SELF-EFFICACY OF CAREGIVING AND CAREGIVER STRESS IN ADULT INFORMAL CAREGIVERS OF INDIVIDUALS AT THE END-OF-LIFE

by

MICHELLE M. HAMPTON

Presented to the Faculty of the Graduate School of
The University of Texas at Arlington in Partial Fulfillment
of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

THE UNIVERSITY OF TEXAS AT ARLINGTON
December 2014

Copyright © by Michelle M. Hampton 2014

All Rights Reserved

Acknowledgements

I must open this with a heartfelt thank you to Jarrott, Hayden, and Halle Hampton. You have all believed in me, patiently waited, and supported me in achieving my goal of pursuing higher education. To my parents, Robert Paul and Mary Jane Lackey, I thank you for pushing me to reach my highest potential. You have always encouraged me, and I am very grateful for all you have given me. To my brother, Dr. Robert Lackey, I thank you for always being there, especially when dad could not be. You have graciously taken his place on this earth, and I am forever indebted. Maurine and Terry Hampton, thank you for all you have done for me. I am truly blessed. I dedicate this project to you all.

Thank you to my friends at THFW hospital who have cheered me on each and every step of the way. Devonna McNeill, you know I will take care of you as you have taken care of me. Thank you to all of the staff from Community Hospice of Texas and Odyssey Hospice who helped me recruit the caregivers who participated in this study. I especially thank Brian Barrett and David McGee for giving me the final push I needed to finish the study. I thank the PhD faculty for providing me the “tools” I needed. Special appreciation goes to my entire committee: Dr. Lauri John for making me a better writer and for steering me in the right direction, Dr. Patricia Newcomb for explaining stats in a way I could understand and for being my mentor, and Dr. Barbara Raudonis for giving me a better understanding of Hospice and Palliative Nursing. I also want to thank my classmates who along the way have provided me the encouragement I needed. Tommie Rimes and Linda Frye, you do not know how much your support and encouragement mean to me.

November 21, 2014

Abstract

SELF-EFFICACY OF CAREGIVING AND CAREGIVER STRESS IN ADULT INFORMAL CAREGIVERS OF INDIVIDUALS AT THE END-OF-LIFE

Michelle M. Hampton, PhD

The University of Texas at Arlington, 2014

Supervising Professor: Lauri D. John

Researchers have established an association between the stressors of providing informal care and physiological and psychological health risks (Applebaum & Breitbart, 2013; Au et al., 2010; Bainbridge, Krueger, Lohfeld, & Brazil, 2009; Gilliam & Steffen, 2006; Mausbach et al., 2012; Merluzzi, Philip, Vachon, & Heitzmann, 2011; Perez, Ussher, Butow, & Wain, 2011). Despite the recognized negative consequences of informal care, researchers have identified the existence of mediators which have the potential to buffer, manage, transform, or prevent the negative influence of stress (Bolden & Newsome-Wicks, 2008; Kreitler, Peleg, & Ehrenfeld, 2007; Merluzzi et al., 2011; Roscoe, Corsentino, Watkins, McCall, & Sanchez-Ramos, 2009). The purpose of the study was to determine the relationship between self-efficacy and stress in adult informal caregivers providing end of life care while controlling for caregivers' socioeconomic status.

A cross-sectional, associational design which included 78 adult informal caregivers who were providing end-of-life care for an adult was conducted. Caregivers answered a demographic questionnaire and three survey instruments measuring caregiver self-efficacy, perceived stress, and perceived health. The Stress Process

Model (Pearlin, Mullan, Semple, & Skaff, 1990) was used to guide this study. The study was approved by the University of Texas at Arlington Institutional Review Board.

Study participants included a convenience sample of 78 cognitively intact, English speaking, adult informal caregivers who were providing end-of-life care for an adult in the North Central Texas Region. Caregivers were caring for individuals with a variety of illnesses, the most frequent of which was reported as cancer. A majority of the care recipients resided with the caregivers, and all of the sampled caregivers were receiving some level of caregiving support from an agency that provided end-of life supportive services.

Caregiver self-efficacy had a significant, negative correlation with perceived stress ($r = -.53$; $p < .01$). Caregiver self-efficacy explained 28.3% of the variance in perceived stress. Because self-efficacy is a multi-dimensional construct, a multivariate regression was performed to explore the relationship between caregivers' confidence in managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions and perceived stress. Caregivers' confidence in caring for themselves had a significant negative relationship with perceived stress ($r = - .63$, $p < .01$). Caring for oneself predicted 38% of the variance in perceived stress.

Caregivers with higher levels of confidence in managing demands of caregiving had lower levels of perceived stress. More specifically, caregivers' with higher levels of confidence in caring for themselves had lower levels of perceived stress. These findings highlight the importance of caregivers' self-care needs. Healthcare practitioners must recognize and intervene to support caregivers' self-care needs. Further research is needed to investigate caregivers' self-care needs as well as to investigate interventions which might enhance caregivers' self-care.

Table of Contents

List of Illustrations

List of Tables

Chapter 1

Introduction

Advances in medical care, shorter hospital stays, and changes in healthcare delivery have resulted in a shift from inpatient to outpatient medical care (Brazil, Bainbridge, & Rodriguez, 2010). This shift has placed increased caregiving responsibility on family members, friends, and neighbors, requiring them to provide needed emotional support and manage care demands of ailing loved ones (Rosenberg, Jullamate, & Azeredo, 2009; Tang, 2009). This unpaid assistance which is provided to someone who is to some degree physically or mentally incapacitated and needs help is described as informal or family caregiving (Pearlin et al., 1990).

Informal caregiving is a complex phenomenon. Researchers have established an association between the stressors of providing informal care and physiological and psychological health risks. The demands and emotional strains associated with caregiving leave caregivers vulnerable to psychological and physiological health consequences resulting in feelings of burden (Applebaum & Breitbart, 2013; Au et al., 2010; Bainbridge et al., 2009; Gilliam & Steffen, 2006; Mausbach et al., 2012; Merluzzi et al., 2011), stress (Merluzzi et al., 2011), depression, and anxiety (Perez et al., 2011).

Chapter one includes a discussion of the background and significance of providing informal care to adult family members, friends, and neighbors with an end-of-life diagnosis. The chapter also includes an introduction of the research framework, propositions, study purpose, research question, and assumptions of the theoretical framework.

Background and Significance

Prevalence of Informal Caregiving

Informal caregivers provide valuable support to ailing family members and friends, and informal caregivers supplement formal health services. There are an estimated 52 million informal caregivers in the United States (US) providing care to someone 18 years of age or older who have a chronic life-limiting disability or illness (Coughlin, 2010). This figure represents over 36.5 million households. Approximately 87% of the long-term care in the US is provided by informal caregivers (National Alliance for Caregiving & American Association of Retired Persons, 2009). The number of informal caregivers providing care for the chronically medically ill is expected to increase by as much as 85% by the year 2050 (Family Caregiver Alliance, 2012a).

Informal caregivers are the main providers of end-of-life care (Tang, 2009). The availability of an informal caregiver support system is a major determinant of whether a dying patient can remain at home (Burns, Abernathy, Dal Grande, & Currow, 2013). Wolff, Dy, Frick, and Kasper (2007) reported that informal caregivers provided care to 75% of people who were in their last year of life.

Economic Value of Informal Caregiving

The economic value of informal caregiving is substantial. In 2009, the estimated economic value of informal caregiving was approximately $450 billion dollars (Feinberg, Reinhard, Houser, & Choula, 2011). This figure represented a $75 billion increase from 2006. The estimated annual cost exceeds the national total annual cost of long-term care services, which was $206.6 billion dollars in 2005 (Family Caregiver Alliance, 2012a).

Demographics of Informal Caregiving

According to the National Alliance of Caregiving and the American Association of Retired Persons (2009), informal caregivers reside mostly with the care recipient, are predominately female (66%), are most often a spouse (70%), and have an average age of 48.1 years. They also reported that these caregivers provide care to adults (over the age of 18 years) with a variety of conditions, most commonly reported as old age, Alzheimer’s disease, dementia, mental illness, emotional illness, cancer, heart disease, and stroke. Among caregivers in the US caring for adults, approximately 72% are white, 13% are African-American, and 12% are Hispanic. Caregivers have been in the caregiving role for an average of 4.6 years, and on average, caregivers spend 20.4 hours per week providing care (National Alliance for Caregiving & American Association of Retired Persons, 2009).

Informal caregivers are the main providers of end-of-life care (Tang, 2009). They are a major determinant of whether a dying patient can remain at home (Burns et al., 2013). End-of-life informal caregivers include spouses, partners, parents, children, siblings, friends, and neighbors of people who are dying. Wolff et al. (2007) reported that informal caregivers provided care to 75% of people who were in their last year of life. They found that characteristics of end-of-life caregivers are similar to those of the larger caregiving population. End-of-life caregivers are primarily female (75.1%), and most are spouses (41.5%). The average age of end-of-life caregivers is 64 years, and frequently the caregivers have age-related health problems. End-of-life caregivers provide assistance for durations of less than one year (26.5%) to over four years (31.5%), and over 80% of them provide daily support and assistance, with most providing care more than 43 hours per week (Wolff et al., 2007).

Roles and Responsibilities of Informal Caregivers

Roles and responsibilities of informal caregivers are not disease specific. Informal caregivers of individuals with a variety of conditions (including old age, Alzheimer's disease, dementia, mental illness, emotional illness, cancer, heart disease, and stroke) supply essential resources and support that enable individuals to remain in their own homes (Feinberg, Newman, Gray, & Kolb, 2004).

Caregivers provide physical, psychological, financial, and emotional support. Caregivers provide advocacy and care coordination (Feinberg et al., 2004). Unique to end-of-life caregivers is the responsibility of assisting with bereavement support, helping with funeral arrangements, supporting decisions of competent individuals, and making decisions for individuals who cannot make decisions for themselves (Bee, Barnes, & Luker, 2009; Empeño, Raming, Irwin, Nelesen, & Lloyd, 2011; National Hospice and Palliative Care Organization, 2013).

Consequences of Providing Informal Care

Researchers have documented the negative psychological and physical effects associated with informal caregiving (Au et al., 2010; Bolden & Newsome-Wicks, 2008; Gallagher et al., 2011; Gilliam & Steffen, 2006; Mausbach et al., 2012; Perez et al., 2011; Romero-Moreno et al., 2011; Semiatin & O'Conner, 2012). Negative effects include depression, anxiety, worsened immune system functioning, and increased rates of infection (Bainbridge et al., 2009; Gilliam & Steffen, 2006; Harmell et al., 2011; Merluzzi et al., 2011).

Pearlin and colleagues have conceptualized the negative bio-psychosocial effects associated with caregiving as caregiver stress (Pearlin et al., 1990). Caregiver stress refers to individuals' response to a condition that is either consciously or unconsciously deemed noxious, and stress outcomes are represented by the overall well-being of individuals, including their physical, mental, and spiritual health (Pearlin et al., 1990). Caregiver stress has been reported in approximately 60% of caregivers (Family Caregiver Alliance, 2012a).

Despite the recognized negative consequences of informal care, researchers have identified the existence of mediators which have the potential to buffer, manage, transform, or prevent the negative influence of stress (Bolden & Newsome-Wicks, 2008; Kreitler et al., 2007; Merluzzi et al., 2011; Roscoe et al., 2009). Researchers have recently begun to study factors that influence the caregiving stress process (Bolden & Newsome-Wicks, 2008; Roscoe et al., 2009), enhancing caregivers' ability to cope (Merluzzi et al., 2011). Internal motivators, internal coping mechanism, and intrinsic behaviors, including mastery, resilience, and self-efficacy, have been shown to mediate negative outcomes of caregiving (Judge, Menne, & Whitlatch, 2009; Merluzzi et al., 2011). Caregivers with greater levels of mastery, resilience, and self-efficacy have reported lower levels of psychological illness, reduced rates of burnout, and greater levels of well-being (Bandura, 2006; Kreitler et al., 2007; Merluzzi et al., 2011). Although the constructs of mastery, resilience, and self-efficacy have similar attributes, self-efficacy provides a more general assessment of an individual's ability to manage specific tasks. Self-efficacy, unlike the global constructs of mastery and resilience, can have an impact on everything from an individual's psychological state to behavior to motivation (Bandura, 2006).

Caregiver Self-Efficacy

Caregiver self-efficacy is conceptualized as individuals' beliefs in their ability to carry out activities and tasks specific to caregiving (Bandura, 2006). In regard to caregiving, self-efficacy theory suggests that individuals with higher levels of self-efficacy will have a greater level of success in completing caregiving tasks, lower levels of psychological and physical illness, reduced rates of burnout, and greater levels of well-being than those with low levels of self-efficacy (Bandura, 2006). Researchers have shown the potential for self-efficacy to transform negative outcomes resulting from caregiving (Kreitler et al., 2007), including depression, burden, strain, and stress (Bandura, 1977; Gallagher et al., 2011; Lockenhoff, Duberstein, Friedman, & Costa, 2011; Merluzzi et al., 2011; Montoro-Rodriguez & Gallagher-Thompson, 2009). High levels of self-efficacy in informal caregivers has been associated with lower levels of depression, lower perceived burden, lower blood pressure, and decreased risk for cardiac disease (Au et al., 2010; Gallagher et al., 2011; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009; Perez et al., 2011; Romero-Moreno et al., 2011); however a majority of the studies were conducted on informal caregivers of individuals with Alzheimer's disease or dementia. Researchers must study the influence of self-efficacy on the caregiving outcomes of adult informal caregivers providing care beyond those providing care to individuals with Alzheimer's disease or dementia. Identification of factors that reduce negative outcomes is vital to the psychological and physical health of informal caregivers (Kreitler et al., 2007). In this study, the researcher investigated the relationship between caregiver self-efficacy and caregiver stress among adult informal caregivers providing end of life care for individuals while controlling for caregivers' socioeconomic status (SES).

Framework

The theoretical framework for this correlational study is the Pearlin Stress Process Model (Pearlin et al., 1990). Stress process models have been used throughout the caregiving literature to describe the relationship between the caregiving experience, caregiving stressors, and outcomes of caregiving (Au et al., 2010; Bainbridge et al., 2009; Roscoe et al., 2009). The Pearlin Stress Process Model provides a representation of the informal caregiving processes that have an impact on the overall health and well-being of the caregiver and reflects a process that changes over time. The model includes an illustration of the relationships between background and contextual factors, caregiving stressors, and outcomes of caregiving (Pearlin et al., 1990). The key constructs, concepts, and their relationships are illustrated in Figure 1.

Background and Contextual Factors

Key characteristics of the caregiver and recipient of care influence all aspects within the framework (Pearlin et al., 1990). The background and context of stress refers to the basic characteristics of the caregiver and care recipient such as age, gender, the severity of the care recipient's illness, the relationship between the caregiver and recipient, the caregiver's SES, and availability of support and supportive services (Pearlin et al., 1990).

Stressors

Stressors are problematic conditions and difficult circumstances experienced by caregivers that exceed their capacity to adapt. The sources of stress are conceptualized as primary stressors and secondary strains (Pearlin et al., 1990).

Primary stressors

Within the Pearlin Stress Process Model, primary stressors are those variables that are directly influenced by care recipients' disease processes (Pearlin et al., 1990). Primary stressors are further classified as objective and subjective stressors.

Objective stressors are based on health, behavior, and functional capabilities of the impaired care recipient. Objective assessment of care recipient behaviors and capabilities provides an indication of the current demands of caregiving. Common objective stressors include changes in care recipients' cognitive status, problematic behaviors, and functional disabilities (Pearlin et al., 1990).

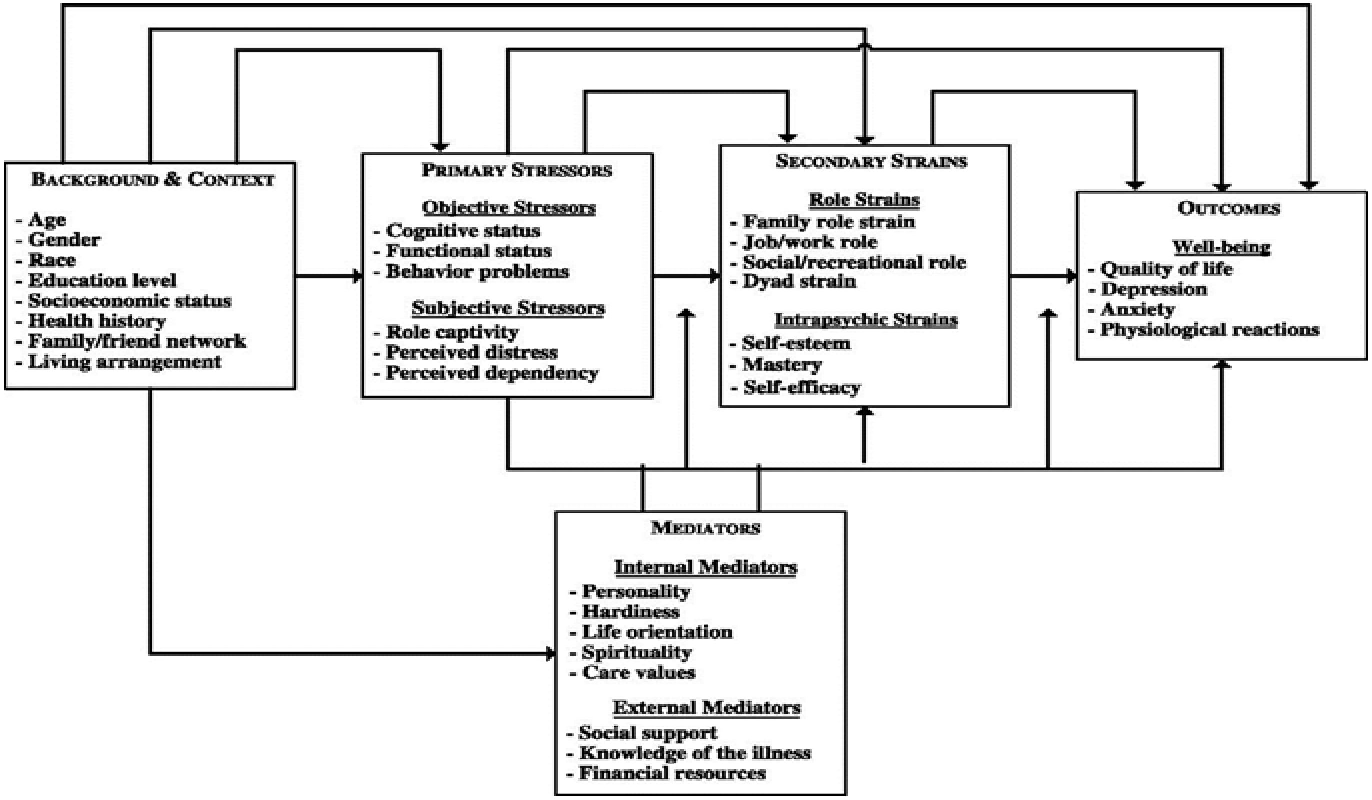

Figure 1. The Stress Process Model (Pearlin et al., 1990). This figure illustrates the core concepts and relationships within the Stress Process Model.

Subjective stressors reflect the extent to which caregiving duties are demanding on care- givers, requiring their effort and attention. These stressors are not affected by the condition of care recipients; they are related to hardships experienced by the caregiver. These stressors include feelings of overload (fatigue from caregiving duties), role captivity (feeling trapped within the role), worry and strain, and relational deprivation (changes in the former relationship within the caregiving dyad) (Pearlin et al., 1990).

Secondary strains

Secondary strains are difficulties that indirectly result from primary stressors (Pearlin et al., 1990). These strains reflect caregivers' assessments of the influence of primary stressors on their lifestyle and well-being. Secondary role strains represent the impact of caregiving on caregivers' roles including familial roles, occupational roles, economic roles, and social roles. Intrapsychic strains reflect changes to caregivers' self-concept and include the loss of self, the lack of confidence in caregiving skills, and a negative perception of caregiving (Pearlin et al., 1990).

Mediators

The Stress Process Model allows for the existence of mediators or protective factors that influence the relationship between caregiving stressors and outcomes (Bolden & Newsome-Wicks, 2008; Pearlin et al., 1990; Roscoe et al., 2009). Mediators vary in intensity and have the potential to transform stress and promote coping and adjustment (Kreitler et al., 2007). They regulate the effects of stressors on health outcomes and play a significant role in caregivers' ability to manage the experience. Mediators have been classified as internal and external. Internal mediators originate from within the individual and reflect lifelong coping and adaptation. Examples of internal mediators include resilience, personality, mastery, and self-efficacy (Judge et al., 2009). External mediators are coping resources that stem from the individual's environment.

Examples of external mediators include social support and spirituality (Pearlin et al., 1990).

Outcomes

Within the informal caregiving experience, stress is not a unitary phenomenon. Pearlin, Menaghan, Lieberman, and Mullan (1981) suggested that stress refers to the individual’s response to a condition that is either consciously or unconsciously deemed noxious. Caregiver stress is described as a variety of circumstances, experiences, and resources that influence the caregiver’s health and behavior (Pearlin et al., 1990). Stress outcomes represent the overall well-being of individuals, including their quality-of-life, psychological responses, and physiological reactions (Pearlin et al., 1990).

Manifestations of stress include alterations in well-being, impaired physical and mental health, and the inability of caregivers to sustain their own social roles (Bainbridge et al., 2009). Caregivers are at increased risk of developing adverse physical and psychological health effects, including depression, worsened immune system functioning, and increased rates of infections (Bainbridge et al., 2009; Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Outcomes are the result of the complex interactions among the model constructs (context and background of stress, sources of stress, and mediators) and are indicators of caregivers’ overall emotional, psychological, and physical well-being (Pearlin et al., 1990).

Throughout the literature, the terms distress, burden, stress, and strain have been used to describe the physical and psychological effects of the informal caregiving experience. Distress, burden, stress, and strain resulting from the caregiving experience are associated with caregivers’ overall well-being.

Caregiver burden

Caregiver burden refers to caregivers' subjective perception of caregiving overload in at least one of four domains: physical, psychological, financial, and/or social (Pearlin et al., 1981). Caregiver burden is a multidimensional bio-psychosocial reaction that results from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and social resources. Burden resulting from caregiving affects caregivers' overall well-being (Bainbridge et al., 2009).

Caregiver strain

Caregiver strain describes feelings of fatigue, emotional irritability, depression, loneliness, isolation, fear, and dissatisfaction often felt by informal caregivers (Haley et al., 2003). Feelings of depression, anxiety, loneliness, isolation, fearfulness, and irritability occur as a result of the demands placed on caregivers. Caregiver strain continues over time and is exacerbated with changes in the patient's condition (Haley et al., 2003).

Caregiver stress

Within the informal caregiving experience, stress is not a unitary phenomenon. Caregiver stress is described as a variety of circumstances, experiences, and resources that influence the caregiver's health and behavior (Pearlin et al., 1990). The relationship between caregiving and health is typically described in terms of stress. Caregiver stress arises from social circumstances beyond one's control and is identified as a major contributor to emotional distress, behavioral disorders, and suppression of the immune system. Stress originates at an intersection between caregivers' external environment and internal state; it arises when caregiving demands collide with caregivers' ability to respond or when the demands collide with caregivers' pursuit of their own goals. The nature of stress is multi-dimensional, and stress manifests in a variety of ways, including depression, anxiety, and physical ailments (Pearlin et al., 1990).

Relationships in the Model

The Pearlin Stress Process Model (1990) illustrates the relationships among multifaceted constructs and concepts and specific variables that reflect them. The model depicts several factors which affect the caregiving experience. This study described the relationship between caregiver self-efficacy (mediator) and caregiver stress (outcome) among adult informal caregivers providing end of life care while controlling for caregivers' SES income (background and contextual factor). Conceptual and operational definitions of the variables are included in Chapter 3. Figure 2 includes a depiction of the concepts of interest for the proposed study.

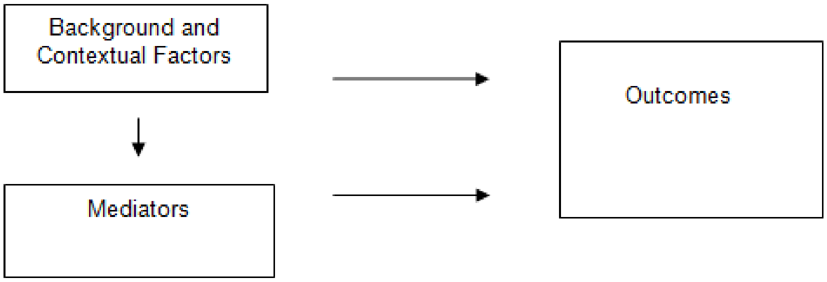

Figure 2. Proposed study concepts. This figure illustrates the core concepts and relationships within the proposed study.

Propositions

Based on the review of literature and the conceptual framework, the following propositions guided this study:

1. Background and contextual factors are associated with caregiving outcomes.
2. Background and contextual factors are associated with caregiving mediators.

3. Caregiving mediators are associated with caregiving outcomes.

Purpose

The purpose of the study was to determine the relationship between self-efficacy and stress in adult informal caregivers providing end of life care while controlling for SES.

Research Question

The following question was addressed in this study: What is the relationship between self-efficacy and stress in adult informal caregivers providing end of life care?

Assumptions

The assumptions that guided this study include:

1. Informal caregivers of adults at the end-of-life experience similar stressors of caregiving.
2. Informal caregivers of adults at the end-of-life experience negative outcomes of providing care including caregiver stress.
3. Caregiver self-efficacy has a relationship with caregiver stress.
4. Caregivers will be willing to report about their perceived stress and self-efficacy with honesty.

Summary of Chapter

This chapter included an overview of information to support the importance of conducting this research study. The background and significance of providing informal care to adult family members, friends, and neighbors with an end-of-life diagnosis were addressed. The research framework, propositions, study purpose, research question, and assumptions of the theoretical framework were also included.

Chapter 2

Critical Review of Relevant Literature

Advances in medical care, shorter hospital stays, and changes in healthcare delivery have resulted in a shift from inpatient to outpatient medical care (Brazil et al., 2010). This shift has placed increased caregiving responsibility on family members, friends, and neighbors, requiring them to provide needed emotional support and manage care demands of ailing loved ones (Rosenberg et al., 2009; Tang, 2009). This unpaid assistance which is provided to someone who is to some degree physically or mentally incapacitated and needs help is described as informal or family caregiving (Pearlin et al., 1990).

Chapter 2 includes a critical review of the literature regarding informal caregiving. Information about the prevalence, economic value, demographics, and roles and responsibilities of informal caregivers will be presented. Literature involving end-of-life caregiving, informal caregiving stressors, and consequences of caregiving will be included. Finally, literature regarding caregiver self-efficacy will be reviewed. This literature review includes the evidence to support the need for a study of the relationship between self-efficacy and stress in adult informal caregivers providing end of life care.

Prevalence of Informal Caregiving

Caregiving is a universal experience. Informal caregivers represent people of all races, ethnicities, ages, genders, and socioeconomic classes (Feinberg et al., 2003). There are an estimated 52 million informal caregivers in the US providing care to someone 18 years of age or older who has a chronic life-limiting disability or illness (Coughlin, 2010). This figure represents over 36.5 million households. The number of informal caregivers providing care for the chronically medically ill is expected to increase by as much as 85% by the year 2050 (Family Caregiver Alliance, 2012a).

Informal caregivers play a key role in the US healthcare delivery system (Institute of Medicine, 2008). Rising health care costs coupled with cost containment policies have resulted in shorter hospital stays. Patients are discharged from healthcare facilities much quicker than in past years, and many patients have complex needs requiring family members and friends to assist with day to day care (Feinberg et al., 2003). Informal caregivers provide the largest source of long-term care in the US. The National Alliance for Caregiving and American Association of Retired Persons (2009) reported that an estimated 87% of long-term care is provided by informal caregivers.

Informal Caregiving in Texas

Texas is the second most populous state in the US (Feinberg et al., 2004). In 2012, there were an estimated 5 million informal caregivers in Texas providing 3.2 million hours of caregiving per year (Family Caregiver Alliance, 2012b). A majority of informal caregivers in Texas were caring for a spouse or other family member, one-third of them have been providing informal care for 5 years or less, and approximately one-third provided care for more than 40 hours per week (Feinberg et al., 2004).

Economic Value of Informal Caregiving

Informal caregivers provide an important contribution to the US healthcare delivery system. The economic value of informal caregiving is substantial. Informal caregivers' contributions reduce the use of formal acute and long term care services, offering substantial savings to the US economy. In 2009, the estimated economic value of informal caregiving was approximately $450 billion dollars (Feinberg et al., 2011). This figure represented a $75 billion increase from 2006. The estimated annual cost exceeds the national total annual cost of long-term care services, which was $206.6 billion dollars in 2005 (Family Caregiver Alliance, 2012a). In Texas, the economic value of informal caregiving was over $240 million dollars (Coughlin, 2010; Feinberg et al., 2004).

Demographics of Informal Caregiving

According to the National Alliance for Caregiving and American Association of Retired Persons (2009), informal caregivers reside mostly with the care recipient, are predominately female (66%), are most often a spouse (70%), and have an average age of 48.1 years. They also reported that these caregivers provide care to adults (over the age of 18 years) with a variety of conditions, most commonly reported as old age, Alzheimer's disease, dementia, mental illness, emotional illness, cancer, heart disease, and stroke. Among caregivers in the US caring for adults, approximately 72% are white, 13% are African-American, and 12% are Hispanic. Caregivers have been in the caregiving role for an average of 4.6 years, and on average caregivers spend 20.4 hours per week providing care (National Alliance for Caregiving and American Association of Retired Persons, 2009).

Roles and Responsibilities of Informal Caregivers

Informal caregivers supply essential resources and support that enable individuals in need of informal care to remain in their own homes (Feinberg et al., 2004). Informal caregivers have multiple roles that have been described as physically and emotionally challenging (Empeño et al., 2011). Caregivers support the safety of care recipients and perform basic activities of daily living (ADL) such as cooking, cleaning, dressing, bathing, toileting, and ambulating. Caregivers provide transportation to and from medical appointments, communicate with and between health care professionals, and monitor symptoms resulting from chronic illnesses and manage medications. These caregivers manage care recipients' finances and often times offer financial support. Informal caregivers also give much needed emotional support including listening to and being there for care recipients (Feinberg et al., 2004).

End of Life Caregiving

Informal caregivers are the main providers of end-of-life care (Tang, 2009). The availability of an informal caregiver support system is a major determinant of whether a dying patient can remain at home (Burns et al., 2013). End-of-life informal caregivers include spouses, partners, parents, children, siblings, friends, and neighbors of people who are dying. Wolff et al. (2007) reported that informal caregivers provided care to 75% of people who were in their last year of life. They found that characteristics of end-of-life caregivers are similar to those of the larger caregiving population. End-of-life caregivers are primarily female (75.1%), and most are spouses (41.5%). The average age of end-of-life caregivers is 64 years, and frequently the caregivers have age-related health problems. End-of-life caregivers provide assistance for durations of less than one year (26.5%) to over four years (31.5%), and over 80% of them provide daily support and assistance, with most providing care more than 43 hours per week (Wolff et al., 2007).

End-of life caregiving affects all aspects of caregivers' lives (Tang, 2009). The demands of end of life care negatively affect even the most capable caregiver. End of life informal caregivers provide extensive assistance to dying individuals. Individuals at the end-of-life have unique needs, which are different from the needs of those not facing an impending death. End-of life caregivers describe the role as a physically and emotionally demanding process (Empeño et al., 2011). They are overwhelmed with physical, emotional, and financial burdens of providing care while also coping with the anticipated death of a loved one (Empeño et al., 2011; Stajduhar et al., 2010).

The National Hospice and Palliative Care Organization (NHPO) (2013) has identified a number of responsibilities for end-of-life caregivers including advocacy and care coordination, attendance to physical and psychological needs, and provision of financial and bereavement support. End-of-life caregivers coordinate a team of healthcare providers who often come into the home. They arrange for medical equipment and organize additional services the dying person may need and take on the responsibility of medication administration, pain management, and symptom management. Caregivers manage physical needs, including personal needs such as bathing, toileting, bowel care, bladder care, and ambulation. They also provide meals and manage household chores. End-of-life caregivers provide needed emotional support during the process of dying, including spiritual support, listening, and a social presence. Caregivers provide financial support to individuals at the end-of-life including the purchase medications, supplies, and equipment. Unique to end-of-life caregivers is the responsibility of assisting with bereavement support, helping with funeral arrangements, supporting decisions of competent individuals, and making decisions for individuals who cannot make decisions for themselves (Bee et al., 2009; Empeño et al., 2011; NHPO, 2013).

Informal Caregiving Stressors

Care related stressors are defined as external factors (environmental or social) or internal factors (biological or psychological) that challenge an individual to adapt or change. Stressors are conceptualized as "the conditions, experiences, and activities that are problematic for people" (Pearlin et al., 1990; p. 586). Caregiving stressors have further been conceptualized as primary stressors and secondary strains (Pearlin et al., 1990).

Primary Stressors

Primary stressors are problematic conditions and difficult circumstances that are directly influenced by care recipients' overall health, disease processes, behavior, and functional capabilities (Pearlin et al., 1990). These stressors may be objective or subjective in nature, and they change as individuals' illnesses progress (Au et al., 2010).

Common primary stressors occur as a result of changes in care recipients’ cognitive and functional status (Pearlin et al., 1990).

Researchers have identified the requirement for assistance with ADLs such as bathing, feeding, dressing, mobility, and incontinence management as primary stressors (Au et al., 2010; Gallagher et al., 2011; Gilliam & Steffen, 2006; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009; Romero-Moreno et al., 2011). They also identified declining functional status, cognitive impairment, memory loss, and reductions in motor skills in care recipients as primary caregiving stressors.

Problematic behaviors of care recipients are primary stressors that have been cited as a distressing aspect of providing care for Alzheimer’s or dementia patients (Au et al., 2010; Gallagher et al., 2011; Gilliam & Steffen, 2006; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009; Romero-Moreno et al., 2011). Some of these problematic behaviors which caregivers have to manage in Alzheimer’s patients include screaming at inappropriate times, verbal repetitions, and emotional outbursts. As care recipients’ illnesses progress, these problematic behaviors become more frequent and severe.

Secondary Strains

Stressors not directly influenced by care recipients are referred to as secondary strains (Pearlin et al., 1990). These secondary strains reflect the extent to which caregiving duties are demanding and require caregivers’ efforts and attention. They reflect the hardships experienced by caregivers rather than characteristics of care recipients.

Secondary strains identified by researchers include feelings of overload, role captivity, worry, and changes in the former relationship within the caregiving dyads (Mausbach et al., 2012; Pearlin et al., 1990). Caregivers of loved ones with Alzheimer’s disease and Multiple Sclerosis (MS) have reported personal activity restrictions and the inability to engage in social and recreational activities due to caregiving demands (Khan et al., 2007; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009). Feelings of overload and the inability to meet their own personal needs have been identified as secondary strains (Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009). Caregivers have also reported that they have sleep disturbances, little time for themselves, disruptions in personal schedules, and lack of privacy (Khan et al., 2007; Montoro-Rodriguez & Gallaher-Thompson, 2009; Perez et al., 2011).

Caregivers' own perceived health status has been identified as a stressor of caregiving (Au et al., 2010; Perez et al., 2011). Physically demanding caregiving tasks and lower levels of care recipient function are associated with lower levels of caregiver perceived health (Au et al., 2010). A direct relationship between the presence of caregiver health issues and caregiver stress has also been identified (Au et al., 2010; Lockenhoff et al., 2011). In one study of cancer caregivers, caregivers reported an increase in the number of caregiver health related issues as a result of providing care (Perez et al., 2011).

A majority of the studies identifying informal caregiving stressors were conducted with Alzheimer's disease and dementia caregivers. The primary stressors identified in those studies reflect the health, behavior, and functional capabilities of individuals suffering from Alzheimer's disease and moderate levels of dementia. It is unclear in the literature whether caregivers of individuals with other illnesses and disorders experience caregiving stressors similar to those of Alzheimer's disease and dementia caregivers. Caregivers of individuals with other illnesses and disorders may not experience the same stressors as those experienced by Alzheimer's disease and dementia caregivers. Researchers must expand studies to include caregivers of individuals with other illnesses and disorders, such as individuals at the end of life, in order to accurately reflect caregiving stressors.

Consequences of Caregiving

Research about the negative consequences of caregiving has grown rapidly over the past twenty years. Providing care for ill family members has consistently been shown to compromise caregivers' physical, psychological, and spiritual health and their well-being (Au et al., 2010; Bainbridge et al., 2009; Gallagher et al., 2011; Gilliam & Steffen, 2006; Harmell et al., 2011; Khan et al., 2007; Lockenhoff et al., 2011; Mausbach et al., 2011; Mausbach et al., 2012; Merluzzi et al., 2011; Montoro-Rodriguez & Gallaher-Thompson, 2009; Perez et al., 2011; Romero-Moreno et al., 2011; Tang, 2009). Caregivers providing care to individuals with a variety of illnesses are at increased risk of developing adverse physical and psychological health effects, including depression, worsened immune system functioning, and increased rates of infections (Bainbridge et al., 2009; Gilliam & Steffen, 2006; Harmell et al., 2011; Merluzzi et al., 2011).

Caregiver burden refers to informal caregivers' physical and emotional responses to demands of caregiving that result from an imbalance in care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and social resources (Bainbridge et al., 2009). Consequences of caregiver burden are described as caregiver stress, and caregiver stress negatively affects the overall well-being of the caregiver (Bainbridge et al., 2009; Gallagher at al., 2011; Khan et al., 2007; Merluzzi et al., 2011; Perez et al., 2011; Saban, Sherwood, DeVon, & Hynes, 2010).

Caregiver stress is a global concept that has been reported in approximately 60% of caregivers (Family Caregiver Alliance, 2012a). Caregiver stress has been found to be associated with depression (Empeño et al., 2011; Gallagher et al., 2011; Gilliam & Steffen, 2006; Perez et al., 2011), anxiety (Empeño et al., 2011; Perez et al., 2011), sleep disturbance (Khan et al., 2007), emotional irritability (Bolden & Newsome-Wicks, 2008), loneliness, isolation, fatigue, and ailing health (Au et al., 2010). Stress is associated with worsened immune system functioning, increased rates of infections, inability to maintain social roles, and decreased sense of well-being (Bainbridge et al., 2009; Merluzzi et al., 2011).

Despite the high incidence of caregiver stress, not all caregivers experience similar negative aspects of caregiving (Gilliam & Steffen, 2006). Some caregivers experience significant distress; others report high levels of role satisfaction, sense of accomplishment, and emotional fulfillment (Lopez, Lopez-Arrieta, & Crespo, 2005). Researchers have identified an association between internal coping mechanisms and lower levels of stress resulting from caregiving demands (Bolden & Newsome-Wicks, 2008; Kreitler et al., 2007; Pearlin et al., 1990; Roscoe et al., 2009).

One internal coping mechanism that researchers have recently begun to investigate is self-efficacy. Self-efficacy is conceptualized as individuals' beliefs in their own ability to perform specific tasks (Bandura, 1977). Researchers have found an inverse relationship between stress resulting from caregiving and individuals' self-efficacy (Merluzzi et al., 2011).

Caregiver Self-Efficacy

Caregiver self-efficacy is conceptualized as individuals' beliefs in their ability to carry out activities and tasks specific to caregiving (Bandura, 2006). In regard to caregiving, self-efficacy theory suggests that individuals with higher levels of self-efficacy for performing tasks of caregiving have greater levels of success in completing the tasks, lower levels of psychological and physical illness, reduced rates of burnout, and greater levels of well-being than those with low levels of self-efficacy (Bandura, 2006).

Caregiver self-efficacy is a multi-dimensional construct that varies across caregiving task demands and changes over time (Bandura, 1977). Several dimensions have been described for caregiver self-efficacy, including self-efficacy for caregivers' self-care, self-efficacy for controlling caregivers' cognitions and upsetting thoughts specific to caregiving, self-efficacy for caregivers' coping, self-efficacy for managing care recipients' disruptive behaviors, and self-efficacy for managing care recipients' symptoms (Merluzzi et al., 2011; Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). Researchers have supported the multi-dimensionality of self-efficacy and have investigated the relationship between the multiple dimensions of self-efficacy and depression, burden, and physical health.

Depression

Depression is the most frequently cited negative consequence of caregiving (Au et al., 2010; Gallagher et al., 2011; Gilliam & Steffen, 2006; Mausbach et al., 2012; Merluzzi et al., 2011; Montoro-Rodriguez & Gallagher-Thompson, 2009; Perez et al., 2011; Romero-Moreno et al., 2011). In a study of 134 informal caregivers of patients with Alzheimer's disease, Au et al. (2010) found that higher levels of caregiver dependence were associated with higher levels of caregiver depression. Similar findings were reported in a study of 84 Alzheimer's disease caregivers in which researchers found an association between caregivers' depression and care recipients' declining functional status ($r = -.39$, $p = .001$) (Gallagher et al., 2011). Caregivers of Alzheimer's disease patients also report feelings of role overload. In a study of 62 elderly Alzheimer's caregivers, Mausbach et al. (2011) found a significant correlation between role overload and depression ($r = .46$, $p < 0.05$). Increases in perceived role overload were correlated with an increased number of caregivers' reported depressive symptoms (Mausbach et al., 2011). In a subsequent study of 126 Alzheimer's caregivers, Mausbach et al. (2012)

found a significant relationship between the presence of care recipient problematic behaviors and depression ($r = .36, p < 0.05$). Caregivers who reported the presence of more problematic behaviors reported higher levels of depression (Mausbach et al., 2012).

Various dimensions of self-efficacy have been inversely correlated with depression, including self-efficacy for obtaining respite, self-efficacy for managing disruptive behaviors, self-efficacy for controlling upsetting thoughts, self-efficacy for managing symptoms, self-efficacy for managing caregiving tasks, and self-efficacy for coping (Au et al., 2010; Gallagher et al., 2011; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009; Romero-Moreno et al., 2011). Researchers in all of the studies found significant inverse relationships between the self-efficacy dimension and depression. Research findings have supported the hypothesis that higher levels of self-efficacy are associated with lower levels of depression (Au et al., 2010; Gallagher et al., 2011; Mausbach et al., 2012; Montoro-Rodriguez & Gallagher-Thompson, 2009; Perez et al., 2011; Romero-Moreno et al., 2011).

Burden

Caregivers' perceptions of burden have been shown to predict the general health, mood, and satisfaction of caregivers (Khan et al., 2007). Khan et al. (2007) measured perceived burden in a study of 185 Latina and non-Hispanic white female caregivers of older adults with Alzheimer's disease. They found that caregivers providing care for individuals with more memory and behavior problems reported greater levels of burden ($r = .24, p < .05$). In another study of Alzheimer's disease patient caregivers, Au et al. (2010) found correlations between the lack of privacy and burden ($r = .76, p < 0.05$) and changes in caregivers social lives and burden ($r = .69, p < 0.05$). Gallagher et al. (2011), in a study of Alzheimer's disease caregivers, found an inverse relationship between care recipients' cognitive function and caregivers' perceptions of burden (r = -

.27, p = 0.015). They also found a relationship between care recipients' declining functional status and caregivers' perception of burden (r = -.50, p = .001).

Lockenhoff et al. (2011) found a significant correlation between caregivers' perceptions of their own health and caregivers' perception of burden. Individuals with high levels of subjective physical health had lower levels of perceived strain (r = -.40, p < .001); additionally, individuals with higher levels of subjective mental health had lower levels of caregiver burden (r = -.31, p < 001).

Self-efficacy has also been correlated with caregivers' perceived burden in a number of recent studies (Gallagher et al., 2011; Khan et al., 2007; Meluzzi et al., 2011; Montoro-Rodriguez & Gallagher-Thompson, 2009; Romero-Moreno et al., 2011). Researchers in three studies found significant relationships between self-efficacy and perceived burden. Perceived burden was inversely related to self-efficacy for symptom management (r = -.42, p < .0001) (Gallagher et al., 2011) and to self-efficacy for managing thoughts related to caregiving (r = -.21, p < 001) (Montoro-Rodriguez & Gallagher-Thompson, 2009). In a sample of 133 informal caregivers of individuals with a variety of illnesses, including cancer (52.1%), chronic obstructive pulmonary disease (COPD) (8.75%), stroke (5.95%), heart failure (HF) (9.5%), and dementia (6.1%), Merluzzi et al. (2011) found an inverse relationship between caregiver self-efficacy and burden (r = .-.37, p = .001).

One study was found that did not reveal a significant relationship between self-efficacy and burden (Perez et al., 2011); however the self-efficacy measure used in the study was a global self-efficacy measure. Self-efficacy measures must include the most relevant domains specific to the task demands (Bandura, 2006). Global self-efficacy instruments might not capture caregivers' confidence in their managing of specific caregiving demands.

Physical Health

Researchers have shown that chronically stressed individuals suffer from negative physical health consequences (Segerstrom & Miller, 2004). Researchers have concluded that caregivers are chronically stressed; however not all caregivers demonstrate compromised health. Researchers in two studies found physiologic advantages related to self-efficacy. Harmell et al. (2011) found that individuals with higher levels of self-efficacy for problem focused coping were more likely to have lower mean arterial blood pressure (MAP) than individuals with lower levels of self-efficacy when controlling for diet, exercise, and genetic determinants of hypertension. Similarly, Mausbach et al. (2011), in a study of Alzheimer's disease caregivers, found a positive association between role overload and increased levels of IL-6 when coping self-efficacy was low. Elevated levels of IL-6 have been linked with health morbidity and risk for cardiovascular disease (CVD).

Literature Critique

Findings of various studies have supported the possibility that higher self-efficacy may be predictive of physiologic and psychological advantages, perhaps by buffering chronic stress. Studies reviewed showed the relationships between self-efficacy and depression, burden, and physical health. Despite the significant findings, the studies were not without limitations. Caregiving stressors change over time and with the progression of illness (Pearlin et al., 1990). All of the studies reviewed were cross-sectional in nature which hinders the ability to draw conclusions about causality and directionality of effects.

Depression was investigated in a majority of the studies; however, depression was measured by a variety of instruments. Similarly, caregivers' perceived burden was measured by a variety of instruments, and although the depression and burden scales used to measure each of the concepts had good reliability and validity, inconsistent definitions and measures make it difficult to draw valid comparisons across studies. Measures were also based on subjective ratings, and although subjective measures have been linked to objective health indicators, future studies must include measures of both subjective and objective health.

Researchers used global measures of self-efficacy in many of the studies reviewed. Global measures are not specific to the informal caregiving experience. Global measures rate individuals' perceived confidence across a wide range of stressful situations. This limits researchers' ability to draw conclusions about specific activities or tasks.

A majority of the studies included samples comprised of Alzheimer's disease and dementia caregivers. Caregivers of individuals with other illnesses and disorders may not experience the same stressors as those of Alzheimer's disease and dementia. Samples were also primarily comprised of Caucasian women providing care for spouses. The selective sample does not reflect diversity of the overall US caregiving population. Studies must expand target populations to include male caregivers, ethnically and culturally diverse caregivers, and caregivers of individuals with other illnesses and disorders, such as those at the end of life.

Conclusion

Identification of factors that reduce stress resulting from informal caregiving is vital to the psychological and physical health of informal caregivers (Kreitler et al., 2007). Study findings illustrate the possibility that higher self-efficacy can have physiologic and psychological advantages, perhaps by buffering chronic stress. High levels of self-efficacy in caregivers have been associated with lower levels of depression, lower perceived burden, lower blood pressure, and decreased risk for cardiac disease (Au et al., 2010; Gallagher et al., 2011; Harmell et al., 2011; Lockenhoff et al., 2011).

In the future, the demand for family caregivers will likely outpace the supply (Raphael & Cornwell, 2008). The informal caregiving role is complex, and healthcare providers must recognize factors that may affect informal caregivers' development of caregiver stress. Despite an increased interest in the ability of self-efficacy to moderate the caregiving stress process, research has focused primarily on caregivers of Alzheimer's disease and dementia patients. More research is needed on caregivers of patients at the end-of-life, specifically on relationships between the self-efficacy of end-of-life caregivers and caregiver stress. The purpose of this research study was to determine the relationship between self-efficacy and stress among adult informal caregivers providing end of life care while controlling for SES. Research findings may lead researchers to develop interventions designed to enhance caregivers' self-efficacy.

Chapter Summary

Information in Chapter 2 focused on a review of the literature regarding informal caregiving. Literature related to the prevalence, economic value, demographics, and roles and responsibilities of informal caregivers was presented. Literature involving end-of-life caregiving, informal caregiving stressors, and consequences of caregiving was included. Finally, literature regarding caregiver self-efficacy was reviewed. This literature review provided the evidence to support the need for a study of the relationship between self-efficacy and stress in adult informal caregivers providing end of life care.

Chapter 3

Methods and Procedures

This chapter includes a description of the methods and procedures used to describe the relationship between caregivers' self-efficacy and caregivers' perceived stress in adult informal caregivers providing end-of-life care controlling for SES. The chapter also includes a description of the research design, sample, research setting, measurement methods, procedures, ethical considerations, and data analysis.

Research Design

A cross-sectional, associational design was used for this study. The purpose of the research study was to determine the relationship between self-efficacy and perceived stress in adult informal caregivers providing end-of-life care, controlling for caregivers' SES. This design was appropriate because few researchers have investigated the relationship between self-efficacy and perceived stress in adult informal caregivers providing end of life care.

Cross-sectional studies are less expensive and take less time to conduct than longitudinal studies. Data are gathered at a single point in time, so there is no requirement for follow-up and less opportunity for attrition; however, the design has limitations. The design prevents the calculation of incidence because the design lacks a series of events; additionally, rare predictors and causal relationships cannot be assessed well (Gliner, Morgan, & Leech, 2009); however the advantage of this design is that it allows the researcher to quantify associations among variables simultaneously (Gliner et al., 2009).

Sample

Population

The target population for this study included adult informal caregivers providing end-of-life care in North Central Texas. Adult informal caregivers included individuals who were at least 18 years of age (U.S. Department of State, 2012), were providing unpaid assistance to someone who was to some degree physically or mentally incapacitated, dying, and needed help. Recipients of care included individuals who were over the age of 18 years receiving end-of-life care. End-of-life care includes activities such as bathing, toileting, and managing symptoms of illness which are provided to individuals who need help with symptoms or impairment resulting from underlying irreversible, life-threatening disease (National Institutes of Health, 2004).

The accessible population included informal adult caregivers who were providing end-of- life care to individuals over 18 years of age with an underlying irreversible, life-threatening disease. There is not an inclusive registry of informal caregivers within North Central Texas, so randomization from an overall population, as probability sampling requires, was not an option. The accessible population therefore included a convenience sample of adult informal end-of- life caregivers recruited from community-based hospice agencies and personal contacts from North Central Texas.

Sample Size Calculations

The sample size for this study was determined using the G*power 3.1.3 program (Buchner, Erdfelder, & Faul, 1997). An a priori, linear multiple regression: fixed model, R2, deviation from zero was utilized to calculate the appropriate sample size. Previous research did not reveal an adequate estimation for effect size of self-efficacy on stress, so a postulated moderate effect size of 0.15 between caregiver self-efficacy and caregiver stress was used. This estimated effect size was supported by the identified theoretical framework. A two-sided alpha of 0.05, power of 0.80, a moderate effect size anticipated for self-efficacy of caregiving (0.15), and two predictors were used in the sample size calculation, resulting in a required sample of 77 end-of-life caregivers.

Inclusion and Exclusion Criteria

Participants in this study included cognitively intact, adult informal caregivers providing end-of-life care for an adult in North Central Texas. Non-English speaking caregivers were excluded from this study because of limited translational resources.

Research Setting

Participants completed the survey in a location of their choice. Most of the participants chose to complete the survey in their home.

Measurement Methods

Construct validity of the study was supported through the utilization of multiple measures that were congruent with the research question and theoretical framework. The three instruments administered to participants as part of the proposed research study have evidence of validity and reliability and have been utilized in previous studies involving informal caregivers. Caregiver self-efficacy was measured by the Caregiver Inventory (CGI); caregivers' perceived stress was measured by the Perceived Stress Scale (PSS); caregivers' perceived physical health status and perceived mental health status was measured using the Short Form12v2™ (SF-12v2™) Health Survey. The conceptual and operational definitions of the primary study variables are presented in Table 1. Permission to use the CGI was granted by Dr. Thomas Merluzzi on February 14, 2014 (Appendix A). Permission for use of the PSS is not necessary when used in nonprofit academic research or nonprofit educational purposes. Permission to use the SF-12v2™ was granted on February 22, 2014 (Appendix B). Along with the described instruments, participants were asked to complete a demographic questionnaire

(Appendix C) including questions such as caregivers' gender, age, ethnicity, and annual household income which served as a proxy for SES. Care recipients' primary illness, gender, age, and ethnicity were also measured. Demographic information assisted in describing the convenience sample and comparing it to the theoretical population, which allowed the primary investigator to judge the representativeness of the sample.

Table 1 Conceptual and Operational Definitions of Primary Study Variables

Study Variable	Conceptual Definition	Operational Definition
Caregivers' Self-Efficacy	Caregiver self-efficacy was conceptually defined as an internal mediator reflected in individuals' confidence in their ability to provide self-care and to manage caregiving demands including managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions (Merluzzi et al., 2011).	Operationalized by the total score on the CGI.
Caregivers' Perceived Stress	Caregivers' perceived stress was conceptually defined as a primary stressor reflected in the degree to which situations are perceived as taxing (Cohen & Williamson, 1988).	Operationalized by the total score on the PSS.
Caregivers' Perceived Physical and Mental Health Status	Caregivers' perceived physical and mental health status was conceptually defined as an outcome of the stress process reflected in caregiver's perception of their physical and mental well-being (Ware, Kosinski, & Keller, 2002).	Operationalized by the Physical and Mental Component Summaries of the SF-12v2™.

CGI

The CGI (Appendix D) is a non-disease specific measure of caregiver self-efficacy. Caregiver self-efficacy is conceptually defined as an internal mediator reflected in individuals' confidence in their ability to provide self-care and to manage caregiving demands. Caregiving demands include managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions (Merluzzi et al., 2011). The CGI's purpose, conceptual definition, and factor structure are consistent with the research framework and research question of the proposed study.

The CGI is a self-administered, norm-referenced questionnaire that includes 21 questions designed to measure caregivers' overall confidence in their ability to manage caregiving demands (Merluzzi et al., 2011). The questionnaire takes approximately fifteen minutes to complete. The 21 Likert-type items on the CGI have possible responses ranging from 1 for "not-at-all confident," to 5 for "moderately confident," to 9 for "totally confident." The questions are arranged into four sub-scales: managing medical information (three items), caring for the care recipient (seven items), caring for oneself (five items), and managing difficult interactions and emotions (six items).

The subscale mean represents the subscale score (subscale mean = sum of item scores/number of items in the subscale). A high subscale score of nine would indicate total confidence and high self-efficacy for the subscale; a low subscale score of 1 indicates a lack of confidence and low self-efficacy for the subscale.

The CGI also includes a total score. The total score is the sum of each subscale score. A high score of 36 would indicate that caregivers have a high level of confidence and high self-efficacy in their ability to manage caregiving demands; a low score of four indicates a lack of confidence or low self-efficacy in managing caregiving demands.

During development of the CGI, the authors generated evidence to support reliability and validity (Merluzzi et al., 2011).

PSS

The PSS (Appendix E) is a widely used, self-report, one-dimensional psychological instrument that measures individuals' perceptions of stress in response to specific life situations. The PSS was designed to assess how unpredictable, uncontrollable, and overloaded respondents find their lives (Cohen, Kamarck, & Mermelstein, 1983). Specifically, the PSS is a measure of the degree to which situations are appraised as taxing (Cohen & Williamson, 1988). The survey is an empirically established index of general stress appraisal and should take about 10 minutes to complete. There are 10 Likert-type items on the PSS. Each item has possible responses ranging from 0 for "never" to 4 for "very often." Total scores on the PSS are calculated by summing the scores on the individual items and can range from 0 to 40. Higher scores on the PSS indicate higher levels of stress; lower scores on the PSS indicate lower levels of stress. The instrument has evidence of reliability and validity for use in the general population (Cohen & Williamson, 1988).

SF-12v2™

The SF-12v2™ (Ware et al., 2002) (Appendix F) provides a generic profile of functional health and well-being. The instrument was developed from the original Short Form Health Survey-36, which originated from the Medical Outcomes study by the Research and Development Corporation. The SF-12v2™ has been widely recommended for health status monitoring and evaluating health changes over time (Ware et al., 2002).

The SF-12v2™ is a self-administered questionnaire and includes 12 Likert-type questions (Table 2) (Ware et al., 2002). The instrument produces two summary measures of self-perceived health including physical and mental health component summaries. The physical health components include four health attributes: a) physical functioning, including mobility and ability to perform activities of daily living; b) bodily pain (whether individuals experience pain and to what degree this pain interferes in their daily lives); c) role limitations resulting from physical health problems, including physical health limitations; and d) general health perceptions, including disease exacerbations or worsened health. The mental health components include four attributes: a) general mental health, including the presence of anxiety and depression; b) role limitations due to emotional problems; c) social functioning (participation in social events); and d) vitality, specifically energy and fatigue levels (Table 2). The anticipated length of time required to complete the SF-12v2™ is five to ten minutes (Ware et al., 2002).

The SF-12v2™ is weighted and summed to provide summary scores for physical and mental health (Ware et al., 2002). Physical and mental health summary scores are computed using the scores of twelve questions and range from 0 to 100, where a zero score indicates the lowest level of health and 100 indicates the highest level of perceived health. Each scale is scored to have the same mean and standard deviation in the SF12v12 general population database. Anytime a subscale score is less than the 50th percentile rank, health status is considered below average for the SF12v12 population database. The summary scores will be calculated using a computer program provided by Quality Metric Incorporated. The instrument has evidence for reliability and validity (Ware et al., 2002).

Table 2 SF12v12 Model

Measure	Summary Measure	Likert Scale	Responses (Low to High)
Physical Functioning (2 items; # 2a, 2b)	Physical Health	1-3	Not Limited at All to Limited a Lot
Role Limitations, Physical (2 items; # 3a, 3b)	Physical Health	1-5	None of the Time to All of the Time
General Physical Health (1 item; # 1)	Physical Health	1-5	Poor to Excellent
Bodily Pain (1 item; #5)	Physical Health	1-5	Not at All to Extremely
Social Functioning (1 item; #7)	Mental Health	1-5	All of the Time to None of the Time
Role Limitations, Emotional (2 items; # 4a, 4b)	Mental Health	1-5	All of the Time to None of the Time
General Mental Health (2 items; # 6a, 6c)	Mental Health	1-5	All of the Time to None of the Time
Vitality (1 item; #6b)	Mental Health	1-5	All of the Time to None of the Time

Procedures

Recruitment

After Institutional Review Board (IRB) approval was obtained from the University of Texas at Arlington (UTA), the researcher contacted directors of community-based hospice agencies in order to obtain permission to recruit caregivers for the research study. Permission to recruit caregivers of patients seeking agency services was received from two community-based hospice agency directors, and an acknowledgement letter (Appendix G) and sample questionnaire packet was sent to each agency.

After agency approval, participants were recruited through community-based hospice agency visits. The researcher delivered research packets containing an information letter (Appendix H), the CGI, the PSS, the SF12v12, a demographic questionnaire, and a pre-addressed stamped envelope. The researcher instructed hospice staff (registered nurses, chaplains and social workers) about eligibility requirements for the study and their role in delivery of the research packets to eligible caregivers. Hospice staff (registered nurses, chaplains and social workers) was provided a script (Appendix I) to use when they delivered research packets to eligible participants. The script included instructions to caregivers to contact the researcher at any point if they had questions about the study procedures. The packet included the researcher's name and contact information on the outside and instructions to call the researcher with any questions about the study. Caregivers who decided to participate in the research completed the research packet (including completion of the demographic questionnaire and surveys) in a location of their choice. Participants returned the completed questionnaires to the researcher at the UTA College of Nursing via U.S. mail using the self-addressed, stamped envelope included in the research packet.

Approval from the UTA IRB was also obtained to allow recruitment via personal contact of adult informal caregivers providing end-of-life care. The additional participants included caregivers of patients receiving end of life care in their homes but who were not necessarily receiving formal hospice care. The researcher delivered to the personal contacts research packets containing an information letter (Appendix J), the CGI, the PSS, the SF12v12, a demographic questionnaire, and a pre-addressed stamped envelope to give to caregivers who met eligibility criteria. The researcher instructed the personal contacts to read the script (Appendix K) to explain to caregivers why they were receiving information about the study. Caregivers who decided to participate in the research completed the research packet (including completion of the demographic questionnaire and surveys) in the location of their choice. Participants returned the completed questionnaires to the researcher at the UTA College of Nursing via U.S. mail using the self-addressed, stamped envelope included in the research packet.

Research Procedure

The research procedure included having participants complete the CGI, the PSS, the SF-12v2™, and a demographic questionnaire in a location of their choice. The questionnaires took about 45 minutes to complete. The questionnaires did not contain any identifying information. The questionnaires had a participant number so that the data from each participant's questionnaires could be analyzed together.

Data from the completed questionnaires were kept on an electronic spreadsheet and saved on an encrypted jump drive. Collected information was not shared with anyone, and the data may be used indefinitely.

Ethical Considerations

Written permission to conduct the proposed study was obtained from the IRB at UTA (Appendix L). The UTA IRB was the IRB of record because the individual hospice agencies do not subscribe to an IRB. The risk benefit ratio for this study was minimal. The study possessed no risks for physical harm. Participants were informed that there was a minimal risk for emotional discomfort when answering some questions on the questionnaires. Participants were informed that, if any of the questions caused discomfort, they could skip those questions or stop answering the questions and withdraw from the study at any time. Potential risks and benefits were clearly stated in the informational letter that potential participants received in the research packet along with the researcher’s contact information which could be used for additional questions or comments. Participants were not likely to benefit in any way from participating in the study; however, research findings might benefit informal caregivers providing end-of-life care in the future. The researcher will share research findings through scholarly activities including published articles and presentations.

Data Analysis

Preparation for Data Analysis

Prior to statistical analysis, data were assessed for missing data pieces and identifiable inconsistencies. Values were missing from the age and annual household income variables. All other responses on the surveys were complete. Two values were missing from the age variable. Mean age was imputed because missing age data were judged to be missing at random. On the other hand, nineteen cases (25%) did not report annual income. Survey literature reports a typical nonresponse rate to questions concerning income between 20% and 40% (as cited in Yan, Curtin, & Jans, 2010). These data were determined not to be missing at random which limited the ability to continue with analyses as planned. Data analysis was performed with the cases deleted; however a large variance in annual income data ($10,000 - $200,000) prevented multivariate regression analysis. It was determined that analyses using the data would not result in a fair representation of the sample population, so further analysis of SES (annual household income) was removed from the study.

One subject reported the lowest possible endorsement for every single item on all tools. A family member identified the subject as being unusually negative through a hand-written note on the returned survey. Given these circumstances extremity bias was suspected. The case was retained for utilization of demographic data, but the case was withdrawn from subsequent data analyses.

Description of the Sample

Statistical analysis was completed using the Statistical Package of Social Science 20 (SPSS). Descriptive statistics were used to summarize variables in order to describe the sample. Frequencies and percentages were calculated for demographic variables measured at the nominal level: caregivers' and care recipients' gender and ethnicity and care recipients' residence. Frequency, percent, mode, median, range, mean, and standard deviation were calculated for demographic variables measured at the interval level: caregivers' and care recipients' age and caregivers' perceived physical health and perceived mental health.

Descriptive Statistics were used to examine criterion and predictor variables: caregivers' self-efficacy, subscale scores obtained from the CGI (managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions), and caregivers' perceived stress. Criterion and predictor variables were described according to range of scores, means, standard deviations, and skew.

Research Question

The following research question was answered in the proposed study: What is the relationship between perceived stress and self-efficacy in adult informal caregivers providing end of life care? Linear regression analysis was planned to answer this question.

Linear regression relies on assumptions of linearity, reliability of measurement, homoscedasticity, and normality (Osborne & Waters, 2002). When assumptions are not met, results may not be trustworthy, resulting in a Type I or Type II error, or over-or under-estimation of significance or effect size (Gliner et al., 2009). Linearity was evaluated using p-p plots. The internal consistency reliability of study instruments in this study sample was calculated using Cronbach's alphas. Homoscedasticity was evaluated by the regression standardized residual plot using perceived stress as the criterion variable, and normality was assessed by visual inspection. It was determined that the assumptions were met and linear regression analysis could be performed.

A univariate regression was computed in order to explore the relationship between the criterion variable of caregivers' perceived stress (PSS score) and the predictor variable of caregiver self-efficacy (CGI total score). Total PSS and the total score on the CGI were included in the regression model. This determined if caregivers' self-efficacy predicted caregivers' perceived stress. A two-sided alpha of 0.05 was used to determine significance.

Caregiver self-efficacy is a multi-dimensional construct that varies across caregiving task demands (Bandura, 1977). Global measures of self-efficacy rate individuals' perceived confidence across a wide range of stressful situations. This limits researchers' ability to draw conclusions about specific activities or tasks. In order to account for the multiple dimensions of caregiving, CGI subscales replaced the total CGI score in a second multivariate regression analysis. Total PSS score and CGI subscale scores (managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions) were included in the regression model. This would show which (if any) efficacy domain(s) significantly predicted perceived stress. A two-sided alpha of 0.05 was used to determine significance.

Summary

This chapter included a description of the methods and procedures used in this study. Research design, sample, research setting, measurement methods, procedures, ethical considerations, and data analysis were described.

Chapter 4

Findings

The findings of this cross-sectional, associational study are presented in this chapter. These results provided information regarding the relationship between caregivers' self-efficacy and perceived stress in adult informal caregivers providing end-of-life care. Sample characteristics are presented first followed by data to answer the research question.

Study Results

Sample Description

Study participants included a convenience sample of 78 cognitively intact, English speaking, adult informal caregivers who were providing end-of-life care for an adult in the North Central Texas Region. The sample of caregivers was 74% female and 95% White and averaged 61 years of age. Caregivers were caring for individuals with a variety of illnesses, most frequently reported as cancer (37.7%). The sample of care recipients was primarily female (53%) and White (92%) and averaged 77 years of age. A majority of care recipients resided with the caregiver (64%), and all of the sampled caregivers were receiving some level of caregiving support from an agency that provided end-of life supportive services. Further description of the sample is presented in Table 3 and Table 4.

Table 3 Frequencies and Percentages of Demographic Variables (N = 78)

Variable	Response	Frequency and Percentage f(%)
Caregivers’ Gender	Male Female	20 (25.6) 58 (74.4)
Caregivers’ Ethnic Group	White Black Hispanic Other	74 (94.9) 1 (1.3) 1 (1.3) 2 (2.6)
Care Recipients’ Residence (Does the individual you are caring for live with you?)	Yes No	49 (62.8) 29 (37.2)
Care Recipients’ Gender	Male Female	36 (46.2) 42 (53.8)
Care Recipients’ Ethnic Group	White Black Hispanic Other	72 (92.3) 1 (1.3) 1 (1.3) 4 (5.1)
Care Recipients’ Primary Illness	Cancer Heart Problems Old Age Dementia Renal Failure Multiple Illnesses Stroke Respiratory Disease Other	29 (37.7) 14 (18.2) 9 (11.7) 10 (11.7) 4 (5.2) 3 (3.9) 3 (3.9) 3 (3.9) 3 (3.9)

Table 4 Descriptive Statistics of Continuous Demographic Variables (N = 78)

Variable	Mode	Median	Range of Scores	Mean (SD)
Caregivers’ Age	64	63	21 - 90	61.21 (13.91)
Care Recipients’ Age	86	79	32 - 97	77.01 (12.85)
Perceived Physical Health	59.38	54.43	24.28 - 65.87	51.66 (9.70)
Perceived Mental Health	22.77	43.94	21.57 - 66.23	43.60 (11.21)

Caregivers' self-efficacy (CGI total score), CGI subscale scores (managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions), and caregivers' perceived stress (PSS score) are presented in Table 5. The table includes the range of scores, the mean, the standard deviation, the skew, and the Cronbach's alpha.

Table 5 Descriptive Statistics of Dependent and Predictor Variables (N=77)

Study Variable	Range of Scores	Mean	Standard Deviation	Skewness Statistic	Cronbach's alpha
Caregivers' Self-Efficacy (CGI total score)	13.36 - 36.00	26.81	5.10	- .58	.93
Managing Medical Information	2.67 - 9.00	7.20	1.73	- .86	.84
Caring for the Care Recipient	3.86 - 9.00	7.73	1.35	- 1.28	.89
Caring for Oneself	1.00 - 9.00	5.46	1.83	- .31	.87
Managing Difficult Interactions and Emotions	2.83 - 9.00	6.40	1.46	- .33	.74
Caregivers' Perceived Stress	0 - 33	18.26	7.17	- .27	.85

Caregiver self-efficacy

Caregiver self-efficacy was measured by the CGI total score. Cronbach's alphas of the instrument indicated good to excellent reliability. Cronbach's alphas ranged from .74 to .89 for the subscales and .93 for the total scale. Caregivers' reported a moderate level of confidence in their ability to manage caregiving demands which was indicated by the CGI total score ($\bar{x}$ = 26.81; SD = 5.10). Caregiving demands measured by the CGI total score included: managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions (Merluzzi et al., 2011). Caregivers in the sample reported the highest level confidence in caring for the care recipient ($\bar{x}$ = 7.73; SD = 1.35). Caregivers reported the lowest level of confidence in caring for oneself ($\bar{x}$ = 5.46; SD = 1.83).

Perceived stress

Caregiver stress has been previously reported in approximately 60% of caregivers (Family Caregiver Alliance, 2012a). Scores of 20 or greater on the PSS indicate high levels of perceived stress (Ware et al., 2002). Forty-three percent of surveyed caregivers in this sample scored 20 or greater on the PSS. The average score on the PSS was 18.26 (SD = 7.17). Cronbach's alpha of the PSS scale indicated good internal consistency (α = .85).

An independent samples t-test was performed to detect differences in PSS scores between caregivers who were less than 60 years of age and caregivers who were 60 years of age or older. The independent samples t-test failed to detect a significant difference in PSS scores between caregivers in the different age cohorts. An additional independent samples t-test was performed to detect differences in PSS scores among caregivers who lived with the care recipient and caregivers who did not live with the care recipient. The independent samples t-test failed to detect a significant difference in PSS scores between the two groups. The homogeneity of the sample prevented the assessment of group differences on gender and ethnicity.

Table 6 Independent Samples t-test for PSS Scores

	Mean (SD)	t	Significance
Age < 60 years of age 60 years of age or older	17.76 (7.34) 18.84 (6.70)	t = - .642	p = .523
Care Recipient Residence Lived with care recipient Did not live with care recipient	19.52 (6.34) 16.54 (7.95)	t = - 1.81	p = .075

Perceived health

Caregivers completed the SF12v12 which provided two summary measures of self-perceived health: physical health and mental health. Higher scores indicate better functioning and well-being. Subscale scores less than the 50th percentile rank indicate below average results (Ware et al., 2002). Surveyed caregivers reported above average perceived physical health (51st percentile rank) and below average perceived mental health (43rd percentile rank).

Four health attributes are included in the perceived mental health component summary measure: general mental health, including the presence of anxiety and depression; role limitations due to emotional problems; social functioning (participation in social events); and vitality, specifically energy and fatigue levels. Caregivers' percentile rankings on individual attributes of the SF12v12 ranged from 43.45 to 48.68 and are included in Table 7. SF12v12 scoring software did not include reliability statistics.

Table 7 Caregivers’ Rankings on Mental Health Attributes of SF12v12

Mental Health Attributes of SF12v12	Percentile Rank (using SF12v12 general population norm)
Mental Component Summary	43.45
Vitality (energy and fatigue levels)	48.68
Social Functioning (participation in social events)	45.12
Role Limitations due to Emotional Problems	44.06
Mental Health (presence of anxiety and depression)	44.02

A Pearson product-moment correlation was performed to determine the relationship between caregivers’ perceived stress scores and caregivers’ mental health percentile rankings. The data showed no violation of normality, linearity, or homoscedasticity. There was a significant negative correlation between caregivers’ perceived stress and caregivers’ mental health percentile rankings ($r = -.586$, $p < .001$).

Research Question

The aim of the study was to determine the relationship between caregivers’ self-efficacy (CGI total score) and perceived stress (PSS score) in adult informal caregivers providing end of life care. A univariate linear regression analysis was performed in order to determine whether caregiver self-efficacy (CGI total score) had a significant relationship with perceived stress (PSS). Caregiver self-efficacy (CGI total score) was significantly related to perceived stress (PSS scores). Caregiver self-efficacy had a significant, negative correlation with perceived stress ($r = -.53$; $p < .01$) (Table 8). Caregiver self-efficacy explained 28.3% of the variance in PSS scores.

Table 8 Univariate Linear Regression:

Caregiver Self-Efficacy and Perceived Stress (N = 76)

Predictor	Mean (SD)	Unstandardized (B) coefficient	t	Significance	95% Confidence Interval
Caregiver Self-efficacy (CGI total score)	26.74 (5.08)	- .740	- 5.41	* p < .01	- 1.01 to -.47

Because self-efficacy is a multi-dimensional construct, a multivariate regression was performed to explore the relationship between CGI subscales (managing medical information, caring for the care recipient, caring for oneself, and managing difficult interactions and emotions) and perceived stress (PSS score). Multivariate regression analysis revealed a significant relationship between the CGI subscale of caring for oneself and perceived stress (PSS score). Multivariate regression analysis failed to identify a significant relationship between additional CGI subscale scores and perceived stress (PSS score) (Table 9). Caring for oneself had a significant negative relationship with perceived stress (r = - .63, p < .01). Caring for oneself predicted 38% of the variance in PSS scores.

Table 9 Multivariate Regression: CGI Subscales and Perceived Stress

Predictor	Mean (SD)	Unstandardized (B) coefficient	t	Significance	95% Confidence Interval
Managing Medical Information	7.18	- .370	-.75	p = .46	- 1.36 to .620
Caring for the Care Recipient	7.72	.69	1.007	p = .32	- .672 to 2.04
Caring for Oneself	5.44	-2.10	-7.059	* p < .01	-3.145 to - 1.760
Managing Difficult Interactions	6.37	-.80	-1.24	p = .49	-2.07 to .49

Chapter Summary

This chapter included the findings of this cross-sectional, associational study. Sample characteristics were presented first followed by data to answer the research question. The results provided information regarding the relationship between caregivers' self-efficacy and perceived stress in adult informal caregivers providing end-of-life care.

Chapter 5

Discussion

Despite the recognized negative consequences of informal care, researchers have identified the potential for individuals' self-efficacy to buffer the negative influence of stress (Merluzzi et al., 2011). This cross-sectional, associational study examined the relationship between self-efficacy and perceived stress in adult informal caregivers providing end-of-life care. The conceptual framework utilized in this study was the Pearlin Stress Model (Pearlin et al., 1990). This chapter includes a discussion of the study findings, limitations, conclusions, implications, and recommendations for future research.

Interpretation of Major Findings

Sample Characteristics

The study included a sample of cognitively intact, English speaking, adult informal caregivers who were providing end-of-life care for an adult with a variety of life-limiting conditions in North Central Texas. The sample included a group of primarily female (74%), middle class, White (95%) informal caregivers with an average age of 61 years. Recipients of care included a group of female (53%), White (92%), older adults (age 60 and above) suffering a life limiting condition most often described as cancer (38%). Proportions of caregiver gender and age were similar to those reported in the end-of-life caregiving literature; however ethnic distribution of the sample differed from caregiving literature (Wolff et al., 2007). The under-representation of ethnic minorities may have been related to recruitment procedures including the utilization of two local community-based hospice agencies and personal contacts. Perhaps a sample more representative of the overall caregiving population might be obtained by expanding the number/geographic location of community-based hospice agencies as well using research assistants who have access to minority caregivers.

In this study, caregivers reported high levels of confidence in caring for the care recipient ($\bar{x}$ = 7.72; SD = 1.36). It is plausible that high levels of confidence in caring for the care recipient could be related to the receipt of caregiving support which was offered through an agency that provided end-of life supportive services. Surveyed caregivers reported a low level of confidence in caring for themselves ($\bar{x}$ = 5.44; SD = 1.83). This finding is consistent with findings from a similar study (Merluzzi et al., 2011) and is supported by the belief that caregivers ignore their own health and well-being while managing caregiving responsibilities (Family Caregiving Alliance, 2012c). It is possible that healthcare practitioners provide caregivers with support to manage the practical demands of caregiving, but healthcare practitioners do not provide caregivers with the tools needed for their self-care needs.

The sample participants reported above normal physical health. This finding was not supported by recent caregiver literature which indicates the presence of an increased number of health issues as a result of caregiving and lower levels of perceived physical health (Au et al., 2010; Perez et al., 2011). The presence of an increased number of health issues or changes in caregivers' perceptions of perceived physical health was not measured in this cross-sectional study. Longitudinal research is needed to detect changes in caregivers' perceptions of physical health over time and throughout the caregiving experience.

Despite reports of above normal physical health in the current sample, 82% of the surveyed caregivers rated perceived mental health below the SF12v12 general population. Forty-three percent of surveyed caregivers reported high levels of perceived stress and caregivers in this sample indicated the presence of more anxiety and depression than the general SF12V12 database population. These findings are supported throughout the literature. Researchers have found an association between the demands and emotional strains associated with caregiving and stress (Merluzzi et al., 2011), depression, and anxiety (Perez et al., 2011).

A significant negative correlation between caregivers' perceived stress and caregivers' mental health percentile rankings ($r = - .586$, $p < .001$) was identified in the current study, suggesting a negative relationship between perceived mental health and stress. Future studies are needed to validate this finding.

Research Question

According to the Pearlin Stress Process Model, intrinsic factors including self-efficacy influence the relationship between caregiving stressors and outcomes (Bolden & Newsome-Wicks, 2008; Pearlin et al., 1990; Roscoe et al., 2009). Intrinsic factors regulate the effects of stressors on health outcomes and play a significant role in caregivers' ability to manage the experience. Study findings support the Stress Process Model in which caregiver self-efficacy influences caregiving outcomes. In the present study, caregiver self-efficacy had a significant negative relationship with PSS scores ($p < .05$); higher levels of self-efficacy were associated with decreased perceived stress. These findings are congruent with previous research findings. Merluzzi et al. (2011) identified an inverse relationship between stress resulting from caregiving and individuals' self-efficacy.

The total CGI scores reflected the multi-dimensional nature of caregiving efficacy, so an additional analysis of data from the CGI subscales was performed. Multivariate regression revealed a significant negative relationship between caregivers' confidence in caring for oneself and perceived stress ($p < 0.05$). These findings indicate that higher levels of confidence in one's ability to care for oneself are associated with decreased stress. The findings of the present study are consistent with other caregiver studies. In a study by Mausbach et al. (2012), caregivers reported feelings of overload and reported the inability to meet their own personal needs which led to feelings of stress. Additionally, caregivers have reported sleep disturbances, little time for themselves, and disruptions in personal schedules (Khan et al., 2007; Montoro-Rodriguez & Gallaher-Thompson, 2009; Perez et al., 2011). Caregivers' inability to maintain social roles has also been related to decreased sense of well-being in previous studies (Bainbridge et al., 2009; Merluzzi et al., 2011).

In this sample, caregivers' confidence in their ability to manage medical information, to care for the care recipient, and to manage difficult interactions was not significantly associated with perceived stress. It is possible that, in this sample, caregivers' confidence in managing the tasks of caregiving (managing medical information, caring for the care recipient, and managing difficult interactions) was associated with end-of-life services they were receiving. Agencies involved with the caregivers in this sample may have given caregivers the education and support needed to care for the care recipient; however caregivers may not have been given the education and support needed to care for themselves. Future research should focus on the development of pathways of self-care for caregivers, including physical, mental, emotional, spiritual, and social mechanisms.

According to the Stress Process Model, SES has the potential to influence all aspects within the framework including caregiver stress (Pearlin et al., 1990). Even through SES could be a confounder, the variable was removed from analysis because of non-random missing data and a large variance in reported income. It is not known whether SES might have been related to perceived stress in this sample of caregivers.

Study Limitations

The study population included a convenience sample of informal caregivers who were receiving some level of caregiving support from an agency that provided end-of life supportive service because this segment of the population was most accessible. Caregivers from the sample may be more likely to be proactive enough to be receiving help. Participants receiving support may also have higher self-efficacy than caregivers not receiving support; additionally, perceived stress levels of individuals receiving support may be different from those who are not receiving support. Although end of life caregivers who are not receiving support services may be different in terms of their stress levels and self-efficacy, it was not feasible to obtain a sample that includes this segment of the population for this study. Future studies should include caregivers who are not receiving supportive services.

Caregiving stressors change over time and with the progression of the illness (Pearlin et al., 1990). The cross-sectional nature of the present study hindered the ability to study changes over time. It also prevented the ability to draw conclusions about causality and directionality of effects.

Conclusions

Despite study limitations, several conclusions can be drawn from this study. First, caregiver self-efficacy is associated with perceived stress in White, adult, female caregivers caring for White, older adults suffering a variety of life limiting conditions. Findings support the Stress Process Model and increase evidence in support of the promising potential of caregiving self-efficacy. Findings also highlight the importance of caregivers’ confidence in providing self-care and support the notion that caregivers with more confidence in their self-care have less perceived stress.

Implications

Study findings have important implications for healthcare. The importance of caregiver self-efficacy and caregiver self-care was supported by the study findings. Healthcare providers need to recognize the importance of caregiver self-efficacy. Healthcare providers must identify and support the needs of caregivers to strengthen ability to manage the demands of caregiving. Healthcare providers should include an assessment of caregivers' self-care needs and self-care resources. Healthcare practitioners should educate and support caregivers in the utilization of effective self-care actions.

Recommendations for Future Research

Although end of life caregivers who are not receiving support services may be different in terms of their stress levels and self-efficacy, it was not feasible to obtain a sample that includes this segment of the population. Future studies of end-of-life caregivers who are not receiving supportive services should be conducted.

Participants from diverse backgrounds should be recruited to increase the likelihood that a more diverse sample might be obtained. Socioeconomic status was removed from analysis because of a large variance in reported annual income data. Future studies should employ alternative methods to assess SES so that SES can be included in data analysis.

Stress and self-efficacy are dynamic characteristics that have the potential for change in response to changing situations. Future research should therefore include longitudinal studies in order to measure changes in stress and self-efficacy over time.

Future research should include assessment of caregivers' self-care needs and self-care resources. The results of those studies could be used to help develop interventions to promote caregivers' self-care efficacy which should be tested in future research studies.

High levels of role satisfaction, sense of accomplishment, and emotional fulfillment (Lopez, Lopez-Arrieta, & Crespo, 2005) have been recognized as positive outcomes of caregiving. Additional research should focus on positive aspects of caregiving.

Chapter Summary

This chapter included a discussion of the findings of this study within the context of current literature. Study limitations, conclusions, and implications were also described. In addition, recommendations for future research were presented.

Appendix A

Permission to Use the CGI

Re: Request for permission to use the CGI

Thomas Merluzzi []

You replied on 2/14/2014 5:17 PM.

Sent: Friday, February 14, 2014 4:34 PM

To: Hampton, Michelle M

Michelle. Please use the CGI. Hope you project come out well. The self-care aspect if the CGI is particularly interesting. Tom

Sent from my iPhone

On Feb 14, 2014, at 4:01 PM, "Hampton, Michelle M" <mhampton@uta.edu> wrote:

> Dr. Merluzzi

> I am a PhD in Nursing student currently enrolled at the University of Texas at Arlington. I am studying end-of-life informal caregivers and am interested in caregiving self-efficacy and caregiver stress. I am interested in using the Caregiver Inventory for my dissertation research and am requesting permission to use the instrument. I have designed a correlational study with the following purpose: The purpose of the research study is to determine the relationships between caregiving self-efficacy and caregivers' perceived stress among adult informal caregivers providing end of life care controlling for caregivers' annual household income, caregivers' ethnicity, caregivers' age, caregivers' gender, and caregivers' perceived health status.

>

> Will you grant me permission to use the Caregiver Inventory? I am defending my proposal on 4/21 with the plan to survey caregivers beginning in May 2014.

>

> Thank you,

> Michelle Hampton.

Appendix B

Permission to Use the SF12V12

OPTUM

NON-COMMERCIAL LICENSE AGREEMENT
Office of Grants and Scholarly Research (OGSR)

License Number: QM023670

Licensee Name: Michelle Hampton c/o University of Texas at Arlington

Licensee Address: 710 Rambling Court, , Granbury, TX 76049

Approved Purpose: Non-commercial academic research and/or thesis – Unfunded Student.

Study Name: The Relationship Between Caregiving Self-Efficacy and Caregiver Stress in End-of-Life Informal Caregivers
Study Type: Thesis/Dissertation Study
Data Collection Method: Paper

Therapeutic Area: Wellness & Lifestyle

Royalty Fee: None, because this License is granted in support of the non-commercial Approved Purpose

Other Definitions: As indicated on Appendix B "License Agreement – Details", including without limitation: Licensed Surveys, Modes of Administration, Fees, Administrations, Services, Approved Languages and (if applicable) Study Term

Licensee accepts and agrees to the terms of this Non-Commercial License Agreement (the "Agreement") from the Office of Grants and Scholarly Research (OGSR) of OptumInsight Life Sciences, Inc. (f/k/a QualityMetric Incorporated) ("OptumInsight") as of the date of last signature below (the "Effective Date").

Subject to the terms of this Agreement, including the OptumInsight Non-Commercial License Terms and Conditions attached as Appendix A: OptumInsight grants to Licensee, and Licensee accepts, a non-exclusive, non-transferable, non-assignable, non-sublicensable worldwide license to use, solely for the Approved Purpose and during the License Term, the Licensed Surveys in the authorized Data Collection Methods, Modes of Administration, and Approved Languages indicated on Appendix B and to administer the Licensed Surveys only up to the approved number of Administrations (and to make up to such number of exact reproductions of the Licensed Surveys necessary to support such Administrations) in any combination of the specific Licensed Surveys and Approved Languages, Data Collection Methods, and Modes of Administration and to use any related software provided by OptumInsight.

Capitalized terms used in this Agreement shall have the meanings assigned to them above, or in Appendices A and B attached hereto. Appendices A and B attached hereto are incorporated into and made a part of this Agreement for all purposes.

EXECUTED, as of the Effective Date, by the duly authorized representatives as set forth below.

OptumInsight Life Sciences, Inc. [OptumInsight]	**Michelle Hampton c/o University of Texas at Arlington** [Licensee]
Signature:	Signature:
Name: G. Gardner	Name: Michelle Hampton
Title: President and COO	Title: Student Researcher
Date: 03/31/2014	Date: 3/22/14

Filename: University of Texas at Arlington Michelle Hampton
Lic. No.: «Sales_Header_No»
Template: OGSR Unfunded Student LA - 2014-01-13

an OptumInsight company

Page 1 of 5

Appendix C

Demographic Questionnaire

Please check the appropriate spaces or write the answers in the blanks.

These questions will let the researcher know more about you.

What is your gender?

Male _____ Female _____

How old are you? ________

What is your ethnic group?

White ______

Black _____

Hispanic _____

Other _____

If you selected other, please write your ethnic group _______________________

What is your average household income to the nearest $10,000? _________________

The following questions are about the person for whom you are providing care.

What is the care recipient’s primary illness? ____________________________

Does the individual you are caring for live with you?

Yes _____ No _____

What is the care recipient’s gender?

Male _____ Female _____

How old is the individual you are caring for? _______

What is the care recipient’s ethnicity?

White ______

Black _____

Hispanic _____

Other _____

If you selected other, please write your ethnic group _______________________

Is the care recipient currently receiving hospice care? Yes _____ No ____

Is the recipient of care receiving any formal supportive services? Yes _____ No ____

If the recipient is receiving formal supportive services, what formal services are being provided?

Appendix D

Caregiver Inventory

This questionnaire contains many things that a person might do when caring for a person with an illness. We are interested in how confident you are that you can do those things. Make sure your ratings reflect your confidence whether or not you have done in the past. So, your ratings reflect your confidence that could do those things in the new future.

Please read each numbered item. Then rate that item on how confident you are that you can accomplish the behavior. Circle a number on the scale. If you circle ‘1’ you would be stating that you are not-at-all confident that you can accomplish that behavior. If you circle a ‘9’ you would be stating that you are totally confident that you can accomplish that behavior. Numbers in the middle of the scale indicate that you are moderately confident that you can accomplish that behavior.

Please rate the items. If you are not sure about an item, please rate it as best you can.

(**Scale 1-9; Not at all Confident, Moderately Confident, Totally Confident**)

Coping with information overload	1	2	3	4	5	6	7	8	9
Listening and learning from the person as to how to care better for him/her	1	2	3	4	5	6	7	8	9
Letting go of things I can’t control	1	2	3	4	5	6	7	8	9
Expressing negative feelings about the illness	1	2	3	4	5	6	7	8	9
Maintaining hope	1	2	3	4	5	6	7	8	9
Being able to notice the ‘good moments” in caregiving when they occur	1	2	3	4	5	6	7	8	9

Allowing the person to have and express his/her own feelings	1	2	3	4	5	6	7	8	9
Assisting the person with Activities, such as feeding, washing, dressing, or toileting	1	2	3	4	5	6	7	8	9
Continuing to take care of yourself (for example: exercise, diet, sleep)	1	2	3	4	5	6	7	8	9
Talking openly and honestly with the person	1	2	3	4	5	6	7	8	9
Continuing to engage in personal activities that you like to do	1	2	3	4	5	6	7	8	9
Talking about death and dying	1	2	3	4	5	6	7	8	9
Providing emotional support to the person I’m caring for	1	2	3	4	5	6	7	8	9
Understanding medical information from doctors, nurses or other sources	1	2	3	4	5	6	7	8	9
Seeking support for yourself	1	2	3	4	5	6	7	8	9
Dealing with feelings of helplessness	1	2	3	4	5	6	7	8	9
Dealing with the person expressing negative feelings toward you when they occur	1	2	3	4	5	6	7	8	9
Assisting and encouraging the person in following through with all treatments and taking all prescribed medications	1	2	3	4	5	6	7	8	9
Asking physicians and nurses questions	1	2	3	4	5	6	7	8	9
Dealing with criticism from others	1	2	3	4	5	6	7	8	9
Maintaining as close relationship with the person I’m caring for	1	2	3	4	5	6	7	8	9

Appendix E

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please rate the question on how often you felt or thought a certain way. Circle the number that best fits how often you felt or thought that way.

(Scale 0: Never, 1 Almost Never, 2 Sometimes, 3 Fairly Often, 4 Very Often)

1. In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3. In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the last month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the last month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Appendix F

SF12v12

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 Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
b Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

3. **During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

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

4. **During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (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 Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. **During the past week, how much did pain 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 week</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 week</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 week</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with 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!

Appendix G

Acknowledgement Letter (Sample)

Thank you so much for taking the time to learn more about my dissertation research. The purpose of this study is to investigate the relationship between caregivers' confidence in providing care and stress in adult informal caregivers providing end of life care.

Participants in this study will include adult informal caregivers who are providing end-of-life care for an individual over the age of 18 years. Non-English speaking caregivers will be excluded from this study because of limited translational resources. It is assumed that the caregiver is cognitively intact.

Three valid and reliable instruments will be administered to participants as part of the research study. Self-efficacy will be measured by the Caregiver Inventory (CGI); perceived stress will be measured by the Perceived Stress Scale (PSS); Overall health status will be measured using the Short Form12v2™ (SF-12v2™) Health Survey.

Participants will also be asked to answer a series of demographic questions. The questionnaires should take about 45 minutes to complete. The questionnaires will not contain any identifying information; participants' responses will be kept anonymous and confidential. Data from the questionnaires will be kept on an electronic spreadsheet and saved on an encrypted jump drive. Collected information will not be shared with anyone and the data may be used indefinitely.

I will assemble research packets which will include a letter containing my contact information for specific study questions, the three survey instruments, and the demographic questions. The packets will also include a stamped envelope that is pre-addressed with the University of Texas at Arlington College of Nursing address.

I will deliver the packets to the agency for distribution. I will provide information for your staff on the study including their role. Hospice staff will distribute the packets to caregivers who meet study criteria and will ask caregivers' to complete the questionnaire. Completed questionnaires will be mailed to the University of Texas at Arlington College of Nursing via the included stamped envelope.

Please feel free to contact me for any additional questions or concerns. I look forward to beginning this research study.

Michelle Hampton, MSN, RN, CCRN
PhD Nursing Candidate, University of Texas at Arlington, College of Nursing
mhampton@uta.edu;

I ____________________________________ authorize Michelle Hampton to gain access to patient caregivers
at ____.

____
Signature and Date

Appendix H

Informational Letter

Dear Caregiver,

My name is Michelle Hampton, and I am a graduate student completing a PhD in Nursing at the University of Texas at Arlington (UTA) College of Nursing. I am conducting a research study to find out more about the confidence and stress of informal caregivers providing end-of-life care. The title of my research study is “Self-efficacy of Caregiving and Caregiver Stress in Adult Informal Caregivers of Individuals at the End-of-Life.” The hospice agency that is helping you has agreed to help me with distributing information about my research study, but the research study is entirely separate from the care you are receiving through the hospice agency.

You are being asked to participate in this research study because you are providing “free care” for an adult with a serious, life-threatening illness. Your participation in this study is voluntary. Refusal to participate or discontinuing your participation at any time will involve no penalty or loss of benefits to which you are otherwise entitled. If you have questions or there is anything you do not understand, please contact me at to ask any questions.

PROCEDURES:

If you decide to participate in this research study, you will be asked to do the following:
Answer questions about yourself and the person for whom you are providing care.
Answer questions about your confidence in giving care.
Answer questions about your stress.
Answer questions about your health.
Return the questionnaires to me by U.S. mail in the enclosed self-addressed, stamped envelope.

It should take up to 45 minutes for you to answer the questions. There are no “right” or “wrong” answers, and you can skip any questions that you do not want to answer. If you decide to participate, please DO NOT put your name on any of the questionnaires so that your answers will remain anonymous. There will be about 80 informal caregivers in this study.

RISKS/BENEFITS/COMPENSATION/ALTERNATIVES:

There are no known likely risks to you for participating in this study unless answering questions about stress is upsetting to you. If any of the questions make you uncomfortable, you can skip those questions or stop answering the questions and not return the packet to the researcher. You can also contact Michelle Hampton at if you are upset or have any questions.

There are no known direct benefits to you from participating in this study, and you will not be paid for being in this study. The information learned from the study may help us understand how to help others providing “free care” for an adult with a serious, life-threatening illness. There are no alternative procedures for this study, but you can decide not to participate in the study or quit at any time with no consequence. Your decision to participate or not to participate in the study will not affect any care you are receiving from the hospice agency.

CONFIDENTIALITY:

To protect your confidentiality, I am asking that you NOT write your name on any of the questionnaires or the envelope in which the questionnaires will be returned. All information collected from this study will be stored in a locked file cabinet at the UTA College of Nursing in the Center for Nursing Research for at least three (3) years after the end of this study. The results of this study may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained, the Secretary of the

Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law or as noted above. The IRB at UTA has reviewed and approved this study and the information within this information form. If in the unlikely event it becomes necessary for the IRB to review your research records, UTA will protect the confidentiality of those records to the extent permitted by law.

CONTACT FOR QUESTIONS:
If you have any questions, problems, or research-related medical problems at any time, you may call me, Michelle M. Hampton MSN, RN, CCRN, PhD Nursing Student, at or my faculty advisor, Lauri D. John, PhD, RN, CNS, at . You may call the Office of Research Administration, Regulatory Services at or regulatoryservices@uta.edu if you have any questions about your rights as a research subject.

VOLUNTARY PARTICIPATION:
Participation in this research study is voluntary. You have the right to decline participation in any or all study procedures or quit at any time with no consequence. If you decide to participate in the study, your completion and return of the questionnaires in the enclosed envelope will be considered your informed consent to participate. I am not asking you to complete a written informed consent so that your information can remain anonymous.

By returning the completed questionnaires, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed in this letter about this study's purpose, procedures, and possible benefits and risks, and you voluntarily agree to participate in this study. You have been given the opportunity to ask questions by contacting me at 817-408-5011 and understand that you can ask other questions at any time.

Thank you,
Michelle M. Hampton MSN, RN, CCRN
PhD Nursing Student, UTA College of Nursing

FACULTY ADVISOR
Lauri D. John, PhD, RN, CNS (Oncology)
Clinical Associate Professor, UTA College of Nursing

Appendix I

Script for Hospice Agency Staff

I have a packet from Michelle Hampton, a UTA graduate nursing student who is doing a research study to find out more about the confidence and stress of caregivers.

I am helping the student with distributing the information about her research study, but the research study is completely separate from the care you are receiving through the hospice.

Her study is completely voluntary. It is your choice to decide if you want to be in the study or not.

The packet includes an information letter about the study and some questionnaires.

If you do not want to be in the study, you can throw the packet away.

If you want to be in the study, there is a self-addressed, stamped envelope in the packet for you to mail the questionnaires to the student.

If you have any questions about the study, please contact Michelle Hampton at .

Appendix J

Informational Letter Non-Hospice Agency Staff

Dear Caregiver,

My name is Michelle Hampton, and I am a graduate student completing a PhD in Nursing at the University of Texas at Arlington (UTA) College of Nursing. I am conducting a research study to find out more about the confidence and stress of informal caregivers providing end-of-life care. The title of my research study is “Self-efficacy of Caregiving and Caregiver Stress in Adult Informal Caregivers of Individuals at the End-of-Life.”

You are being asked to participate in this research study because you are providing “free care” for an adult with a serious, life-threatening illness. Your participation in this study is voluntary. Refusal to participate or discontinuing your participation at any time will involve no penalty or loss of benefits to which you are otherwise entitled. If you have questions or there is anything you do not understand, please contact me at to ask any questions.

PROCEDURES:
If you decide to participate in this research study, you will be asked to do the following:
Answer questions about yourself and the person for whom you are providing care.
Answer questions about your confidence in giving care.
Answer questions about your stress.
Answer questions about your health.
Return the questionnaires to me by U.S. mail in the enclosed self-addressed, stamped envelope.

It should take up to 45 minutes for you to answer the questions. There are no “right” or “wrong” answers, and you can skip any questions that you do not want to answer. If you decide to participate, please DO NOT put your name on any of the questionnaires so that your answers will remain anonymous. There will be about 80 informal caregivers in this study.

RISKS/BENEFITS/COMPENSATION/ALTERNATIVES:
There are no known likely risks to you for participating in this study unless answering questions about stress is upsetting to you. If any of the questions make you uncomfortable, you can skip those questions or stop answering the questions and not return the packet to the researcher. You can also contact Michelle Hampton at if you are upset or have any questions.

There are no known direct benefits to you from participating in this study, and you will not be paid for being in this study. The information learned from the study may help us understand how to help others providing “free care” for an adult with a serious, life-threatening illness. There are no alternative procedures for this study, but you can decide not to participate in the study or quit at any time with no consequence.

CONFIDENTIALITY:
To protect your confidentiality, I am asking that you NOT write your name on any of the questionnaires or the envelope in which the questionnaires will be returned. All information collected from this study will be stored in a locked file cabinet at the UTA College of Nursing in the Center for Nursing Research for at least three (3) years after the end of this study. The results of this study may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law or as noted above. The IRB at UTA has reviewed and approved this study and the information within this information form. If in the unlikely event it becomes

necessary for the IRB to review your research records, UTA will protect the confidentiality of those records to the extent permitted by law.

CONTACT FOR QUESTIONS:
If you have any questions, problems, or research-related medical problems at any time, you may call me, Michelle M. Hampton MSN, RN, CCRN, PhD Nursing Student, at or my faculty advisor, Lauri D. John, PhD, RN, CNS, at . You may call the Office of Research Administration, Regulatory Services at or regulatoryservices@uta.edu if you have any questions about your rights as a research subject.

VOLUNTARY PARTICIPATION:
Participation in this research study is voluntary. You have the right to decline participation in any or all study procedures or quit at any time with no consequence. If you decide to participate in the study, your completion and return of the questionnaires in the enclosed envelope will be considered your informed consent to participate. I am not asking you to complete a written informed consent so that your information can remain anonymous.

By returning the completed questionnaires, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed in this letter about this study's purpose, procedures, and possible benefits and risks, and you voluntarily agree to participate in this study. You have been given the opportunity to ask questions by contacting me at 817-408-5011 and understand that you can ask other questions at any time.

Thank you,
Michelle M. Hampton MSN, RN, CCRN
PhD Nursing Student, UTA College of Nursing

FACULTY ADVISOR
Lauri D. John, PhD, RN, CNS (Oncology)
Clinical Associate Professor, UTA College of Nursing

Appendix K

Script for Non-Hospice Agency Staff

I have a packet from Michelle Hampton, a UTA graduate nursing student who is doing a research study to find out more about the confidence and stress of caregivers.

I am helping the student with distributing the information about her research study.

Her study is completely voluntary. It is your choice to decide if you want to be in the study or not.

The packet includes an information letter about the study and some questionnaires.

If you do not want to be in the study, you can throw the packet away.

If you want to be in the study, there is a self-addressed, stamped envelope in the packet for you to mail the questionnaires to the student.

If you have any questions about the study, please contact Michelle Hampton at .

Appendix L

IRB Approval Letter

Office of Research Administration
Regulatory Services
817-272-3723
regulatoryservices@uta.edu
http://www.uta.edu/research/administration

Institutional Review Board
Notification of Exemption
May 21, 2014
Michelle Hampton
Dr. Lauri John
College of Nursing
Protocol Number: 2014-0631
Protocol Title: Self-efficacy of Caregiving and Caregiver Stress in Adult Informal Caregivers of Individuals at the End-of-Life

EXEMPTION DETERMINATION
The UT Arlington Institutional Review Board (IRB) Chair, or designee, has reviewed the above referenced study and found that it qualified for exemption under the federal guidelines for the protection of human subjects as referenced at Title 45CFR Part 46.101(b)(2).

- (2)Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:(i) information obtained is recorded in such a manner that human subjects can be identified, either directly or through identifiers linked to the subject; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

You are therefore authorized to begin the research as of May 20, 2014.
Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, “promptly report to the IRB any proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are not initiated without prior IRB review and approval except when necessary to eliminate apparent immediate hazards to the subject.” Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to the Office of Research Administration; Regulatory Services within 24 hours of the occurrence or upon acknowledgement of the occurrence. All investigators and key personnel identified in the protocol must have documented Human Subject Protection (HSP) Training on file with this office. Completion certificates are valid for 2 years from completion date.
The UT Arlington Office of Research Administration; Regulatory Services appreciates your continuing commitment to the protection of human subjects in research. Should you have questions, or need to report completion of study procedures, please contact Robin Dickey at 817-272-9329 or robind@uta.edu. You may also contact Regulatory Services at 817-272-3723 or regulatoryservices@uta.edu.

References

Applebaum, A. J., & Breitbart, W. (2013). Care for the cancer caregiver: A systematic review. Palliative and Supportive Care, 11, 231-252. doi:10.1017/S1478951512000594

Au, A., Lau, K., Sit, E., Cheung, G., Lai, M., Wong, S. K. A., & Fok, D. (2010). The role of self-efficacy in the Alzheimer's family caregiver stress process: A partial mediator between physical health and depressive symptoms. Clinical Gerontologist: The Journal of Aging and Mental Health, 33, 298-315. doi:10.1080/07317115.2010.502817

Bainbridge, D., Krueger, P., Lohfeld, L, & Brazil, K. (2009). Stress processes in caring for an end-of-life family member: Application of a theoretical model. Aging and Mental Health, 13, 537-545. doi:10.1080/13607860802607322

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. Psychological Review, 84, 191-215. Retrieved from http://psycnet.apa.org/journals/rev

Bandura, A. (2006). Guide for constructing self-efficacy scales. In F. Pajares & T. Urdan (Eds.), Self-efficacy beliefs of adolescents (pp. 308-337). Charlotte, N.C.: Information Age Publishing.

Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. Journal of Clinical Nursing, 18, 1379-1393. doi:10.1111/j.1365-2702.2008.02405.x

Bolden, L., & Newsome-Wicks, M. N. (2008). The clinical utility of the stress process model in family caregivers of liver transplant patients. Progress in Transplantation, 18(2), 74-79. Retrieved from http://www.progressintransplantation.org

Brazil, K., Bainbridge, D., & Rodriguez, C. (2010). The stress process in palliative cancer care: A qualitative study on informal caregiving and its implication for the delivery of care. American Journal of Hospice and Palliative Medicine, 27, 111-116. doi:10.1177/1049909109350176

Buchner, A., Erdfelder, E., & Faul, F. (1997). How to use G*Power [WWW document]. Retrieved from http://www.psycho.uni-duesseldorf.de/aap/projects/gpower/how_to_use_gpower.html

Burns, C. M., Abernathy, A. P., Dal Grande, E. D., & Currow, D. C. (2013). Uncovering an invisible network of direct caregivers at the end of life: A population study. Palliative Medicine, 27, 608-615. doi:10.1177/0269216313483664

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. Journal of Health and Social Behavior, 24, 385-396. Retrieved from http://www.jstor.org/stable/2136404

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the U.S. In S. Spacapam & S. Oskamp (Eds.), The social psychology of health: Claremont Symposium on Applied Social Psychology. Newbury Park, CA: Sage.

Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. Outcomes and Insights in Health Management, 2, 40185. Retrieved from http://www.healthways.com/success/library.aspx?id=615

Empeño, J., Raming, N. T., Irwin, S. A., Nelesen, R. A., & Lloyd, L. S. (2011). The hospice caregiver support project: Providing support to reduce caregiver stress. Journal of Palliative Medicine, 14, 593-597. doi:10.1089/jpm.2010.820

Family Caregiver Alliance. (2012a). Selected caregiver statistics. Retrieved from http://www.caregiver.org

Family Caregiver Alliance. (2012b). State of the states in family caregiver support: State profile Texas. Retrieved from http://www.caregiver.org

Family Caregiver Alliance. (2012c). Taking care of you: Self-care for family caregivers Retrieved from http://www.caregiver.org

Feinberg, L. F., Horvath, J., Hunt, G., Plooster, L., Kagan, J., Levine, C., …Wilkinson, A. (2003). Family caregiving and public policy: Principles for change. Retrieved from http://www.caregiving.org/data/principles04.pdf

Feinberg, L. F., Newman, S. L., Gray, L., & Kolb, K. N. (2004). The state of the states in family caregiver support: A 50 state study. San Francisco, CA: Family Caregiver Alliance. Retrieved from http://www.caregiver.org/caregiver/jsp/content/pdfs/state_profile_tx.pdf

Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the invaluable: 2011 Update, the growing contributions and costs of family caregiving. Retrieved from http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html

Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., … Lawlor, B. A. (2011). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers. Aging & Mental Health, 15, 663-670. doi:10.1080/13607863.2011.562179

Gilliam, C. M., & Steffen, A. M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. Aging & Mental Health, 10, 79-86. Retrieved from http://www.tandfonline.com/loi/camh20

Gliner J. A., Morgan, G. A., & Leech, N. L. (2009). Research methods in applied settings: An integrated approach to design and analysis. New York: Routledge.

Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression, and life satisfaction among spousal caregivers in hospice: Application of a stress process model. Journal of Palliative Medicine, 6, 215-224. Retrieved from http://www.liebertpub.com/jpm

Harmell, A. L., Mausbach, B. T., Roepke, S. K., Moore, R. C., von Känel, R., Patterson, T. L., … Grant, I. (2011). The relationship between self-efficacy and resting blood pressure in spousal Alzheimer's caregivers. British Journal of Health Psychology, 16, 317-328. doi:10.1348/135910710X504932

Institute of Medicine. (2008). Retooling for an aging America: Building the health care workforce. Washington, DC: National Academic Press. Retrieved from http://www.iom.edu/Reports/2008/Retooling-for-an-aging-America-Building-the-Health-Care-Workforce.aspx

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2009). Stress process model for individuals with dementia. The Gerontologist, 50, 294-302. doi:10.1093/geront/gnp162

Khan, F., Pallant, J., & Brand, C. (2007). Caregiver strain and factors associated with caregiver self-efficacy and quality of life in a community cohort with multiple sclerosis. Disability and Rehabilitation, 29, 1241-1250. doi:10.1080/0144361060096414

Kreitler, S., Peleg, D., & Ehrenfeld, M. (2007). Stress, self-efficacy, and quality of life in cancer patients. Psycho-Oncology, 16, 329-341. doi:10.10002/pon.1063

Löckenhoff, C. E., Duberstein, P. R., Friedman, B., & Costa, P. T., Jr. (2011). Five-factor personality traits and subjective health among caregivers: The role of caregiver strain and self-efficacy. Psychology & Aging, 26, 592-604. doi:10.1037/a0022209

Lopez, J., Lopez-Arrieta, J., & Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. Archives of Gerontology and Geriatrics, 4(1), 81-94. doi:10.1016/j.archger.2004.12.001

Mausbach, B. T., Roepke, S. K., Chattillion, E. A., Harmell, A. L., Moore, R., Romero-Moreno, R., … Grant, I. (2012). Multiple mediators of the relations between caregiving stress and depressive symptoms. Aging and Mental Health, 16, 27-38. doi:10.1080/13607863

Mausbach, B. T., von Känel R., Roepke, S. K., Moore, R., Patterson T. L., Mills P. J., … Allison M. (2011). Self-efficacy buffers the relationship between dementia caregiving stress and circulating concentrations of the pro-inflammatory cytokine interleukin-6. American Journal of Geriatric Psychiatry, 19, 64-71. doi:10.1097./JGP.0b013e3181df4498

Merluzzi, T. V., Philip, E. J., Vachon, D. O., & Heitzmann, C. A. (2011). Assessment of self-efficacy for caregiving: The critical role of self-care in caregiver stress and burnout. Palliative and Supportive Care, 9, 15-24. doi:10.1017/S1478951510000507

Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009). The role of resources and appraisals in predicting burden among latina and non-hispanic white female caregivers: A test of an expanded socio-cultural model of stress and coping. Aging & Mental Health, 13, 648-658. doi:10.1080/13607860802534658

National Alliance for Caregiving and American Association of Retired Persons. (2009). Caregiving in the U.S. Retrieved from http://caregiving.org

National Hospice and Palliative Care Organization. (2013). Caregiving. Retrieved from http://www.nhpco.org/caregiving

National Institutes of Health. (2004). State-of- the-science conference statement on improving end-of-life care: Components of End-of-Life. Retrieved from http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm

Osborne, J. W., & Waters, E. (2002). Four assumptions of multiple regression that researchers should always test. Practical Assessment, Research, and Evaluation, 8(2), 1-5. Retrieved from http://pareonline.net/

Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. Journal of Health and Social Behavior, 22, 337-356. doi:10.2307/2136676

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. Gerontologist, 30, 583-594. doi:10.1093/geront/30.5.583

Perez, J., Ussher, J. M., Butow, P., & Wain, G. (2011). Gender differences in cancer carer psychological distress: An analysis of moderators and mediators. European Journal of Cancer Care, 20, 610-619. doi:10.1111/j1365-2354.2011.01257.x

Raphael, C., & Cornwell, J. L. (2008). Influencing support for caregivers: Lessons from home health care. American Journal of Nursing, 108, 78-82. doi:10.1097/01.NAJ.0000336428.73064.f4

Romero-Moreno, R., Losada, A., Mausbach, B. T., Marquez-Gonzalez, M., Patterson, T. L., & Lopez, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. Aging and Mental Health, 15, 221-231. doi:10.1080/13607869.2010.505231

Roscoe, L. A., Corsentino, E., Watkins, S., McCall, M., & Sanchez-Ramos, J. (2009). Well-being of family caregivers of persons with late stage Huntington's Disease: Lessons in stress and coping. Health Communication, 24, 239-248. doi:10.1080/10410230902804133

Rosenberg, E., Jullamate, P., & Azeredo, Z. (2009). Informal caregiving: Cross-cultural applicability of the Pearson Environment Model. Health Sociology Review, 18, 399-411. Retrieved from http://hsr.e-contentmanagement.com/

Saban, K. L., Sherwood, P. R., DeVon, H. A., & Hynes, D. M. (2010). Measures of psychological stress and physical health in family caregivers of stroke survivors: a literature review. Journal of Neuroscience Nursing, 42, 128-138. doi:10.1097/JNN.0b013e3181d4a3ee

Semiatin, A. M., & O'Conner, M. K. (2012). The relationship between self-efficacy and positive aspects of caregiving in Alzheimer's disease caregivers. Aging and Mental Health, 1, 1-6. doi:10.1080/13607863.2011.651437

Segerstrom, S. C., & Miller, G. E. (2004). Psychological stress and the human immune system: A meta-analytic study of 30 years of inquiry. Psychological Bulletin, 130, 601. Retrieved from psycnet.apa.org

Stajduhar, K. I., Funk, L., Toye, C., Grande, G. E., Aoun, S., & Todd, C. J. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998-2008). Palliative Medicine, 24, 573-593. doi:10.1177/0269216310371412

Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. Journals of Gerontology Series B-Psychological Sciences and Social Sciences, 57(1), 74-86. doi:10.1093/geronb/57.1.P74

Tang, W. (2009). Hospice family caregivers' quality of life. Journal of Clinical Nursing, 18, 2563-2572. doi:10.1111/j.1365-2702.2008.02753x

U. S. Department of State. (2012). When a child becomes an adult. Diplomacy in Action. Retrieved from http://www.state.gov/m/dghr/flo/c21961.htm

Ware, J. E., Kosinski, M., Turner-Bowker, D. M., & Gandek, B. (2002). How to score version 2 of the SF-12® health survey: With a supplement documenting version 1. Lincoln, RI: QualityMetric.

Wolff, J. L., Dy, S. M., Frick, K. D., & Kasper, J. D. (2007). End-of-life care: Findings from a national survey of informal caregivers. Archives of Internal Medicine, 167, 40-46. Retrieved from http://www.archinternmed.com

Yan, T., Curtin, R., & Jans, M. (2010). Trends in income nonresponse over two-decades. Journal of Official Statistics, 26(1), 145-164. Retrieved from http://www.degruyter.com/view/j/jos

.

Biographical Information

Michelle M. Hampton received her BSN from Tarleton State University in 1996. She received her MSN with a focus on Nursing Administration from the University of Texas at Arlington in 2004. Michelle has worked as a registered nurse for 18 years in both clinical practice and academia. Currently, she is the Magnet Program Manager for Texas Health Harris Methodist Hospital Fort Worth. Michelle is a member of the American Association of Critical Care Nurses, the American Nurses Association, and the Texas Nurses Association. Michelle is currently a District 3 Delegate for the Texas Nurses Association House of Delegates.

Michelle's research interests include informal caregiving, transition to practice, and nursing quality of care in acute care settings. She has been the local primary investigator for nationally funded projects including: Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice (MINC), the National Database of Nursing Quality Indicators (NDNQI) Pain Study, and a Nurses Improving Care for Healthsystem Elders (NICHE) study. Michelle's dissertation research examined the relationship between caregiver self-efficacy and caregiver stress in adult informal caregivers who were providing end-of-life care. Michelle received the Kyba Fellowship to assist with her dissertation research.