2021

Alzheimer’s Dementia Care: Impact on Family Caregivers

Rose Anne Pierre
Walden University

Walden University

College of Health Professions

This is to certify that the doctoral study by

Rose Anne Pierre

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. Pelagia Melea, Committee Chairperson, Public Health Faculty
Dr. Claire Robb, Committee Member, Public Health Faculty
Dr. Egondu Onyejekwe, University Reviewer, Public Health Faculty

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

Walden University
2021

Abstract

Alzheimer’s Dementia Care: Impact on Family Caregivers

by

Rose Anne Pierre

MD, Washington University School of Health Sciences, 2018

MPH, Walden University, 2015

BA, Florida Atlantic University, 2010

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Public Health

Walden University

February 2021

Abstract

Patients with dementia of the Alzheimer's type increasingly become dependent on caregivers. Researchers have demonstrated that these caregivers experience serious burdens during their caregiving experiences. They face emotional, physical, and financial burdens. The objective of this paper was to discuss the burden and strains of Alzheimer's disease on the older caregivers in the United States. The stress process model and the quality of life were used in this study. The study used a descriptive and analytical approach to analyze 2015 secondary data retrieved in 2018 from the National Alliance for Caregiving. The adult Alzheimer's dementia caregivers were selected. A multiple regression analysis was conducted looking at the relationship between caregiver type, age, gender, and strain. The results revealed a statically significant association between caregiver type and strain [*Beta*=-.701, 95% CI (-1.340, -.063), $p<.05$]. A multiple linear regression was conducted for the second research question, looking at the relationship between caregiver type, age, gender, and burden. The results revealed caregiver type, age, and gender not to be statistically significant predictors of burden ($p>.05$). A simple linear regression analysis was conducted for the third research question looking at the relationship between burden and strain. Burden was found to be statistically significant predictor of strain [*Beta*=0.973, 95% C.I. (6.46, 1.299), $p<.05$). The positive social change implication: public health practitioners can use the findings of the study to raise more awareness and advocate for the family and nonfamily caregivers. It can raise awareness about the many responsibilities of the family, friends, and neighbors that are caregivers and maximize community engagement.

Alzheimer’s Dementia Care: Impact on Family Caregivers

by

Rose Anne Pierre

MD, Washington University School of Health Sciences, 2018

MPH, Walden University, 2015

BA, Florida Atlantic University, 2010

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Public Health

Walden University

February 2021

Acknowledgments

“I come as one, but I stand as ten thousand” Maya Angelou.

Thank you to everyone who has been with me on this journey, especially my family, colleagues, chair, and committee member. It was a long journey, but it was achievable because of all of you.

Table of contents

List of tables

List of figures

Section 1: foundation of the study and literature review

Introduction

Alzheimer’s disease is the most common type of dementia among people over 60 and about 60% to 70% of all dementia cases are due to Alzheimer’s (Esandi, Nolan, Alfaro, & Canga-Armayor, 2018). Different types of dementia are dementia with Lewy bodies, vascular dementia, mixed dementia, and frontotemporal dementia (Centers for Disease Control and Prevention [CDC], 2016). Patients with dementia gradually lose orientation, decision making, and communication skills, which subject them to constant supervision and caregiving (Adreakou, Papadopoulos, Pangiotakos, & Niakas, 2016). Because of the cognitive decline, Alzheimer’s dementia patients become dependent on caregivers to survive.

In this study I examined at the burden associated with the caring for individuals with dementia. I focused on the older caregivers that are overlooked in previous studies to create potential positive social change. The idea was to generate more community support for these caregivers and create policy in the future to help relieve the burdens.

This section of the study covers the problem statement and purpose of the study. It also includes the research questions, the theoretical foundation, the nature of the study, the significance of the study, definitions, assumptions, scope, and the literature review.

Problem statement

Alzheimer's disease causes progressive irreversible dementia (U.S. Department of Health and Human Services [HHS], n.d., National Institutes of Health [NIH], n.d., National Institute on Aging [NIA], n.d.). Dementia leaves Alzheimer patients with difficulty performing daily activities and consequently becoming dependent on others (Montgomery, Goren, Kahle-Wrobleski, Nakamura, & Ueda, 2018). Caring for these patients is becoming a problem for family members and relatives (Roberts & Struckmeyer, 2018). Daily home lives for families are affected (Roberts & Struckmeyer, 2018). The mental and physical health of the caregivers can be affected by the many caregiving tasks including managing the person's safety and behavioral changes (Black, Johnston, Rabins, Morrison, Lyketos, & Samus, 2013).

Dementia is considered a public health priority by the World Health Organization. Older people that become caregivers should get additional assistance. The quality of life of the caregivers can affect the type of care provided to the person with Alzheimer's (Hazzan et al., 2016). Older caregivers are a special group that needs special attention and interventions that improve their quality of life. Taking care of these caregivers will in the future alleviate their burnout and alleviate the burden in the healthcare system as the costly prevalence in Alzheimer's disease is increasing.

There is a need to study the quality of life of the caregivers as it can impact the quality of care provided to Alzheimer's patients (Hazzan et al., 2016). There is a literature gap on how caregiving affects the different types of caregivers, especially between younger and older caregivers. Previous studies conducted in that subject show contradictory results on the level of burden on different age groups of caregivers. In the comprehensive literature review conducted by Chiao, Wu, and Hsiao (2015), they found that some studies reported more burden for older caregivers, while other studies reported more burden for younger caregivers. According to Chiao et al., there is a need for future research that examines burden patterns in the family of the caregiver of individuals with dementia.

Dahlrup, Ekstrom, Nordell, and Elmstahl (2015) proposed that a general policy program is necessary to identify caregivers' needs at an early stage. Manthorpe and Bowling (2016) clarified the issue is there are great political and policies in place in dementia research, that methods to measure the quality of life outcomes of caregivers are still needed giving rise to current and future unmet needs for health and social care and support for these caregivers. Manthorpe and Bowling also added that rigorous conceptual and methodological research on caregivers is needed to address the gap. The quality of life of the caregivers can be measured by analyzing the strain and burden on the caregivers physically, emotionally, and financially.

Purpose of the study

The purpose of this study was to explore the different sociocharacteristics of the strain and burden of Alzheimer’s disease on the caregivers in the United States. The caregivers often suffer from anxiety and depression (Lavarone et al. 2014). From a public health perspective, this can promote practices to improve the quality of life for these caregivers. The focus of the study was to investigate how sociodemographic characteristics, like type of caregivers, gender, and age, impact caregivers physically, emotionally, and financially. I investigated the problem by considering questions that can measure the strains and burden affecting these caregivers and the association between the two.

Research question(s) and hypotheses

RQ1: Is there a statistically significant relationship between (a) caregiver type, (b) caregiver gender, (c) caregiver age, and strain (physical, emotional, and financial) of Alzheimer's dementia caregivers?

$H_0$1: There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, and financial) of Alzheimer's dementia caregivers.

H_a1: There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, and financial) of Alzheimer's dementia caregivers.

RQ2: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (1. low burden, 2. Med burden, 3. high burden) of Alzheimer's dementia caregivers?

$H_0$2: There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (1. low burden, 2. Med burden, 3. high burden) of Alzheimer's dementia caregivers.

H_a2: There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (1. low burden, 2. Med burden, 3. high burden) of Alzheimer's dementia caregivers.

RQ3: Is there an association between burden and strain?

$H_0$3: There is no association between burden and strain.

H_a3: There is an association between burden and strain.

Theoretical foundation for the study

The stress process model developed by Pearlin, Menaghan, Lieberman, and Mullan (1981) is focused on stressors that mediate the effects of stress and health outcomes. The stress process model has been used to examine stress for family caregivers of patients with dementia (Pearlin et al., 1990). It examines the relationships between the stresses experiencing by the caregivers and their wellbeing (Haley et al., 1996). In my study, I looked at the relationship between physical, emotional, and financial strains and the burden on caregivers of patients with dementia of the Alzheimer’s type. Using the stress process model by focusing on the physical, emotional, and financial stressors variables can help predict the health outcomes of the caregivers whether they are spouses and children. This model (see Figure 1) can be used in this study to predict the caregivers’ burden based on their sociodemographic factors.

Figure 1. Basic of stress process model

The theory of quality of life can be used in this study to evaluate the factors affecting the caregiver quality of life and help to fulfill their needs. The theory of quality of life was established by Maslow in 1962 (Ventegodt, Merrick, & Andersen, 2003). In this theory Maslow established that health, happiness, and ability to function result from the fulfillment of specific needs (Ventegodt, Merrick, & Andersen, 2003). Some of the specific needs are physiological needs such as sleep, food, and clothes and safety needs

(Ventegodt, Merrick, & Andersen, 2003). Quality of life is a metric used by public health professionals to accomplish need assessment, and the determination of needs specific to a population (Sirgy, 1986).

The quality of life theory is relevant to all three research questions as they are aiming to find to understand how characteristics like caregiver type, gender, and age of caregivers of Alzheimer’s dementia patients impact the caregiver’s physical, emotional, and financial quality of life. The physical, emotional, and financial burdens in the caregivers can affect their quality of life. Thus, the quality of life theory can also be used to assess the physical, emotional, and financial strains as it relates to the first research question. Baker and Intagliata (1982) explained that when it comes to the quality of life outcomes, finances, and health status can be sources of dissatisfaction.

Nature of the study

The nature of the study was quantitative using secondary data. The study design was both descriptive and analytical as I examined quantifiable information from the dataset to understand the stresses on the caregivers of Alzheimer’s dementia patients.

For RQ1 the strain was the dependent variable and caregiver type, age, and gender were the independent variables. The dependent variable for the second research question was a burden and the independent variables were caregiver type, age, and gender.

For RQ3 the dependent variable for the third research question was strain and the independent variable was burden.

The data used in this study were made public in 2015 by the National Alliance for Caregiving and the American Association of Retired Person (AARP). The National Alliance for Caregiving is a nonprofit organization that partnered with AARP since 1997 to study caregiving in the United States (Caregiver.org, n.d.). This a national research collected data on caregivers that is made available for public use. Their data collected on Alzheimer’s dementia caregivers was analyzed in this study.

Literature search strategy

This literature review section of the proposal incorporates published articles on Alzheimer’s dementia caregivers that support this study using different library databases. The libraries used are the Walden University Library, Google Scholar, PubMed, the Oxford Academic the Gerontologist, Wiley Online Library, Science Daily, and Sage Journals. A thorough review of the literature on previous studies on adult caregiver was conducted using key terms such as *Alzheimer's caregiving, caregiving for the patient with dementia, caregivers for Alzheimer’s patient over 65 years of age, family caregiving, Alzheimer’s disease symptoms, the burden on caregivers, strains of caregiving,* and *type of caregivers*.

The literature review includes relevant articles already been published and known on the topic of Alzheimer’s dementia from 2014 to 2020. This section also includes facts from important organizations that have collected data and studied caregiving from the Alzheimer’s Association, the CDC, and National Alliance for Caregiving databases. Any articles before 2014 were excluded from literature review section. Articles on non-Alzheimer’s dementia were excluded from this literature review.

Literature review

Signs and symptoms of Alzheimer’s disease

The clinical syndrome associated with Alzheimer’s disease is dementia. Dementia is a progressive decline involving two or more cognitive impairments including memory, language difficulties, and behavioral changes, which leads to the inability to perform basic daily activities (Weller & Budson, 2018). According to the National Institute on Aging (2017), in Alzheimer's disease, the damage to the brain starts at least 10 years before any signs and symptoms appear. People diagnosed with Alzheimer's disease will be put in two categories: late-onset or early-onset. Most people are diagnosed with late-onset Alzheimer’s disease, and the first symptoms will appear in their sixties (National Institute on Aging, 2017). People diagnosed with early-onset Alzheimer’s disease will start showing symptoms in their thirties (National Institute on Aging 2017).

The earliest symptom in dementia of the Alzheimer’s type is short-term memory loss, following by disorientation, mood swings, loss of motivation, sleep disorders, and behavioral issues (Etindele Sosso, Nakamura, & Nakamura, 2017). The behavioral changes include apathy, aggression, and depression (Silva et al., 2019). Wandering falls, and hygiene becomes increasing issues (Ulep, Saraon, & McLean, 2018). Eventually, the patients lose brain functions leading to death (Etindele Sosso et al., 2017).

The sixth leading cause of death in the United States is Alzheimer’s disease (CDC, 2017). Alzheimer’s disease is a progressive disease that starts with mild symptoms, then progresses to moderate, to severe symptoms. In the mild stage, the person will appear healthy with subtle memory loss, poor judgment, mood, and personality changes increased anxiety, and/or aggression (National Institute on Aging 2017). In the moderate stage, the person will have increase memory loss. confusion, language difficulty, inability to learn new things, problem recognizing family and friends, hallucination, delusions, and paranoia (National Institute on Aging 2017). In the severe stage, the person is unable to communicate, weight loss, seizures, swallowing issues, loss of bowel/bladder control, and increased sleepiness (National Institute on Aging 2017).

Prevalence of Alzheimer's disease

Alzheimer's disease is the most common dementia in the world (Weller & Budson, 2018). As of 2015, 30 million people had Alzheimer's disease worldwide (Etindele Sosso et al., 2017). Five point eight million people in the United States have Alzheimer's dementia (Alzheimer's disease facts and figures, 2019). Ten percent of people over 65 have dementia of the Alzheimer's type (Alzheimer's disease facts and figures, 2019). Most patients diagnosed are over 65 years of age, and around 5% of cases have early-onset Alzheimer's diagnosed before 65 (Etindele Sosso et al., 2017). Alzheimer's Disease is the sixth leading cause of death in the United States (Alzheimer's disease facts and figures, 2019).

Type of caregivers

Family members tend to be the primary caregivers for patients with dementia of the Alzheimer's type (Janssen-Aguilal et al., 2019). Kourakos, Kafkia, and Minasidou (2016) explained that the majority of the caregivers are either spouses or children, with a few being cared for by extended relatives. Sixty percent of these caregivers are either married or in a long-term relationship with the patient with Alzheimer's (2019

Alzheimer’s disease facts and figures, 2019). Chiao et al. (2015) found that over 50% of the patients reside with the caregivers. In my study caregiver types refer to the different type of relationships between caregivers and person with dementia such as spouses or children.

Cost of caregiving

Taking care of patients with Alzheimer's disease is costly. According to the Alzheimer's Association (year), by 2050 the cost of care will rise to over $1 trillion. Caring for Alzheimer's patients requires that the caregivers change their working conditions or even resign from their jobs (Kourakos et al., 2016). Roberts and Struckmeyer (2018) found that caregivers often have to give up work to care for the person affected by the disease creating additional strain on resources.

In research conducted by Bouldin et al. (2017) they found that one in six caregivers delayed a medical visit due to cost. According to Yang and Levey (2015), women caregivers face higher risks of financial drain from caring for their spouses than men. The healthcare cost for Alzheimer’s caregivers is around $9.7 billion in the United States in 2014 (Alzheimer’s Association, 2015). Seventy percent of the out of pocket healthcare costs are paid by family caregivers (Alzheimer’s Association, 2018). Caregivers worked unpaid for 18.5 billion hours which is equivalent to $233.9 billion in 2018 (2019 Alzheimer’s disease facts and figures, 2019).

Strains of caregiving

In research conducted by Cheng (2017), the specific strains on dementia caregivers are relationship strain, social isolation strain, emotional strain, and physical strain. The chronic stress of caregiving can result in a physical and mental strain that can lead to depression, endocrine, and immune dysfunction (Bien-Barkowska, Doroszkiewicz, & Bien, 2017). Dahlrup, Nordell, and Elmstahl (2018) found that 36% of caregivers reported not only depression but also tension and musculoskeletal symptoms. Cheng explained that depressive symptoms can be a result of not only behavioral strain but also physical strain. Cheng added that helping with activities of daily living can be a great source of strain for caregivers of dementia individuals.

Burden on caregivers

Caring for a loved one with dementia can be a long draining process. According to the Family Caregivers Alliance (2019), caregivers provide care for a longer time than caregivers caring for someone with another illness. Support for the families of patients with Alzheimer's Disease at various stages in their caregiving journey is needed (Esandi et al., 2018).

Research on the health and health-promoting self-care of family caregivers is limited (Oliveira, Sousa, & Orrel, 2019). Chiao et al. (2015) explained that there is a need to further research the characteristic caregiver burden patterns in family caregivers of people with dementia. There is a need to explore approaches to promote health and self-care among family caregivers (Oliveira et al., 2019). Roberts and Struckmeyer (2018) identified the need to study how dementia caregiving affects the care of spouses in a late-life marriage.

Many caregivers themselves are elderly with many health issues. It is common for service providers to neglect the caregiver's advanced age, physical health, mental health, and reluctance to accept support before the caregivers reach a crisis point (Oliveira et al., 2019). Hazzan et al., (2016) mentioned the need to investigate the relationship between the quality of life of caregivers in the quality of care provided. According to the Alzheimer’s Association (2019), women providing care are more likely to suffer from depression and health problems than men (Alzheimer’s disease facts and figures, 2019). However, no mention of the financial burden between genders has been reported.

The high caregiving demand for caregivers leads to more health problems relative to the normal population (Oliveira et al., 2019). Caregivers are subject to sleep deprivation, social isolation, poor diet, substance abuse, and untreated mental and physical health problems (Oliveira et al., 2019). Also, they are at risk of exacerbating their own chronic health condition if they neglect their own care (Bouldin et al., 2017). A patient’s relationship with their caregiver, cognitive ability, behavioral symptoms, and adversity in life may all be compromised with increased caregiver burden (Campbell et al., 2008). Hazzan et al. (2016) explained that further research is necessary to investigate whether caregiver well-being is associate with the quality of care they provide.

Definitions

Caregiver Burden: Caregiver burden is defined as a negative response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience (Zhou et al., 2016). The burden can be subjective and objective. The objective burden is the time spent providing care (Wolfs et al., 2016). While the objective is the impact of proving care on the caregiver (Travonia et al., 2014).

Caregiver Strain: Caregiver strain is the overwhelming feeling of stress and anxiety caregivers experienced and they are unable to perform their role as caregivers (Stringfellow, 2018).

Dementia: Dementia is clinically referred to as the symptoms of memory loss, difficulty in language, and behavior. (Robinson, Eugene, & John-Paul, 2015) with an additional decline in problem-solving and thinking skills (Alzheimer's Association, n.d.).

Family Caregiver: The family caregiver is described by Family Caregiver Alliance (2014) as a relative, partner, friend, or neighbor who assists someone with a chronic or disabling condition. The role of a family caregiver may involve providing direct care and assistance with daily activities (Schulz, 2016).

Quality of life: Quality of life is defined by Hornquist (1982) as the degree of fulfillment within the physical, psychological, social, activity, material, and structural areas. The National Institute of Health (2014) defined quality of life as the overall enjoyment of life.

Assumptions

It was assumed that the quality of life of caregivers is affected when they have to care for family members with dementia. It is also assumed that there is an association between the quality of life of the caregivers as a whole and the type of caregivers. In a study conducted by Srivastava et. al (2016) on caregiver burden and quality of life, different social and family characteristics could not be studied. One more assumption is that social-demographic characteristics also have an impact on caregivers. Thus, I examined the data collected by the National Alliance of Caregivers in partnership with the American Association of Retired Person to evaluate these assumptions.

Scope and delimitations

This research specifically focused on the physical, emotional, and financial factors affecting caregivers of Alzheimer’s patients. As caregiving is becoming a problem for the caregivers, alleviating these burdens is a positive step toward increasing their quality of life. I also looked at the sociodemographic characteristics that can affect the quality of life or caregivers. The specific aspect of the problem addressed in this study is the strains on caregivers. The study focused on the physical, emotional, and financial strain association between different types of caregivers, different ages groups, and finance. The specific focus was chosen because the previous studies on this topic generalized the caregiving experience. The problem affecting the different type of caregivers were not taken into consideration.

This study only included unpaid caregivers who provide care for Alzheimer's disease and dementia. All caregivers that will be analyzed in this study were over 18 years of age. Any caregivers that are not taking care of a person with Alzheimer’s and dementia and are under 18 were excluded, which makes this research not generalizable for caregivers of other illnesses.

Significance

The significance of the study is to raise more awareness and advocate for the dementia family caregivers that play a vital role in the management of Alzheimer’s dementia disease. The health and well-being of family caregivers are very important for the care of Alzheimer's and dementia patients. When these patients are cared for by family the progression of their symptoms is delayed (Kourakos et al., 2016). In the United States, over 5 million Americans have Alzheimer’s disease (Alzheimer’s Association, 2018). Eighty percent of people with Alzheimer’s disease and related dementias receive care from home (CDC, 2016). It is important to study the impact on older caregivers of Alzheimer’s patients to influence more community-based interventions that can lessen the burden and that can provide support to these caregivers. This study may provide information for the development of programs aimed to improve the quality of life of caregivers and lessen their burden by making more resources available to them. Communities should then be better equipped to help prolong the lives of the caregivers which eventually will benefit the loved ones that depend on them. The result of the research can be used for educational interventions that can help raise awareness about the financial responsibilities of the caregivers and maximize community engagement to consequently help reduce the pressure of the disease on these individuals and communities.

The social change contribution of the study is to increase the understanding of caregiving burden thereby creating more home-based and community-based support that can be utilized by these caregivers. I intend to help public health practitioners creating policies that can help create more these home-based and community-based social support entities to alleviate stress on caregivers to improve their quality of life.

Summary

In summary, caregiving for Alzheimer's patients is challenging. In this section, the problem statement and purpose of the study, three research questions, and hypotheses were provided. The theoretical framework, nature of the study, definitions, assumptions, and scope of delimitations were described. The literature review shows that previous literature indicates that there are many burdens associated with caring for these patients. Their health can decline because of the emotional and physical toll caregiving has on them. Research studies show that caregiving can be costly. It could leave the family caregivers in financial ruins especially if they modified the work-life to take care of their loved ones. Research on these burdens on older caregivers needs further investigation.

Section 2: Research design and data collections

Introduction

As previously stated in the first section, patients with dementia gradually lose the ability to take care of themselves. They become increasingly dependent on caregivers to survive over the years. The caregivers will eventually feel different types of burdens that can affect their health. Thus, continuous community effort and future policy changes are required to assure these caregivers stay healthy during their caregiving journey. The purpose of this study was to explore the physical, emotional, and financial burden of Alzheimer's disease on older caregivers in the United States. Also, I investigated how demographic characteristics like caregiver type, gender, and age impact caregivers' physical, emotional, and financial strains.

The second section of this study focused on the research design and rationale of the study. It also includes the study methodology and threats to validity.

Research design and rationale

I used a descriptive and analytical approach to analyze the secondary data collected by the National Alliance for Caregiving. In the dataset, there are the necessary variables that are needed to examine the physical, emotional, and financial strains on the caregiver. This research analyzed the relationships between independent and dependent variables.

In RQ1 the dependent variable was a strain. The strain was the dependent variable on a continuous scale. The first independent variable will be caregiver type relationship with patient as the variable of interest. The second independent variable was gender with males as the baseline and female as the caregiver of interest. And the third variable was age (<65 years old and 65+ years old).

In RQ2 the dependent variable was a burden. The burden was the dependent variable on a continuous scale. The first independent variable was caregiver type of relationship with patient as the variable of interest. The second independent variable was gender with males as the baseline and female as the caregiver of interest. And the third variable was age (<65 years old and 65+ years old).

In RQ3 the dependent variable was a strain on a continuous scale. The independent variable was a burden.

Inclusion and exclusion criteria

The secondary data is comprised of information for all different kinds of caregivers. However, the selection criteria for this study was only Alzheimer's and dementia caregivers for all three research questions. The National Alliance for Caregiving target's population was unpaid caregivers over 18 years of age. Only adult caregivers were selected to participate in the research. Since this study is only focused on Alzheimer's dementia caregivers, the selection criteria was Alzheimer's and dementia data.

Methodology

Population

The data source for this study is from the National Alliance for Caregiving, and the target population is Alzheimer's dementia caregivers. According to the National Alliance for Caregiving Report (2015), 1,248 caregivers of adults were interviewed, with

698 White non-Hispanic caregivers, 206 non-Hispanic African American caregivers, 208, Hispanic caregivers, 95 Asian American caregivers, and 41 caregivers of another race (National Alliance for Caregiving Report, 2015).

Sampling

The National Alliance for Caregiving and AARP collected the data through online and telephone interviews in late 2014, between September 11 and November 5. According to the National Alliance for Caregiving Report (2015), GfK's national online KnowledgePanel® conducted the online interviews. KnowledgePanel® is specifically designed to represent the U.S. population (National Alliance for Caregiving Report, 2015). The participants were selected randomly over the phone or by mail. There were some initial questions to identify adult caregivers over 18 years of age, and only these adult caregivers could continue with the interviews.

Once chosen, the participants given access to KnowledgePanel® for the online questionnaires (National Alliance for Caregiving Report, 2015). People with no computer access were provided laptops and the internet at no cost. Some participants were interviewed over the phone. One thousand two hundred forty-eight caregivers ages 18 and older participated in the quantitative interview with an oversampling of 209 caregivers of 65 years of age and over.

The questionnaires online were in both Spanish and English. The phone interviews were conducted in the language the participants preferred. The National Alliance for Caregiving made this dataset available free of charge to the public.

Power analysis

RQ1: G*Power software was used to conduct the priori power analysis for RQ1. The power analysis for this question is calculated using *F* tests for multiple linear regression assuming an alpha level of 0.05 and estimating the sample size needed to achieve power for the test power (1- β err prob) at 0.80 with three predictor variables, and assuming the projected population effect at 0.15. The minimum sample size required for RQ1 is 77 to have a power of 0.80.

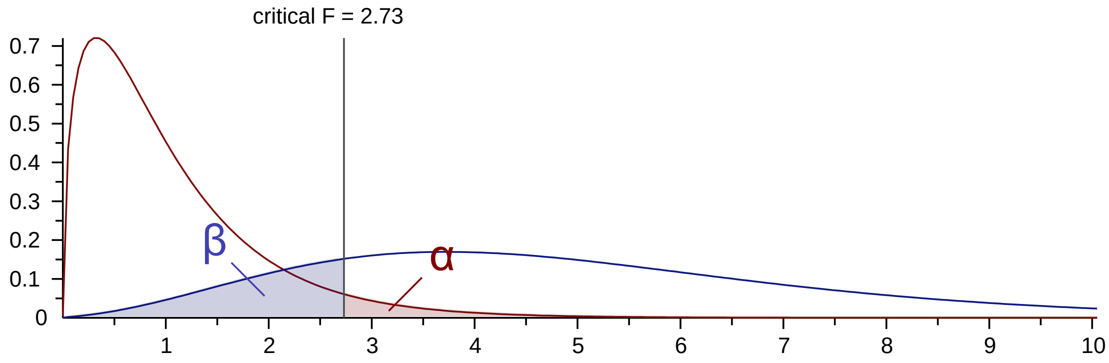

Figure 2. *F* test for multiple linear regression for RQ1

RQ2: G*Power software was used to conduct the power analysis for RQ2. The power analysis is calculated using *F* tests for multiple linear regression assuming an alpha of 0.05, estimating the sample size needed to achieve power for the test power (1- β err prob) at 0.80 with three predictor variables, and assuming the projected population effect at 0.15. The minimum sample size required for RQ2 is 77 to have a power of 0.80.

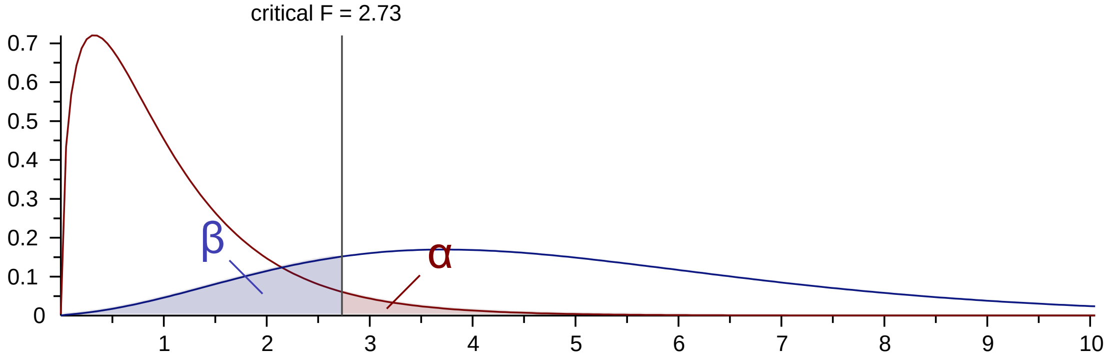

Figure 3. F test for multiple linear regression for RQ2

RQ3: G*Power software was used to conduct the power analysis for RQ3. The power analysis is calculated using *F* tests for simple linear regression assuming an alpha of 0.05, estimating the sample size needed to achieve power for the test power (1- β err prob) at 0.80 with one predictor variable, and assuming the projected population effect at 0.15. The minimum sample size required for RQ3 is 55 to have a power of 0.80.

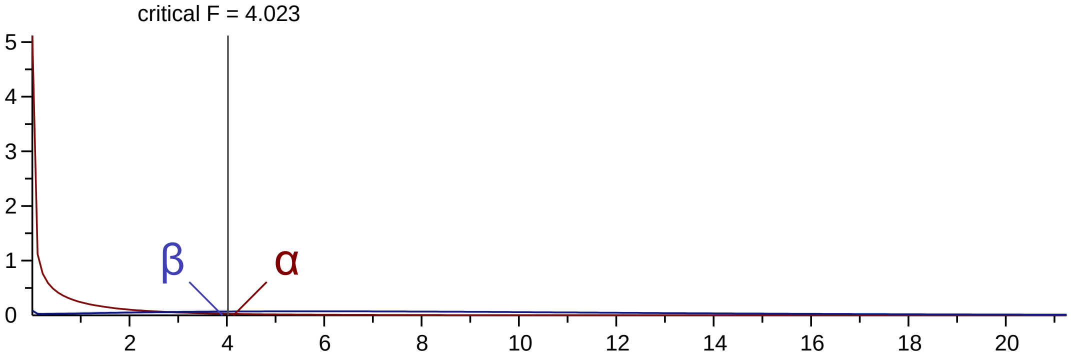

Figure 4. F test for simple linear regression for RQ3

In this research there was no possibility to increase sample size since it is using secondary data, thus this power analysis used an estimated effect size. Perugini, Gallucci, and Costantini (2018) explained that when conducting power analysis, the effect size is usually unknown and researchers should use the best available guess of the population effect size. The effect size for this research was estimated at 0.15 to calculate the power for all three research questions. This effect size is required to avoid a Type II error concluding that there is no effect when one exists (Sullivan & Feinn, 2012).

Instrumentation & Operationalization

Table 1

Operationalization of variables for RQ1 and RQ2

Name of Variables	Type of Variable	Level of Measurement
Caregiver type	Independent variable	Nominal categorical
Caregiver gender	Independent variable	Nominal categorical
Caregiver age	Independent variable	Nominal categorical
Strain	Dependent	Continuous
Burden	Dependent	Continuous

RQ1: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?

$H_0$1: There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?

H$_a$*1*: There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?

For RQ1 caregiver type, caregiver gender, and caregiver age are independent predictor nominal categorical variables. The caregiver type is a nominal categorical scale of measurement, with two categories, (1) children and (2) spouse. Gender is a nominal categorical scale with two categories, (1) male and (2) female. The caregiver age is a nominal categorical scale with two categories, (1) under 65 and (2) 65 and above. The strain is the dependent variable three subscales physical, emotional, and financial. The scale of measurement of the dependent variable physical strain is an ordinal scale.

RQ2: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender (3) caregiver age, and burden (three responses) of Alzheimer's dementia caregivers?

H$_0$2*:* There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (three responses) of Alzheimer's and dementia Caregivers?

H$_a$2*:* There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (three responses) of Alzheimer's and dementia caregivers?

For RQ2 caregiver type, caregiver gender, and caregiver age are independent predictor nominal categorical variables. The caregiver type is a nominal categorical scale of measurement, with two categories, (1) children and (2) spouse. Gender is a nominal categorical scale with two categories, (1) male and (2) female. The caregiver age is a nominal categorical scale with two categories, (1) under 65 and (2) above 65. The burden is the dependent variable with three responses. The scale of measurement of the dependent variable physical strain is an ordinal scale.

RQ3: Is there an association between burden and strain?

H_0 3: There is no association between burden and strain.

H_a 3: There is an association between burden and strain.

For RQ3 the dependent variable is a strain with three categories (physical, emotional, financial) and burden as the independent continuous variable with three responses.

Table 2

Statistical procedure per research question and hypothesis

Research Questions	Hypothesis	Variables	Statistical procedures
RQ1: Quantitative: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?	H_0 1: There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?	IV: Caregiver type, caregiver gender, and caregiver age DV: Strain	Multivariable: DV vs all IV. Multiple linear regression

H_a 1: There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer’s and dementia caregivers?

RQ2: Quantitative: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender (3) caregiver age, and burden (three responses) of Alzheimer’s dementia caregivers?	(H_0 2: There is no statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (three responses) of Alzheimer’s and dementia Caregivers? H_a 2: There is a statistically significant association between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (three responses) of Alzheimer’s and dementia caregivers?	IV: Caregiver type, caregiver gender, and caregiver age DV: Burden	Multivariable: DV vs all IV. Multiple linear regression
RQ3: Is there an association between Burden and Strain?	H_0 3: There is no association between Burden and Strain. (H_a 3)- There is an association between Burden and Strain.	IV: Burden DV: Strain	Bivariate: DV vs IV. Simple linear regression

Data analysis plan

Statistical Program for the Social Sciences (SPSS) 25 software was used to perform the statistical analysis. The data was imputed into SPSS and all three research questions were tested using linear regression. Linear regression gave an estimation of the coefficients of the linear equation between one or more independent variables and a dependent variable (Alexopoulos, 2010). Each research question in this study analyzed the association between a dependent variable and three independent predictor variables; thus, a multiple regression method was appropriate.

The independent variables for RQ1 are caregiver type, gender, and age, and the dependent variable is the strain. The independent variables for RQ2 are caregiver type, gender, and age, and the dependent variable is the burden. The independent variable for RQ3 is the burden and the dependent variable is the strain.

A descriptive analysis was conducted to find the frequencies for Alzheimer's disease people receiving care. For the research RQ1 and RQ 2, since there are three predictor variables, a multivariable analysis was performed using multiple linear regression. RQ3 only have one predictor variable for one independent variable, a bivariate analysis was performed using simple linear regression.

Threats to validity

Using secondary data can be a threat to validity. A threat to internal validity is the online data collection process. The interviews were conducted by phone and online. The phone interviews were conducted in the preferred language of participants. However, online interviews were only provided in English and in Spanish. Not having the other languages to accommodate certain participants can be a threat to validity.

Ethical procedures

The proposal of the study was submitted to Walden University's Internal Review Board (IRB) for approval. This study used de-identified secondary data conducted by the National Alliance for caregivers and AARP public policy institute that followed proper data collection protocols. Confidentiality protocols were respected. No personal or identifying information was released for public use. The dataset was stored in my personal password-protected computer and made available only to Walden university research quality office for the analysis tutoring session. The data will be destroyed 2 years after the completion of the study.

Summary

In this section, the research design, methodology, data analysis, threats to validity, and ethical procedures were described. The research used a descriptive and analytical approach to analyze secondary data. Linear regression was used to find the significance between the physical, emotional, financial strain, and caregiver type, gender, age using SPSS. The data is from the National Alliance for Caregiving in partnership with AARP public Policy institute. The target population is caregivers of Alzheimer's disease individuals. Using G*Power, the sample size for this study is estimated at 77 for both RQ1 and RQ2 to have significant power. The sample size for RQ3 is 55 to have significant power.

Section 3: presentation of the results and findings

Introduction

The purpose of this study was to explore the physical, emotional, and financial strain and burden of Alzheimer's disease on caregivers in the United States. Also, I investigated how demographic characteristics like caregiver type, gender, and age impact caregivers' physical, emotional, and financial strains. Section 3 shows the results of the statistical analysis from the National Alliance for Caregiving using SPSS software, version 25. Multiple linear regression was used for both RQ1 and RQ2. Simple linear regression was used for RQ3. The results for each research questions are displayed in this section including descriptive analysis results. The statistical significance is considered at $p<0.05$.

Data collection of secondary dataset

Time Frame and Response Rates

The National Alliance for Caregiving and AARP collected the data through online and telephone interviews between September 11 and November 5 in 2014. According to the National Alliance for Caregiving Report (2015), 1,248 adult caregivers for different diseases were interviewed.

Demographics of the sample

The data sample represented the different ethnic/racial groups in the United States. According to the National Alliance for Caregiving Report (2015), 698 White non-Hispanic caregivers, 206 non-Hispanic African American caregivers, 208, Hispanic caregivers, 95 Asian American caregivers, and 41 caregivers of another race (National

Alliance for Caregiving Report, 2015) were sampled. Two hundred and nine caregivers of 65 years of age and over were over sampled. For this study, only caregivers of patients with Alzheimer's disease were analyzed. The initial plan was to consider primary caregivers like children and spouses for patient with Alzheimer's disease; however, the sample was only 58 for spouses, smaller than expected. To increase the sample size first degree relatives, all other relatives, and nonrelative caregivers were included increasing the sample to 379 caregivers of Alzheimer's.

Study results

Characteristics of Caregivers

Table 3 shows nearly (38% caregivers were children of parents with Alzheimer's disease. Fifteen percent caregivers were taking care of their spouses. Other relatives, like grandchildren, brothers, sisters, nieces, nephews, in-laws, and cousins account for nearly 35% of caregivers. Nine percent of caregivers were friends, 2% were neighbors, and 1.3% were other non-relative. Table 4 shows 10% of the caregivers were between the aged of 18 and 34. Nearly 50% of caregivers were between the ages of 35 and 64. Thirty-eight percent were over 65 years old. Table 5 shows 50% of caregivers were female and 42% were male.

Table 3

Univariate Characteristics of Caregiver Type (N=379)

Relationship to Patient	*n*	%
Children	145	38
Spouses	58	15
Other Relatives	109	35

Friends	33	9
Neighbors	9	2
Other Non-Relatives	5	1.3

Table 4

Univariate Characteristics of Caregiver's Age (N=346)

Age	*n*	%
18-34	36	9.5
35-64	180	47.5
65 +	130	34.3

*Note: There were missing data that were excluded from percentages.

Table 5

Univariate Characteristics of Caregiver's Gender (N=379)

Gender	*n*	%
Male	159	42
Female	220	58

RQ1: Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and strain (physical, emotional, financial) of Alzheimer's and dementia caregivers?

To approach RQ1, a multiple linear regression analysis was conducted to predict strain from caregiver type, caregiver age, caregiver gender.

Assumptions for RQ1 multiple linear regression

According to Leard Statistics (2018), there are eight key assumptions that must be met for the multiple linear regression analysis. The assumptions for RQ1 were all met and described below.

The first assumption is having the dependent variable on continuous scale interval or ratio. The dependent variable for RQ1 was strain, it was measured with three levels on a continuous scale interval from 1 to 7. The second assumption is having two or more independent variables that are nominal, ordinal, or interval. RQ1 has three independent variables: caregiver types, caregiver age, and caregiver gender. Caregiver type is nominal, caregiver age is ordinal, and caregiver gender is nominal. The third assumption is independence of residuals, meaning the residuals should have no correlation (Kenton, 2019). According Kenton (2019), the Durbin-Watson statistic test for residuals for regression analysis value should be between 0 to 4, and a value from 2 to 4 indicate negative correlation with independent residuals. Using the Durbin-Watson statistic to test the assumption of having independence of residuals, the results came out at 2.094 for RQ1 showing no correlation, which means no dependence. The fourth assumption is the relationship between the dependent variable and each independent variables must be linear. In Figure 5, scatterplot RQ1 shows linear relationship between strain and caregiver type, caregiver age, and caregiver gender.

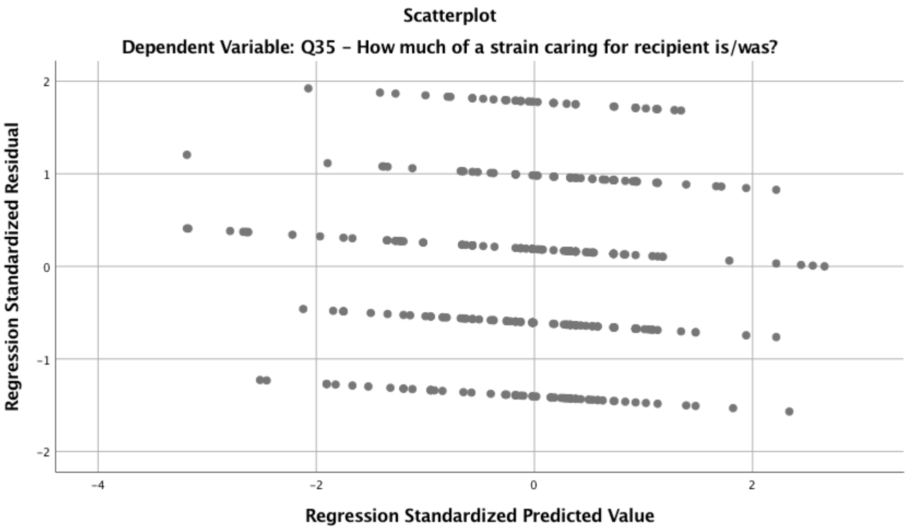

Figure 5. Scatterplot linear relationship between strain and caregiver type, caregiver age, and caregiver gender

The fifth assumption is that data need to show homoscedasticity. Using Figure 5, the data show a rectangular pattern of dots that is showing homoscedasticity. The sixth assumption is the data must not show multicollinearity, the correlation values between predictor variables must be less than 0.7. Values more than 0.7 have strong correlation (Hazra & Gogtay, 2016). For RQ1, the correlation value between caregiver type and caregiver age is 0.203, the value between caregiver type and caregiver gender is -0.014, the relationship between caregiver age and caregiver gender is -0.019. All the correlation values are less than 0.7, thus the data do not show multicollinearity.

Table 6

Correlation Values Between Predictor Variables

Predictors	Caregiver Type	Caregiver Age	Caregiver Gender
Caregiver Type	1.000	.203	-0.014
Caregiver Age	.203	1.000	-0.019

Caregiver Gender	-0.014	-0.019	1.000

The seventh assumption is there should be no outliers, high leverage points or highly influential points. The Cook's distance shows no high influential point since the value was between .000 and .019. A Cook's distance above 1 indicates influential point (Statistics How To, 2016). And a boxplot presented in Figure 6 shows no outliers.

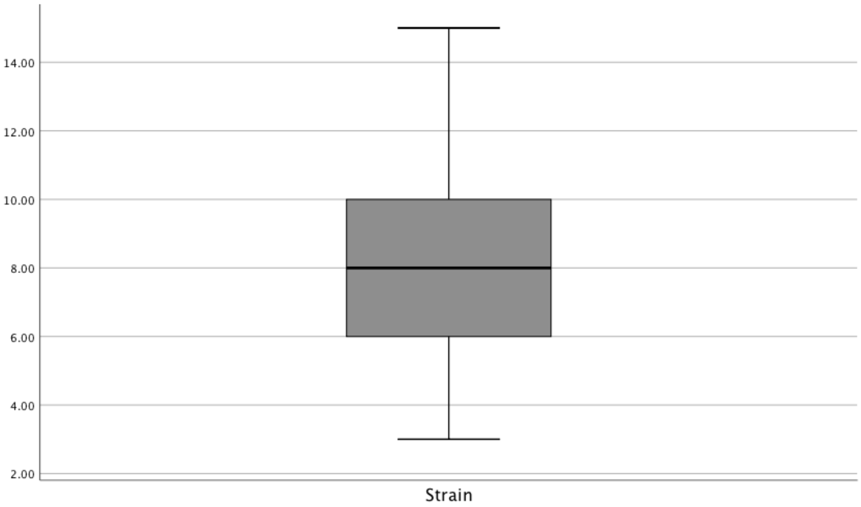

Figure 6. Boxplot showing no outliers for RQ1

The final assumption is that residuals are normally distributes. A histogram for RQ1 was created and showed normal distribution that stays between -3 and 3. The minimum standard residual is -1.419 and the maximum is 2.275.

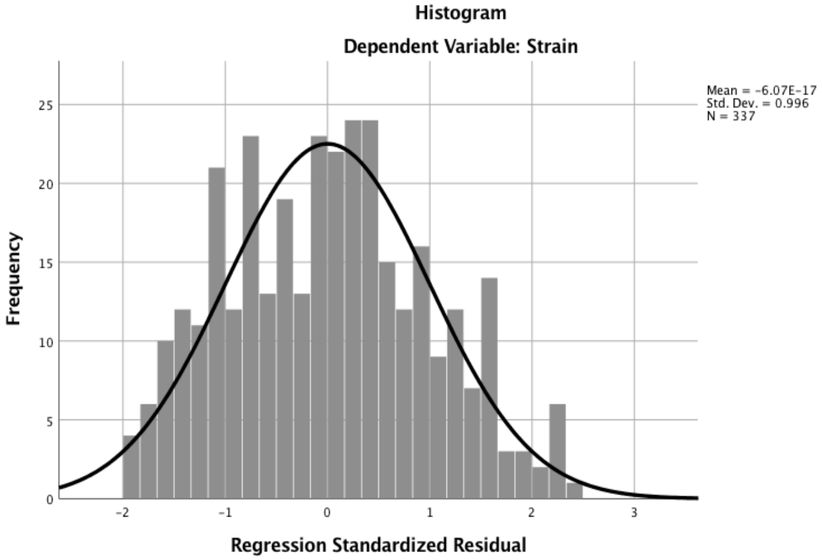

Figure 7. Histogram of Standardized Residual for RQ1

RQ1 Descriptive and Multi Linear Regression Results

The result of the descriptive analysis represented in table 6 shows the mean, standard deviation and *N* value for the dependent variable strain and the independent variables caregiver type, gender, and age.

The results of the multiple linear regression analysis in table 7 revealed caregiver age and caregiver gender not to be statistically significant predictors of the model (p>.05). However, the results of the multiple linear regression analysis revealed a statically significant association between caregiver type and *strain*. Controlling for the predictor variable caregiver type, the regression coefficient is [*Beta*=-.701, 95% C.I. (-1.340, -.063), *p*<.05] in association with the outcome variable *strai*n. For each unit of the predictor that changes the outcome will change -.701. The confidence interval associated with the regression analysis does not contain 0 and the p value is less than 0.05 which shows and association between caregiver type and *strain.* The null hypos thesis is rejected, the alternative hypothesis is retained.

Table 6

Descriptive Statistics for RQ1

	Mean	Std. Deviation	N
Strain	8.44	2.978	337
Caregiver Type	1.54	.499	337
Caregiver Age	4.93	1.595	337
Caregiver Gender	1.56	.487	337

Table 7

Multiple Linear Regression for RQ1 Analysis Between Caregiver Types, Caregiver Age, Caregiver Gender and Strain

Predictors	Outcome	*B*	95% C.I	*b*	*t*	*P*
Caregiver Type	Strain	-.118	(-1.340, -.063)	-.701	-2.160	**.031**
Caregiver Age		.002	(-.197, .203)	.003	.032	.974
Caregiver Gender		-.030	(-.823, .461)	-.181	-.554	.580

(RQ2)- Is there a statistically significant relationship between (1) caregiver type, (2) caregiver gender, (3) caregiver age, and burden (three responses) of Alzheimer's dementia caregivers? The dependent variable for the second research question will be a burden and the independent variables will be caregiver type, age, and gender.

To approach RQ2, a multiple linear regression analysis was conducted to predict *burden* from caregiver type, caregiver age, caregiver gender.

Assumptions for RQ2 Multiple linear Regression

First assumption is having the dependent variable on continuous scale interval or ratio. The dependent variable for RQ2 is *burden*, it is measured on a continuous scale interval from 1 to 5.

The second assumption is having two or more independent variables that are nominal, ordinal, or interval. RQ2 has three independent variables: caregiver types, caregiver age, and caregiver gender. Caregiver type is nominal, caregiver age is ordinal, and caregiver gender is nominal.

The third assumption is independence of residuals. Using the Durbin-Watson statistic to test the assumption of having independence of residuals, the results came out at 2.064 for RQ2 showing no correlation. A value of 2 or more shows no correlation which means no dependence.

The fourth assumption is the relationship between the dependent variable and each independent variables must be linear. In figure 4, scatterplot RQ2 shows linear relationship between burden and caregiver type, caregiver age, and caregiver gender.

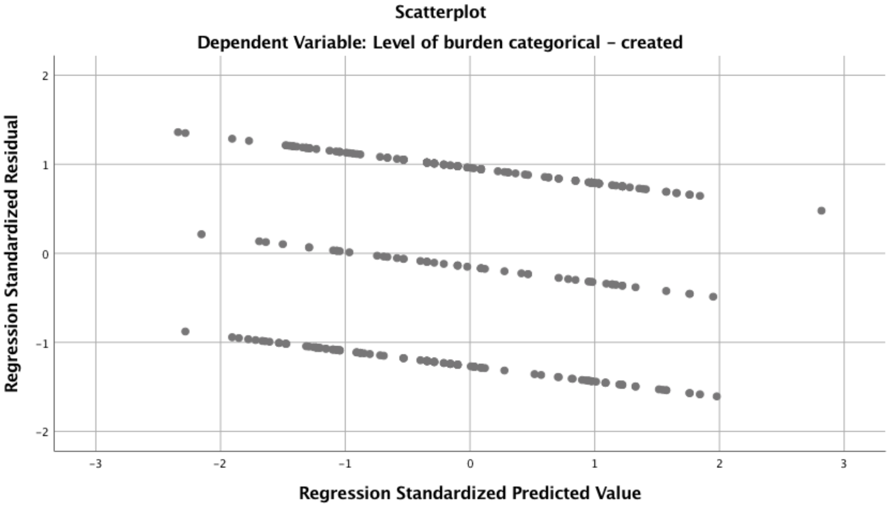

Figure 8. Scatterplot linear relationship between burden and caregiver type, caregiver age, and caregiver gender.

fifth assumption is that data need to show homoscedasticity. Using figure 4, the data show a rectangular pattern of dots that is showing homoscedasticity.

The sixth assumption is the data must not show multicollinearity, the correlation values between predictor variables must be less than 0.7. For RQ2, the correlation value between caregiver type and caregiver age is 0.251, the value between caregiver type and caregiver gender is -0.067, the relationship between caregiver age and caregiver gender is -0.022. All the correlation values are less than 0.7, thus the data do not show multicollinearity.

Table 8

Correlation Values Between Predictor Variables

Predictors	Caregiver Type	Caregiver Age	Caregiver Gender
Caregiver Type	1.000	.251	-0.067
Caregiver Age	.251	1.000	-0.022
Caregiver Gender	-0.067	-0.022	1.000

The seventh assumption is there should be no outliers, high leverage points or highly influential points. The Cook's distance shows no high influential point since the value was between .000 and .019. And a boxplot presented in Figure 5 shows no outliers.

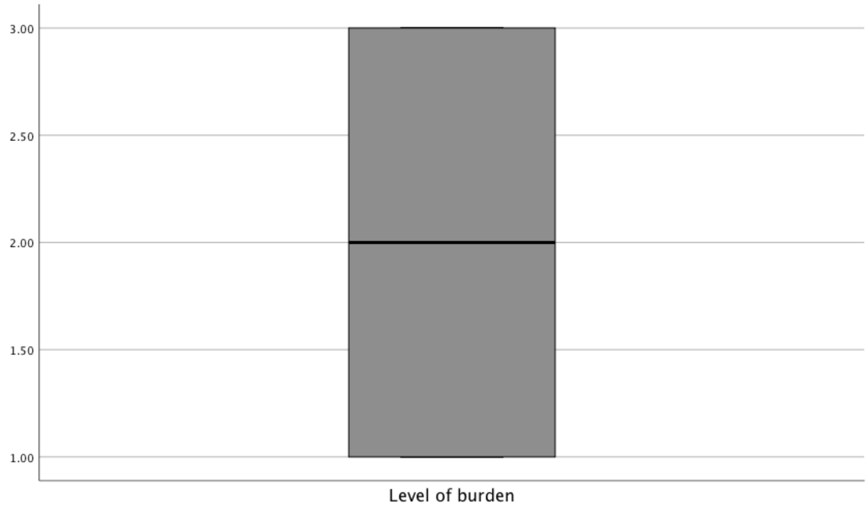

Figure 9. Boxplot Showing no Outliers for RQ2

The last assumption is that residuals are normally distributed. A histogram for RQ2 shows a normal distribution that stays between -3 and 3. The minimum standard residual is -1.419 and the maximum is 2.275.

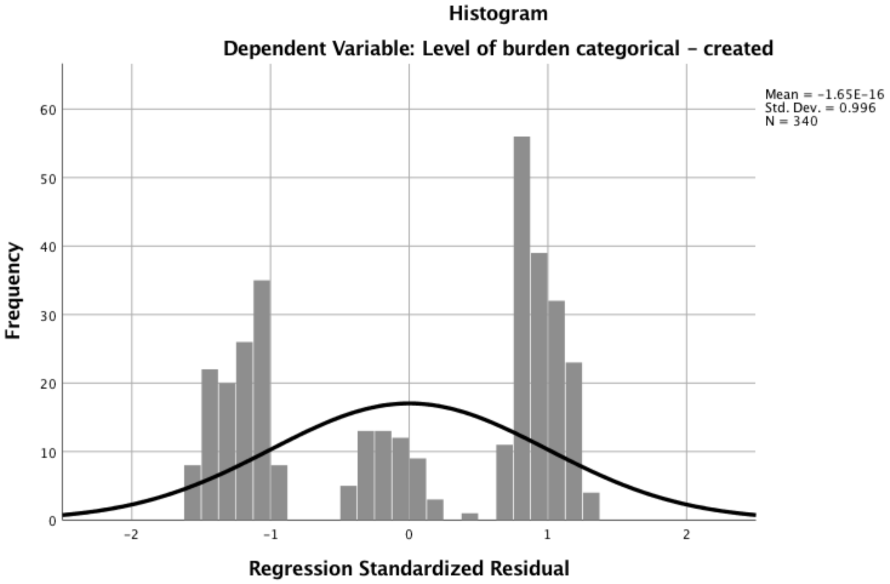

Figure 10. Histogram of standardized residual for RQ2

RQ2 Multiple Linear Regression Result

The result of the descriptive analysis shows the mean, standard deviation and *N* value for the dependent variable burden and the independent variables caregiver type, gender, and age. The results of the multiple linear regression analysis in table 9 revealed caregiver type, caregiver age and caregiver gender not to be statistically significant predictors of burden (p>.05). The null hypothesis is retained, the alternative hypothesis is rejected.

Table 9

Descriptive Statistics for RQ2

	Mean	Std. Deviation	N
Burden	2.13	.90639	340
Caregiver Type	1.54	.499	340

Caregiver Age	4.95	1.583	340
Caregiver Gender	1.56	.497	340

Table 10

Multiple Linear Regression for RQ2 Analysis Between Caregiver Types, Caregiver Age, Caregiver Gender and Burden

Predictors	Outcome	*B*	95% C.I	*b*	*t*	*P*
Caregiver Type	Burden	.093	(-.025, .362)	.168	1.709	.088
Caregiver Age		.085	(-.013, .109)	.048	1.563	.119
Caregiver Gender		.014	(-.170, .219)	-.025	.250	.803

(RQ3)- Is there an association between burden and strain?

To investigate RQ3 a simple linear regression analysis was conducted. The predictor was burden and the outcome was *strain.*

Assumptions for RQ3 Simple linear Regression

According to Leard Statistics (2018), there are some key assumptions that must be met for the simple linear regression analysis. The assumptions for RQ1 are all met and described below.

The first assumption is that both variables are continuous. Both burden and strain are continuous. Burden is measured on a continuous scale interval from 1 to 5, and three level of strain that are measured from 1 to 7.

The second assumption is that both variables have a linear relationship. A scatterplot shows the linear relationship between the variables.

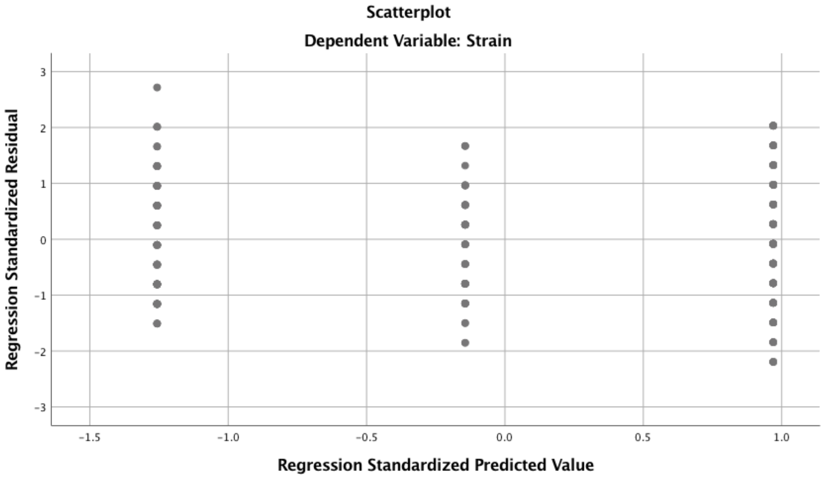

Figure 11. Scatterplot linear relationship between strain and burden

The third assumption is no significant outliers in the data. The scatterplot for the dependent variable strain in figure 1 shows no outliers. The fourth assumption is the presence of independence of observation. The Durbin-Watson value is 1.954 close to 2 showing no dependence.

The fifth assumption is that the data must show homoscedasticity. The scatterplot of figure 7 is rectangular and following the same pattern showing homoscedasticity.

The last assumption is that the residuals approximately normal distributed. A histogram for RQ3 shows normal distribution that stays between -3 and 3. The minimum standard residual is -2.195 and the maximum is 2.716.

Simple Linear Regression results for RQ3

The result of the descriptive analysis in table 10 shows the mean, standard deviation and *N* value for the dependent variable strain and the independent variable burden.

The burden in table 12 was found to be statistically significant predictor of *strain* [*Beta*=0.973, 95% C.I. (6.46, 1.299), *p*<.05), indicating that for every one unit increase in burden the strain changed by .973. The model explained approximately R squared *100% of the validity [R squared=.087]. Therefore, the null hypothesis is rejected and the alternative hypothesis is retained.

Table 11

Descriptive Statistics for RQ3

	Mean	Std. Deviation	N
Strain	8.38	2.967	364
Burden	2.1291	.89832	364

Table 12

Simple Linear Regression for RQ3 Analysis between Burden and Strain

Predictor	Outcome	*B*	95% C.I.	*b*	*t*	*P*
Burden	Strain	.294	(6.46, 1.299)	.973	5.862	**.000**

Summary

In conclusion, there is no relationship between gender of caregivers, age of caregivers and strain. However, there is a statistically significant relationship between caregiver type and strain. There is not relationship between caregiver type, caregiver age, caregiver gender and burden. There is also a statistically significant relationship between burden and strain.

Section 4- Application to Professional Practice and Implications for Social Change

Introduction

The purpose of this study was to explore the strain of Alzheimer's disease on caregivers in the United States. Also, I investigated how demographic characteristics like caregiver type, gender, and age impact caregivers' physical, emotional, and financial strains. The nature of the study was quantitative using secondary data to find statically significance between demographic characteristics between caregivers’ age, gender, type, and strain and burden. The results showed no relationship between the gender, the age of caregivers, and strain. However, there was a statistically significant relationship between caregiver type and strain. For burden, the result showed no relationship with caregiver type, caregiver age, and caregiver gender. There was also a statistically significant relationship between burden and strain.

Interpretation of the Findings

Type of Caregivers

According to Kourakos et al. (2016), most of the caregivers are either spouses or children, with a few being cared for by extended relatives. The result of this research did show about 53% of the caregivers are spouses and children, 35% of the caregivers were other family members, but also 13% of caregivers were just friends, neighbors, and other nonfamily members. Nonfamily caregivers such as friends, neighbors, and others represent a fair number of caregivers, which was surprising. Previous studies mostly focused on family caregivers and no real information on nonfamily caregivers were found.

Stringfellow (2018) defined caregiver strain is the overwhelming feeling of stress and anxiety caregivers experienced and they are unable to perform their role as caregivers. This study showed a statistically significant relationship between caregiver type and strain but did not show a relationship between caregiver type and burden. This result indicates that different caregivers will experience strain during the time they are providing care to persons with Alzheimer’s. There is a possibility the relationship to the care recipient plays a role in adding strain. For example, spouses and children may have a different type of strain as compared to other family members or nonfamily members. Some caregivers may experience emotional strain, physical strain, and financial strain. Others may only experience one or two of these strains, not all.

The Age of Caregivers

This study shows that nearly 48% of caregivers were between the ages of 35 and 64. 34% were over 65 years old. The over 65+ demographic consists of people that are physically frail with their own health challenges. They are at a greater risk of physical and cognitive declines like chronic disease and disability (National Academies Press, 2016).

The study revealed caregiver age not to be a statistically significant predictor of strain. No previous studies found looked at the significance of age and strain. This study appeared to be the only one. There is an opportunity for future research to investigate this further to gather valuable information for future evidence-based intervention programs.

The study shows no relationship between the age of caregivers and burden. Previous studies had contradictory results on the level of burden on different age groups of caregivers. Chiao et al. (2015) conducted a literature review and found that some studies reported more burden for older caregivers, while other studies reported more burden for younger caregivers.

Regardless of the conclusions in the study, both younger and older caregivers may benefit from interventions that aim to produce better quality of life. However, if more burden were reported for older caregivers it would be imperative that public health address it. As previously mentioned, older caregivers are a special group that with health issues themselves, and these caregivers' reluctance to accept support before reach a crisis point (Oliveira et al., 2019).

The Gender of Caregivers

58% of caregivers in this study were women and 42% were men. Women being the majority agrees with previous studies. Kourakos et al. (2016) showed 75% adult children caregivers were women and nearly 59% spousal caregiver were also women. A smaller study by Xion et al. (2020) showed out of 76 caregivers, 42 were females and 34 were males.

Xion et al. (2020) explained that previous studies of gender differences demonstrated the female caregivers have more burden and strain than male care givers, specifically higher level of depressive symptomatology, poorer physical health, and more emotional distress. My study however showed no relation between caregiver gender and burden nor strain. The other studies showing higher level of burden among family caregiver often do not take into account other factors like the severity of dementia and the length of time spent on caregiving during statistical analyses (see Xion et al., 2020).

Relationship between Burden and Strain

The burden on caregivers manifests as a negative response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience (Zhou et al., 2016). While strain is the overwhelming feeling of stress and anxiety caregivers experienced and they are unable to perform their role as caregivers (Stringfellow, 2018). This study found a relationship between burden and strain.

Findings to Stress Process Model Theoretical Framework

Caregiver type. This study showed a statistically significant relationship between caregiver type and strain. As mentioned previously, the stress process model was used in the past to examine stress for family caregivers of patients with dementia (Pearlin et al., 1990). Focusing on the physical, emotional, and financial strains using the stress process model can help predict the health outcomes of the caregivers, whether they are spouses and children. The results of this study may help predict the outcome of the strain based on the type of the caregivers and the type of stress they are experiencing.

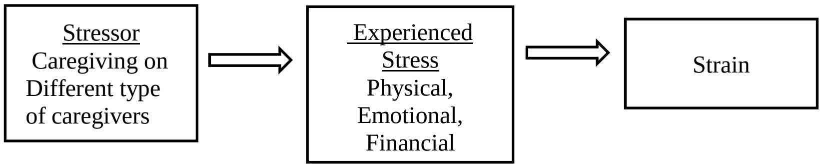

Figure 12. Stress process model for caregivers

Findings to Quality-of-Life Theoretical Framework

Burden and strain. The result of this study shows the burden is statistically related to strain. Using the theory of quality of life to evaluate the factors affecting the caregiver quality of life to reduce the physical, financial, and emotional burdens on the caregivers can lead to less strain. Lessen the strain can establish health and happiness. Some of the specific needs that can be addressed to reach health and happiness according to Ventegodt, Merrick, and Andersen, (2003) adequate sleep, food, clothes, and safety. Strains that mediate the burden can possibly determine health outcomes.

Limitations of the study

Possible limitations of the study should be considered. The caregiver selected are indeed taking care of a person with Alzheimer’s disease, however many other factors can affect their caregiving experience. Thus, this study does not take into account the full spectrum of strain and burden. Caregivers may have other responsibilities that affect their daily lives, not just being caregivers. For example, the adult children taking care of parents with Alzheimer’s may also have children or spouses that require constant attention and care. Another limitation is physical, emotional, and financial strains where not defined in data collection. Also, there is no way to verify if these strains were already present before caregiving started.

Although the study has some limitations, it is important because it targeted the right population of Alzheimer’s caregivers when looking at the burden and the strain they are facing. It also had a good enough sample for the results to be reliable when it comes to overall strain and burden affecting the caregivers.

Recommendations

The result of this study shows that there is no relationship between the gender of caregivers, the age of caregivers, and strain. However, the study did show a statistically significant relationship between caregiver type, and strain. If there is a relationship between different types of caregivers and strain, it is important to find out which type of caregivers experienced the most strain. There are a few questions that further research can explore. Are the non-family caregivers getting the same recognition as family caregivers? Do they get the same benefits that can improve their quality of life? These are also important questions for policy consideration to give these caregivers' access to the same benefits as family caregivers.

Future research should also take into consideration other factors such as other commitments, jobs, other caregiving duties, caring for children or other family members that can contribute to the burden of caregivers taking care of persons with dementia. As previously mentioned, some caregivers may also be taking care of another family member or have children that may have contributed to the burden. These factors may have not been taken into consideration during data collection.

Since strain can be physical, emotional, and financial, further studies can aim to identify which type of strain is more prevalent in different types of caregivers. There is a possibility that older caregivers will experience more physical burden, and younger caregivers will experience more financial burden, further research is required to validate this claim.

Implication for professional practice and social change

Public health practitioners can use the findings of the study to raise more awareness and advocate for the family and non-family caregivers. These caregivers play an essential role in the management of Alzheimer's dementia disease and their health and well-being must be taken into consideration. Family caregivers need help to alleviate the burden associated with the lengthy caregiving experience of loved ones with dementia. However, this study reveals 13% of caregivers are only friends and neighbors that should also be taken into account. Just like family, they are very important for the care of the people affected with dementia.

In most states in the United States, the Family and Medical Leave Act covers only caregivers for spouses, domestic partners, children, and parents (National Conference of State Legislature, 2020). In a few states like Maine and Minnesota, siblings and grandparents are covered by the Family and Medical Leave Act (National Conference of State Legislature, 2020). Thus, 13% of non-family caregivers are left with no coverage to take care of their loved ones. There is a need for new policies at the state and even at the federal level that can benefit these non family caregivers. Also, the Family and Medical Leave Act does not cover any caregiver for the long-term which lives Alzheimer’s caregivers without the ability to offer caregiving long-term and maintain full-time employment.

This research can also influence more community-based interventions that can lessen the burden and that can provide support to these caregivers. The results provide information for the development of programs aimed to improve the quality of life of caregivers and lessen their burden by making more resources available to them.

The study did show a relationship between strain and burden. Kourakos, Kafkia, & Minasidou, (2016) recommended that caregivers place patients that are more difficult to treat at home at a nursing home or a specialized facility to alleviate the burden. These facilities are very expensive, the cost can put a great financial strain on caregivers leading to an even greater burden.

Creating more affordable community facilities should be a priority. Having these facilities can be great resources for the caregivers and eventually help prolong the lives of the caregivers which eventually will benefit the loved ones that depend on them. The result of the research can help raise awareness about the many responsibilities of the family, friends, and neighbors that are caregivers and maximize community engagement to consequently help reduce the pressure of the disease on these individuals and communities.

Conclusion

The purpose of this study was to explore the different socio-characteristics of the strain and burden of Alzheimer's disease on the caregivers in the United States. The relationship between caregiver type, caregiver age, caregiver gender, and strain were analyzed. The study didn't find a relationship between caregiver age, caregiver gender, and strain. Caregiver type was statistically significant for strain. Depend on their type of relationship to the person with dementia, some caregivers may experience emotional strain, physical strain, and financial strain.

The study did not find a relationship between caregiver type, caregiver age, caregiver gender, and burden. However, there was a relationship between burden and strain. When caregivers face physical, psychological, emotional, social, and financial burdens they will feel overwhelming strain which is the feeling of stress and anxiety. The strain can make them unable to perform their caregiving role.

As the number of people with Alzheimer’s disease increases, the need for reliable caregivers will increase. Because of the dementia associated with the disease patient will continue to rely on family or non-family caregivers to survive. It is important to promote practices to improve the quality of life for these caregivers.

References

2019 Alzheimer’s disease facts and figures. (2019). *Alzheimer's & Dementia: The Journal of the Alzheimer’s Association*, *15*(3), 321–387. https://doi-org.ezp.waldenulibrary.org/10.1016/j.jalz.2019.01.010

Alexopoulos E. C. (2010). Introduction to multivariate regression analysis. *Hippokratia*, *14*(Suppl 1), 23–28. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3049417/

Alzheimer’s Association (2018). 2018 Alzheimer’s Disease Facts and Figures. Retrieved from https://www.alz.org

Alzheimer’s Disease International (2015). World Alzheimer Report 2015: The global impact of dementia, an analysis of prevalence, incidence, cost and trends. London, UK: Author. Retrieved from: https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf

Baker, J., & Intagliata, J. (1982). Quality of life in the evaluation of community support systems. *Evaluation and Program Planning*, 5, 69-79.

Bień-Barkowska, K., Doroszkiewicz, H., & Bień, B. (2017). Silent strain of caregiving: exploring the best predictors of distress in family carers of geriatric patients. *Clinical interventions in aging*, *12*, 263–274. https://doi.org/10.2147/CIA.S125664

Black, B.S., Johnston, D., Rabins, P.V., Morrison, A., Lyketsos, C., & Samus, Q. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *Journal of* *the American Geriatrics Soc. 2013, 61*(12):2087-2095.

Bouldin, E. D., Shaull, L. S., Andresen, E. M., Edwards, V. J., & McGuire, L. C. (2017). Financial and health barriers and caregiving-related difficulties among rural and urban caregivers. *Journal of Rural Health*, *34*(3), 263-274

Campbell, P., Wright, J., Oyebode, J., Crome, P., Bentham, P., Jones, L., & Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International J Geriatric Psychiatry 23,*1078–1085

Campos-Puente, A. de L. M., Avargues-Navarro, M. L., Borda-Mas, M., Sánchez-Martín, M., Aguilar-Parra, J. M., & Trigueros, R. (2019). Emotional exhaustion in housewives and Alzheimer patients' caregivers: Its effects on chronic diseases, somatic symptoms and social dysfunction. *International Journal of Environmental Research and Public Health*, *16*(18). https://doi-org.ezp.waldenulibrary.org/10.3390/ijerph16183250

Cheng, S. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Rep 19*, 64. https://doi.org/10.1007/s11920-017-0818-2

Centers for Disease Control and Prevention (2016). Caregiving for Person with Alzheimer's Disease or a Related Dementia. Retrievedfrom: https://www.cdc.gov/aging/caregiving/alzheimer.htm

Chiao, C. Y., Wu, H. S. and Hsiao, C. Y. (2015), Caregiver burden for informal caregivers. International Nursing Review, *62*, 340-350. doi:10.1111/inr.12194

Dahlrup, B., Ekström, H., Nordell, E., & Elmståhl, 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*(2), 261–270. https://doi.org/10.1016/j.archger.2015.06.007

Esandi, N., Nola, M., Alfaro, C., & Canga-Armayor, A. (2018). Keeping Things in Balance: Family Experiences of Living with Alzheimer’s Disease. *Gerontologist, 58*(2), e56-e67. https://doi.org/10.1093/geront/gnx084

Etindele Sosso FA, Nakamura O, Nakamura M (2017) Epidemiology of Alzheimer’s disease: Comparison between Africa and South America. Journal of Neurology and Neuroscience *8*,3.

Family Caregivers Alliance (2019). Caregiver Statistics: Demographics [Online]. San Francisco, CA: Family Caregivers Alliance. Available at: https://www.caregiver.org

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., … Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association*, *13*(5), 572–581. https://doi-org.ezp.waldenulibrary.org/10.1016/j.jalz.2016.12.010

Glanz, K. & Rimer, B.K. (1997). Theory at a glance: A guide for health promotion practice. *National Cancer Institute*.

Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A. C., Collins, R. P., & Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in Black and White family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology*, *64*, 121-129.

Hazra, A., & Gogtay, N. (2016). Biostatistics Series Module 6: Correlation and linear regression. *Indian Journal of Dermatology*, *61*(6), 593–601. https://doi.org/10.4103/0019-5154.193662

Hazzan, A. A., Shannon, H., Ploeg, J., Raina, P., Gitlin, L. N., & Oremus, M. (2016). The association between caregiver well-being and care provided to persons with Alzheimer's disease and related disorders. *BMC Research Notes, 9*, 344. https://doi.org/10.1186/s13104-016-2150-z

Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric Disease and Treatment*, *10*, 1407–1413. https://doi.org/10.2147/NDT.S58063

Janssen-Aguilar, R., Erosa-Villarreal, R. A., Gonzalez-Maldonado, L. A., Mendez-Dominguez, N. I., Inurreta-Diaz, M. (2019). Epidemiological characteristic of dementia-related mortality in Mexico between 2012- and 2016. Retrieved from: https://www.researchgate.net

Kenton, W. (2019). Durbin Watson Statistic Definition. Instropedia. Retrieved from: https://www.investopedia.com/terms/d/durbin-watson-statistic.asp

Kourakos, M., Kafkia, T., Minasidou, E. (2016). Social support and care for patients with Alzheimer’s disease in the community. Int J Caring Sci. 9:1186. Retrieved from: http://www.internationaljournalofcaringsciences.org

Leard Statistics (2018). Multiple Regression Analysis using SPSS Statistics. Retrieved from: https://statistics.laerd.com/spss-tutorials/multiple-regression-using-spss-statistics.php#procedure

Lee, K., Puga, F., Pickering, C. E. Z., Masoud, S. S., & White, C. L. (2019). Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review. *International Journal of Nursing Studies, 96*, 119–131. https://doi-org.ezp.waldenulibrary.org/10.1016/j.ijnurstu.2019.02.007

McDonald, J.H. (2014). Basic concepts of hypothesis testing. Retrieved from: Hypothesis testing - Handbook of Biological Statistics Support for Caregivers

Manthorpe, J, & Bowling, A. (2016). Quality of life measures for carers for people with dementia: measurement issues, gap in research and promising paths. *Research, Policy and Planning* (2016) 31(3), 163-178

Montgomery, W., Goren, A., Kahle-Wrobleski, K., Nakamura, T., & Ueda, K. (2018). Alzheimer's disease severity and its with patient and caregiver quality of life in Japan: results of a community-based survey. *BMC geriatrics*, *18*(1), 141. doi:10.1186/s12877-018-0831-2

National Academies Press (2016). Families Caring for Aging America. https://www.ncbi.nlm.nih.gov/books/NBK396397/

National Alliance for Caregiving Report (2015). Caregiving in the U.S. https://www.caregiving.org

National Conference of State Legislature (2020). State Family and Medical Leave Laws. https://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx

National Institute of Aging (2017). What are the signs of Alzheimer's disease. Retrieved from: https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease

National Institute of Health (n.d.). Quality of Life Definition. http://www.cancer.gov/dictionary?cdrid=45417, Retrieved March 5, 2020.

Oliveira, D., Sousa, L., & Orrell, M. (2019). Improving health-promoting self-care in family carers of people with dementia: a review of interventions. *Clinical interventions in aging*, *14*, 515–523. https://doi.org/10.2147/CIA.S190610

Pearlin, L. I., Menaghan, E.G., Leiberman, M. A., & Mullan, J. T. (1981). The Stress Process. *Journal of Health and Social Behavior,* 22, 337-356.

Perugini, M., Gallucci, M., & Costantini, G. (2018). A Practical Primer to Power Analysis for Simple Experimental Designs. *International Review of Social Psychology*, *31*(1), 20. DOI: http://doi.org/10.5334/irsp.181

Roberts, E., & Struckmeyer, K. M. (2018). The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives. *Inquiry: A Journal of Medical Care Organization, Provision and Financing*, *55*, 0046958017751507. http://doi.org/10.1177/0046958017751507

Robinson, L., Tang, E., & Taylor, J.-P. (n.d.). Dementia: timely diagnosis and early intervention. *BMJ-British Medical Journal*, *350*. https://doi-org.ezp.waldenulibrary.org/10.1136/bmj.h3029

Rodriguez, C.B., Castineira, B.R., Nunes, L. C. (2019). Alzheimer's disease and the quality of the informal caregiver. *Revista Espanol de Geriatria y Gerontologia*, 54, 81-87. Retrieved from: https://www.ncbi.nlm.nih.gov/pubmed/30792138

Schulz, R. (2016). Family caregiving roles and impacts. In: Schulz R, Eden J, editors. Families caring for an aging America. Washington, DC: *National Academies of Sciences, Engineering, and Medicine,* p. 73–122. https://www.ncbi.nlm.nih.gov/books/NBK396398/

Silva, M.V.F., Loures, C.d.M.G., Alves, L.C.V. *et al.* Alzheimer's disease: risk factors and potentially protective measures. *J Biomed Sci* **26,** 33 (2019). https://doi.org/10.1186/s12929-019-0524-y

Sirgy, M. (1986). A Quality-of-Life Theory Derived from Maslow's Developmental Perspective: 'Quality' Is Related to Progressive Satisfaction of a Hierarchy of Needs, Lower Order and Higher. *The American Journal of Economics and Sociology, 45*(3), 329-342. Retrieved from: http://www.jstor.org/stable/3486692

Srivastava, G., Tripathi, R. K., Tiwari, S. C., Singh, B., & Tripathi, S. M. (2016). Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia. *Indian journal of psychological medicine, 38*(2), 133–136. https://doi.org/10.4103/0253-7176.178779

Statistics How To, (2016). Cook’s Distance/Cook’s D: Definition, Interpretation. Retrieved from: https://www.statisticshowto.com/cooks-distance/

Stringfellow, A. (2018). What is Caregiver Role Strain? Seniorlink. Retrieved from: https://www.seniorlink.com/blog/what-is-caregiver-role-strain

Sullivan, G. M., & Feinn, R. (2012). Using Effect Size-or Why the P Value Is Not Enough. *Journal of graduate medical education*, *4*(3), 279–282. https://doi.org/10.4300/JGME-D-12-00156.1

Travonia, B. H., Betty, S. B., Marilyn, A., Laura, N. G., Deirdre, M. J., Constantine, G. L., & Quincy, M. S. (2014). Correlates of objec- tive and subjective measures of caregiver burden among demen- tia caregivers: Influence of unmet patient and caregiver dementia- related care needs. *International Psychogeriatrics*, *26*(11), 1875–1883 doi:10.1017/S1041610214001240

Ulep, M. G., Saraon, S. K., & McLean, S. (2018). Alzheimer Disease. *The Journal for Nursing Practitioners,* 14(3), 129-135

U.S. Department of Health and Human Services, National Institutes of Health, National Institute on Aging, n.d. *Alzheimer’s Disease Facts Sheet*. Retrieved from: https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet

Ventegodt, S., Merrick, J., & Andersen, N.J. (2003). Quality of Life Theory III. Maslow Revisited. *The Scientific World Journal*, 1050. https://doi-org.ezp.waldenulibrary.org/10.1100/tsw.2003.84

Weller, J., & Budson, A. (2018). Current understanding of Alzheimer's disease diagnosis and treatment. *F1000Research*, *7*, F1000 Faculty Rev-1161. https://doi.org/10.12688/f1000research.14506.1

Wolfs, C. A., Kessels, A., Severens, J. L., Brouwer, W., de Vugt, M. E., Ver- hey, F. R., & Dirksen, C. D. (2016). Predictive factors for the objective burden of informal care in people with dementia: A systematic review. *Alzheimer Disease and Associated Disorders*, *26*(3), 197–204. doi:10.1097/WAD.0b013e31823a6108

Xion, C., Biscardi, M., Astell, A., Nalder, E., Cameron, J.I., Mihailidis, A., & Colantonio, A. (2020). Sex and gender differences in caregiving burden experiences by family caregivers of person with dementia: A systematic review. *Plos One*, 15 (4)

Yang, Z., & Levey, A. (2015). Gender differences: a lifetime analysis of the economic burden of Alzheimer’s disease. *Women’s Health Issues*, 25, 436-440.

Zhou, Y., Ning, Y., Rosenheck, R., Sun, B., Zhang, J., Qu, Y., & He, H. (2016). Effect of living with patients on caregiver burden of individ- ual with schizophrenia in China. *Psychiatry Research*, *245*, 230–237. doi:10.1016/j.psychres.2016.08.046