter). Research Proposal: Quality of life in patients with implantable cardioverter defibrillators. *Nursing Research Consortium Newsletter, 1*(3), 1.

Professional Presentations

Women and Heart Disease: What you don't know could kill you. Faculty Development USF, Fort Wayne, IN 3/07.

Just when you thought you knew it all…the latest research on cardiovascular risks for women. Advanced Heart Care Clinic, Indianapolis, IN 9/29/06.

An Update on Women and Heart Disease: Just when you thought you had it all figured out… A Scholarship of Teaching presentation to USF Dept. of Nursing, Ft. Wayne, IN 11/05.

The Nature of pain in late stage heart failure patients. 17th Annual Midwest Alliance for Health Education Student Research Presentation Dinner, IU School of Medicine, Fort Wayne, IN 8/4/04.

End-of-Life Care for Patients with chronic heart failure. Palliative Care: Quality Care at the End of Life, sponsored by VA Northern Indiana Health System Patient Care Support Service, Fort Wayne, IN 3/7/03.

End-of-Life Care for Patients with chronic heart failure. 6th Annual Scientific Meeting of Heart Failure Society of America, sponsored by HFSA Boca Raton, FL 9/22-25/02.

Preliminary results of research: the experience of end of life for heart failure patients. A presentation for USF faculty, Fort Wayne, IN 2/02.

Case Management: what is it? A presentation for USF Masters in Nursing students, Nursing 501 Fort Wayne, IN 5/23/01.

Strategies to Adapt to Chronic Illnesses: A Review of the Literature. Indiana University, Indianapolis, IN 4/26/01.

The Impact of Disease State Management Programs on the Outcomes of Heart Failure Patients: A Scholarly Review of the Literature, Indiana University, Indianapolis, IN 10/12/01

Case Management: What it means to nursing. A presentation for University of Saint Francis BSN leadership students, Fort Wayne, IN 3/98.

Successful Critical Thinking Strategies for theEexperienced Teacher. 22nd Annual Workshop: Creative Teaching for Nursing Educators, sponsored by the University of Memphis, Memphis, TN March 1997.

Easy Critical Thinking Strategies: Getting Started. 22nd Annual Workshop: Creative Teaching for Nursing Educators, sponsored by the University of Memphis, Memphis, TN March 1997.

Critical Thinking: Customer Satisfaction Tool. 22nd Annual Midwest Conference sponsored by the Chicago Area AACN Chapter, Schamburg, IL March 1997.

Is there Life after ICU: Career Management for Critical Care Nurses. 22nd Annual Midwest Conference sponsored by the Chicago Area AACN Chapter, Schamburg, IL March 1997.

Successful Critical Thinking Strategies for the Experienced Teacher. 21st Annual Workshop: Creative Teaching for Nursing Educators, sponsored by the University of Memphis, Memphis, TN March 1996.

Easy Critical Thinking Strategies: Getting Started. 21st Annual Workshop: Creative Teaching for Nursing Educators, sponsored by the University of Memphis, Memphis, TN March 1996.

Quality of Life in Patients with Implantable Cardioverter Defibrillator. New Dimensions in Nursing Research: Expanding The Foundations of Practice, provided by Northwest Indiana Nursing Research Consortium and Zeta Epsilon Chapter of Sigma Theta Tau, Merrillville, IN 10/25/95.

Quality of Life in Patients with Implantable Cardioverter Defibrillators. Research Utilization: Linking Practice and Research provided by Zeta Theta chapter of Sigma Theta Tau, Toledo, OH 9/8/95.

Quality of Life in Patients with Implantable Cardioverter Defibrillators. Research Fellowship Program presentations, sponsored by Midwest Medical Research Foundation, Fort Wayne, IN 8/9/95.

Successful Strategies for Teaching Critical Thinking for the 21st century. Third Annual Associate Degree Faculty Development Conference, sponsored by Sinclair Community College, Dayton, OH 8/95

Quality of Life in Patients with Implantable Cardioverter Defibrillators: preliminary finding., Midwest Medical Research Foundation, Fort Wayne, IN 7/24/95.

Quality of Life in Patients with automatic Implantable Cardioverter Defibrillators: A Pilot Study. Promoting Health- The Cutting Edge of Nursing Research, sponsored by the Kalamazoo Nursing Research Collective, Kalamazoo, MI 4/6/95

High School Guidance Counselors' Views of an Ideal Career versus Nursing as a Career. Pathways to Excellence Working Together in a Changing Health Care Environment, sponsored by the National Conference for Nursing Leaders, Detroit, MI 11/3/94.

Quality of Life in Patients with automatic Implantable Cardioverter Defibrillators: A Pilot Study. Issues and Trends in Research: An Emphasis on Qualitative Methods, sponsored by Fort Wayne Nursing Research Colloquium, Fort Wayne, IN 10/28/94.

Quality of Life in Patients with automatic Implantable Cardioverter Defibrillators: A Pilot Study. Sixth Annual Nursing Research Conference, sponsored by Lambda Sigma chapter of Sigma Theta Tau and Indiana State University School of Nursing, Terre Haute, IN 9/30/94.

Expert versus Beginner's Minds: Skirts that flat out and high flying piles of hair: a brief workshop in thinking about Critical Thinking for IPFW faculty sponsored by TEIG, Fort Wayne, IN 4/94.

High School Students' Attitudes about an Ideal Career versus a Nursing Career. Nursing Research Symposium sponsored by Delta Omega Chapter of Sigma Theta Tau, Akron, OH 4/15/94.

A Comparison of High School Students' and Guidance Counselors' Attitudes about an Ideal Career versus a Nursing Career. Expanding Research Through Collaboration sponsored by Eta Chi Chapter of Sigma Theta Tau, Marion, IN 3/17/94.

Women in White-High School Students' and Counselors' Misconceptions about Nursing. New Dimensions in Nursing Research: Expanding the Foundations of Practice provided by Northwest Indiana Nursing Research Consortium Research Conference, Merrillville, IN 10/15/93.

Women in White: High School Students' and Counselors' Misconceptions about Nursing. A report of research in progress to The Practical Application of Research sponsored by Saint Francis College, Fort Wayne, IN 5/7//93.

Poster Presentations

The Nature of pain in late stage heart failure patients. 17th Annual Midwest Alliance for Health Education Student Research Presentation Dinner, IU School of Medicine, Fort Wayne, IN 8/4/04.

End of Life Care for patients with chronic heart failure. Palliative Care: Quality Care at the End of Life sponsored by VA Northern Indiana Health System Patient Care Support Service, Fort Wayne, IN 3/7/03.

End of Life Care for patients with chronic heart failure. 6th Annual Scientific Meeting of Heart Failure Society of America, sponsored by HFSA Boca Raton, FL 9/22-25/02.

"Quality of Life in Patients with Implantable Cardioverter Defibrillators" *Research Fellowship Program presentations,* sponsored by Midwest Medical Research Foundation, Fort Wayne, IN 8/9/95.

High School Students'Attitudes about an Ideal Career versus a Nursing Career. Nursing Research Symposium sponsored by Delta Omega Chapter of Sigma Theta Tau, 4/15/94.

A Comparison of High School Students'Attitudes about an Ideal Career versus a Nursing Career. Creating a Research Climate sponsored by IPFW Department of Nursing, Fort Wayne, IN 11/5/93.

Professional Memberships

Sigma Theta Tau International Honor Society 1974-present
dual member of Alpha and Xi Nu chapter

American Association of Critical Care Nurses (AACN) 1974-present

American Heart Association (AHA) 1979-1996

Indiana State Nurses' Association (ISNA) 1993-present

American Nurses' Association (ANA) 1993-present