

2022

Relationships Among Burden, Quality of Life, and Self-Efficacy in Caregivers of an Older Family Member

Dr. Marietta Margaret Miller
Walden University

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>



Part of the [Family, Life Course, and Society Commons](#), and the [Quantitative Psychology Commons](#)

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact ScholarWorks@waldenu.edu.

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Marietta Margaret Miller

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee

Dr. Leann Stadtlander, Committee Chairperson, Psychology Faculty
Dr. Martha Giles, Committee Member, Psychology Faculty
Dr. Peggy Gallaher, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2022

Abstract

Relationships Among Burden, Quality of Life, and Self-Efficacy in Caregivers of an

Older Family Member

by

Marietta Margaret Miller

MS, Walden University, 2006

BS, University of Central Florida, 1987

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Psychology

Walden University

February 2022

Abstract

Informal caregivers of a family member who has been dementia diagnosed play a substantial personal, social, and economic role in the care of their family member. However, this type of caregiving can have detrimental effects on a caregiver's psychological, financial, physical, social, and emotional well-being. This quantitative study addressed possible relationships between caregiver burden and quality of life, and caregiver burden and self-efficacy as measured by the Zarit Burden Interview, the World Health Organization Quality of Life-BREF, and the Caregiver Self-Efficacy Scale. The theory of transactional stress and the stress process model provided the theoretical foundation. The participants of this study were 219 caregivers born between the years 1946 and 1964 who were caring at least 20 hours per week for their family member who had been dementia diagnosed. Participants were recruited through social media. Multiple linear regression analyses and correlation analyses were used to examine the possible relationships between the variables. Findings showed a significant negative correlation between caregiver burden and self-efficacy and a negative correlation between caregiver burden and total quality of life. The findings of this study could be used for positive social change by physicians, social workers, and therapists to help these caregivers with the remediation of burden, quality of life, and stress, improving their lives and the lives of those for which they care.

Relationships Among Burden, Quality of Life, and Self-Efficacy in Caregivers of an

Older Family Member

by

Marietta Margaret Miller

MS, Walden University, 2006

BS, University of Central Florida, 1987

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Psychology

Walden University

February 2022

Dedication

This dissertation is dedicated to baby boomer caregivers who are the champions of compassion, resilience, self-efficacy, and perseverance. Caring for a family member who has been dementia diagnosed can create a myriad of challenges and obstacles. I am one with you and am inspired by your heroic efforts including the mental, physical, emotional, and financial sacrifices you make. You provide a vital contribution to society and your efforts have not gone unrecognized.

Acknowledgments

I would like to thank my mother, who taught me the value of education, hard work, and perseverance. I would like to thank my grandmother, for her example of an extraordinarily strong woman, a single mom, who graduated from college in 1920. I would like to thank my son, Todd, for keeping me on track by reading my work and leaving suggestions on each draft. His patience while helping me with all the technical aspects of this project throughout the entire doctorate process was priceless. I would like to thank my daughter, Stephanie, for her unwavering love and support while she cheered me on throughout this journey, especially when I felt discouraged. I would like to thank my grandchildren, JC, Caroline, and Zeb, for helping me see the reality and humor in life throughout this adventure. I would like to thank my sisters Rae and Jody, Connie, my extended family, and friends just being there for me. Also, I must acknowledge my dissertation buddies, Geary, Judi, Emma, and Ricki.

I would like to thank my chair, Dr. Leann Stadlander, for her support, encouragement, and constructive feedback during the completion of this endeavor. I would like to thank Dr. Martha Giles for her insights on this manuscript, and I would like to thank Dr. Amy Sickle for her positive and empowering words when I needed them the most. I want to express my gratitude to Greg Murphy, my student advisor from the beginning of my master's program and throughout all the fun of my doctorate.

Table of Contents

List of Tables	iv
Chapter 1: Introduction to the Study.....	1
Background.....	3
Problem Statement.....	5
Purpose of the Study.....	6
Research Questions and Hypotheses	7
Theoretical Framework.....	8
Nature of the Study.....	8
Definitions of Terms.....	10
Assumptions.....	12
Scope and Delimitations	12
Limitations	13
Study Significance	13
Summary.....	14
Chapter 2: Literature Review.....	16
Literature Search Strategy.....	17
Theoretical Framework.....	17
Literature Review Related to Key Variables	21
Caregivers	21
Dementia.....	23
Family Caregiving	25

Baby Boomer Caregivers	27
Caregiver Burden	29
Self-Efficacy	31
Caregiver Quality of Life.....	34
Summary	35
Chapter 3: Research Method.....	37
Research Design and Rationale	38
Research Design.....	38
Rationale for Using a Quantitative Design	39
Methodology.....	40
Population	40
Sampling and Sampling Procedures	40
Procedures for Recruitment, Participation, and Data Collection.....	42
Instrumentation and Operationalization of Constructs	43
Data Analysis Plan.....	47
Threats to Validity	50
Ethical Considerations	51
Data Security.....	52
Summary	53
Chapter 4: Results.....	55
Data Collection	55
Data Cleaning and Assumption Testing	56

Results.....	58
Summary.....	64
Chapter 5: Discussion, Conclusions, and Recommendations.....	66
Interpretation of the Findings.....	67
Limitations of the Study.....	70
Threats to Validity	70
Recommendations.....	71
Implications.....	72
Positive Social Change	72
Conclusions.....	75
References.....	77

List of Tables

Table 1. Frequency for Selected Variables	60
Table 2. Psychometric Characteristics for the Seven Scale Scores	61
Table 3. Pearson Correlations for the Seven Demographic Variables with Caregiver Burden.....	62
Table 4. Pearson Correlations for Self-Efficacy and Quality of Life Scales with Caregiver Burden.....	62
Table 5. Prediction of Caregiver Burden Based on Self-Efficacy and Quality of Life Variables	63

Chapter 1: Introduction to the Study

Nearly 70% of dementia-diagnosed individuals receive in-home care provided by family members (Fonareva & Oken, 2014). Taking care of a family member diagnosed with dementia can be rewarding and has important benefits to society. Caregivers are critical to the quality of life of the care recipients (Brodaty & Donkin, 2009). But family caregivers of an older family member who has been diagnosed with dementia are often called invisible second patients (Aneshensel et al., 1995; Brodaty & Donkin, 2009) due to an increased risk of physical illness, diminished emotional well-being, increased social isolation, and growing financial challenges. Even though the effects of being a family caregiver are sometimes positive, they have been found to be generally negative, with high rates of burden and psychological morbidity and financial hardship, poor physical health, and social isolation (Alzheimer's Association [AA], 2020; Brodaty & Donkin, 2009).

The three variables highlighted in this study were caregiver burden, caregiver quality of life, and self-efficacy. Caregiver burden is a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual (Kim et al., 2012). Caregiver burden describes the effects of being a family caregiver that have been found to be generally negative (AA, 2018; Brodaty & Donkin, 2009; Schulz et al., 1995). Quality of life is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life when dealing with the many facets of being a caregiver. Self-efficacy is the extent or strength of one's belief in their own ability to complete tasks and reach goals (T. M. Steffen et al., 2002). Two

facets of self-efficacy that were of interest in the present study included the ability to control thoughts and the ability to manage behavioral problems of both the caregiver and the patient. Both elements relate to the issues of caregivers' burden, quality of life, and stress as they provide for their family member. Bandura (1994) described positive self-efficacy as the perseverance to complete an action, independent of the difficulties and obstacles encountered during the process. Bandura and Locke (2003) suggested person with stronger levels of self-efficacy may see challenges as opportunities to show their management skills, and when unable to master a situation, they strive to control it. Baby boomer caregivers' self-efficacy is a variable who has been minimally studied as a possible relationship between stress.

Few studies have examined whether the caregivers' level of self-efficacy related to the stress or burden levels of baby boomers caring for a family member who has been dementia diagnosed (Marquez-Gonzales et al., 2009). In general, a higher level of self-efficacy may predict a better quality of life for family caregivers of dementia-diagnosed persons (Marquez-Gonzales et al., 2009; Schumacher et al., 2006). Thus, the present study addressed the relationships between caregiver burden and the quality of life, and caregiver burden and self-efficacy of baby boomer caregivers of a family member diagnosed with dementia.

In this chapter, the background of the study and the problem statement are examined. There is also a discussion on the purpose of the study and the research questions (RQs) and hypotheses. The theoretical framework is also outlined, along with a review of the nature of the study. Definitions are highlighted followed by the

assumptions, scope and delimitations, and limitations of the study. This chapter concludes with a discussion of the study's significance and a summary.

Background

Dementia describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to lower a person's ability to perform everyday activities (AA, 2020). AA reported that, as of 2020, 6 million people have been diagnosed with Alzheimer's disease and other dementias. In 2020 Alzheimer's was also the sixth leading cause of death (AA, 2020). In 2020, Alzheimer's and other dementias was predicted cost the United States \$305 billion, and by 2050, these costs could rise as high as \$1.1 trillion dollars (AA, 2020). In 2019, 16.1 million family and friends gave 18.6 billion hours of unpaid care to those diagnosed with Alzheimer's and other dementias; the value of this care was \$244 billion (AA, 2020).

Alzheimer's disease and other dementias are not fatal; most patients live for more than 5 years after diagnosis, many for 10 to 15 years if they were otherwise healthy (AA, 2018; AA, 2016). Due to the increase in longevity of these elders, the task of caregiving can last for many years. When death does occur, the cause is usually due to complications of mobility such as falls, pneumonia, urinary tract infections, pressure sores, or aspiration (AA, 2018). The many years of caregiving can cause these caregivers both physical and mental health issues in combination with, personal, financial, social, family and work-related issues (Conde-Sala et al., 2014). Due to these issues, dementia caregivers had \$9.7 billion in additional health care costs of their own in 2014 (AA, 2015).

Research on baby boomers caring for a family elder who had been dementia diagnosed is important to ensure caregivers are both physically and psychologically healthy enough to provide ongoing care for their family member. This study addressed the gap in literature of baby boomers caring for their elders who had been dementia diagnosed. It also documents the level of burden in these specific caregivers when compared to their personal level of self-efficacy and quality of life. The volunteers for this research were found through social media. There were two main research sites used to find volunteers: (a) the Trial Match® program that was a part of the Alzheimer's Association International Research Center in Chicago, IL, and (b) the Alzheimer's Prevention Registry, established and led by the Banner Alzheimer's Institute. Both sites required an application filled out by the researcher and approved before the study could be posted on their virtual volunteer site. Once the applications were approved, Trial Match® and Alzheimer's Prevention Registry both sent emails to volunteers of their programs that matched the demographics of the study. The Survey Monkey links were included in the emails sent to the volunteers. Only those volunteers of baby boomer age who were caregivers of a family member who had been dementia-diagnosed, for at least 20 hours per week, were included in this process. After volunteers completed their surveys, the data were downloaded and analyzed using IBM SPSS 26. to look for the possible relationship of burden, quality of life, and self-efficacy.

The results of this study could enable doctors, therapists, the community and families with insights on the empowerment of caregivers who care for themselves and are able to lower their level of burden. These caregivers realized how they can increase their

self-efficacy and their quality of life while lowering their level of burden and are able to care for their family member longer before institutionalization.

Problem Statement

In 2018, AA documented that the current number of persons diagnosed with Alzheimer's disease and other dementias was 5.7 million. Alzheimer's disease has also been found to be the most diagnosed dementia and the sixth leading cause of death (AA, 2018). In addition to costs, dementia caregiving can negatively impact caregivers' health, employment, social life, family life, income, and financial security (AA, 2020). With the older population living longer and families having fewer children who could become caregivers, the task of caregiving can last for many years (Fingerman et al., 2012), leading to baby boomers, born between 1946 and 1964, caring for their family members diagnosed with dementia. The multidimensional intergenerational support model addresses factors underlying baby boomers' decisions about whether to help each of their grown children or their aging parent (Fingerman & Birdett, 2011). This will be discussed fully in Chapter 2.

There was a wealth of literature documenting available resources for reducing burden and increasing the quality of life among caregivers of family members diagnosed with dementia (Cheng et al., 2012; Stockwell-Smith, 2010; Whittier et al., 2005). But research was lacking on studies of baby boomers caring for family members who had been dementia diagnosed. In a study of nearly 10 million adult children over the age of 50 who were caring for their aging family member, the family caregivers were aging themselves and providing care at a time when they needed to be planning, saving for their

retirement, and enjoying their families (MetLife Mature Market Institute, 2011). This led to lost wealth from stopping work to care for their family member as well as negative impacts on health from years of caregiving (MetLife Mature Market Institute, 2011). Thus, the present research emphasized the gap in literature related to the relationship of baby boomer caregivers' burden, quality of life and self-efficacy. Good health, including lower levels of burden and higher levels of self-efficacy and quality of life of these specific caregivers is essential to their mental, physical, social, and financial life and the lives of individuals for whom they care. Findings from this study could promote the development of interventions that could empower the caregivers by increasing their level of self-efficacy and quality of life. This study could empower psychologists, doctors, therapists, and social workers in their efforts to help baby boomer caregivers. These interventions may enable caregivers to keep their family member home longer before institutionalization (Gómez-Gallego et al., 2012).

Purpose of the Study

The purpose of this quantitative study was to investigate the level of caregiver burden of baby boomers caring at least 20 hours per week for a family member who has been dementia diagnosed. This investigation examined a possible correlation of caregiver burden, quality of life, and self-efficacy. It was hypothesized there may be a relationship between caregiver burden and self-efficacy, and caregiver burden and quality of life. The current study may help psychologists, doctors, therapists, and social workers create interventions including ways to empower these caregivers to keep their family member

home with them longer before possible institutionalization (Gómez-Gallego et al., 2012; Perren et al., 2006).

Research Questions and Hypotheses

RQ 1: Is caregiver burden related to self- efficacy?

H₀1: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and self-efficacy is zero.

H_a1: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between caregiver burden and self-efficacy.

RQ 2: Is caregiver burden related to quality of life?

H₀2: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and quality of life is zero.

H_a2: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between caregiver burden and quality of life.

RQ 3: Which is the best predictor of caregiver burden, self-efficacy, or quality of life??

H₃: In the population of baby boomer caregivers of dementia-diagnosed family members, there will not be a correlation between quality of life, self-efficacy, and caregiver burden.

H_a3: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between quality of life, self-efficacy, and caregiver burden.

Theoretical Framework

The theory of transactional stress was the framework for the current study; it is the basis for caregivers' abilities to properly identify, categorize, and assess danger in their life (Lazarus & Folkman, 1987; Merluzzi et al., 2011). A mistaken assessment of environmental stressors could lead to psychological harm due to the aggregate effects of these stressors (Merluzzi et al., 2011). The transactional model is a part of the cognitive theory of stress that views the person and environment in a mutually reciprocal and bidirectional relationship. This interpretation of stress focused on the transaction between people and their external environment (Lazarus & Folkman, 1984). The stress process model was also a part of this study. It provided a comprehensive understanding of the developmental process and outcomes in caregiver burden (Pearlin et al., 1990).

The current study focused on the significance of caregiver burden, quality of life, and self-efficacy in respect to transactional stress. This allowed insights into recognizing the effects of efficacy retention and the caregivers' stress appraisal. A fundamental proposition of the transactional model is that the interaction of the person and environment creates stress for the individual (Lazarus, 1966; Lazarus & Folkman, 1984). In the current study, those cared for were part of the environment.

Nature of the Study

The present study used a quantitative research design that employed correlational and multiple regression analyses. Quantitative research is consistent with understanding the possible relationship of caregiver burden on the dependent variables: caregiver stress and quality of life. The criterion variable (burden) with the predictor variables (self-

efficacy and quality of life) were used in multiple regression analyses. A correlational design was used because the variables were not manipulated. I gathered information about the relationships of the predictor and criterion variables to answer the research questions. This research allowed the testing of theories by examining relationships between the variables (Creswell, 2009).

The volunteers for this research were found through social media. There were two main research sites used to find volunteers: The TrialMatch® program and the Alzheimer's Prevention Registry established and led by the Banner Alzheimer's Institute. Both sites required an application be filled out and approved before this study was posted on the individual virtual volunteer sites. TrialMatch® and Alzheimer's Prevention Registry sent emails to volunteers of their program that matched the demographics of the study. The Survey Monkey link to the study were included in the emails sent to the volunteers. The survey link included a demographic questionnaire, and questions from three assessments: the Zarit Burden Interview (ZBI; Bédard et al., 2001), the World Health Organization Quality of Life-BREF (WHOQOL-BREF), and the Caregiver Self-Efficacy (CSE) Scale (A. M. Steffen et al., 2002). Demographics included were gender, age, race, relationship of caregiver and those cared for, number of years caring for their family member, highest level of education, and marital status. Consent forms were the first page of the study. The survey also consisted of a total of 34 questions taken from the assessments. Data were analyzed using SPSS 26.0 looking for the possible relationship of burden, quality of life, and self-efficacy.

Definitions of Terms

Alzheimer's disease: A progressive brain disorder that gradually destroys a person's memory and ability to learn, reason, make judgments, communicate, and carry out daily activities. As the disease progresses, individuals may also experience changes in personality and behavior (e.g., anxiety, suspiciousness, agitation, delusions, or hallucinations; AA, 2015).

Baby boomer: Refers to people born during the demographic post–World War II era approximately between the years 1946 and 1964 (Vincent & Velkoff, 2010).

Caregiver: Refers to someone who cares for a person who is young, old, or sick (Cambridge Dictionary, n.d.).

Caregiver burden: A multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual (Kim et al., 2012).

Caregiver stress: A condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent (Schulz & Beach, 1999).

Caregiving: Refers to attending to another individual's health needs (AA, 2018).

Cognitive impairment: The impaired ability to think and make appropriate judgments (Folstein et al., 1985).

Dementia: A broad category of brain diseases that cause a long term and often gradual decrease in the ability to think and remember such that a person's daily functioning is affected (Folstein et al., 1985).

Environmental factors: Internal or external stimuli that continually disrupt homeostasis; an organism's present condition is a state of constant flux moving about a homeostatic point that is that organism's optimal condition for living (Tung et al., 2005).

Family caregiver: Refers to the primary person assisting a family member diagnosed with Alzheimer's disease/dementia (Alzheimer's & Dementia, 2020).

Perceived stress: A perception that the caregiving situation exceeds the caregiver resources with which to cope (Chwalisz, 1992).

Quality of life: A broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life (World Health Organization [WHO] Quality of Life Assessment, 2012).

Self-efficacy: The extent or strength of one's belief in one's own ability to complete tasks and reach goals (T. M. Steffen et al., 2002).

Social cognitive theory: Posits a person's attitudes, abilities, and cognitive skills compromise the self-system. Self-efficacy is an essential part of this system (Bandura, 1994).

Stress: The physiological response to an internal or external stimulus that triggers the fight-or-flight response. It can be external and related to the environment (Kamiya et al., 2014).

Stressors: Conditions and experiences that have the capacity to arouse states of stress (Lazarus & Folkman, 1984).

Stress process model: Provides a comprehensive understanding of the developmental process and outcomes in caregiver burden (Pearlin et al., 1990).

Transactional model: A part of the cognitive theory of stress that views the person and environment in a mutually reciprocal and bidirectional relationship. The interpretation of stress that focuses on the transaction between people and their external environment (Lazarus & Folkman, 1984).

Assumptions

It was assumed all participants answered assessment questions truthfully and to the best of their ability. It was assumed the actual baby boomer caregiver answered the questions. It is also assumed the assessment tools have accurately measured the burden, quality of life and self-efficacy of the study participants.

Scope and Delimitations

This study was focused on the stress process related to caregivers of a family member diagnosed with dementia and the varied stressors that may show a relationship with caregivers' level of burden, quality of life, and self-efficacy. Participants of this study were baby boomers born between 1946 and 1964 living in the United States who are caring for a family member who is dementia diagnosed. The two ways participants were able to join the study was to be a volunteer of either the AA TrialMatch® program or Banner Health's Alzheimer's Prevention Research program. The participants were required to live in the United States with and caring for their family member at least 20 hours a week. Not included in the study were baby boomer caregivers who were not participating in the Alzheimer's International Research TrialMatch® program or Banner Health's Alzheimer's Prevention Registry.

Limitations

One limitation of this research was that the volunteers for this study who were recruited from the databases of the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry must be computer literate to complete the study online. Another limitation is that the study sample may not have an adequate number of male participants. Studies have shown women are more likely to be caregivers of elder family members than men (Papastavrou et al., 2009).

Study Significance

The importance of the mental, physical, financial, social, and family health of a baby boomer caring for a family member who has been dementia diagnosed is becoming significant as the population ages. The caregivers' burden, quality of life, and self-efficacy can affect the quality of care provided to their family member and their own personal health. Studies analyzing the relationship of burden, quality of life, and self-efficacy have focused their attention on the relationship between stressors and distress. Findings have shown the relationship between burden, quality of life, and self-efficacy, and are key elements of the stress process (Romero-Moreno et al., 2011). These elements include (a) the effect of burden for controlling upsetting thoughts on the relationship between self-efficacy, caregivers' distress, depression and anxiety, and (b) the effect of self-efficacy for managing behavioral problems on the relationship between frequency of behavioral problems and the effect of burden for controlling upsetting thoughts on the relationship between self-efficacy, caregivers' stress, depression, and anxiety (Romero-Moreno et al., 2011).

The current study could help psychologists, doctors, nurses, therapists, and social workers by incorporating the findings and create interventions as a tool of empowerment for these caregivers. Findings may enable caregivers to keep their family members home with them longer before the need for institutionalization (see Gómez-Gallego et al., 2012; Khan et al., 2007; Perren et al., 2006). This research may contribute to positive social change by focusing on ways to improve and empower these caregivers' level of self-efficacy, lowering their level of burden, and improving their quality of life through interventions.

Summary

Caregivers' burden has been studied as a potential reconnection between stressors and distress (Anthony-Bergstone et al., 1988). Studies have shown the effects this variable has on dementia caregivers' distress (Marquez-Gonzalez et al., 2009; Rabinowitz et al., 2007; T. M. Steffen et al., 2002). However, this variable has not been examined in the current context of baby boomers as caregivers. Caregivers born between 1946 and 1964 are experiencing their own aging issues and hardships in their own life and need help to understand their options of caring for their family member and ways to empower themselves. More studies on this topic need to delve into the possible relationship of caregiver burden, self-efficacy, and quality of life to help the baby boomer caregivers learn new ways to handle the burden of caregiving (Black et al., 2010). The potential implications of these findings could lead to caregiver interventions, which could help them (a) manage disruptive behaviors by learning to reduce their burden and (b) learn

ways to control upsetting thoughts that could enhance their quality of life (Farina et al., 2017; Marquez-Gonzalez et al., 2009; McCurry et al., 2005).

Chapter 1 included an introduction of the current research on baby boomer caregivers' burden and possible relationship to self-efficacy, and quality of life. Chapter 2 reviews the current research on baby boomers who are caregivers of a family member diagnosed with dementia. It also provides previous research related to earlier studies of these specific caregivers' and the variables of caregiver burden, self-efficacy, quality of life. A review of the strengths and limitations of the quantitative design were also discussed in Chapter 2. Chapter 3 includes an explanation of the methodology for the study's design.

Chapter 2: Literature Review

Caring for a family member who has been dementia diagnosed can be rewarding for the caregiver, and it has important benefits to society. However, dementia caregiving can create a negative impact on the caregivers' health, employment, family life, and financial security (AA, 2018; Conde-Sala et al., 2014; Coughlin, 2010; García-Alberca et al., 2012; Iavarone et al., 2014; Romero-Moreno et al., 2011; Romero-;). Although it has important benefits to society it is also taxing on the health of the individual in the caregiving role as they continue to feel an increase of stress and burden and a loss in their quality of life. Family caregiving can be demanding with major stressors including psychological, physical, and health issues born of financial insecurity, social isolation, and delaying or completely stopping their personal or career goals to care for a family member who has been dementia-diagnosed (Conde-Sala et al., 2014; Iavarone et al., 2014; Vitaliano et al., 2003; Vitaliano et al., 2004). But there is a lack of research on self-efficacy, quality of life and the possible relationship of burden by baby boomers caring for a family member who has been dementia diagnosed. The purpose of the current study was to address this gap, exploring the caregiver dynamic of caregiver burden, quality of life, and self-efficacy. The findings could promote the development of new interventions to empower these family caregivers to take care of themselves during their years of caregiving.

This chapter is an overview of literature on caregivers and more specifically baby boomer caregivers of a family member who has been dementia diagnosed. The literature review begins with an examination of the theoretical foundation used, which included

transactional theory and the stress-process theory. The review culminates with a discussion of the importance of empowering caregivers, their family, and society.

Literature Search Strategy

The literature for this study was found in peer-reviewed professional journals, online reports on the aging population, and books on stress and caregivers. Seminal literature was searched from 1970 to the present time. Peer-reviewed literature was searched under 2011 to the present. Databases used were Google Scholar, NIH, EBSCO, PsycINFO, PsycARTICLES, Mendeley, CINAHL Plus with Full Text, ProQuest Dissertation and Thesis, AA Research database, and the O’Leara Library found at the Central Florida Chapter of the American AA, and Banner Health’s Alzheimer’s Prevention Registry database. Recent research was found by constantly watching for new articles by the AA publications and new dissertations on the topic. Key words used for the research include *Alzheimer’s Association AND research, Caregiver, Family Caregiving, Dementia, Baby Boomers, Family Caregivers, Alzheimer’s Disease, Self-Efficacy, Self-Efficacy AND quality of life, self-efficacy AND caregiver stress, stress AND quality of life, burden AND dementia caregiving, stress AND family caregiving, aging, aged, transactional theory, transactional theory AND family caregiving AND caregiver stress, caregivers AND financial stress, family caregivers AND quality of life, family stress AND caregiving, coping, appraisal, and stress and emotion.*

Theoretical Framework

Beginning in the 1960s and 1970s stress was thought to be a transactional phenomenon that was dependent on the meaning of the stimulus to the perceiver

(Lazarus, 1966). The transactional model of stress and coping is a parameter for assessing the actual process of one's ability to cope with stress-filled life events that are construed as person–environment transactions (Lazarus & Cohen, 1977). Stressors are demands made by the internal or external environment that creates an unbalance, which in turn affects the physical and psychological well-being and requires action to restore balance (Lazarus & Cohen, 1977; Tung et al., 2005). In other words, the interaction of the person and environment creates stress for the individual (Lazarus, 1966; Lazarus & Folkman, 1984). Lazarus (1966) further postulated that stress is not a property of the person or of the environment but arises when there is exposure to a specific kind of environment and a person that leads to the threat of stress (see also Lazarus & Folkman, 1987).

The theory also describes how an individual evaluates and copes with a situation. An individual's primary appraisal refers to whether there is any personal stake in the encounter and has been referred to as the motivational relevance of an encounter (Lazarus, 1966). The primary appraisal process is an evaluation of the significance of an encounter or transaction for a specific individual. As part of this process, there are three types of evaluations (Lazarus & Cohen, 1977; Lazarus & Folkman, 1987; Lazarus et al., 1985). First, an irrelevant encounter is one that has no personal significance for the individual and is ignored. The second evaluation is a benign-positive encounter that is considered beneficial and/or desirable. Third is a stressful encounter regarded as harmful, threatening, or challenging (Lazarus & Folkman, 1987). Further, a stake in an encounter generates the potential for emotion (Lazarus & Folkman, 1987). If individuals determine they have a stake in the encounter, they will engage in a secondary appraisal to change

conditions perceived to be undesirable. This appraisal focuses on the available coping options for altering the perceived harm, threat, or challenge so a more positive environment is created (Lazarus, 1984). Coping is expected to be consistent with a determination of whether anything can be done to change the situation (Folkman & Lazarus, 1985). For example, problem-focused coping is expected to be used in situations appraised as unchangeable. Ultimately, the individual choice of a coping mechanism is determined by their perceptions of personal control over the stressful situation (Folkman & Lazarus, 1980). Personal control reflects an individual's beliefs at a given point in time in their ability to effect change in a desired direction on the environment (Greenberger & Strasser, 1986). Coping outcomes at least partially depend on the goodness of the fit between appraisal and coping (Lazarus & Folkman, 1984).

Lazarus also included a third cognitive appraisal that he labeled "reappraisal" (Lazarus & Folkman, 1987). Reappraisal represents the feedback process wherein changes in both primary and secondary appraisals are brought about by individual reactions/coping and the environmental counter-reactions. According to Lazarus & Folkman (1987), these reactions and counter-reactions are appraised by the individual, which leads to reappraisals of the person–environment relationship.

A significant amount of research has supported the transactional model by demonstrating how people evaluate what is happening in their environment (see Lazarus, 1966; Lazarus et al., 1985; Lazarus & Folkman, 1987; Merluzzi et al., 2011). This is done with respect to their well-being, the how they cope with changes in their environment, and whether psychological stress from the intensity of the stress (Lazarus, 1966).

Findings show an erroneous assessment of the effects of the environment (those cared for) stressors may precede psychological harm due to their aggregate affects and thus influencing individual efficacy (Merluzzi et al., 2011). Nevertheless, even if these theories are used, several issues may remain unresolved. For example, although problem-focused strategies are used most often with caregiver-related stress (Folkman & Lazarus, 1984), some individuals consistently choose emotion-focused strategies. Some studies also propose coping is characterized by high levels of consistency (MacNair & Elliott, 1992; MacNair et al., 2014), whereas others have found coping strategies of an individual are characterized more by variability than consistency (i.e., the individual attempts to match the specific coping strategy to the situation; Folkman & Lazarus, 1984). Newer research has posited that the theory of transactional stress promotes guidance on the significance of self-determination and transactional stress, which promotes insights into recognizing the effects of efficacy retentions and the individuals' stress process (Katerndahl et al., 2002; Merluzzi et al., 2011).

The theory of transactional stress builds the basis for an individual's ability to properly identify, categorize, and evaluate danger in their own well-being. An erroneous assessment of the effects of environmental stressors may precede psychological harm due to their aggregate effects thus influencing individual efficacy (Merluzzi et al., 2011). This research and application of the constructs of transactional stress and coping offer guidance on the significance of self-determination and transactional stress. The stress-process model of caregiving additionally posits that there are multiple levels of support and stress at the individual, family, and community level with a focus on predicting

mental health outcomes. The theories of transactional stress blend with the tenets of caregiver burden, self-efficacy, and quality of life. These theories were used as a model to study the topics of caregiver burden, quality of life, and self-efficacy.

None of the studies cited here adequately accounted for the impact of different stressors on family caregivers of a family member who has been dementia-diagnosed. These arise during a stressful encounter, and they are linked to different causal dimensions (Conde-Sala et al., 2014; Iavarone et al., 2014). This failure to consider specific emotions seems surprising, as individuals, when asked about situations concerning caregiving that cause stress, invariably find it necessary to go beyond the event and discuss the situation in terms of intensity, frequency, and meaning (Dewe, 1989).

Literature Review Related to Key Variables

Caregivers

The definition of caregiving takes many forms. Family caregivers can include being a child's primary caregiver, a caregiver of a younger adult (18–49), or those caring for an older adult (50 and older; AA, 2015). A child's primary caregiver is the adult who assumes the most responsibility in caring for the health and well-being of a child (birth–18 years). This is commonly thought to be the child's parents, but it may be other adults, such as grandparents, other relatives, or a legal guardian (AA, 2015). Many caregivers help family members and friends every day who are older, sick, or disabled but do not consider themselves caregivers. Caregiving can range from providing short-or long-term

financial assistance to taking someone shopping or to doctor's appointments or providing comprehensive round-the-clock care.

Statistics related to caregiving When a family member becomes disabled and needs care, one family member usually takes on the role of primary caregiver (Horowitz, 1985). That person most likely will be a parent or spouse, but in the case of elder caregiving, the role of caregiver may be an adult child, most likely a daughter (Horowitz, 1985). More individuals care for their own adult child (32%) than any other relation followed by a spouse or partner (17%; sibling or sibling-in-law, 13%; or a parent, 9%; Hunt & Reinhard, 2015). Most needing care (75%) rely on unpaid assistance from families, friends, and neighbors (Hunt & Reinhard, 2015). There are at least 5.6 million adults in the United States who have given unpaid care to an adult family member or friend between the age of 18 and 49 years of age (Hunt & Reinhard, 2015), and an estimated 16.1 million American adults have served as an unpaid caregiver to someone age 50 or older in the prior 12 months (AA, 2018). Those caring for someone 50 or older are 50.3 years old, on average, and most are female (60%; AA, 2015). The majority (86%) of 50 or older caregivers provide care for a relative and 47% care for a parent or parent-in-law. One in 10 cares for a spouse. Twenty-five percent of those caring for someone 50+ are providing care to those who are ages 85 or older, the oldest-old. On average, 50+ caregivers' recipients are 74.7 years old (Hunt & Reinhard, 2015).

Impact on caregivers An estimated 21% of households in the United States are impacted by caregiving responsibilities (AA, 2018; Hunt & Reinhard, 2015). Half of the caregivers in a study by the NAC who shared their health had gotten worse due to

caregiving also said the decline in their health affected their ability to care (Hunt & Reinhard, 2015). Results of research completed by the NAC also posited that unpaid caregivers provide an estimated 90% of long-term care, and many of them did not go to the doctor themselves because they put their family's needs first (Hunt & Reinhard, 2015). More than half (51%) shared they do not have time to take care of themselves and almost half (49%) said they are too tired to do so (Hunt & Reinhard, 2015). Research over the past several decades has yielded a wealth of information on interventions to support caregivers and improve their health and well-being (Burgio et al., 2009; Mittelman et al., 2006).

Dementia

Family members who are dementia diagnosed have varied needs according to which type of dementia has been diagnosed. Dementia is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to lower a person's ability to perform everyday activities (AA, 2020). Alzheimer's disease is the most common cause of dementia among older people (AA, 2020). Clinical records sometimes use the broader term dementia as the diagnosis rather than the specific disorder. For this study, the use of the term Alzheimer's disease will encompass individuals with Alzheimer's disease and other similar dementias.

There are nine examples of dementia given by the AA that lend understanding to why the term "dementia" is not a specific disease. Alzheimer's accounts for 60%–80% of the cases of dementia. Revised criteria for diagnosing Alzheimer's were published in 2015 with the recommendation that Alzheimer's disease be considered a slowly

progressing brain disease that begins well before any symptoms emerge (AA, 2015).

Early symptoms include loss of short-term memory and names or events; later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes, and difficulty speaking, swallowing, and walking (AA, 2015).

Vascular dementia is the second most common type of dementia, which can occur after a stroke. This type of dementia is less common than Alzheimer's and accounts for about 10% of dementia cases (AA, 2015). Dementia with Lewy bodies displays a loss of memory and thinking problems that are common in Alzheimer's disease but are more likely to show early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features (AA, 2015). Mixed dementia has abnormalities linked to more than one type of dementia: most commonly Alzheimer's, vascular dementia, and possibly dementia with Lewy bodies (AA, 2015). As Parkinson's disease progresses, it results in dementia like Alzheimer's or dementia with Lewy bodies (AA, 2015).

Frontotemporal dementia includes dementias such as behavioral variant, primarily progressive aphasia, Pick's disease, and progressive supranuclear palsy (AA, 2015).

Creutzfeldt-Jacob disease is the most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals. Variant Creutzfeldt-Jacob disease ("mad cow disease") occurs in cattle, and it can be transmitted to people under certain circumstances. It is a rapidly fatal disorder that impairs memory, coordination, and behavior changes (AA, 2015). Normal pressure hydrocephalus is a type of dementia that is caused by the buildup of fluid on the brain. It has symptoms of memory loss, difficulty

walking, and inability to control urination (AA, 2015). Finally, Huntington's disease is a progressive brain disorder caused by a single defective gene on chromosome 4.

Symptoms of this disease are abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression, and other mood changes (AA, 2015).

Alzheimer's disease is the most common cause of dementia among older people. Clinical records will sometimes use the broader term dementia as the diagnosis rather than the specific disorder. For this report, use of the term Alzheimer's will encompass individuals with Alzheimer's and other similar dementias (AA, 2020).

Family Caregiving

Caregiver demand is driven by the steady increase in the older adult population. As the number of older Americans increase, so does the number of caregivers that will be needed. (Talley & Crews, 2007). The 2020 Alzheimer's Disease Facts and Figures reported the population of Americans aged 65 and older is projected to grow from 56 million in 2020 to 88 million by 2050 (AA, 2020). The number of people 65 years old and older is projected to rise by 101% between 2000 and 2030, at a rate of 2.3% each year (AA, 2020). This causes a huge gap in the number of family members available to care for their elders. With the aged population living longer, research is lacking on baby boomers caring for a family member who has been dementia-diagnosed. The focus of this study was baby boomers caring for a family member who has been dementia-diagnosed. More specifically, this research will ask the question: Does caregiver burden relate to

self-efficacy or the quality of life of a baby boomer caring for a family member who has been dementia-diagnosed?

The MetLife Mature Market Institute (2011) study of caregiving costs to working caregivers was produced in partnership with the NAC, the Center for Long Term Care Research, and the Policy at New York Medical College. Baby boomers over the age of 50 were part of the MetLife study that examined many aspects of health, financial, and family issues due to caring for their aging family member. The study noted family caregivers are themselves aging and providing care at a time when they need to be planning, saving for their retirement, and enjoying their families (MetLife Mature Market Institute, 2011). Findings document financial burden and lost wealth due to early retirement of these family caregivers due to time involved with caring for their family member. The study also documented the negative impact on the health of these caregivers due to their years of caregiving (MetLife Mature Market Institute, 2011). In the present study, it is hypothesized the previously mentioned strains on these caregivers may cause increased burden and a loss to their quality of life (Zarit et al., 1980).

The present study is important to our society and its economy. The healthier the family caregivers are, the longer they will be able to care for their family member before institutionalization in a long-term care setting. In 2019, the estimated economic value of the care provided by family members to those with a dementia diagnosis was \$244 billion (AA, 2020). The \$244 billion represents 18.6 billion hours of unpaid care given by the family caregiver (AA, 2020). The ongoing need for family caregivers will continue to grow as the aging population lives longer.

Variables in this study include caregiver burden, quality of life, and self-efficacy. An erroneous assessment of the effects of environmental (i.e., those being cared for) stressors may precede psychological harm to the caregiver due to the aggregate effects that may influence individual efficacy (Merluzzi et al., 2011; Thomas et al., 2006). This research and application of the constructs of transactional stress and coping offers guidance toward understanding the significance of burden, self-determination, transactional stress, self-efficacy, and the quality of life. This study promotes insight into the burden of having a possible relationship with the quality of life and self-efficacy of caregivers of a family member who is dementia-diagnosed.

Baby Boomer Caregivers

A new generation has become dementia caregivers—the baby boomers. A baby boomer is defined as anyone born post World War II. The name comes from the baby boom between the years of 1946 and 1964 (U.S. Census Bureau, 2012). More babies were born in 1946 than ever before: 3.4 million, 20% more than in 1945. In 1947, another 3.8 million babies were born; 3.9 million were born in 1952; and more than 4 million were born every year from 1954 to 1964 (Jordan & Cory, 2010). At that point, there were 76.4 million baby boomers in the United States, which made up 40% of the nation's population (Jordan & Cory, 2010). In 2019, the 2020 Alzheimer's Disease Facts and Figures report noted there were more than 16.1 million American's providing unpaid care for people with Alzheimer's (AA, 2020). Baby boomer caregivers of a family member who has been dementia-diagnosed are a rapidly growing population. There has been little research on this specific caregiver group, about caregiver burden being related to self-

efficacy, or about caregiver burden being related to quality of life. Researchers posit many baby boomers born between 1946 and 1964 turned 65 years old in 2011 (American Psychological Association, 2012; U.S. Census Bureau, 2012). Based on the U.S. Department of Health and Human Services' Administration on Aging, in 2030 the number of Americans aged 65 or older is expected to double to 72 million (American Psychological Association, 2012). A Pew Research survey documented 14% of adults in their 50s and 60s have already cared for an aging parent or other elderly family member. Nearly 70% say it is very (48%) or somewhat (20%) likely they will become a caregiver of a family member in the future (Parker & Patten, 2013).

There are many differences in the last few decades of caregiving. Elders are living longer, families are having fewer children who could become caregivers, and intergenerational relationships have changed (Fingerman et al., 2012). These baby boomers are also known as the "sandwich generation" and are much more involved with their own children and grandchildren, both financially and emotionally. The previous generations were much more involved with their aging parents. The multidimensional intergenerational support model addresses factors underlying baby boomers' decisions to help each of their grown children or their aging family member (Fingerman & Birdett, 2011). This is also different from previous generations of caregivers because the increase in longevity of this aging generation can cause a need for family members caring for multiple family members; aging family members and spouses (Parker & Patten, 2013). Research conducted on this specific group of caregivers (baby boomers caring for family members) has been difficult to find. The study will add to the minimal amount of

previously published research on the topic of possible relationship of caregiver burden and self-efficacy, and caregiver burden and quality of life of baby boomers caring for a family member who is dementia-diagnosed.

It is well known that a chronically disabled family member may disorganize the life of the baby boomer caregiver and their entire family. This can change the family's overall lifestyle and disrupt the established balance within the family (Glozman, 2004). As the primary caregiver is needed more and more by their disabled family member, the caregiver may not be able to continue working, which changes their personal work and social status. He or she loses relationships that had been previously formed; often the carers find it necessary to stop working completely due to the total dependence of the disabled family member. When this happens, it may increase the importance of intrafamily relationships. According to Glozman (2004), this change of lifestyle can lead to the reassignment of family members, which inevitably influences the nature of interpersonal perceptions between family members. These interpersonal perceptions in the family may contribute or interfere with the ongoing care of their elder family member.

Caregiver Burden

Caregiver burden is defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual (Kim et al., 2011). Many of the early studies on caregiving focused on the actual burdens of caregiving. As a result, it is now well established that providing care to a disabled relative creates emotional, physical, and financial strains (Horowitz, 1985). Bandura (2006)

reported caregiver stress is caused by various types of stress related to financial, physical, emotional, and social limitations. Caregiver burden speaks to the stress a person experiences due to the responsibilities of being a family caregiver (Shankar et al., 2014). This chronic stress can have a negative impact on the caregiver's psychological, physical, social, work, family, and personal finances. Burden may be presented as anxiety, depression, anxiety, guilt, or frustration. It may come from failing to complete the important tasks of caregiving (Brownie et al., 2014; Iavarone, 2014; Naden et al., 2013). Caregiver physical or mental health may decline due to caregiver burden (Brownie et al., 2014; Conde-Sala et al., 2014; Naden et al., 2013; Reed et al., 2014; Shankar et al., 2014). If the caregiver's overall health declines, it can limit the quality of life experienced by the patient and the caregiver, due to their not caring for themselves (Shankar et al., 2014). Many different characteristics of caregivers have been used to explain their ability or inability to cope with stress of being a caregiver. Some of these characteristics include employment, education, gender, race, and support from friends and family. Most caregivers experience some level of chronic stress, also referred to as caregiver burden (Iavarone et al., 2014). In caregivers of patients with Alzheimer's disease, chronic stress often appears as depression, clinical anxiety, and a major decline in physical health (Iavarone et al., 2014).

Assessing the long- term financial impact of caregiving for family members is very important because this can jeopardize the caregiver's future financial security. The MetLife Mature Market Institute (2011) study of caregiving costs to working caregivers found evidence caregivers experience considerable health issues because of their focus on

caring for family members. They surmise adult children 50 years or older who are both working and caring for a parent are more likely to have fair or poor health compared to those who do not care for a parent (MetLife Mature Market Institute, 2011; Townsend et al., 1989). The study's findings on losses in total wages, Social Security, and private pensions due to leaving the labor force early because of caregiving average \$303,880 for a typical caregiver (MetLife Mature Market Institute, 2011). The total amount lost is \$2,947,636,000,000, or nearly \$3 trillion, when this average loss is multiplied by the 9.7 million people 50 or older who are caring for their family member (MetLife Mature Market Institute, 2011); these numbers may be much higher by now.

The financial impact on family members needs to be addressed before they make a drastic change in their lives. Those who quit their jobs, decrease their hours of work back to part-time, or take a lower paying job because of the flexibility needed for caregiving will have a greater financial loss than those who are not caring for their family member (MetLife Mature Market Institute, 2011). Family caregivers also need to stay vigilant concerning their own well-being while focused on the needs of their family members.

Self-Efficacy

Self-efficacy is the individual's belief in his or her ability to complete a specific difficult task and to allow their motivation, cognitive resources, and a course of action to meet the demands of a challenging situation (Bandura, 1977). However, self-efficacy is not a global entity, and it may vary across activity domains and task demands (Bandura, 2002). Findings note perceived self-efficacy refers to the belief that one can cope

adequately with specific caregiving issues that most likely will arise (Bandura, 2002). Mittelman et al. (2006) wrote that improving a caregiver's well-being delays nursing home placement of patients who have been dementia-diagnosed.

There is little research on the relationship between self-efficacy for dementia-related tasks of the caregivers and symptoms of burden and quality of life in caregivers (Gallagher et al., 2011; Kamiya et al., 2014; Vellone et al., 2008). Gallagher et al. (2011) noted further longitudinal studies are warranted to investigate whether self-efficacy might be considered a target in future studies of interventions to lessen the symptoms of burden and depression in dementia caregivers. Once a caregiver's level of self-efficacy has been appraised it may be beneficial to train these caregivers to manage their upsetting thoughts (Bodner & Kiecolt-Glaser, 1994; Marquez-Gonzales et al., 2007), use new behavior techniques for managing disruptive behavior, or to enlighten these caregivers of alternative strategies to help them be more efficient as a caregiver (Clarke et al., 2015).

The concept of self-efficacy lies at the center of Bandura's (1977) social cognitive theory; he posited a person's abilities, attitudes, and cognitive skills comprise what is known as the self-system (Marquez-Gonzales et al., 2009). This system dictates how one perceives a situation and how they behave in response to these situations. Self-efficacy is an essential component of this self-system (Marquez-Gonzales et al., 2007). According to Bandura's early works, self-efficacy is a psychological construct that plays a crucial role in the mediation and moderation of health-related behavior in general. According to Bandura, self-efficacy is seen as a belief in one's capabilities to organize and execute a course of action required to manage prospective predicaments. Bandura and other

researchers posit self-efficacy can have an impact on everything from psychological states to behavior and motivation (Bandura, 1977; Marquez-Gonzales et al., 2007).

Everyone can identify goals they want to accomplish, things they would like to change, and things they would like to achieve. Bandura theorizes an individual's self-efficacy plays a major role in how goals, tasks, and challenges are approached.

There are major differences in those with a strong sense of self-efficacy and those showing a weak sense of self-efficacy (Bandura, 1977, 1994). Other researchers suggested people with a strong sense of self-efficacy see challenging problems as tasks to be mastered, develop deeper interest in the endeavors in which they participate, form a stronger sense of commitment to their interests, and recover quickly from setbacks and challenges of life as a caregiver. Research shows people with a weak sense of self-efficacy avoid challenging tasks and believe difficult tasks and situations are beyond their capabilities. These weak-sensed caregivers focus on personal failings and negative outcomes; quickly losing confidence in their personal abilities (Bandura, 1994). Considering caregivers of a family member who has been dementia-diagnosed, together with Bandura's works, confirm the use of this variable in the investigation of self-efficacy as possibly relating to quality of life and of caregiver burden (Bandura, 1994). The current study explored the dynamic of a) caregiver burden and quality of life and b) caregiver burden and self-efficacy. It examined those aspects of baby boomers who are caring for a dementia-diagnosed family member.

Caregiver Quality of Life

Quality of life is defined by the WHO (1998) as the “Individual’s perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns” (WHO, 1998). This concept includes insights about the physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship with the environment in which people live (de Olivera et al., 2015; WHO, 1998). This is a broad and multidimensional idea (Bosboom et al., 2012; WHO, 1998). The WHOQOL-BREF can be used to understand how quality of life may be affected over time by disease, disability, or disorder while caregiving (Frisch et al., 1992). This is a self-administered assessment tool. The WHOQOL-BREF is an abbreviated version of the WHOQOL-100; it has 26 questions and will provide a quality-of-life profile that documents four main Domain scores—Domain 1, physical health; Domain 2, psychological; Domain 3, social relationships; and Domain 4, environment. This assessment tool is a broad and comprehensive assessment. It is a standard means of assessment for interventions in both health and social care. It looks at dimensions that may indicate how life conditions may affect one’s self-perception of their life quality and how these dimensions reflect how the stress and burden generated by caring may affect family caregivers’ self-perception of their mental health, physical health, and social life. A measure using the WHOQOL-BREF showed “.an extensive understanding of the impact of caring on a caregiver” (de Olivera et al., 2015, p. 19; WHO, 1998).

Summary

This research study is unique in that it looks at a specific group of family caregivers; adult children of the person who has been dementia-diagnosed. These adult children have been born between 1946 and 1964 and are known as baby boomers (Jordan & Cory, 2010).

This work delves into the possible relationships of caregiver burden and self-efficacy, and caregiver burden and quality of life of these baby boomers. There is a distinct gap in the literature about this specific population. By understanding levels of self-efficacy, caregiver burden, and quality of life primary physicians, social workers, gerontologists, and psychologists can develop treatment plans to help empower these caregivers. In their activities and roles, family caregivers experience considerable burden, stress, and disruption of their own well-being and social activities. Research showed they were at risk for emotional and physical health problems.

A study by the American Medical Association noted highly strained family caregivers are at risk for premature mortality (Beach et al., 2005). Others found that risk also includes coronary heart disease and stroke, particularly under conditions of high strain (Haley et al., 1987; Haley & Pardo, 1989; Schulz & Beach, 1999). The results of this study provided insight into how stress affects those caring for a family member who has been dementia-diagnosed and how their personal level of self-efficacy could help or hinder said stress. The results aided in the development of new ways to empower these caregivers to take care of themselves during times of stress.

Helping family caregivers is important to society and its economy because a healthy caregiver can provide a longer period of care for their family member (AA, 2020). In 2019, the estimated economic value of the care provided by family caregivers of people with Alzheimer's and other dementias was \$244 billion (AA, 2020). This number represents 18.6 billion hours of unpaid care (AA, 2020). The need for home-based caregivers will continue to grow as the aging population continues to live longer.

Chapter 2 included a review of the current research on baby boomer caregivers of family members diagnosed with dementia. It looked specifically at their level of caregiver burden, quality of life, and self-efficacy. Chapter 3 reviews the strengths and limitations of the quantitative design; it also includes an explanation of the methodology for the study's design.

Chapter 3: Research Method

The purpose of this quantitative study was to investigate the level of caregiver burden of baby boomers caring for a family member who has been dementia diagnosed and to examine a possible relationship of (a) caregiver burden and quality of life and (b) caregiver burden and self-efficacy. It was hypothesized there may be a relationship between caregiver burden and quality of life and caregiver burden and self- efficacy. This study may help psychologists, doctors, therapists, and social workers create interventions and ways to empower these caregivers. This may enable caregivers to keep their family member home with them longer before possible institutionalization (Gómez-Gallego 2012; Perren et al., 2006).

This chapter reviews the research design, provides a description of the population and the sample, and outline the instruments and measures used in the study. These instruments included the WHOQOL-BREF (WHO, 1998), the ZBI (Bédard et al., 2001; Zarit et al., 1980), and the CSE Scale (T. M. Steffen et al., 2002). These were included in the survey to explore the strength of perceived self-efficacy, competence, and relatedness as predictors of family caregivers' quality of life and caregiver burden of those familial caregivers who were caring for their loved one. The demographic questionnaire and consent forms were also included. Following this is a description of the procedures, hypotheses, and data analyses. Finally, participants' rights and ethical considerations are discussed.

Research Design and Rationale

Research Design

The present study used a quantitative research design that employed correlational and multiple regression analyses. The criterion variable (caregiver burden) with the predictor variables (self-efficacy and quality of life) were used in multiple regression analyses and correlation analyses. A correlational design was used because the variables were not manipulated; I gathered information about the relationships of the predictor and criterion variables. According to Burns and Grove (2011), “The independent variables that are most effective in prediction are highly correlated with the dependent variable, but they are not highly correlated with other independent variables in the study” (p. 266).

According to Creswell (2009) all research designs are influenced by threats to validity: internal or external. Internal validity described the ability of the study to identify if a moderating relationship existed between one or more independent variables and one or more dependent variables. External validity is the generalizability of the findings of a piece of research (Creswell, 2009).

The variables considered in this study included caregiver burden, self-efficacy, and quality of life, taking into consideration that the most predictive independent variables are correlated with the dependent variable but not the other independent variables (Burns & Grove, 2011). The instruments included the ZBI (Bédard et al., 2001; Zarit et al., 1980), the WHOQOL-BREF (WHO, 1998); and the CSE Scale (A. M. Steffen et al., 2002), a demographic questionnaire, and a consent form. Bivariate

correlations of the criterion variable (burden) and the predictor variables (self-efficacy and quality of life) using multiple regression analysis were conducted.

Rationale for Using a Quantitative Design

Quantitative research is consistent with understanding a possible relationship of burden, self-efficacy, and quality of life. This research will advance the body of knowledge and serve to inform the physicians, social workers, and family members of the caregiver of a possible need of an intervention to help these specific caregivers to continue caring for their family member. The implications for positive social change include knowledge useful for families, therapists, social workers, gerontologists, family physicians, mental health counselors, and others who are searching for direction in empowering family caregivers of a dementia-diagnosed family member. Long-term results could include less institutionalization of family members (Lau et al., 2008), reduced cost to the community, and more positive coping mechanisms for the caregivers of their family member (Gaugler et al., 2007; Judge et al., 2011).

The design of this study provided for examination of quality of life and caregiver burden and quality of life and self-efficacy of baby boomer caregivers caring for a family member who has been dementia diagnosed. Demographic and quantitative data were obtained from participant responses to the ZBI (Bédard et al., 2001; Zarit et al., 1980), WHOQOL-BREF (WHO, 1998), and the CSE Scale (A. M. Steffen et al., 2002), and the demographic questionnaire. For RQs 1 and 2, the Pearson's correlational coefficient were used to measure the strength of a relationship between the two independent variables (quality of life and self-efficacy) and one dependent variable (caregiver burden). Multiple

regression was used for RQ 3 to analyze a possible relationship between the predictors and an outcome. Appropriate instruments were used to assess levels of caregiver burden, caregiver self-efficacy, and caregiver quality of life. There was a minimum of time and resource constraints.

Methodology

Population

The target population for this study was baby boomer caregivers of a family member who was dementia diagnosed. As of 2017, AA (2018) reported there were 16.1 million family caregivers of demented family members in the United States. Participants of this study were baby boomers born between 1946 and 1964 living in the United States and are caring for a family member who has been dementia diagnosed for at least 20 hours per week. The first set of volunteers were from the Alzheimer's International Research TrialMatch® program. The second set of volunteers were from Banner Health's Alzheimer's Prevention Registry.

Sampling and Sampling Procedures

For participants to qualify to be part of this research they needed to be a volunteer for either the Alzheimer's International Research TrialMatch® program or Banner Health's Alzheimer's Prevention Registry. The volunteers of both programs were made up of families and caregivers of those diagnosed with dementia. To qualify to be a part of the study they were all baby boomer caregivers, born between 1946 and 1964, and cared for a family member who was dementia diagnosed at least at least 20 hours per week.

As I was a doctoral candidate, this study qualified to be a part of both research programs. Once institutional review board (IRB) approval of this study was in place, the study description and link to the Survey Monkey survey was sent to the researchers at both Alzheimer's International Research TrialMatch® and Banner Health's Alzheimer's Prevention Registry. Both research sites posted the link to the Survey Monkey survey on their site. The TrialMatch® researchers and Banner Health's Alzheimer's Prevention Registry created an email list of volunteers who matched the demographics of the study. They both sent emails to qualified volunteers, the link to the survey was included in those letters. Once the volunteers received their email from TrialMatch® and Alzheimer's Prevention Registry, they were able to join the study by opening the link in their email to the study on Survey Monkey. The volunteers then completed the 34 questions from the three assessment tools (ZBI, WHOQOL-BREF, and CSE Scale) and the demographic survey.

Reliability of a study's findings was determined by power, effect, size, and significance level of the statistical analyses (Soper, 2013). Power is the probability of rejecting the null hypothesis when it is false. Effect size defines the strength of the relationship. Significance level defines the probability of rejecting the null hypothesis. This online study involved 219 participants who were baby boomers and a primary caregiver of a dementia-diagnosed family member. Using multiple regression and correlation, one criterion variable and two predictor variables, an anticipated effect size of .15, power level of .8 and probability of .05, the results of the statistical calculator was

a minimum of 76 participants. One hundred participants were requested from each of the two sites to allow for participants dropping out of the study and incomplete data.

Procedures for Recruitment, Participation, and Data Collection

Once this study was approved, the IRB number was added to the TrialMatch® application and the application for Banner Health's Alzheimer's Prevention Registry. When those applications were approved, the description of the study and the link to the study on Survey Monkey were sent to the research department of both the TrialMatch® program and Banner Health's Alzheimer's Prevention Registry. The researchers from both research sites matched qualifying candidates from their database of volunteers using the demographic questionnaire. Demographics included baby boomers (those born between 1946 and 1964) who were currently the primary caregiver of a family member who had been dementia diagnosed and caring for their family member at least 20 hours per week.

Both research sites informed their volunteers they had matched the demographics of a new study that was listed on their site (TrialMatch® or Alzheimer's Prevention Registry). The volunteers were given a link in the email that took them directly to the Survey Monkey survey that contained three assessments, the demographic questionnaire, and the consent form. On the consent form there is a section, *Obtaining Your Consent* that reads, "If you feel you understand the study well enough to decide about it, please indicate your consent by pressing *Next* to begin the surveys." Questions from the assessments and demographic questionnaire were included in the Survey Monkey surveys. Participants exited the Survey Monkey program once they completed the survey.

There were no follow-up procedures. At the end of data collection, data from the study were downloaded from Survey Monkey into SPSS 26.0. Then the appropriate statistical procedures were run using SPSS 26.0.

A pilot study was also conducted to make sure the volunteers taking the surveys understood all the directions and questions being asked. In a follow-up phone call, the six participants of the pilot study were asked how long it took them to complete the survey and if they had issues understanding any of the questions. Volunteers for the pilot study were people from my social network. The demographic group for the pilot study was the same demographic group as the final study, baby boomers born between 1946 and 1964 and caring for a family member who had been dementia diagnosed for at least 20 hours a week. The pilot study findings were not part of the final research project.

Instrumentation and Operationalization of Constructs

The Survey Monkey survey was used for the main study. It included a demographic section and recognized tests of caregiver burden, self-efficacy, and caregiver quality of life. The demographic questions were presented at the beginning of the main survey and asked for information about gender, age, self-rated health, and relationship to the care receiver. The WHOQOL-BREF (WHO, 1998), the ZBI (Bédard et al., 2001; Zarit et al., 1980), the CSE Scale (A. M. Steffen et al., 2002), the demographic questionnaire, and a consent form were placed after the foregoing demographic and health questions.

Zarit Burden Interview

The ZBI (Bédard et al., 2001; Zarit et al., 1980;) provides a single summary measure of the caregiver's appraisal of the impact of caregiving has on their lives. The ZBI is a 22-item self-report, Likert-style scale that I used to measure perceived caregiver stress or burden (Zarit et al., 1980). All questions are answered as never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4). An example of a question asked is: "Do you feel: Strained when you are around your relative?" (Bédard et al., 2001; Zarit et al., 1980).

This tool was originally developed to compute the subjective burden associated with taking on responsibilities of caregivers of persons that had been dementia-diagnosed (Bachner & O'Rourke, 2007; Gallagher et al., 2011; Vitaliano, 1991; Zarit et al., 1980). This scale covers areas most mentioned by caregivers as problematic. These areas include caregivers' health status, psychological wellbeing, social life, finances, and the relationship shared by the caregiver and the person with dementia. Responses range from *never* (0) to *nearly always* (4). Total score ranges from 0–88 with higher scores designating higher perceived burden. The questions are worded subjectively, focusing on the affective response of the caregiver (Papastavrou et al., 2009). Associations of patient and caregiver burden scale scores will be analyzed using Pearson correlations.

Caregiver Self-Efficacy

The CSE Scale (A. M. Steffen et al., 2002; see Appendix A) allowed caregivers to rate their confidence in dealing effectively with caregiving situations such as knowing when to ask for help with a problem. One example of a question from this survey is:

“How confident are you that you could ask a friend or family member to stay with (your loved one) for a day when you need to see the doctor yourself?” (Score between 0 and 100). This scale measures the subjective feelings correlated with the burden of caregiving and in past studies has demonstrated good reliability and validity and high internal consistency (Cronbach’s alpha of .82), with 2-week test-retest reliability moderate and in the acceptable range .70 (A. M. Steffen et al., 2002). Each item on the scale asked the caregiver to assess their confidence level for being able to perform a behaviorally specific task.

The scale was divided into three domains of caregiving self-efficacy: (a) self-care and obtaining respite, (b) responding to disruptive patient behaviors, and (c) controlling upsetting thoughts activated by caregiving activities. The self-care and obtaining respite subscale measures caregivers’ self-efficacy about the ability to ask for assistance (e.g., “How confident are you that you can ask a friend/family member to stay with your family member for a day when you need to see a doctor?”; A. M. Steffen et al., 2002). The responding to disruptive patient subscale assessed the caregivers’ self-efficacy in respect to the ability to respond to the patient’s disruptive behaviors effectively (e.g., “When your family member asks you four times in the first hour after lunch when lunch is, how confident are you that you can answer them without raising your voice?”; A. M. Steffen, 2002). The controlling of upsetting thoughts activated by caregiving activities scale measures caregivers’ self-efficacy about negative or upsetting thoughts concerned with caregiving (e.g., “How confident are you that you can control worrying about future problems that may come up with your family member?” (A. M. Steffen et al., 2002). In

the Gilliam & Steffen (2006) study, the scale was normally distributed with high internal consistency (Cronbach's alpha = .88; Gilliam & Steffen, 2006). Other studies reported good internal consistency as well. Rabinowitz et al., 2007 reported $\alpha = .84, .89,$ and $.89$ for obtaining respite, responding to disruptive behavior, and controlling upsetting thoughts, respectively.

Role strain and personal strain Cronbach's alphas were reported to be $.89$ and $.77$ respectively. This scale is the shortened version that only had 12 items in the questionnaire. This scale asked questions about the stressful feelings due to caregiving. It takes about 5 minutes to complete (Bédard et al., 2001). Associations of patient and caregiver self-efficacy scale scores will be analyzed using Pearson correlations.

World Health Organization Quality of Life-BREF

The WHOQOL-BREF (WHO, 1998) scale can be used to understand the four domains of the quality of life: (a) physical health, (b) psychological, (c) social relationships, and (d) environment. An example of a question from this survey is: "How would you rate your quality of life? Very poor (1), Poor (2), Neither poor not good (3), Good (4), Very good (5)" (WHO, 1998).

The WHOQOL-BREF was used in a study measuring quality of life in health-care staff (Gholami et al., 2013). Responses are provided on a 1–5 scale. Results showed a good internal consistency ($\alpha = .93$) for WHOQOL-BREF. Applying Cronbach's alpha coefficient to examine the internal consistency of WHOQOL-BREF scale (26 items) and the four domains of it. The four domains and their corresponding alpha coefficients are (a) physical health domain (.81), (b) psychological health domain (.81), (c) social

relationship domain (.65), and (d) environmental health domain (.77; Gholami et al., 2013). According to Gholami et al. (2013), there are “statistically significant correlations between all domains” (p. 811).

Another example of an assessment used to study quality of life is the Caregiver Quality of Life (Vickery et al., 2009). This scale has been used to understand the effects of disease, disability, or disorder while caregiving over time. It was developed as a primary evaluation of quality-of-life measure targeted at dementia caregivers (Vickery et al., 2009).

Responses are provided on a 1–5 scale (*not at all bothered* = 1; *extremely bothered* = 5). Internal consistency reliability was $\geq .78$ for all scales; test-retest reliability (interclass correlation) estimates exceeded .70 for the 10 subscales; (1) Assistance with instrumental activities of daily living, (2) Assistance with activities of daily living, (3) Role limitations due to caregiving, (4) Personal time, (5) Family interaction, (6) Demands of caregiving, (7) Worry, (8) Spirituality and faith, (9) Benefits of caregiving, and (10) Caregiver feelings (Vickery et al., 2009). Cronbach’s alpha was used to estimate internal consistency for each multi-item scale (Vickery et al., 2009). Cronbach’s alpha ranged from .78 to .94; interclass correlation coefficients for test-retest reliability ranged from .53 (limitations of caregiving) to .89 (benefits of caregiving; Vickery et al., 2009).

Data Analysis Plan

The software used for analysis was IBM SPSS 26.0. The data cleaning and screening process, according to Pallant (2016), begins by checking the data for any errors and this will involve several steps to be taken. First, errors were checked by looking for

scores that appeared to be out of range appropriate to the study or were missing. Then it was necessary to find exactly where in the data file this error occurred and correct the data (Pallant, 2016). In the case of missing data, those participants were removed.

Research Questions and Hypotheses

RQ1: Is caregiver burden related to self- efficacy?

H01: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and self-efficacy is zero.

HA1: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between caregiver burden and self-efficacy.

RQ2: Is caregiver burden related to quality of life?

H01: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and quality of life is zero.

HA2: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between caregiver burden and quality of life.

RQ3: Which is the best predictor of caregiver burden: self-efficacy or quality of life?

H01: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and self-efficacy is zero.

HA1: In the population of baby boomer caregivers of dementia-diagnosed family members, caregiver burden will correlate to self- efficacy.

H02: In the population of baby boomer caregivers of dementia-diagnosed family members, the correlation between caregiver burden and quality of life is zero.

HA2: In the population of baby boomer caregivers of dementia-diagnosed family members, there is a correlation between caregiver burden, self-efficacy and quality of life.

H03: In the population of baby boomer caregivers of dementia-diagnosed family members, there will not be a correlation between caregiver burden, self-efficacy and quality of life.

HA3: In the population of baby boomer caregivers of dementia-diagnosed family members, there will be a correlation between caregiver burden, self-efficacy and quality of life.

Descriptive and inferential statistics were used in data analysis. The analysis of the sample characteristics included frequencies, percentages, means, medians, modes, standard deviations, and ranges appropriate to the type of variable. The study used bivariate correlation analysis to measure the extent of the relationship between study variables (i.e., caregiver burden and self-efficacy and caregiver burden and quality of life). This procedure was appropriate because it provided the following information about the data: the nature of the linear relationship (positive or negative) between the two variables and the information relating to the strength or magnitude of the linear relationship. The strength of the relationship can vary, ranging from -1 (which indicates a perfect negative correlation) to a $+1$ (which indicates a perfect positive correlation; Burns & Grove, 2011).

Multiple regression analysis and correlation analyses were used to provide information as to how each independent variable (caregiver stress and caregiver self-

efficacy) related to the dependent variable (caregiver burden). The goal was to find the best predictors of burden among functional status, behavioral problems, duration of care, caregiving self-efficacy, quality of life and selected caregiver demographic variables (age, self-related health status, relationship to care-receiver) in the total sample of Alzheimer's caregivers. Multiple regression analysis recognizes multiple factors may impact an observed process, and it measures the relative effect of each factor (Pallant, 2016).

Variables in this study were measured as they exist, with no control or manipulation applied. Even though no effort was made to imply causation, an identification of a strong relationship between study variables could lay the foundation for further study of the relationships, thereby possibly establishing causal links. Given the number of subscales and analyses, the Bonferroni correction was applied (number of analyses divided by the alpha of .05).

Threats to Validity

The vast amount of diversity (culture, ethnicity, social economic status [SES], religion) can and did exist within the targeted population of this research study. Limitless diversity is a factor that was considered as one of the limitations of this study. The researchers from the Alzheimer's TrialMatch® program, and Banner Health's Alzheimer's Prevention Registry matched the demographics of this study with those in their database of volunteers. Specific and stringent guidelines were employed to identify qualified participants, but an enormous amount of diversity may still exist among the qualified and selected participants (the population). Additionally, the purposeful sample

only came from those participants in the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry that was limited to computer literate individuals, which may or may not also be a limitation and/or threat to validity. Unfortunately, this was a sampling method in which not all subjects that made up the population of interest have an equal chance of being included in the research study; such was the case in this study. Therefore, the possibility of limitation exists due to the variability in numbers of the targeted population that are part of the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry.

Ethical Considerations

This research project did not specifically ask for nor require any participant to divulge any protected health information that is defined as protected by HIPAA (Health Insurance Portability and Accountability Act) of 1996. Therefore, information and data collected was limited to the requirements of the study; the WHOQOL-BREF (WHO, 1998), the ZBI (Bédard et al., 2001; Zarit et al., 1980), the CSE Scale (A. M. Steffen et al., 2002), a demographic questionnaire, and a consent form. Participants' specific health-related information or status was not directly solicited.

The possibility existed that participants may self-disclose health-related information during the testing because all surveys used were delivered in a virtual format. Participants were given a link to the survey by the researchers in the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry. Participants saw a consent form when they opened the survey and

were able to press “next” if they agreed to participate; this was done to protect participants’ identities.

During this study, interactions with participants were minimal as the survey was the Survey Monkey. The participants were invited by researchers from both research sites to join the study and were emailed a link to the survey.

Data Security

As for any concerns about the security of Survey Monkey, this site was used due the security it provides to protect participants’ anonymity and its extensive security procedures. Confidentiality is part of this security. Survey Monkey information was included to clarify steps taken for the security of participants’ identity. The following is paraphrased from the Survey Monkey academic site, and it addresses the topic of secure transmission and database security:

Survey Monkey has criteria for academic studies that meet IRB approved and includes an SSL encryption feature. This feature protects sensitive data and protects the participant’s information as it moves along communication pathways between the respondent’s computer and Survey monkey servers. The Database and Server Security for Survey Monkey has physical and environmental controls in place to protect data. Survey Monkey will not use the information collected in the surveys in any way, shape, or form. In addition, any other material provided to Survey Monkey (including images, email addresses, and so forth) will be held in the strictest confidence (www.surveymonkey.com).

Summary

With the aged population living longer, research was lacking about adult children that were caring for a family member who had been dementia-diagnosed. The focus of this study was adult children caring for a family member who had been dementia-diagnosed. The MetLife Mature Market Institute (2011) study of caregiving costs to working caregivers was produced in partnership with the National Alliance of Caregiving (NAC), the Center for Long Term Care Research, and the Policy at New York Medical College. They examined the nearly 10 million adult children over the age of 50 who were caring for their aging family member (MetLife Mature Market Institute, 2011).

This present study is important to our society and its economy because healthier caregivers can care longer for their family members before turning to an institution. In 2019, the estimated economic value of the care provided by family members to those with a dementia diagnosis was \$244 billion (AA, 2020). This number represents 18.6 billion hours of care (AA, 2020). The ongoing need for family caregivers continues to grow as the aging population lives longer.

Findings from this study could empower researchers and practitioners to identify and develop resources for caregiving families that could promote a higher quality of life and a lower level of caregiver burden. As families continue caring for their elders, they will continue to assume more and more responsibility in dealing with their family member's debilitating physical and cognitive decline. Consequently, the physical and psychological health and well-being of caregivers will be an ongoing social priority (AA, 2020, Farina et al., 2017; Gallagher et al., 2011).

This chapter provided a description of the quantitative study, participants of the study, data analysis, and collection procedures. Chapter 3 also included potential threats to validity and methods that were used to strengthen the integrity of the data. The chapter concludes with the ethical concerns and methods to reduce them. Chapter 4 presents the results obtained from applying this methodology.

Chapter 4: Results

The purpose of this quantitative study was to investigate the level of caregiver burden of baby boomers caring for a family member who had been dementia diagnosed and to examine a possible correlation of caregiver burden, quality of life, and self-efficacy using multiple regression and correlation analysis. RQ 1 addressed whether caregiver burden was related to self-efficacy in the population of baby boomer caregivers of dementia-diagnosed family members. RQ 2 addressed whether caregiver burden was related to quality of life in the population of baby boomer caregivers of a dementia-diagnosed family member. RQ 3 addressed which was the better predictor of caregiver burden; self-efficacy or quality of life in the population of baby boomer caregivers of dementia-diagnosed family members. This chapter begins with data collection information and any pertinent changes from Chapter 3. Next, the baseline descriptive and demographics of the sample are reported. Lastly, survey results are presented.

Data Collection

Data collection took place over 7 months. Initial efforts to recruit participants during the first 3 months generated 18 results from the Alzheimer's TrialMatch® program. During the next 4 months there were four more completed surveys from the Alzheimer's TrialMatch® program. They were only able to complete one mailout before the program was stopped due to a new program design taking place in the Alzheimer's TrialMatch® program. More sites were approved by the university's IRB to use the following: social media internet sites, Facebook, the large online university's participant pool, and Banner Health's Alzheimer's Prevention Registry. The Alzheimer's Prevention

Registry was found while searching social media sites that focused on Alzheimer's disease. Again, data collection was completed within a 7-month period with results from both the Alzheimer's TrialMatch® program ($n = 22$) and Banner Health's Alzheimer's Prevention Registry ($n = 269$). In accordance with the IRB, this research did not use snowball sampling or any other direct contact methods to recruit participants.

Alzheimer's TrialMatch® emailed the survey for this study to 300 of their volunteers, at first there were a total of 18 responses. There were four more responses from the Alzheimer's TrialMatch® program during the last 4 months totaling 22 responses. Banner Health's Alzheimer's Prevention Registry emailed the survey to over 10,000 of their volunteers with 269 responses. After selecting only data from those completed surveys with total responses that met the research criteria, had no missing answers, were born between 1946 and 1964, and were caring for their family member who had been dementia diagnosed for at least 20 hours per week, the sample was $n = 219$. The G*Power analysis indicated the need for 76 participants.

Data Cleaning and Assumption Testing

Initially, a total of 269 caregivers began the survey. Selecting only respondents who had either zero missing answers ($n = 227$) or only one missing answer ($n = 22$), this reduced the sample to $n = 249$. Missing answers were either estimated/imputed using the grand mean (for a continuous variable) or the grand mode for a nominal/categorical variable. The selection criteria for the study were “to be a baby boomer caregiver, born between 1946 and 1964, be caring for a family member who had been dementia-

diagnosed, and caring for their dementia-diagnosed family member at least 20 hours per week.” Applying those criteria further reduced the sample to $n= 219$.

According to Laerd Statistics (2020), there are eight assumptions that need to be met for multiple regression:

1. Dependent variable is a continuous scale.
2. Two or more independent variables.
3. Independent observations
4. Linear relationship between the dependent variable and each nondichotomous independent variable both individually and collectively.
5. Homoscedasticity
6. No multicollinearity
7. No significant outliers, high leverage points or highly influential points.
8. Normally distributed residual scores.

Assumptions 1 (continuous dependent variable), 2 (2 or more independent variables), and 3 (independent observations) were met based on the design of the study. Assumptions 4 (linear relationships) and 5 (homoscedasticity) were met based on inspection of the scatterplot of studentized residuals against the unstandardized predicted values and the inspection of the partial regression plots. Assumption 6 (no multicollinearity) was met by inspection of the variance inflation factor statistics in the regression model. Assumption 7 (no outliers or other influential points) were met after identifying no problematic case wise diagnostics, no high Cook’s or leverage values, nor any studentized deleted residuals greater than ± 3 standard deviations. Assumption 8 (normally distributed

residuals) was met based on the inspection of the residual histogram and the P-P plot. The results of the assumption testing taken together, along with the multiple regression model being robust to violations of assumptions in large samples ($N = 219$), the assumptions for multiple regression were adequately met (Laerd Statistics, 2020).

Results

RQ 1: Is caregiver burden related to self- efficacy? To address this RQ, correlations were conducted, Table 4 displays the relevant Pearson correlation. Inspection of the table found a significant negative correlation between caregiver burden and self- efficacy ($r = -.50, p < .001$). This finding provided support to reject the null hypothesis (see Table 4).

RQ 2: Is caregiver burden related to quality of life? To address this RQ, correlations were conducted, Table 4 displays the relevant Pearson correlation. Inspection of the table found a significant negative correlation between caregiver burden and total quality of life ($r = -.58, p < .001$). This finding provided support to reject the null hypothesis (see Table 4).

RQ 3: Which is the best predictor of caregiver burden: self-efficacy or quality of life? To address this question, Table 5 displays the prediction of caregiver burden based on self-efficacy and the four quality of life variables. The overall model was significant ($F [5,213] = 34.19, p = .001$) and accounted for 44.5% of the variance to caregiver burden. Inspection of the table found higher levels of caregiver burden were related to: (a) lower self-efficacy scores ($\beta = -.29, p = .001$); (b) lower psychological quality of life scores ($\beta = -.35, p = .001$); and (c) lower social quality of life scores ($\beta = -.16, p = .02$)

Inspection of the partial correlations for the model ($r_{ab.c}$) which is the correlation for the predictor and the criterion variable with the effects of the other predictors removed found self-efficacy ($r_{ab.c} = -.32$) to have the strongest relationship followed by psychological ($r_{ab.c} = -.28$) and social quality of life ($r_{ab.c} = -.16$; see Table 5).

Table 1 displays the frequency counts for selected variables (Caregiver Age: $M = 65.66$, $SD = 5.17$; Patient Age: $M = 79.65$, $SD = 10.01$; see Table 1). Table 2 displays the psychometric characteristics for the seven scale scores. To determine the bivariate relationships between the seven demographics and caregiver burden. Table 3 displays the relevant Pearson correlations. To answer RQs 1 through 3, Table 4 displays the relevant Pearson correlations. Table 5 displays the multiple regression prediction of caregiver burden based on self-efficacy.

Table 1*Frequency for Selected Variables*

Variable	<i>n</i> (%)
Caregiver Gender	
Male	36 (16.4)
Female	183 (83.6)
Caregiver Age	
56 to 59 years	36 (16.4)
60 to 69 years	119 (54.3)
70 to 74 years	64 (29.2)
Relationship to Patient	
Spouse	107 (48.9)
Child	95 (43.4)
Other	17 (7.8)
Age of Patient	
51 to 59 years	6 (2.7)
60 to 79 years	103 (47.0)
80 to 89 years	68 (31.1)
90 to 104 years	42 (19.2)
Hours per week	
20–39 hours/week	41 (18.7)
40–79 hours/week	35 (16.0)
Over 80 hours a week	143 (65.3)
Caregiver Education	
High school	16 (7.3)
Some college	48 (21.9)
College	68 (31.1)
Graduate school	55 (25.1)
Professional degree (e.g., PhD, MD)	32 (14.6)
Marital Status	
Married/partnered	162 (74.0)
Single (never married)	20 (9.1)
Divorced	22 (10.0)
Other	15 (6.9)

Table 2 displays the psychometric characteristics for the seven scale scores. Cronbach alpha reliability coefficients ranged in size from $\alpha = .66$ to $\alpha = .93$ with the median sized alpha being $\alpha = .84$. All but one of the scales (social quality of life, $\alpha = .66$) had acceptable levels of internal reliability (Crosby et al., 2006). However, because the Cronbach alpha reliability coefficient ($\alpha = .66$) was close to the desired threshold ($\alpha \geq .70$), there were only three items in the scale that typically lowers the reliability coefficient, this is an established instrument, and the current sample size is large ($n = 219$), that reliability coefficient was not deemed to be a problem (Crosby et al., 2006; see Table 2).

Table 2

Psychometric Characteristics for the Seven Scale Scores

Scale	Items	<i>M</i>	<i>SD</i>	Low	High	α
Self-Efficacy	10	60.98	20.94	4.80	99.60	.87
Total QOL	26	3.55	0.58	1.73	4.85	.93
Physical QOL		3.69	0.67	1.86	5.00	.81
Psychological QOL	6	3.34	0.70	1.33	4.83	.84
Social QOL	3	3.03	0.83	1.00	5.00	.66
Environmental QOL	8	3.82	0.61	1.7	5.00	.84
Caregiver Burden	22	2.72	0.60	1.36	4.41	.89

Note. $n = 219$; QOL = Quality of Life.

Table 3 displays Pearson correlations for the seven demographic variables with caregiver burden. This table was provided to determine whether any demographic variables might be important covariates for the multiple regression model. Inspection of the table found none of the seven demographic variables to be significantly related to caregiver burden at the $p < .05$ level (see Table 3).

A further examination of the mean burden scores for the nominal independent variables was performed. Males had a burden score of $M = 2.60$, and the women had a mean score of $M = 2.75$ ($p = .19$). Spouses had a burden score of $M = 2.71$, and nonspouses had a mean score of $M = 2.73$ ($p = .85$). Married caregivers had a burden score of $M = 2.74$; the nonmarried caregivers had a mean score of $M = 2.66$ ($p = .36$).

Table 3

Pearson Correlations for the Seven Demographic Variables with Caregiver Burden

Variable	Caregiver burden
Caregiver Gender	.09
Caregiver Age	-.10
Spouse	-.01
Age of Patient	.01
Hours per week	-.03
Caregiver Education	.00
Married b	.06

Note. $n = 219$; no correlation was significant at the $p < .05$ level.

Table 4 displays the relevant Pearson correlations and coefficients of determination. Inspection of the table found significant negative correlations between caregiver burden and self-efficacy ($r = -.50$, $r^2 = 25.0\%$, $p < .001$) and between caregiver burden and total quality of life ($r = -.58$, $r^2 = 33.6\%$, $p < .001$). Given that total quality of life accounted for more variance in caregiver burden, this finding provided support to reject the null hypothesis (see Table 4).

Table 4

Pearson Correlations for Self-Efficacy and Quality of Life Scales with Caregiver Burden

Variable	Caregiver burden r	r^2
Self-Efficacy	-.50	25.0
Total QOL	-.58	33.6
Physical QOL	-.41	16.8
Psychological QOL	-.59	34.8

Social QOL	-.51	26.0
Environmental QOL	-.44	19.4

Note. $n = 219$; all correlations were significant at the $p < .001$ level.

Table 5 displays the prediction of caregiver burden based on self-efficacy and the four quality of life variables. The overall model was significant ($F [5, 213] = 34.19, p = .001$) and accounted for 44.5% of the variance in caregiver burden. Inspection of the table found higher levels of caregiver burden were related to: (a) lower self-efficacy scores ($\beta = -.29, p = .001$); (b) lower psychological quality of life scores ($\beta = -.35, p = .001$); and (c) lower social quality of life scores ($\beta = -.16, p = .02$). Inspection of the partial correlations for the model ($r_{ab.c}$) which is the correlation for the predictor and the criterion variable with the effects of the other predictors removed found self-efficacy ($r_{ab.c} = -.32$) to have the strongest relationship followed by psychological quality of life ($r_{ab.c} = -.28$) and social quality of life ($r_{ab.c} = -.16$; see Table 5)

A further examination of the mean burden scores for the nominal independent variables was performed. Males had a burden score of $M = 2.60$, and females had a mean score of $M = 2.75$ ($p = .19$). Spouses had a burden score of $M = 2.71$; nonspouses had a mean score of $M = 2.73$ ($p = .85$). Married caregivers had a burden score of $M = 2.74$, and the nonmarried caregivers had a mean score of $M = 2.66$ ($p = .36$; see Table 5).

Table 5

Prediction of Caregiver Burden Based on Self-Efficacy and Quality of Life Variables

Variable	<i>B</i>	<i>SE</i>	β	<i>p</i>	Lower	Upper	$r_{ab.c}$	VIF
Intercept	4.68	0.21		.001	4.27	5.09		
Self-Efficacy	-0.01	0.00	-.29	.001	-0.01	0.00	-.32	1.27
Physical QOL	-0.02	0.06	-.02	.74	-0.15	0.11	-.02	2.00
Psychological QOL	-0.29	0.07	-.35	.001	-0.43	-0.16	-.28	2.61
Social QOL	-0.12	0.05	-.16	.02	-0.21	-0.02	-.16	1.83
Environmental QOL	-0.01	0.07	-.01	.87	-0.15	0.13	-.01	2.07

Note. $n = 219$; full model: $F(5, 213) = 34.19, p = .001. R^2 = .445$. Durbin-Watson = 1.88; $r^{ab.c}$ = partial correlation for the predictor and the criterion variable with the effects of the other predictors removed.

Summary

In summary, this study used survey data from 219 caregivers who were volunteers of the Alzheimer's TrialMatch® program, and Banner Health Alzheimer's Prevention Registry to investigate the level of caregiver burden of baby boomers caring for a family member that had been dementia-diagnosed and to examine a possible correlation of caregiver burden and quality of life and caregiver burden and self-efficacy. RQ 1 (caregiver burden and self-efficacy) was supported (see Table 4). RQ 2 (caregiver burden and quality of life) was supported (see Table 4). RQ 3 (best predictor of caregiver burden) was supported (see Table 5).

Chapter 5 will provide a discussion of the strengths and limitations of this study. Results and findings will be described with reference to the theoretical frameworks of the theory of transactional stress that was the framework for the current study; it is the basis for caregivers' abilities to properly identify, categorize, and assess danger in their life (Lazarus & Folkman, 1987; Merluzzi et al., 2011). A mistaken assessment of environmental stressors could lead to psychological harm due to the aggregate effects of these stressors (Merluzzi et al., 2011). The current study, with its use of the theory of transactional stress, offered guidance on the significance of caregiver burden, quality of life, and self-efficacy in respect to transactional stress. In the final chapter, findings were

compared to the literature, conclusions and implications are drawn, and a series of recommendations are suggested.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of the current quantitative study was to investigate the level of caregiver burden of baby boomers caring for a family member that had been dementia-diagnosed. In this investigation, I examined relationships among caregiver burden, quality-of-life, and self-efficacy. A correlational design was used because the variables were not manipulated; I gathered information about the relationships among predictor and criterion variables. The following RQs guided this study:

1. Is caregiver burden related to self-efficacy?
2. Is caregiver burden related to the quality of life?
3. Which is the best predictor of caregiver burden, quality of life or self-efficacy?

To answer these RQs, I calculated bivariate correlations of the criterion variable (burden) and the predictor variables (self-efficacy and quality of life) using multiple regression analysis. For RQ 1, I found a significant negative correlation between caregiver burden and self-efficacy; as self-efficacy increased, the burden level decreased. For RQ 2, I found a significant negative correlation between caregiver burden and quality of life; with a higher level of quality of life, the burden levels were lower. For RQ 3, the overall model was significant and accounted for half of the variance in caregiver burden. I found higher levels of caregiver burden were related to (a) lower self-efficacy scores, (b) lower psychological quality of life scores, and (c) lower social quality of life scores. With the effects of the other predictors removed, I examined the partial correlations for the model, correlation for the predictor, and the criterion variable and found self-efficacy to have the strongest relationship, followed by psychological quality of life and social quality of life.

In this chapter, I review the results of the analyses presented in Chapter 4. I discuss a summary and interpretation of the findings, practical implications of the results, and links to social change. I also identify possible limitations of the study and make suggestions for future research in conjunction with the discussion of each hypothesis. Finally, I present a summary of the importance of social change for family caregivers of an elder family member who has been dementia diagnosed.

Interpretation of the Findings

The purpose of this quantitative study was to investigate the level of caregiver burden among baby boomers caring for a family member who had been dementia diagnosed and to examine a possible relationship between the level of caregiver burden with the caregivers' quality of life and self-efficacy. Survey responses from 219 family caregivers were analyzed. The transactional model of stress and coping was used as the basis for assessing participants' ability to cope with stress-filled life events (Lazarus & Cohen, 1977; Savla et al., 2021). A fundamental proposition of the transactional model is that it is the interaction of the person and environment that creates stress for the individual (Lazarus, 1966; Lazarus & Folkman, 1984; Savla et al, 2021). The transactional model also depicts coping as a choice that is affected by the primary and secondary appraisals. Coping is predictable and consistent with a determination of what can be done to change the situation (Folkman & Lazarus, 1985; Savla et al., 2021). For example, problem-focused coping is expected to be used in situations appraised as unchangeable. The individual's choice of a coping mechanism is determined by their perceptions of personal control over the stressful situation (Folkman & Lazarus, 1980;

Savla et al., 2021). Personal control reflects an individual's beliefs, at a given point in time, in their ability to effect change in a desired direction on the environment (Greenberger & Strasser, 1986). Coping outcomes at least partially depend on the goodness of the fit between appraisal and coping (Folkman & Lazarus, 1984).

The present research and application of the constructs of transactional stress and coping offer guidance on the significance of self-determination and transactional stress. This allows insights into recognizing the properties of efficacy retention and individuals' stress appraisal. While researching the stress-process model of caregiving, it became clear that there were multiple levels of support and stress at the individual, family, and community level when predicting mental health outcomes. In this study, the theories of transactional stress merged well with the tenets of caregiver burden, self-efficacy, and quality of life (Folkman & Lazarus, 1984; Savla et al, 2021).

An early investigation of research on the three variables used in this research—self-efficacy, caregiver burden, and quality of life—resulted in multiple articles using one or two of these variables but not the three specific variables I used. For example, Khan et al. (2007) demonstrated that self-efficacy could help family caregivers of older adults who had been diagnosed with Alzheimer's disease and other types of cognitive impairment experience lower burden and depression symptoms of severity. Khan et al. redefined the definition of self-efficacy in reference to caregivers of older adults with a dementia diagnoses and other types of cognitive impairment. According to Kahn et al., self-efficacy was found to be the family caregivers' confidence in their ability to manage behavior and other stressors, control upsetting thoughts, acquire medical information,

manage medical issues, obtain self-care across community supports, and maintain a good relationship with a relative, friend, or neighbor of an older adult with cognitive impairment. However, a different point of view was expressed by Park et al. (2019) who noted that caregiver self-efficacy had shown promise in improving the quality of life of these family caregivers. Additional articles were found in reference to self-efficacy and caregivers of family members who had been dementia-diagnosed (Gonyea et al., 2005; Parker et al., 2017; Salamizadeh et al., 2017). Gonyea et al. (2005) found that caregiver interventions aimed to reduce burden may benefit from the inclusion of specific strategies to increase self-efficacy and decrease depressive symptoms self-efficacy. For instance, online group supports for these caregivers has shown a positive effect on social support and self-efficacy (Parker et al., 2017). Spiritual care can also enhance the self-efficacy of family caregivers of people who suffer from Alzheimer's disease (Salamizadeh et al., 2017).

The results of my research show that self-efficacy appears to protect against burden in caregivers of the dementia diagnosed (Gallagher et al., 2011; Savla et al., 2021). The overall model was significant and accounted for half of the variance to caregiver burden. Higher levels of caregiver burden were related to (a) lower self-efficacy scores, (b) lower psychological scores, and (c) lower social quality of life scores. With other predictors removed, I examined the partial correlations for the model, correlation for the predictor, and the criterion variable and found self-efficacy to have the strongest relationship followed by psychological quality of life and social quality of life.

I used multiple regression analysis to examine the bivariate correlations of the criterion variable (burden) and the predictor variables (self-efficacy and quality of life). I found a significant negative correlation between caregiver burden and self-efficacy; as self-efficacy increased, the burden level decreased. The findings show that with a higher level of quality of life, the burden levels were lower. Higher levels of caregiver burden were related to (a) lower self-efficacy scores, (b) lower psychological quality of life scores, and (c) lower social quality of life scores. Such findings have not been previously reported.

Limitations of the Study

A limitation of this research was that volunteer participants were recruited from the databases of the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry. The positive aspect of this approach was that all the volunteers from these programs were caregivers of their family member who had been diagnosed with some form of Alzheimer's disease, and they were computer literate, which was a requirement for this study. There are many other caregivers who are not part of these programs, so further studies could include other volunteers in the future. Another limitation of the study was that there were only a few male participants. This was not surprising because women are more likely to be caregivers of elder family members than men (Papastavrou et al., 2009).

Threats to Validity

A vast amount of diversity (e.g., culture, ethnicity, social economic status) could have existed within the targeted population of this research study. One diversity

recognized was that more female caregivers ($n = 183$, 83.6%) took the survey than male caregivers ($n = 36$, 16.4%; see Table 1 in Chapter 4). Researchers from the Alzheimer's TrialMatch® program and Banner Health's Alzheimer's Prevention Registry matched the demographics of this study with those in their volunteer database. Specific and stringent guidelines were employed to identify qualified participants. The sample came from those participants in the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry and was limited to computer-literate individuals, which may or may not be a limitation and/or threat to validity. Unfortunately, I used a sampling method in which not all subjects comprising the population of interest had an equal chance of being included in the research study. Therefore, the possibility of limitation exists due to the variability in numbers of the targeted population being part of the Alzheimer's International Research TrialMatch® program and Banner Health's Alzheimer's Prevention Registry.

Recommendations

The findings from the current study may help future researchers conduct research on ways to improve quality of life and self-efficacy of family caregivers. The results may help health professionals and support groups plan and develop better programs to empower caregivers to lower their level of caregiver burden and increase their quality of life and self-efficacy as they care for their family member who was diagnosed with Alzheimer's disease.

Future research on this topic could investigate new ways to introduce family caregivers to specific interventions created for this population. These learning

interventions could help local, state, and national programs that are part of a caregivers' network decrease the need for institutionalization of family members, which could reduce the cost of care to the community and provide positive coping mechanisms for caregivers (Brodaty & Donkin, 2009; Dawson & Bangerter, 2020, Whitlatch et al., 2018). As the older population increases, this information will be valuable as more people take on the challenge of family caregiving (Dawson & Bangerter, 2020; Haley et al., 1987; Whitlatch et al., 2018).

A longitudinal study could be conducted to better predict changes in family caregivers' burden, quality of life, and self-efficacy, considering the study factors. Some recommendations for studies using similar variables to those of this study could include those found in an early investigation of the three variables used in this research: self-efficacy, caregiver burden, and quality of life. Future researchers could include different demographics such as varied races, other age groups, same sex couples, males only, or different age groups of the caregivers of a family member who has been dementia-diagnosed.

Implications

Positive Social Change

The implications for positive social change from the results of this study could include knowledge useful for doctors, nurses, therapists, families, social workers, gerontologists, family physicians, mental health counselors, expressive arts therapists, and others who have searched for a direction to empower themselves and the caregivers of a dementia-diagnosed family member with insights into healthier ways of living their

lives. Opportunities created for their specific needs could empower baby boomer caregivers to learn how to care for themselves, lower their levels of burden, and increase their levels of self-efficacy and quality of life. Such opportunities would enable them to stay healthier during their years of caregiving and could also help keep their family member home longer before institutionalization.

Teaching new approaches for these caregivers to communicate with their loved ones and with doctors, mental health therapists, expressive arts therapists, social workers, and additional caregivers—will allow everyone involved to work together as a team to care for their family member. They would then have the information available to share with others at the local, state, and national level (Dawson & Bangerter, 2020, Whitlatch et al., 2018). Sharing this information would also encourage those searching for a path to empower family caregivers of a dementia-diagnosed family member (Brodaty & Duncan, 2009; Dawson & Bangerter, 2020; Whitlatch et al., 2018). Long-term results could include (a) less institutionalization of family members (Lau et al., 2008), (b) a reduced cost to the community, and (c) more positive coping mechanisms for caregivers of their family member (Brodaty & Duncan, 2009; Dawson & Bangerter, 2020; Gaugler et al., 2007; Judge et al., 2011).

Savla et al. (2021) used the theory of transactional stress in studying individuals' abilities to properly identify, categorize, and evaluate danger in their own well-being. An erroneous assessment of the effects of environmental stressors could precede psychological harm due to their aggregate effects, thus influencing their individual efficacy (Merluzzi et al., 2011; Savla et al., 2021). The present research and application of

the constructs of transactional stress and coping offer guidance on the significance of self-determination and transactional stress, which allows insights into recognizing the properties of efficacy retention and the individuals' stress appraisal.

The implications for social change from this study are found in the evidence provided by the research: elevated levels of burden among family caregivers. A curriculum of multiple sessions could be written by an expressive arts therapist to incorporate some of the milieu of variables found to cause this caregiver burden and to encourage caregivers to create an image in some fashion.

Since social change is broadly described as both a process and a product, the product in this example of a social change experience could be the development of a multiple-session curriculum by an expressive arts therapist. These sessions could be used with caregivers virtually, either individually or in a group session. The medium used for this curriculum could be painting, drawing, writing, or even manipulating clay with which caregivers create an image of frustrating things their family member has done on a continual basis. The process would involve the expressive arts therapist working with family caregivers as they create this image. These experiences may lead to healthier caregivers, more positive appraisals of the caregiving experience, and, ultimately, a reduced desire to institutionalize, which could ease financial burdens on families and society.

There are opportunities at the local, state, national, and international levels to address the educational and psychosocial needs of persons living with dementia and their caregivers (Whitlatch et al., 2018). These opportunities include sharing knowledge useful

for families, therapists, social workers, gerontologists, family physicians, mental health counselors, expressive arts therapists, and others who are searching for a direction to improve the health of family caregivers of a dementia-diagnosed family member. Long-term results would include less institutionalization of family members, reduced cost to the community, and more positive coping mechanisms for caregivers. These findings could have a significant effect, not only on caregivers, but also on society—resulting in positive social change (Dawson & Bangerter, 2020; Whitlatch et al, 2018). This change could include the creation of learning opportunities that would empower baby boomers who are caring for their family member who has been dementia-diagnosed.

Conclusions

Future research on this topic may include the development of interventions for caregivers to learn ways to increase their level of self-efficacy. Novel studies could consider the variables of this research: caregiver burden, self-efficacy, and quality of life. The findings of this investigation may empower psychologists, doctors, therapists, expressive art therapists, and social workers in their efforts to help those baby boomer caregivers who are caring for a family member that had been diagnosed with Alzheimer's disease. Diverse types of interventions may help caregivers keep their family member home longer before institutionalization (Gómez-Gallego, et al., 2012). A longitudinal study could be performed to better predict changes in family caregivers' burden, quality of life, and self-efficacy.

The essence of this study showed family caregivers had a higher level of burden after they took on the role of being the primary caregiver of their family member who had

been diagnosed with Alzheimer's disease. In this study, I described the impact on the quality of life of family caregivers for persons with Alzheimer's disease and how caregivers' burden, quality-of-life, and self-efficacy were affected due to caregiving responsibilities.

Findings support past research on the impact of caregiver burden on family caregivers' health (AA, 2020; Salamizadeh, 2017; Savla et al., 2021). Newer research suggests the theory of transactional stress offers guidance on the significance of self-determination and transactional stress, which promote insights into recognizing the effects of efficacy retentions and the individuals' stress process (Merluzzi et al., 2011; Savla et al., 2021; Whitlatch et al., 2018). I hope this study provides valuable information on the effects of caregiver burden on the quality of life and self-efficacy of family caregivers for persons with Alzheimer's disease. The findings may help future researchers explore ways to improve the strain of caregiver burden. The data collected in this study may help health professionals and support groups plan and develop new and better programs for improving the levels of burden, self-efficacy, and quality of life of family caregivers of persons with Alzheimer's disease. Long-term results could include less institutionalization of family members (Lau et al., 2008; Whitlatch et al., 2018), a reduced cost to the community, and more positive coping mechanisms for the caregivers of their family member (Brodaty & Duncan, 2009; Dawson & Bangerter, 2020; Gaugler et al., 2007; Judge et al., 2011; Whitlatch et al., 2018).

References

- Alberts, N. M., Hadjistavropoulos, H. D., Pugh, N. E., & Jones, S. L. (2011). Dementia anxiety among older adult caregivers: An exploratory study of older adult caregivers in Canada. *International Psychogeriatric*, *23*(6), 880–886.
<https://doi.org/10.1017/S1041610211000299>
- Alzheimer's Association. (n.d.). *About TrialMatch: Clinical trial matching service for Alzheimer's and other dementia*. Retrieved August 10, 2021, from http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp
- Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *11*(3), 332–384.
<https://doi.org/10.1016/j.jalz.2015.02.003>
- Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *12*(4), 459–509.
<https://doi.org/10.1016/j.jalz.2016.03.001>
- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *14*(3), 367–429.
<https://doi.org/10.1016/j.jalz.2018.02.001>
- Alzheimer's Association. (2020). 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *16*(3), 391-460. <https://doi.org/10.1002/alz.12068>
- American Psychological Association. (2012). *Who are family caregivers?*
<http://www.apa.org/pi/about/publications/caregivers/faq/statistics.aspx>
- Aneshensel, C., Perlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995).

Profiles in caregiving: The unexpected career. Academic Press.

- Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging*, 3(3), 245–248. <https://doi.org/10.1037/0882-7974.3.3.245>
- Arons, A. M., Krabbe, P. F., Scholzel-Dorenbos, C. J., van der Wilt, G. J., & Rikkert, M. G. (2013). Quality of life in dementia: A study on proxy basis. *Biomedical Central Research Methodology*, 13, Article 13. <https://doi.org/10.1186/1471-2288-13-110>
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215. <https://doi.org/10.1037/0033-295X.84.2.191>
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp. 71–81). Academic Press.
- Bandura, A. (2006). Social cognitive theory. In S. Rogelberg (Ed.). *Encyclopedia of industrial/organizational psychology* (pp. 729–733). SAGE Publications.
- Bandura, A., & Locke, E. A. (2003). Negative self-efficacy and goal effects revisited. *Journal of Applied Psychology*, 88(1), 87–99. <https://doi.org/10.1037/0021-9010.88.1.87>
- Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F. & Lance, C. E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*, 53(2), 255–261. <https://doi.org/10.1111/j.1532-5415.2005.53111.x>

- Bédard, M., Molloy, W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*, 652–657. <https://doi.org/10.1093/geront/41.5.652>
- Black, S. E., Gauthier, S., Dalziel, W., Keren, R., & Correia, J. (2010). Canadian Alzheimer's disease caregiver survey: Baby-boomer caregivers and burden of care. *International Journal of Geriatric Psychology, 8*, 807–813. <https://doi.org/10.1002/gps.2421>
- Bodnar, J. C., & Kiecolt-Glaser, J. K. (1994). Caregiver depression after bereavement: Chronic stress isn't over when it's over. *Psychology and Aging, 9*(3), 372–380. <https://doi.org/10.1037/0882-7974.9.3.372>
- Bosboom, P., Alfonso, H., & Almeida, O. (2012). Determining the predictors of change in quality-of-life self-ratings and carer-ratings for community-dwelling people with Alzheimer disease. *Alzheimer Disease and Associated Disorders, 27*(4), 363–371. <https://doi.org/10.1097/WAD.0b013e318293b5f8>
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*, 217–228. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>
- Brownie, S., Horstmanshof, L., & Garbutt, R. (2014). Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review. *International Journal of Nursing Studies, 51*(12), 1654–1666. <https://doi.org/10.1016/j.ijnurstu.2014.04>
- Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J.

(2009). *Implementing a community-based program for dementia caregivers: An action guide using REACH OUT*. Centers for Disease Control and Prevention and the National Association of Chronic Disease Directors.

www.cdc.gov/aging/caregiving/activities.htm

Burns, N., & Grove, S. K. (2011). *Understanding nursing research: Building on evidence-based practice* (5th ed). Sanders Elsevier.

Cheng, Y., Rosenberg, M. W., Wang, W., Yang, L., & Li, H. (2011). Aging, and place in residential care facilities in Beijing, China. *Social Science & Medicine*, 72(3), 365–372. <https://doi.org/10.1016/j.socscimed.2010.10.008>

Chwalisz, K., Altmaier, E. M., Daniel, W., & Russell, D., (1992). Causal attributions, self-efficacy cognitions, and coping with stress. *Journal of Social and Clinical Psychology*, 11, 377–400. <https://doi.org/10.1521/jscp.1992.11.4.377>

Clarke, T. C., Black, L. I., Stussman, B. J., Barnes, P. M., & Nahin, R. L. (2015, February 10). Trends in the use of complementary health approaches among adults: United States, 2002–2012. *National Health Statistics Reports*, 79. <https://www.cdc.gov/nchs/data/nhsr/nhsr079.pdf>

Conde-Sala, J. L., Turró-Garriga, O., Calvó-Perxas, L., Vilalta-Franch, J., Lopez-Pousa, S., & Garre-Olmo, J. (2014). Three-year trajectories of caregiver burden in Alzheimer's disease. *Journal of Alzheimer's Disease*, 42(2), 623–633. <https://doi.org/10.3233/JAD-140360>

Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. *Outcomes & Insights in Health Management*, 2(1), 1–7.

www.advancingstates.org/sites/nasquad/files/hcbs/files/196/9797/Estimating_the_Impact_of_Caregiving_and_Employment_on_Well-Being.pdf

- Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approach*. SAGE Publications.
- Crosby, R. A., DiClemente, R. I., & Salazar, L. F. (2006). *Research methods in health promotions*. Jossey-Bass.
- de Oliveira, D., Vass, C., & Aubeeluck, A., (2015). Ageing and quality of life in family carers of people with dementia being cared for at home: A literature review. *Quality in Primary Care, 23*(1), 18–30. <http://primarycare.imedpub.com/ageing-and-quality-of-life-in-family-carers-of-people-with-dementia-being-cared-for-at-home-a-literature-review.pdf>
- Dahlrup, B., Ekstrom, H., Nordell, E., & Elmstahl, S. (2015). Coping as a caregiver: A question of strain and its consequences on life satisfaction and health-related quality of life. *Archives of Gerontology and Geriatrics, 61*, 261–270. <https://doi.org/10.1016/j.archger.2015.06.007>
- Dawson, W., Bangerter, L., & Splaine, M. (2020). The politics of caregiving: Taking stock of state-level policies to support family caregivers. *Public Policy & Aging Report, 30*(2), 62–66.
- Dewe, P. J. (1989). Stressor frequency, tension, tiredness and coping: Some measurement issues and a comparison across nursing groups. *Journal of Advanced Nursing, 14*, 308–320. <https://doi.org/10.1111/j.1365-2648.1989.tb03418.x>
- Esterling, B. A., Kiecolt-Glaser, J. K., Bodnar, J. C., & Glaser, R. (1994). Chronic stress,

social support, and persistent alterations in the natural killer cell response to cytokines in older adults. *Health Psychology, 13*(4), 291–298.

<https://doi.org/10.1037/0278-6133.13.4.291>

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Bassett, T., Livingston, G., Knapp, M., Murray, J., & Banderjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia, 13*(5), 572–581.

<https://doi.org/10.1016/j.jalz.2016.12.010>

Farran, C. J., Gilley, D. W., McCann, J. J., Bienias, J. L., Lindeman, D. A., & Evans, D. A. (2004). Psychosocial interventions to reduce depressive symptoms of dementia caregivers: A randomized clinical trial comparing two approaches. *Journal of Mental Health and Aging, 10*(4), 337–350.

<https://doi.org/10.1177/019394590730308>

Fingerman, K. L., & Birditt, K. S. (2011) Relationships between adults and their aging parents. In K. W. Schaie & S. L. Willis (Eds.). *Handbook of the psychology of aging* (7th ed., 219–232). Academic Press.

Fingerman, K. L., Pillemer, K. A., Silverstein, M., & Suttor, J. J. (2012). The baby boomers' intergenerational relationships. *The Gerontologist, 52*(2), 199–209.

<https://doi.org/10.1093/geront/gnr139>

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219–239.

<http://www.jstor.org/stable/2136617>

- Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, *48*(1), 150–170. <https://doi.org/10.1037/0022-3514.48.1.150>
- Folstein, M., Anthony, J., Parhad, I., Duffy, B., & Gruenberg, E. (1985). The meaning of cognitive impairment in the elderly. *Journal of American Geriatrics Society*, *33*(4), 228–235. <https://doi.org/10.1111/j.1532-5415.1985.tb07109.x>
- Fonareva, I. & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatric*, *26*, 725–747. <https://doi.org/10.1017/S1041610214000039>
- Frisch, M. B., Cornell, J., Villanueva, M., & Retzlaff, P. J. (1992). Clinical validation of the Quality-of-Life Inventory. A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment*, *4*(1), 92–101. <https://doi.org/10.1037/1040-3590.4.1.92>
- Gallagher, D., Mhaolain, A. N., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C., Coakly, D., Walsh, J. B., Cunningham, C., & Lawlor, B. A. (2011). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer’s caregivers. *Aging & Mental Health*, *15*(6), 663–670. <https://doi.org/10.1080/13607863.2011.562179>
- Gallagher-Thompson, D. & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *The Journals of Gerontology*, *57*(1), 74–85. <https://doi.org/10.1093/geronb/57.1.p74>

- García-Alberca, J. M., Cruz, B., Lara, J. P., Garrido, V., Gris, E., Lara, A., & Castilla, C. (2012). Disengagement coping partially mediates the relationship between caregiver burden and anxiety and depression in caregivers of people with Alzheimer's disease. Results from the MÁLAGA-AD study. *Journal of Affective Disorders, 36*(3), 848–856. <https://doi.org/10.1016/j.jad.2011.09.026>
- Gaugler, J. E., Pot, A. M., & Zarit, S. H. (2007). Long-term adaptation to institutionalization in dementia caregivers. *Gerontologist, 47*(6), 730–740. <https://doi.org/10.1093/geront/47.6.730>
- Gholami, A., Jahromi, L. M., Zarei, E., & Denghan, A. (2013). Application of the WHOQOL-Bref in measuring quality of life in health care staff. *International Journal of Preventive Medicine, 4*(7), 800–817. <https://pubmed.ncbi.nlm.nih.gov/24049600/>
- Gilliam, C. M., & Steffen, A. M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging and Mental Health, 10*(2), 79–86. <https://doi.org/10.1080/13607860500310658>
- Glozman, J. M. (2004). Quality of life of caregivers. *Neuropsychology Review, 14*(4), 183–189. <https://www.ncbi.nlm.nih.gov/pubmed/15796115>
- Gómez-Gallego, M., Gómez-Amor, J., Gómez-García, J. (2012). Determinants of quality of life in Alzheimer's disease: Perspective of patients, informal caregivers, and professional caregivers. *International Psychogeriatrics, 24*, 1805–1815. <https://doi.org/10.1017/S1041610212001081>
- Gonyea, J. G., O'Connor, M., Carruth, A., & Boyle, P. A. (2005). Subjective appraisal of

- Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden. *American Journal of Alzheimer's Disease & Other Dementias*, 273–280. <https://doi.org/10.1177/153331750502000505>
- Greenberger, D. B., & Strasser, S. (1986). Development and application of a model of personal control in organizations. *The Academy of Management Review*, 11, 164–17. <https://doi.org/10.2307/258338>
- Haley, W. E., Levine, E. G., Brown, S. L., Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology of Aging*, 2, 323–330. <https://doi.org/10.1037/0882-7974.2.4.323>
- Haley, W. E., & Pardo, M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging*, 41, 389–392. <https://doi.org/10.1093/geront/47.6.730>
- Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., Harrell, L. E., & Roth, D. L. (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychology and Aging*, 10(4), 540–552. <https://doi.org/10.1037/0882-7974.10.4>
- Horowitz, A. (1985). Family caregiving to the frail elderly. In M. P. Lawton & G. Maddox (Eds.), *Annual review of gerontology and geriatrics* (pp. 194–246). Springer.
- Hunt, G., & Reinhard, S. C. (2015). The impact of America's changing family upon

- federal and state family caregiving policy. *Generations: Journal of the American Society on Aging*, 39(4), 73–79. <https://www.jstor.org/stable/26556167>
- Iavarone, A., Ziello, A. R., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric Disease and Treatment*, 1(10), 1407–1413. <https://doi.org/10.2147/NDT.S58063>
- Jordan, C., & Cory, D. (2010). Boomers, boomerangs, and bedpans. *National Social Science Journal*, 34(1), 79–84.
- Judge, K. S., Bass, A. L., Snow, N. L., Wilson, R., Morgan, W. J., & Looman, C. (2011). Partners in dementia care: A care coordination intervention for individuals with dementia and their family caregivers. *The Gerontologist*, 51(2), 261–272. <https://doi.org/10.1093/geront/gnq097>
- Kamiya, M., Sakurai, T., Ogama, N., Maki, Y., & Toba, K. (2014). Factors associated with increased caregivers' burden in several cognitive stages of Alzheimer's disease. *Geriatrics and Gerontology International*, 14, 45–55. <https://doi.org/10.1111/ggi.12260>
- Katerndahl, D. M., & Parchman, M. D. (2002). The ability of the stress process model to explain mental health outcomes. *Comprehensive Psychiatry*, 43(5), 351–360. <https://doi.org/10.1053/comp.2002.34626>
- 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. *Journal of Disability and Rehabilitation*, 29, 1241–1250.

<https://doi.org/10.1080/01443610600964141>

- Kim, H., Chang, M., Rose, K. & Kim, S. (2012), Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68, 846–855. <https://doi.org/10.1111/j.1365-2648.201105787.x>
- Laerd Statistics. (2020). *We make statistics easy. The ultimate IBM® SPSS® statistics guides*. <https://statistics.laerd.com/>
- Lau, W. Y., Shyu, Y. I., Lin, L. C., & Yang, P. S. (2008). Institutionalized elders with dementia: Collaboration between family caregivers and nursing home staff in Taiwan. *Journal of Clinical Nursing*, 17(4), 482–490. <https://doi.org/10.1111/j.1365-2702.2007.01955.x>
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. McGraw-Hill.
- Lazarus, R. S., & Cohen J. B. (1977). Environmental stress. In I. Altman I. & J. F. Wohlwill (Eds.), *Human behavior and environment* (pp. 89–127). Springer. https://doi.org/10.1007/978-1-4684-0808-9_3
- Lazarus, R. S., DeLongis, A., Folkman, S., & Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. *American Psychologist*, 40(7), 770–779. <https://doi.org/10.1037/0003-066X.40.7.770>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing.
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1(3), 141–169. <https://doi.org/10.1002/per.2410010304>

- MacNair, R. R. & Elliott, T. (1992). Self-perceived problem-solving ability, stress appraisal, and coping over time. *Journal of Research in Personality*, 26, 150–164. [https://doi.org/10.1016/0092-6566\(92\)90051-55](https://doi.org/10.1016/0092-6566(92)90051-55)
- MacNair, R. R., Shankar, K. N., Hirschman, K. B., Hanlon, A. L., & Naylor, M. D. (2014). Burden in caregivers of cognitively impaired elderly adults at time of hospitalization: A cross-sectional analysis. *Journal of the American Geriatrics Society*, 62(2), 276–284. <https://doi.org/10.1111/jgs.12657>
- Marquez-Gonzalez, M., Losada, A., Lopez, J., & Peñacoba, C. (2009). Reliability and validity of the Spanish version of the Revised Scale for Caregiving Self-Efficacy. *Clinical Gerontologist*, 32, 347–357. <https://doi.org/10.1080/07317110903110419>
- Mausbach, B., Losada, A., & Romero-Moreno, R. (2010). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging & Mental Health*, 14(2), 193–202. <https://doi.org/10.1080/13607860903167838>
- McCurry, S. M., Logsdon, R., & Gibbins, L. E. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45(6), 802–811. <https://doi.org/10.1093/geront/45.6.802>
- 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 burden. *Palliative Support Care*, 9(1), 15–24. <https://doi.org/10.1017/S1478951500000507>
- MetLife Mature Market Institute. (2011). *The mature market institute study of caregiving*

costs to working caregivers.

<http://www.MetLifeMatureMarketInstitute.com/assets/cao/mmi/publications/studies/2011/mmi-market-survey-nursing-home-assisted-living-adult-dayservices-costs.pdf>

Mittelman, M. S., Haley, W. E., Clay, O. J., Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67(9), 1592–1599.

<https://doi.org/10.1212/01.wnl.0000242727.81172.91>

Naden, D., Rehnsfeldt, A., Raholm, M., Lindwall, L., Caspari, S., Aasgaard, T., & Lohne, V. (2013). Aspects of indignity in nursing home residences as experiences by family caregivers, *Nursing Ethics*, 20(7), 748–761.

<https://doi.org/10.1177/0969733012475253>

Neugard, B., Andresen, E. A., McKune, S. L., & Jamoom, M. S. (2008). Health-related quality of life in a national sample of caregivers: Findings from the Behavioral Risk Factor Surveillance System. *Journal of Happiness Studies*, 9, 559–575.

<https://doi.org/10.1007/s10902-008-9089-2>

Oken, B. S., Fonareva, I., & Wahbeh, H. (2012). Stress-related cognitive dysfunction in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, 24, 191–198. <https://doi.org/10.1177/0891988711422524>

Pallant, J. (2013). *SPSS survival manual*. McGraw-Hill.

Papastavrou, E., Charalambous, A., & Tsangari, H., (2009). Exploring the other side of cancer care: The informal caregiver. *European Journal of Oncology Nursing*,

13(2), 128–136. <https://doi.org/10.1016/j.ejon.2009.02.003>

Parker, K., & Patten, E. (2013). *The sandwich generation: Rising financial burdens for middle-aged Americans*. The Pew Research Center.

<http://pewsocialtrends.org/2013/01/30/the-sandwich-generation>

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594.

<https://doi.org/10.1093/geront/30.5.583>

Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregiver's subjective well-being. *Aging and Mental Health*, 10(5), 539–548.

<https://doi.org/10.1080/13607860600637844>

Rabinowitz, Y. G., Mausbach, B. T., Thompson, L. W., & Gallagher-Thompson, D.

(2007). The relationship between self-efficacy and cumulative health risk associated with health behavior patterns in female caregivers of elderly relatives with Alzheimer's dementia. *Journal of Aging and Health*, 19, 946–964.

<https://doi.org/10.1177/0898264307308559>

Reed, C., Belger, M., Dell-Agnello, G., Wimo, A., Argimon, J., Bruno, G., & Vellas, B.

(2014). Caregiver burden in Alzheimer's disease: Differential associations in adult-child and spousal caregivers in the GERAS observational study. *Dementia and Geriatric Cognitive Disorders*, 4(1), 51–64. [https://doi.org/1664-](https://doi.org/1664-5464/14/0041-0051)

[5464/14/0041-0051](https://doi.org/1664-5464/14/0041-0051)

Romero-Moreno, R., Losada, A., Mausbach, B. T., Márquez-González, M., Patterson, T.

- L., & López, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging & Mental Health, 15*(2), 221–231, <https://doi.org/10.1080/13607863.2010.505231>
- Romero-Moreno, R., Márquez-González, M., Mausbach, B., & Losada, A. (2012). Variables modulating depression in dementia caregivers: A longitudinal study. *International Psychogeriatrics, 24*(8), 1316–1324. <https://doi.org/10.1017/S1041610211002237>
- Salamizadeh, A. (2017). The impact of spiritual care education on the self-efficacy of the family caregivers of elderly people with Alzheimer’s disease. *International journal of community-based nursing and midwifery, 5*(3), 231.
- Savla, J., Roberto, K., Blieszner, R., McCann, B., Hoyt, E., & Knight, A. (2021.) Dementia caregiving during the “stay-at-home” phase of COVID-19 pandemic. *The Journals of Gerontology, 76*(4), e241–e245. <https://doi.org/10.1093/geronb/gbaa129>
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association, 282*, 2215–2219. <https://doi.org/10.1001/jama.282.23.2215>
- Schulz, R., O’Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*, 771–791. <https://doi.org/10.1093/geront/35.6.771>
- Schumacher, K., Beck, C. A., & Marren, J. M. (2006). Family caregivers: Caring for older adults, working with their families. *The American Journal of Nursing,*

106(8), 40–49.

https://journals.lww.com/ajnonline/Fulltext/2006/08000/FAMILY_CAREGIVER_S__Caring_for_older_adults.20.aspx

Shankar, K. N., Hirschman, K. B., Hanlon, A. L., & Naylor, M. D. (2014). Burden in caregivers of cognitively impaired elderly adults at time of hospitalization: A cross-sectional analysis. *Journal of the American Geriatrics Society*, 62(2), 276–284. <https://doi.org/10.1111/jgs.12657>

Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology and aging*, 11(2), 247–257. <https://doi.org/10.1037//0882-7974.11.2.247>

Soper, D. S. (2013). *A-priori sample size calculator for multiple regression*. <http://www.danielsoper.com/statcalc>

Steffen, A. M., McKibben, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *The Journals of Gerontology: Series B*, 57(1), 74–86. <https://doi.org/10.1093/geronb>

Steffen, T. M., Hacker, T. A., & Mollinger, L. (2002). Age-and gender-related test performance in community-dwelling elderly people: Six-minute walk test, berg balance scale, timed up & go test, and gait speeds. *Physical therapy*, 82(2), 128–137. <https://doi.org/10.1093/ptj/82.2.128>

Stockwell-Smith, G., Kellett, U., & Moyle, W. (2010). Why carers of frail older people are not using available respite services: An Australian study. *Journal of Clinical*

- Nursing*, 19, 2057–2064. <https://doi.org/10.1111/j.1365-2702.2009.03139.x>
- Strutton, D., & Lumpkin, J. (1992). Relationship between optimism and coping strategies in the work environment. *Psychological Reports*, 71(3), 1179–1186.
<https://doi.org/10.2466/pr0.1992.71.3f.1179>
- Talley, R. C., & Crews, J. E. (2007). Talley and Crews respond. *American Journal of Public Health*, 97(11), 1931–1932.
<https://doi.org/10.2105%2FAJPH.2007.118406>
- Thomas, P., Lalloué, F., Preux, P.-M., Hazif-Thomas, C., Pariel, S., Inscale, R., Belmin, J. & Clément, J. P. (2006), Dementia patients' caregivers' quality of life: The PIXEL study. *International Journal Geriatric Psychiatry*, 21, 50–56.
<https://doi.org/10.1002/gps.1422>
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and Aging*, 4(4), 393–401. <https://doi.org/10.1037/0882-7974.4.4.393>
- Tung, W., Gillett, P. A., & Pattillo, R. E. (2005). Applying the transactional model to physical activity in family caregivers in Taiwan. *Public Health Nursing*, 22, 299–310. <https://doi.org/10.1111/j.0737.1209.2005.220405.x>
- U.S. Census Bureau. (2012, September). *United States summary: 2010*.
<https://www.census.gov/prod/cen2010/cph-2-1.pdf>
- Vellone, E., Piras, G., Talucci, C. & Cohen, M. Z. (2008). Quality of life for caregivers of people with Alzheimer's disease. *Journal of Advanced Nursing*, 61(4) 222–231.
<https://doi.org/10.1111/j.1365-2648.2007.04494.x>

- Vickery, B. G., Hays, R. D., Maines, M. L., Vassar, S. D., Fitten, J., & Strickland, T. (2009). *Caregiver-targeted measure of quality of life for dementia caregivers*. APA PsycTests. <http://doi.org/10.1037/t62162-000>
- Vincent, V. A., & Velkoff, V.A. (2010). *The next four decades: The older population in the United States:2010 to 2050*. U.S. Census Bureau. <https://www.census.gov/prod/2010pubs/p25-1138.pdf>
- Vitaliano, P. P., Young, H. M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia, *The Gerontologist*, *31*(1), 67–75. <https://doi.org/10.1093/geront/31.1.67>
- Vitaliano, P. P., Young, H. M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science*, *13*, 13–16. <https://doi.org/10.1111/j.0963-7214.2004.01301004.x>
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*, 946–972. <https://doi.org/10.1037/0033-2909.129.6.946>
- Whitlatch, C., & Orsulic-Jeras, S. (2018). Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *The Gerontologist*, *58*(1), S58–S73. <https://pubmed.ncbi.nlm.nih.gov/29361068/>
- Whittier, S., Scharlach, A., & Dal Santo, T. S. (2005) Availability of caregiver support services. *Journal of Aging & Social Policy*, *17*(1), 45–62. https://doi.org/10.1300/J031v17n01_03

- World Health Organization. (1998). The World Health Organization Quality of Life (WHOQOL): Development and psychometric properties. *Social Science Medicine*, 46(12), 1569–1585. [https://doi.org/10.1016/s0277-9536\(98\)00009-4](https://doi.org/10.1016/s0277-9536(98)00009-4)
- World Health Organization. (2004). *World Health Organization Quality of Life (WHOQOL)–BREF*.
https://www.who.int/substance_abuse/research_tools/en/english_whoqol.pdf
- Zarit, S. H., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649–655.
<https://doi.org/10.1093/geront/20.6.649>