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Burden and Coping Strategies of Caregivers of Persons with Alzheimer's Disease

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Walden University
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Abstract

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MPS, New School for Social Research 1988

BS, IONA College 1984

RN, Diploma Misericordia School of Nursing 1976

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Healthcare Administration

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Abstract

Alzheimer’s disease (AD) currently presents a huge burden to individuals and families, a burden that is increasing in incidence with the aging of the baby boomer generation. Caring for a spouse diagnosed with AD holds potentially severe negative consequences for the caregiver’s physical and psychological well-being. The current study used secondary data from the 2017 New York State Department of Health/Behavior Risk Factor Surveillance System to identify a relationship, if any, between the time and activities a caregiver spends with the AD person and the caregiver’s self-reported level of general and mental health. A logistic regression was used for RQ1 to examine if there is a relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of caregiver; RQ2 examined the relationship between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits as needed. RQ3 examined the number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability to manage personal time and household tasks. There was a positive relationship between the dependent variable of hours per week the caregiver cares for the family member and the dependent variables of age and the management of personal time of the family member. Evidence from this study may inform administrators, and healthcare professionals, regarding the importance of providing resources for caregivers.

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Dedication

I dedicate this project first to the memories of both my parents Roy and Gwendolyn Tucker who has always supported me in any endeavor I chose to begin. Miss you both. Next, this project is dedicated to my husband Andrew, son Aaron, brother Roy, grandson Amere and all my family members who kept encouraging me with “you got this.” I come from a family of Alzheimer caregivers. I witnessed firsthand how my mother and father cared for my maternal grandmother until her death. Next to my beautiful cousins Cheryl and Gwen who I watched for years as they cared for their mothers without caring for themselves. Witnessing all has led me to do this very important project. Their devotion and support have helped me to get through this doctoral journey. I love you all and I am forever grateful.

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duties as their President knowing I was pursuing my doctorate degree I could not have done it without you. And to all my fellow classmates who kept me grounded when I felt down and out. You know who you are. Thank you.

Table of Contents

List of Tables

List of Figures

Section 1: Foundations of the Study and Literature Review

Introduction

Caregivers for individuals with Alzheimer's disease (AD) and other dementias encounter unique burdens. There are approximately thirty-four million Americans who provide informal, unpaid care to individuals over the age of 50 with disabilities and chronic conditions in the United States (National Alliance for Caregiving and AARP (2015). It is estimated that in 2019 more than 18.5 billion hours of unpaid care was provided to individuals with Alzheimer's and other dementias, at an economic value of nearly $234 billion (Alzheimer's Facts & Figures, 2019). By 2050, it is projected that caring for an Alzheimer individual will cost more than $1.1 trillion (Alzheimer's Facts & Figures, 2019). Caregivers struggle with great physical, emotional, and financial stress as they cope with physical and mental changes in their loved ones. The highest number of hours of caregiving and rates of "high burden" were among African American and Hispanic caregivers (Family Caregiver Alliance and the National Center on Caregiving, 2019). Physical strain has been rated "high" for caregivers in the following areas: (a) caregivers who provided care for 1 year or longer (23%) and (16%) of caregivers who provided care for less than one year, and (b) caregivers aged 65 and older had (31%), higher caregiver burden, (16%) had moderate caregiver burden, (9%) had lower caregiver burden, (c) caregivers who reside with care recipient (25%) and (17%) of caregivers not residing with care recipient (National Alliance for Caregiving & AARP, 2015).

Caregivers for individuals with AD will steadily increase in number as the population ages (Flite & Harman, 2013). Stresses on caregivers may cause burnout. Resource services are needed to provide the right kind of help and assistance for caregivers. Flite and Harman (2013) emphasized that informal caregivers should be supported through interventions that minimize their stress and improve their overall health and well-being. Healthcare administrators must promote cooperation with informal AD caregivers as a means of ensuring that AD patients receive the best possible care and to encourage well-being among caregivers (Flite & Harman, 2013). Additionally, hospitals should adopt interventions for enhancing the caregivers' competence in providing safe and effective care to their patients. Such interventions would not only reduce caregivers' distress, but also enhance their sense of certainty and control (Flite & Harman, 2013). Healthcare administrators must support AD caregivers through structured interventions aimed at providing them with the practical skills required to manage the caregiving (Martín-Carrasco, Domínguez-Panchón, González-Fraile, Muñoz-Hermoso, Ballesteros, & EDUCA Group, 2014). Structured interventions focused on various elements of the caregiving process include identifying patients' behavioral triggers, communicating effectively, aligning tasks with the patients' capabilities, and managing the caregiver's psychological stress. Martin-Carrasco et al. (2014) emphasized that caregivers should be supported through educational and training programs. Caregiver training can be categorized as follows: meeting patients' basic needs, behavioral management, managing caregiver burden, and coping with stress (Martin-Carrasco et al., 2014). Healthcare administrators can play a significant role in supporting caregiver programs and deploying the resources necessary to ensure that AD caregivers are supported effectively.

González-Fraile et al. (2015) asserted in a systemic review that there is a need for efficiency in information training and support of caregivers of people with dementia to reduce the burdens caregivers face and to improve their quality of life. González-Fraile et al. (2015)

posited that AD caregivers should be provided with professional support that includes counseling services with health care professionals. This leads to understanding the influence of informational support and training for caregivers. The findings of the review in this case show that counseling and offering support to caregivers improved their value of life and in turn the value of life of those they are tasked to care for. The findings in this case show the role of administrators in interventions to meet the need for information training and support. Caregivers also should be provided with standardized information by professionals who are knowledgeable about dementia (González-Fraile et al., 2015). Standardization of information improved the quality of support and training, and health administrators can play a crucial role in championing provision for supporting informal AD caregivers (Gonzalez-Fraile et al., 2015). Apart from the role as advocates, administrators are directly involved in shaping the caregiving environment. Gonzalez-Fraile et al. (2015) examined existing evidence on the efficacy of information support and training. The review revealed that provision of information led to opportunities for quality improvement in the lives of caregivers, which in turn improved the quality of care for the people with Alzheimer's. Gonzalez-Fraile et al. (2015) emphasized that the efficacy of informational interventions in this case was examined by checking the outcomes for the caregivers and recipients of care.

This study was based on the most recent version of the 2017 New York State Department of Health (NYSDOH)/Behavior Risk Factor Surveillance System (BRFSS) survey. The BRFSS is a health-related telephone survey that collected statewide data. This public health survey is conducted yearly by all states in coordination with the Centers for Disease Control and Prevention (CDC). The BRFSS was established initially in only 15 states in 1984 but is now collected in all 50 states including the District of Columbia and three United States provinces (CDC, 2015). For this study I extracted information from the 2017 NYSDOH/BRFSS dataset and analyzed it using IBM SPSS statistical software, v 22.0 (2013).

Problem Statement

AD has been estimated to have an emotional impact on millions of Americans over the age of 65 (Alzheimer's Association, 2016). AD places a burden on the patient, their caregivers, and society (Hebert, Weuve, Scherr, & Evans, 2013). Caregivers who continuously deal with AD patients often experience considerable stress and are at risk for mental and physical health issues (Fernández-Calvo, Castillo, Campos, Silva, & Torro-Alves, 2016). As AD progresses, providing care to a family member becomes increasingly demanding, exposing the caregiver to growing emotional and physical demands that may negatively impact the health of the caregiver. A relationship linking caregiver stress and the severity of the AD has been reported suggesting that stress may be due to a lack of balance between the care demands and the support available to AD caregivers (Chen, Chen & Chu, 2015; Fernández-Calvo et al., 2016; Kim, Chang, Rose & Kim, 2012; Lavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014).

The Purpose of the Study

The purpose of this study was to inform health care administrators in New York State who oversee AD programs about the variables that impact the health outcomes of AD caregivers. The dependent variable for this study was hours per week the AD caregiver spent caring for the AD/dementia family member, and the independent variables were age, gender, and ethnicity of the caregiver; self-reported general health of the caregiver; and self-reported level of stress of the caregiver. Caregiver general health was measured by caregiver's ability to manage household tasks, such as shopping and paying bills, use AD support services, obtain annual cholesterol check-up, get an annual flu shot, and follow through on an annual doctor visit.

Informed administrators can implement health policy and programs that provide resources to address the caregiver burden that causes a feeling of a lack of support and impacts the health of AD caregivers, which ultimately affects the care of the AD patient. Health care administrators also can use their influence to ensure that caregivers are educated on the importance of seeking or using available support services (Roche, Croot, MacCann, Cramer, & Diehl-Schmid, 2015). This study used secondary data to identify a correlation, if any, between the use of support services and reduction of caregiver burden among caregivers of AD patients. Results from this study may inform healthcare administrators and New York State Alzheimer disease policy makers regarding gaps in use and effectiveness of support services measured by self-reported physical and social burdens of AD caregivers, so that improvements may be executed.

The severity of the caregiver burden is moderated by the patients' neuropsychiatric and cognitive symptoms; the AD caregivers' evaluation of the situation, and the available resources (Roche et al., 2015). However, AD caregivers may lack knowledge of available support services (Richardson, Lee, Berg-Weger, & Grossberg, 2013). The study explored the influence and effectiveness of AD caregiver support services. The desired outcome was to obtain insight into the importance of formal and informal support services and to improve the health and welfare of AD caregivers.

I retrieved data on these variables from the 2017 New York State, Department of Health Behavior Risk Factor Surveillance Survey (NYSDOH/BRFSS). The BRFSS is a cross-sectional telephone survey that is conducted monthly by state health departments with the help of the Centers for Disease Control and Prevention (CDC). The review has a caregiver module to identify individuals who need assistance from caregivers. The BRFSS survey further evaluates the type of services that would help caregivers in conducting their caregiving role (CDC, 2015). Surveillance is used to gather information to ascertain the potential difficulties and burden that subjective cognitive decline and caregiving impose and to create appropriate interventions. The BRFSS also supports healthcare administrators in making informed decisions in the development of plans and policies. BRFSS assists healthcare administrators in expanding public awareness on Alzheimer's and advocating early detection and diagnosis of the disease via cognitive health in other public health campaigns (CDC, 2015).

Research Questions

The following research questions were adopted for this study:

RQ1: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver?

$H_0$1: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

H_a1: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

RQ2: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed?

$H_0$2: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

H_a2: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

RQ3: What is the relationship, if any, between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services?

$H_0$3:There is not a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

H_a3:There is a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

Theoretical Framework of the Study

The theoretical framework for this quantitative research study centered on the stress buffering model (SBM) developed by physician and epidemiologist J. Cassel and psychiatrist S. Cobb in 1976. The model was created on the premise that certain resources aid in minimizing the implications of negative life events on a person's health. The key component in this model focuses on helping to reduce the impact of negative life experiences on an individual's health status (Gellert et al., 2018). In this study I considered the impact of the dependent variable of number of hours the caregiver spends caring for the AD/dementia family member on the independent variables. The independent variables of the study were age, gender, and ethnicity of the caregiver; self-reported general health of the caregiver; and self-reported level of stress of the caregiver. Caregiver general health was measured by caregiver ability to obtain annual cholesterol check-up, annual flu shot, and annual doctor visit. Gellert et al. (2018) emphasized the SBM of social support by pointing out that social support reduces the impact of negative relationships and posited that the stress-buffering framework can be applied to caregivers of individuals with Alzheimer/dementia.

Gellert et al. (2018) posited that a lack of social support may be linked to dementia. Additionally, social support provides a potential working mechanism for relieving the physical and mental caregiver burden. Social support is viewed as a source of satisfaction by caregivers and has the potential to act as a buffer to the stress arising from the caregiving activities. The Gellert et al. (2018) model viewed social support as measured on variables such as education and counseling, support group use, access to care, and access to healthcare services. As such, the SBM was suitable for the study. Gellert et al. (2018) used a total of 108 participants with AD and 108 of their caregivers (216 persons in couples) from Berlin, Germany. Participants were selected from memory clinics, private practices, nursing services, and other healthcare facilities (Gellert et al., 2018). Table 1 illustrates characteristics by role of care (Gellert et al., 2018).

Table 1

Sample Characteristics by Role of Care

	Partner with dementia mean (*SD*)	Caregiving partner mean (*SD*)
Age in years	74.64 (6.19)	72.04 (6.83)
Gender (n women)	42 (38.9%)	66 (61.1%)
Education in Year	15.06 (14.42)	14.06 (12.9)
Quality of Life (WHO-QoL-BREF/QOL-AD)	36.42 (5.68)	96.72 (12.14)
Perceived social support (F-SozU-14)	54.35 (7.76)	53.48(11.28)
Perceived distress (PSS)	9.81 (5.26)	12.77 (4.35)
Depressive symptoms (GDS)	5.51 (2.36)	4.74 (2.07)
Functional disability (ADL)	88.80 (15.21)	
Cognitive functioning (MMSE)	22.81 (4.33)	

Note. N = 216 participants. Baseline values were reported. Activities of Daily Living (ADL), Mini-Mental Status Examination (MMSE), and Brief Quality Life Instrument of the World Health Organization (WH-QoL-BREF) used in caregivers only. Quality of Life -Alzheimer's Disease (QOL-AD) used in partners with dementia only. Perceived Social Support Questionnaire (F-SozU-14). Perceived Stress Scale (distress subscale) (PSS). Geriatric Depression Scale (GDS). https://doi.org/10.1371/journal.pone.0189849.t001

The aspects of the theoretical SBM outline the stressors that can stem from the experience of being a caregiver. Figure 1 presents the SBM of relationships among stressors, resources, and outcomes for caregivers providing care and support to caregivers.

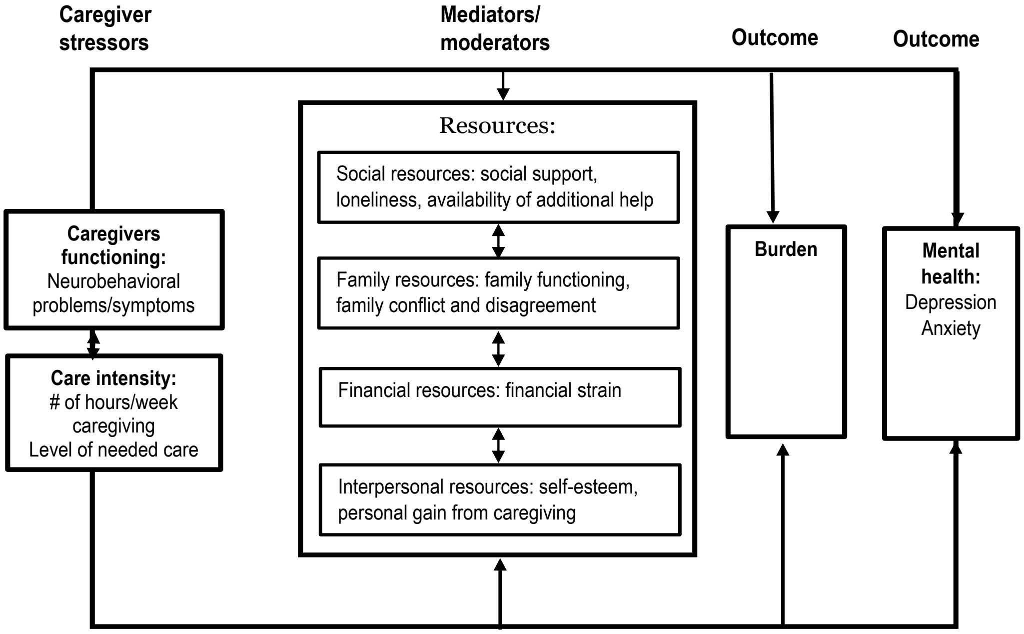

Figure 1. Theoretical model of stress buffering model.

Nature of the Study

This study was a quantitative correlational design that utilized secondary data. A quantitative research design was appropriate for this study because quantitative studies focus on determining the distinct relationship between research variables (McCusker & Gunaydin, 2015). Using the quantitative approach will allow for analysis of statistical data that is centered on the relationship of variables specific to the research topic. A quantitative design may facilitate exploration of the casual relationship between the research variables (Bettany-Saltikov & Whittaker, 2014).

Literature Review

This section presents a review of past research on burden and coping strategies in caregivers of persons with AD. The different subtopics include: the literature search strategy, the role of the administrator, demands of AD caregivers, health problems among AD caregivers, racial comparisons of caregiver burden among informal caregivers, and social support for the AD caregivers. The last section summarizes the literature review and outlines the research gap.

Literature Search Strategy

I retrieved the reviewed articles from different academic databases including EBSCohost, ProQuest, Google Scholar, ResearchGate, Science Direct, MEDLINE, BMJ Clinical Evidence, Health Source, PsycINFO and Cochrane Library. Keywords were used to query the databases to retrieve the relevant articles. The keywords included *caregiving burden among caregivers of AD patients, challenges experienced by AD caregivers, depression among AD caregivers, anxiety among AD caregivers,* and *racial disparities in caregiving burden.*

Table 2.

Literature Search Strategy

Data source	Boolean phrase	Number of references returned	Number of references used in study
EBSCohost	Caregiving burden among caregivers of AD patients	50	10
Google Scholar	Challenges experienced by AD caregivers/ depression among AD caregivers	42 million	30
Science Direct	Caregiver burden	100	10

Literature Review Related to Key Variables and/or Concepts

Ethics and law. Healthcare administrators are required by law and ethical principles guiding healthcare practice to ensure provision of quality services (Flite & Harman, 2013). Administrators are guided by core ethical principles including providing service to others, provision of quality services, improvement of healthcare, and promoting interdisciplinary cooperation and collaboration (Flite & Harman, 2013).

Leadership. The leadership offered by healthcare administrators in hospitals has a significant influence on important metrices such as quality, safety, and patient satisfaction (Parand, Dopson, Renz & Vincent, 2014). Healthcare administrators can adopt a serving leadership model guided by the need to assist formal and informal caregivers to succeed in their roles (Parand et al., 2014). Leaders can spearhead proactive caregiver wellness programs or strategies such as providing caregivers with access to counseling programs, health programs, or other resources that will assist caregivers to maintain their health (Parand et al., 2014).

Demands of the Alzheimer's disease caregivers. AD and related dementias are increasingly becoming a worldwide concern (Edwards, 2014). Edwards (2014) posited that in 2013 approximately 44.35 million individuals suffered from dementia, and by 2050, it is expected the total will increase to 135.46 million. Most dementia patients are cared for by informal caregivers such as family members and friends (Hong & Harrington, 2016). There is a growing demand for caregivers due to the increase in the aging population (Yu et al., 2015). Families will experience an increasing demand to provide care to their members who suffer from AD and other dementias. A rapidly aging population will put pressure on families to provide care for more AD patients (Edwards, 2014; Perlick et al., 2016; Wennberg, Dye, Streetman-Loy,

& Pham, 2015). Informal caregivers have always served significant roles in society (Elmore, 2014). Currently, informal caregivers are an important element of health and long-term care for the aged and physically challenged persons and for those suffering from chronic illnesses (Elmore, 2014).

Ribeiro, Rezende Sa, and Machado (2016) indicated that caregivers experienced challenges in delegating their role to third parties due to the social perception that family care is ideal whereas institutionalizing AD patients means abandonment. In most cases, institutionalization is viewed as a last resort, and the decision involves reflection and consultation. In some instances, family caregivers prefer to take turns in taking care of their sick members rather than institutionalizing them. Institutionalization is commonly done when the disease progresses, placing unbearable demands on the caregivers (Lenox-Smith, Reed, Lebrec, Belger, & Jones, 2016).

Chronic neurological conditions including Alzheimer’s are associated with unpredictable courses and durations (Sullivan & Miller, 2015). As Alzheimer’s progresses, it has significant effects on the patients’ physical, emotional, and cognitive well-being, creating the need for family members or healthcare professionals to provide care to the patients (Sullivan & Miller, 2015). In the family context, the partner/spouse or child commonly performs the care-giving role. The family members adopt multiple responsibilities including financial and household responsibilities in the course and duration of the chronic neurological disease (Sullivan & Miller, 2015). According to Edwards (2014), caregivers assist the patients’ daily living such as cooking, eating, bathing, dressing, toileting, and taking medications, in addition to managing their homes. Edwards (2014) indicated that most caregivers (66%) are female and 65% of the dementia patients are women. Additionally, the typical care giving duties take approximately 20 hours of a caregiver’s time weekly (Edwards, 2014). Caregivers play a significant role in providing patient-centered care to AD patients (Edwards, 2014). Caregivers not only provide information but also facilitate communication with their patients and provide emotional support (Liang et al., 2018).

Caregiver burden. While caregiving can bring families together, it places a significant demand and burden on the caregivers who have minimal time for their own physical, emotional, and cognitive needs (Chakrabarti, 2013; Marimbe, Cowan, Kajawu, Muchirahondo, & Lund, 2016). Caregivers become minimally devoted to their personal needs and those of their children or homes (Chakrabarti, 2013; Marimbe et al., 2016). Notably, caregiving tests the caregiver’s endurance and coping mechanisms (Sullivan & Miller, 2015). Caregivers experience different physical and psychological symptoms that have been conceptualized as caregiver burden (Bastawrous, 2013). There is no single definition of the concept of caregiver burden; however, some researchers use caregiver burden to refer to the psychological dysfunction that arises from the caregiving role such as anxiety and depression (Bastawrous, 2013). Others associated the concept with the tangible aspects of care (Bastawrous, 2013). Sultan, Fatima, Kanwal, and Khurram (2017), defined caregiver burden as the negative feeling and strain arising from caring for chronically ill persons. Sultan et al. (2017) also associated the concept with the emotional distress arising from the effects of caregiving on the caregivers’ psychological, social, and physical health. Therefore, caregiver burden can focus on any of these aspects.

Caregiver burden is classified into a subjective and objective burden. Subjective burden refers to the emotional or psychological stress that arises from the caregiving role whereas objective burden is the physical or instrumental provision of care to patients (Bastawrous, 2013). Janse, Huijsman, Kuyper, and Fabbricotti (2014), emphasized that caregivers experience objective burden that is due to the continuously changing challenges as well as the chronic nature of diseases that affect the elderly, such as dementia and AD. Consequently, caregivers must invest a lot of time and energy to perform increasingly intensive care tasks over a long period of time. Janse et al. (2014) emphasized that caregivers put aside their own needs due to time restrictions. Notably, they lack time for their personal leisure activities such as socializing with friends and fulfilling familial responsibilities. In some instances, the caregivers have no alternative but to minimize their working hours, rearrange their work schedules, or take unpaid leave to care for their patients. Consequently, the role affects the caregivers' financial situations (Janse et al., 2014). The magnitude of the challenges experienced by the caregivers increased their subjective burden. Janse et al. (2014) defined subjective burden as the caregivers' perceptions of the effects of objective burden. Most caregivers perceive a decline in their physical, social, and psychological performance due to subjective burden. Caregiver burden further affects caregiver well-being and health. Janse et al. (2014) conducted a quasi-experimental design to determine the effects of an integrated care model on objective and subjective burden as well as the quality of life of informal caregivers; the results indicated that the interventions significantly reduced subjective burden among the caregivers.

Several studies have been conducted to evaluate caregiver burden among those caring for AD patients. Kahn, Wishart, Randolph, and Santulli (2016) focused on caregiver stigma and burden among caregivers of patients suffering from memory disorders. Specifically, the researchers focused on the impacts of caregiver burden based on caregiver type and gender.

Kahn et al. (2016) aimed to establish differences in the burden among spousal and adult child caregivers of dementia patients. The quantitative study was conducted among 82 caregivers who completed the Zarit Burden Inventory-Short Form as well as the Caregiver Section of the Family Stigma in Alzheimer's Disease Scale. Kahn et al. (2016) indicated that female caregivers experience more burden (t [80] = −2.68, p = .009) compared with their male counterparts. Similarly, adult child caregivers reported higher levels of burden compared with spousal caregivers (t [80] = −2.65, p = .010). Kahn et al. (2016) emphasized the importance of supporting female and adult child caregivers in order to alleviate their suffering.

Huang et al. (2013) investigated caregiver burden among dementia patients. The quantitative, cross-sectional study was conducted among 57 caregivers who completed the Revised Memory and Behavior Problems Checklist. Their patients experienced behavioral and memory problems as well as depression, which led to caregiver burden. Caregivers indicated that the patients demonstrated disruptive behavior. Further, researchers indicated that caregiver burden was greater when the caregivers adopted avoidance coping strategies (Huang et al., 2013). Avoidance coping is a maladaptive form of coping that entails a person changing behavior to avoid thinking or feeling things that are uncomfortable rather than confronting them.

Sultan et al. (2017) conducted a study among 312 caregivers to determine their coping strategies and indicated that female caregivers adopt emotion focused strategies whereas male caregivers use problem-focused strategies. Emotion-focused strategies include distancing, self-control, escape avoidance, and positive reappraisal. Problem-focused strategies include confrontive coping, accepting responsibility, constructive problem solving, and seeking social support.

Hall et al. (2014) focused on the factors associated with high levels of caregiver burden among caregivers of AD. The researchers emphasized that most of the caregivers reported great levels of stress and emotional burden. Researchers argued that some of the caregivers’ stress stems from the patients’ decreased functional independence and behavioral disturbances. The quantitative study by Hall et al. (2014) was conducted among 100 caregivers. Data were collected using the Caregiver Burden Scale (CBS). The researchers hypothesized that greater caregiver burden correlated with severe cognitive impairment, minimal independent functioning, and many behavioral disturbances among patients. They found a statistically significant relationship between high CBS scores and severity of diagnosis (mean>25, p =. 002). Furthermore, the findings established a significant correlation between high CBS scores and the patients’ inability to perform basic self-care tasks independently. These tasks included shopping (p-.006), cleaning (p=. 001), driving (p=. 041), cooking (p=. 008), finances (p=. 022) and taking medication (p=. 001). According to the study findings, there was no relationship between CBS scores and the patients’ ability to use the telephone (p=. 161). Additionally, the study established a strong correlation between CBS scores and behavioral challenges such as appetite (p<. 001), depression (p=. 001), agitation (p=. 001), and irritability (p=. 001). CBS scores were further correlated with anxiety (p=. 011), hallucinations (p=. 021), dis-inhibition (p=0.11), nighttime disturbances (p=. 022), delusions (p=. 025), and apathy (p=. 024). The researchers did not establish a significant correlation between caregiver burden and behavioral disturbances such as elation and motor disturbance (p>.10). However, the study had several limitations due to the small sample size and its homogeneous nature.

Lavarone et al. (2014) used a correlational, quantitative study to explore caregiver burden and coping strategies in caregivers of patients with AD. The study involved 86 caregivers who completed the Caregiver Burden Inventory (CBI) and the State-Trait Anxiety Inventory (STAI Y-1 and Y-2). The researchers assessed the coping tactics based on the Coping Inventory for Stressful Situations (CISS) and indicated that caregivers experienced high levels of caregiver burden, which increased with the severity of dementia. Higher CBI scores were noted among women and elderly caregivers. Furthermore, caregivers principally adopted task-focused coping strategies while female caregivers used emotion-focused strategies leading to higher levels of distress. The Caregiver Burden Inventory (CBI) measures the impact of social support on AD caregivers. CBI describes caregiver burden measures in five different domains: time-dependence, developmental, physical, social, and emotional burden. Time-dependence focuses on the time restrictions of caregivers as they lack time to participate in activities enjoyed by their peers due to their caregiving responsibilities. AD caregivers must forego social activities to take care of their patients. Notably, they also sacrifice opportunities and personal or professional goals to care for their patients. Physical burden focuses on feelings of chronic fatigue and physical health problems and social burden highlight the inability of caregivers to achieve a balance between their many roles. Emotional burden is characterized by negative feelings towards patients (Laing et al., 2018). The researchers emphasized the need to support caregivers through tailored strategies for improving their coping skills.

Chen, Huang et al. (2015) investigated the efficacy of an intervention involving different coping strategies for alleviating the burden shouldered by dementia patients’ caregivers. Chen et al. (2015) developed an intervention with the purpose of improving coping strategies for caregivers of elderly dementia patients. The quantitative, experimental study was conducted among 57 caregivers and data collection was achieved through the Revised Ways of Coping Checklist and the CBI. The experimental study included different interventions such as problem-solving skills, social resources, and knowledge of dementia, and included emotional support every two weeks while the control group was exposed to the normal clinical management. The experimental group experienced improvements in problem-focused coping and seeking social support. Additionally, the experimental group experienced less caregiver burden, thereby accentuating the importance of psychosocial interventions in helping caregivers to adopt problem-focused strategies as well as seeking social support with the goal of minimizing caregiver burden.

Health problems among AD caregivers. Caregiving has a significant impact on the caregivers' physical and mental health, and caregiving is founded on the mind-body connection, which has existed for centuries (Elmore, 2014). There is a connection between the biological, psychological, and social functioning in humans (Elmore, 2014). The biopsychosocial approach hypothesizes that human thoughts arise from the brain and changes in thoughts trigger changes in the brain and the body. The approach outlined that neurotransmitters, hormones, and cytokines act as the communication channel that is used by the nervous, endocrine, and immune systems (Elmore, 2014).

Caregivers experienced stress owing to their roles. Stress occurs as the body tries to respond to stressful live events. When faced with such events, people seek physiological stability, a process known as allostasis. However, the balance is attained at a cost as individuals experience metabolic wear and tear, otherwise known as allostatic loading. Persistent or excessive allostatic loading exposed people to diseases (Elmore, 2014). Notably, the high levels of stress experienced by caregivers expose them to diverse health problems. Anand, Dhikav, Sachdeva, and Mishra (2016) argue that stress significantly strains caregivers of AD patients significantly. Researchers conducted an experimental study among caregivers of patients diagnosed with AD (n=24) and Mild Cognitive Impairment (MCI) (n=7). The control group was comprised of caregivers of patients diagnosed with Osteoporosis (n=12), diabetes and hypertension (n=6), and psychiatric disorders such as anxiety, depression, and psychosomatic disorders (n=10). The study established the mean score for perceived stress as 23.29 ± 7.17 among the caregivers for AD and MCI patients. The mean perceived stress score among the control groups was 7.5 ± 3.12 indicating that the caregivers for AD and MCI patients experienced higher levels of perceived stress (Anand et al., 2016). Clearly, caregiving is a stressful role that predisposes the caregivers to negative mental health outcomes. Table 3 presents data from the study by Anand et al. (2016).

Table 3.

Stress Levels Among Caregivers

Type of caregiver	Mean perceived stress
AD & MCI caregivers	23.29 ± 7.17
Osteoporosis, diabetes and hypertension, psychiatric caregivers	7.5 ± 3.12

Depression among AD caregivers. Several studies have evaluated depression among caregivers of AD patients. Andreakou, Papadopoulos, Panagiotakos, and Niakas (2016) evaluated depressive symptomatology for the caretakers using the Zung Depression Rating Scale (ZDRS). Researchers established that the ZDRS scores for the caregivers were highest in the physical functioning (PF 80 ± 22, 5) and lowest in the emotional role (RE 44, 7 ± 44). The scores show that the caregivers experienced emotional problems due to high levels of stress. Samadi et al. (2015) focused on anxiety, depression, and spirituality among AD caregivers. Samadi and colleagues emphasized that caregivers are exposed to high levels of psychological distress that can lead to the development of psychological disorders. Samadi et al. (2015) argued that severe and long-term stress linked with the role predisposes the caregivers to subclinical or clinical anxiety as well as depression (Samadi et al., 2015). Samadi and colleagues conducted a correlational study among a purposive sample of 209 caregivers of AD patients. In the study, anxiety and depression were evaluated using the Hospital Anxiety-Depression scale, and the caregivers had a mean score of 7.1± 2.2 and 6.8± 2.3 for depression and anxiety, respectively. The total mean score for depression and anxiety was 13.9±3.2. In terms of prevalence, 45.4% of the caregivers exhibited either mild (36.4%) or severe depression (9%). Additionally, 47.3% of the caregivers expressed mild (45%) or severe anxiety (2.3%) (Samadi et al., 2015). The study’s findings are presented in Table 4 below.

Table 4.

Prevalence of Caregiver Outcomes

Caregiver Outcome	Prevalence	Total Mean Score
Mild depression	36.4%	
Severe Depression	9%	7.1± 2.2
Mild Anxiety	45%	
Severe Anxiety	2.3%	6.8± 2.3

Note: The study did not calculate the total mean score values for mild depression and mild anxiety, the study did not calculate them. The studies only presented mean scores for severe depression ads severe anxiety, as noted in Table 4.

AD caregiver anxiety. As indicated by Samadi et al. (2015), caregivers of AD patients experienced mild to clinical anxiety. In another study, Vespa et al. (2015) investigated whether there are differences in anxiety levels between caregivers of AD patients and non-caregivers. The experimental study was conducted among an intervention group of 60 caregivers and a control group of 104 subjects. A random sampling technique was used to select the participants. Quantitative data on anxiety and depression were collected using the IPAT-ASQ test and IPAT-CDQ tests. The tests are adopted to a self-report method for depression. T-tests were utilized to compare the intervention and the control groups. The caregivers had higher or medium-high levels of anxiety compared to the control group. Similarly, the caregivers were associated with higher levels of depression or serious depression. Vespa et al. (2015) associated the high levels of anxiety and depression with excessive involvement in providing care for AD patients that leads to stress, and the sense of uneasiness, as well as the state of depression.

Medrano, Rosario, Payano, and Capellan (2014) investigated burden, anxiety, and depression among AD caregivers in the Dominican Republic. The descriptive cross-sectional study was conducted among a non-probabilistic sample of 67 caregivers of AD patients. The Zarit scale was used to evaluate different aspects such as emotional impacts of caregiving and, social support, as well as problem management strategies. The researchers indicated that 36% of the caregivers experienced caregiver burden. The burden was higher among female caregivers (91%) among whom 17% reported intense burden (Medrano et al., 2014). The caregivers indicated that they worked long hours such as 13 and 16 hours a day, and the caregiving burden increased with age as the caregivers who were over 40 years recorded higher levels of burden. Nineteen percent of the caregivers experienced anxiety. Most of the caregivers who reported high levels of anxiety were female and worked between 13 and 16 hours daily. Almost half of the caregivers (43%) were affected by consistent depression (Medrano et al., 2014). The affected caregivers demonstrated mild (72%), moderate (10%), and severe (17%) depression. Female caregivers were still the most affected by depression. The study established that caregivers' anxiety is positively correlated with depression. Additionally, there is a positive relationship between caregiver burden and anxiety and between caregiver burden and depression (Medrano et al., 2014).

Dawood (2016) investigated caregiver burden and its impact on quality of life and risk of psychopathology among caregivers of dementia and AD patients. The cross-sectional study was conducted among a purposive sample of 60 caregivers. Caregiver burden was evaluated using the Zarit Burden Interview, and the quality of life was assessed through the World Health Organization Quality of Life Scale. Anxiety and depression subscales were used to evaluate the caregiver's vulnerability to psychopathology. Dawood indicated that caregiver burden is negatively correlated with the physical, psychological, social, and environmental aspects of quality of life. However, there is not a significant relationship among caregiver burden, quality of life, anxiety, and depression. Independently, caregiver burden and quality of life did not serve as predictors for anxiety among the caregivers (F (5, 52) =1.29, p=0.28). This was also the case in the depression subscale (F (5, 52) =0.15, p=0.98). Additionally, caregivers may have been adopting effective coping strategies, thereby minimizing the impact of caregiver burden on their psychological health. Dawood (2016) further argued that the findings could be explained by the nature of therapy provided to the patients.

AD impact on caregiver health. AD is associated with negative impacts on the caregivers' physical health. Researchers indicate that the risk of negative impacts on physical health increase over time with the increase in care demands. Caregiving tasks strain the caregivers' physical health, leading to direct and indirect physical health consequences such as elevated levels of stress hormones, failure of antibodies to respond to vaccination, and poor sleep quality (Elmore, 2014). According to Roth, Fredman, and Haley (2015), caregivers are more likely to report poorer physical health when compared with non-caregivers. Studies conducted among dementia caregivers associate caregivers with a higher inflammatory burden (Roth et al., 2015).

Williams, Wang, and Kitchen (2014) compared the effects of caregiving across caregivers involved in end-of-life care (n = 471), long-term care (n = 2722), and short-term care (n = 2381). The quantitative study associated caregiving with negative implications on the caregivers' health. The three groups of caregivers reported poor self-assessed health, though the end-of-life caregivers reported higher levels of poor health. Williams et al. (2014) noted that female caregivers had a higher likelihood of experiencing poor health compared with males. Caregiving has more impact on female caregivers. Sullivan and Miller (2015) argued that caregiving affects the caregivers' physical health because the caregivers neglect their health care needs. They also failed to participate in wellness activities that played a significant role in maintaining physical health.

Caputo, Pavalko, and Hardy (2016) explored the impacts of caregiving on women's health and mortality. Caputo et al. (2016) argued that studies that have investigated the impacts of caregiving on physical health had focused on elderly caregivers and established that caregiving can lead to physical health challenges such as cardiovascular disease and mobility limitations. Caputo et al. (2016) argued that these studies offered significant insights into the effects of caregiving on the caregivers' physical health. However, they cautioned that the elderly caregivers could be experiencing negative health effects owing to old age which is associated with a trajectory of declined health (Caputo et al., 2016).

Caputo et al. 2016 conducted their study using the National Longitudinal Survey of Mature women to understand how caregiver burden impacts the health of midlife caregivers. The quantitative study was conducted among stratified samples of caregivers with depressive symptoms (n=2705), functional limitations (n=2550), and mortality (n=3,267). Caregivers experienced functional limitations overtime. This is particularly the case among in-home caregivers who experience more negative health effects compared with out-of-home caregivers (Caputo et al., 2016). In addition, that caregivers who operated within a home environment had a 33.2% mortality risk compared with a 20.7% mortality risk for those who cared outside the home. The researchers associated these findings with the fact that in-home caregiving is more stressful than out-of-home caregiving.

Racial comparisons of caregiver burden among informal caregivers. Branin and Juarez (2013) explored the variation of caregiving-related burden, skills and, self-efficacy between African American and Caucasian. To obtain the required data the participants were personally interviewed, and they exhibited variation in terms of caregiving burden between African American and Caucasian caregivers. The study also revealed that African American caregivers felt higher levels of burden than their Caucasian counterparts (Branin & Juarez, 2013).

Arévalo-Flechas, Acton, Escamilla, Bonner, and Lewis (2014) examined the psychosocial effect and perception among Latino caregivers and non-Hispanic (NH) white caregivers of patients with AD. Arévalo-Flechas et al. (2014) adopted a survey design utilizing Screen Caregiver burden, a symptom survey, perceived stress scale and Coping Resources inventory among others. A sample of 202 participants was used, including 53 Latino caregivers. The remainder of the participants (149) were non-Hispanic white caregivers for AD patients. Arévalo-Flechas et al. (2014) employed a convenience sample of caregivers. All the participants completed in-depth qualitative interviews that enabled them to share their experiences as caregivers or AD patients. The results of the Screen Caregiver Burden survey revealed that Latino caregivers had higher burden when compared with their non-Hispanic counterparts. Additionally, the Latino participants also reported higher levels of body pains as well as somatic signs. The caregivers indicated that they experienced serious stress that in turn may negatively influence their physical and emotional well-being in the long run.

Karlin, Weil, and Gould (2012) aimed at understanding the differences as well as similarities between Hispanic informal caregivers and non-Hispanic White informal caregivers of AD patients. In addition, the comparison took place among informal caregivers reporting higher levels of burden. The study included 34 participants equally distributed in the two racial groups and there were differences and similarities between Hispanic and non- Hispanic caregivers from various areas. The Hispanic caregivers indicated that they had minimal sources of income and low investment money for treatment of family members. Caregivers further indicated that caregiving tends to greatly interfere with their overall life accomplishments. Furthermore, Bekhet (2015), through a descriptive and cross-sectional study compared perceived burden among 45 Caucasian American and 28 African American caregivers. Karlin et al. (2012) assessed the burden level through a 22-item Zarit Burden Interview revealing that there is greater burden among Caucasian American caregivers when compared with African American counterparts. The wellbeing of caregivers is mainly determined by race and perceptions of the caregiving-related burden.

Wajnberg, Soones, Smith, Russell, Ross, and Federman, (2016) asserted that there is a limited number of studies exploring whether the burden associated with caregiving varies across racial groups. Wajnberg et al. (2016) explored the variation among these vulnerable groups. The caregiver burden was examined utilizing the Zarit Caregiver Burden Scale as well as the Center for Epidemiologic Studies-Depression Scale. The Zarit scale was provided to the informal caregivers and their individual responses were summed to give a score ranging from 0 to 88 with the higher score indicating higher levels of burden. A total of 49 informal caregivers completed the organized interview (Wajnberg et al., 2016). More than 60% of the informal caregivers had either severe or moderate burden while 30% had considerable depression. The sampled white caregivers indicated greater burden when compared with their Hispanic and black counterparts (Wajnberg et al., 2016).

Namkung, Greenberg, and Mailick (2017) investigated the impact of kinship relationship and race on caregivers' well-being. The researchers argued that race is among the significant structural factors that moderate the effect of caregiving burden on individuals. They also emphasized that there is a close link between race and cultural norms that determined expectations regarding caregiving. For example, African Americans and Hispanics have cultural traditions of providing care that may influence the extent to which caregivers experience burden. Namkung et al. (2017) indicated that the minority caregivers have a higher probability of having a stronger bond with members of their extended families compared with Whites. Studies have established that Whites are more affected by caregiving burden compared to African Americans. Specifically, available evidence revealed that African American and Hispanic caregivers record lower levels of caregiver burden and depression than Whites. However, caregiver burden has more significant impacts on the physical health of ethnic minority caregivers such as African Americans and Hispanics, who record poorer physical health outcomes compared with Whites (Namkung et al., 2017).

In the experimental study Namkung et al. (2017) showed that White caregivers had greater depressive symptoms compared with minority groups (mean=1.14, F=5.36, $p < .05$). White caregivers reported lower levels of life satisfaction compared with minority caregivers (mean=3.50, F=7.16, $p< .01$). Minority caregivers were associated with higher levels of perceived control compared with Whites (F=4.82, $p < .05$). Namkung et al. (2017) further affirmed that caregiving takes a greater toll on the physical health of minority caregivers compared with Whites. This was associated with lack of economic resources preventing the caregivers from using paid services to help in the caregiving role, as well as limiting the use of preventative medical care services for personal health needs (Namkung et al., 2017). Comparison of caregiver outcomes among Whites and minorities is presented in Table 5.

Table 5

Comparison of Caregiver Outcomes Among Whites and Minorities

Race	Level of depressive symptoms	Self-rated health	Life satisfaction	Perceived control
White	1.90	3.62	3.23	3.55

Social support for the AD caregiver. According to Yurtsever, Oage, Kara, Yandım, Kalav, and Yeşil (2013), the majority of the Alzheimer's patients are under the care of family members (caregivers) who are not well prepared. Caregivers require social support from healthcare professionals, friends, and neighbors so that they can cope with economic, social, psychological, and physical challenges. Yurtsever et al. (2013) carried out a cross-sectional study with an aim to assess the link between care burden and social support for caregivers of Alzheimer patients. The study was comprised of 107 caregivers. The researchers indicated that there is a positive correlation between social support and caregiver burden. Caregivers need to be taught how to manage stress that is caused by looking after patients, and caregivers that receive professional support appeared to have physical health, ideal quality of life and less care burden (Yurtsever, 2013).

Heo (2014) focused on the link between social support, religious coping, and positive factors of caregiving, burden, and depression among caregivers. The researchers, using data from Resource for Enhancing Alzheimer's Caregiver Health (REACH) showed that social support was negatively linked to depression and burden. In contrast, positive religious coping was linked to positive effects on caregivers. Heo (2014) also suggested that maintaining religious coping plays a significant role in promoting social support and enhancing positive aspects of the caregivers.

Kelley, Lewis, and Southwell (2017) postulated that many of the social support studies have examined support from an individual perspective and fail to focus on a broader context of support as perceived by caregivers. Social support is a valuable resource as it enables caregivers to cope with the burden of caring for AD patients. Kelley et al. (2017) examined how caregivers perceived that interpersonal as well as organizational social support impacts care-recipient health. Social support was associated with caregiver confidence and care-recipient health. In their study, Hornillos and Crespo (2012) indicated that support groups for caregivers are normally used as interventions by institutions as well as associations. The intent of the study was to review the use of support groups for caregivers of Alzheimer patients, and it was indicated that caregivers can access assistance to tackle challenges associated with caregiving experience.

According to Berwig et al. (2017), individuals caring for individuals with dementia require a considerable amount of time as well as commitment emphasizing the importance of offering them support. On-site support groups positively impact on caregiver well-being (Berwig et al., 2017). However, there are cases where caregivers have no time to attend support groups or there are no social groups nearby. Berwig et al. (2017) suggested a telephone-based support group within Germany to close this gap. They conducted a randomized control trial with 88 participants and revealed that telephone-based support is an effective intervention among caregivers.

Taati, Bahramnezhad, Seyedfatemi, Sharifi, and Navab (2016) examined the impact of support groups on anxiety, depression, and stress level among caregivers of patients suffering from Alzheimer's. Taati et al. (2016) carried out a single-blind randomized clinical controlled trial. The study involved 80 family caregivers of individuals with Alzheimer's (each group had 40 participants). They indicated that taking part in support groups had no impact on depression, stress, and anxiety among caregivers. Furthermore, Dam, van Boxtel, Rozendaal, Verhey, and de Vugt (2017) indicated that online social media support interventions present a fresh opportunity to enhance accessibility to social support and interactions within care networks. As a result, Dam et al. (2017) focused on the development of an online social support and carried out a feasibility study of the intervention together with its effectiveness. Dam et al. (2017) were guided by the Medical Research Council framework. The program focused on group sessions with web designers and experts and involved individual caregivers through interviews. In addition, a pilot study was conducted with 25 informal caregivers to examine the feasibility of the support program. The researchers reported that the program recorded a good feasibility score of 7.1 out of 10.

Chiatti et al. (2015) conducted a randomized clinical trial involving AD patients and their separate principal caregivers. Four hundred and fifty (450) patient-caregiver dyads were randomized into three groups that received varying combinations of support, case management, nurse visits and educational brochures. The researchers linked social support with reduced care burden among caregivers. Similarly, Chiatti et al. (2015) discovered that social support has a positive impact on the burden of caregivers of Alzheimer patients. Social support interventions focused on supporting caregivers of AD patients can result in considerable improvement in both their mental and physical health through reduction of stress and burden.

Dam, de Vugt, van Boxtel, and Verhey (2017) argued that the use of social media can facilitate support for dementia caregivers. Dam et al. (2017) developed a social support tool known as “Inlife”. A randomized control trial was conducted with 122 caregivers of AD patients. The caregivers were assigned to a social support group or a control group. The researchers offered significant insights in terms of effectiveness as well as usability of the Inlife intervention. Similarly, Kiral, Yetim, Özge, and Aydin (2017) established that there is a positive relationship between social support and reduced depression among caregivers. Social support can play a considerable role in the alleviation of depression. The researchers concluded that social support can be helpful in the long run in alleviating depression in caregivers of patients with Alzheimer’s

Vandepitte et al. (2016) conducted a systematic review with intent to assess the effectiveness of varying supportive strategies on the well-being of caregivers. They revealed that psycho-educational support results in positive outcomes for caregivers indicating that cognitive behavioral therapy minimizes dysfunctional thoughts in caregivers. Vandepitte et al. (2016)

concluded that supporting caregivers is an effective means of enhancing the caregivers' well-being. Boots, Vugt, Knippenberg, Kempen, and Verhey (2014) examined the effectiveness of Internet-based support interventions for caregivers of AD patients. To achieve this, Boots et al. (2014) conducted a systematic review of the existing literature. A total of 12 studies published by the year 2013 were identified. Boots et al. (2014) examined the quality of these studies in accordance with the Cochrane evidence level as well as Cochrane Back Review Group and indicated that Internet-based social support among caregivers can enhance numerous aspects related to their well-being. This kind of social support can reduce depression and enhance the confidence of the caregivers.

The Fisher Center for Alzheimer's Research Foundation (2018) is an organization with a specific mission related to AD that focuses on projects for supporting caregivers for Alzheimer's patients across the United States. The Center is developing a caregiver-training program that seeks to empower caregivers with coping skills. While searching for the cause and developing a cure for AD, the Fisher Center provides financing for projects that help the families and caregivers of Alzheimer's patients in the United States. Identification of effective interventions is needed to assist caregivers with the burden of coping with the patient's behavioral problems such as anxieties and aggressiveness is needed (Fisher, 2018).

The National Alliance for Caregiving (NAC) aims to provide important societal and financial contributions to maintain the quality of care and well-being of the AD patients. In addition, NAC provides technical assistance to a national network of caregiving coalitions representing nearly 30 states and localities in the US (National Alliance for Caregiving in the U.S., 2009).

Definition of Terms

Caregiving: Attending to another individual's health needs (Alzheimer's Association, 2016).

Caregiving activities/activities of daily living: Medication administration, feeding, dressing, bathing, and meal preparation.

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 depression: Caregiving leading to feelings of stress, guilt, anger, sadness, isolation, and depression. Caregivers may experience depression soon after the family member's diagnosis of AD. Caregivers can also experience depression as the AD progresses and the family member's cognitive abilities decline (Alzheimer's Association, 2016).

Assumptions

The assumption is that data has been validated by using the 2017 NYSDOH/BRFSS that participants responses to the survey questions were truthful and honest in their answers concerning the variables used in this study, and that dependent and independent variables were contained in the secondary dataset that was identified for this study. The second assumption is that AD caregivers are vulnerable to caregiver burden arising from day-to- day daily care demands, and they experience deterioration in their ability to perform activities of daily living as the AD progresses. The final assumption is that not all Alzheimer caregivers have experienced negative consequences as a result of their caregiving.

Scope and Delimitations

The scope of this study was based on the 2017 NYSDOH/BRFSS data. The NYSDOH/BRFSS data examined different variables that could influence caregiver burden and was limited due to the use of secondary data from existing databases. The data set was dependent on the researchers who collected the primary data. Thus, only variables available in the dataset were analyzed. Insights from this study should assist administrators and healthcare leaders of organizations and policy makers to create a sustainable solution to alleviate the caregiver's burden, reduce caregiver stress and, improve the caregiver's quality of life.

Significance of the Study

The study may provide information to close a gap in the literature regarding the variables that AD patient caregivers consider an influence on coping capabilities and well-being. The study may advance professional practice by informing administrators and health care policy makers regarding necessary support services for AD caregivers, which may enhance the mental and physical health of the caregiver and quality of care for the patient. Anderson, Goodman, Holtzman, Posner, and Northridge (2012) posited that the available literature indicates that 20% of the American population will be aged 65 years or older by 2025. This population will have a significant impact on public health in the United States, with the key problem of helping them stay healthy and maintaining a high quality of life. Public health professionals were required to find innovative approaches for addressing the lack of healthcare professionals trained in aging and aiding in managing the demands placed on formal and informal caregivers. The study is relevant to the current national health resources that influence caregivers' health. New York's uninsured rate is 8%. The study may contribute toward the attainment of Healthy People 2020 goals by creating health equity for AD caregivers through the creation of opportunities for social inclusion, as well as increasing access whereas the rate of uninsured in individual countries ranges from 5% to 13%. The uninsured rate among racial groups in New York ranges from 5% to 15% (County Health Rankings report, 2018). Notably, some of the AD patients lack access to health insurance meaning that they can only rely on informal caregivers. According to the Community Need Index, the poverty rates among racial groups in New York are Whites (9%), Blacks (26%), Hispanics (24%), and others (14%). The average poverty rate is 15%. AD caregivers may have poverty-level incomes, thereby creating the need for supporting them to cope with the caregiver's burden.

Healthy People 2020's framework focuses on prioritizing health issues. In 2007-2009, 34.8% of adults aged 65 and older were diagnosed with AD. Healthy People 2020 specific objectives and goals include increasing the number of adults aged 65 and above with dementia who are aware of the diagnosis and reducing preventable hospitalization (Healthy People 2020, 2017). AD is a leading cause of disability in the United States. As the AD worsens, individuals will require additional medical and support services, and may require long-term care. Healthy People 2020 posited that these challenges can extract an emotional, physical, and financial toll on family, caregivers, and society (U.S. Department of Health & Human Services, 2010).

Significance to Social Change

The burden of AD/dementia will increase as the aging population increases. By 2050 it is estimated there will be 115 million individuals with AD/dementia (Suzman & Beard, 2015). According to Yenilmez (2015) the United States aging population has affected all aspects of our society to include health, social security, education, socio-cultural activities, and family life.

Approximately 25% of US adults aged 18 years and older have reported providing care or assistance to persons with AD. Caregivers are at an increased risk for negative health consequences, including stress, depression, and the increased need for resource services to preserve their own well-being (Anderson, Edwards, Pearson, Talley, McGuire & Anderson, 2013). According to Alzheimer's disease Facts and Figures (2019) the costs of healthcare and long-term care for AD/dementia individuals are substantial. AD is one of the costliest conditions in our society. According to Bond-Nelms of AARP, AD/dementia continues to escalate, and further financial stress will be placed on health care programs. Trends will continue to increase the need for caregivers nationwide. In 2019, AD/dementia will cost the nation $290 billion including $ 195 billion in Medicare and Medicaid payments.

Evidence from this research may create positive changes by informing administrators, healthcare professionals, and hospital leaders regarding the importance of providing resources to AD caregivers that could shed light on support services. Health administrators can guide health policy and programs that provide resources to address caregiver burden. Administrators and health care providers may be able to use the results to developing community-based responses to address family challenges in the home. Administrators and health care providers can become advocates for AD caregivers resulting in a change in attitudes towards those family members and in social support to manage AD persons with advancing AD at home. Results from this study may help to educate caregivers about where to access the help and support they need to provide quality of care. Awareness and new knowledge from this study may help caregivers find solutions that will allow for better care of their health while caring for the individual with AD. This study also helps to bring social change by informing administrators, health care professionals, and hospital leaders about providing resources to AD caregivers about the use of support services.

Summary

The demand for informal or family caregivers has increased significantly due to the growth in the number of elderly persons or those who suffer from chronic diseases (Edwards, 2014; Elmore, 2014). Dementia disorders such as AD are among the chronic conditions that have led to the increase in the demand for caregivers. Caregivers assist their patients to perform basic tasks such as eating, bathing, and taking medications (Edwards, 2014). Caregiving has an impact on the caregivers', physical, emotional, and cognitive well-being known as caregiver burden (Bastawrous, 2013). In addition, the caregiving role has an impact on the caregivers' finances. Researchers have indicated that caregiving leads to anxiety and depression among caregivers. The role affects the caregivers' physical health. However, the impact of caregiving is moderated by race, as Caucasians experience greater levels of depression due to caregiving while minority caregivers such as African Americans and Latinos exhibit greater effects on physical health (Namkung et al., 2017). As reported in the available literature, female caregivers experience greater effects of caregiver burden.

Caregivers require support services to cope with the demands of their roles (Namkung et al., 2017). Support moderates the impact of the burden on caregivers and professional support improved the caregivers' quality of life and physical health (Dam et al., 2017; Vandepitte et al., 2016; Yurtsever et al., 2013). Conversely, caregivers from African American and Latino groups rarely use the available support services. This study seeks to explore the effect of support services on the coping capabilities among caregivers of AD patients. The study also investigated the effect of such services on the caregivers’ health and well-being. The next section presents the research procedures that will be used in the study.

Conclusion

In this section, I presented an overview of literature that was associated with caregiver burden. The topics reviewed included the role of healthcare administrators in supporting AD caregivers, leadership, demands of the AD caregivers, caregiver burden, health problems among AD caregivers, Alzheimer disease impact on caregiver’s health, racial comparisons of caregiver burden among informal caregivers and social support for the AD caregiver. I justified the application of the SBM as the theoretical framework highlighting that social support reduces the impact of negative relationships (Gellert et al., 2018). The section concluded with a description of the study’s potential impact for positive social change. This study seeks to explore the effect of support services on the coping capabilities among caregivers of AD patients. The study will also investigate the effect of such services on the caregivers’ health and well-being. The next section presents the research procedures that was used in the study.

Section 2: Research and Data Collection

Introduction

The purpose of this study was to inform health care administrators in New York State who oversee AD programs about the variables that impact the health outcomes of AD caregivers. The number of new cases of AD in America is projected to increase by 15% between 2018 and 2025 (Alzheimer's Association Facts and Figures, 2019)

The dependent variable for this study was hours per week the AD caregiver spends caring for the AD/dementia family member and the independent variables were age, gender, and ethnicity of the caregiver; self-reported general health of the caregiver; and self-reported level of stress of the caregiver. Caregiver general health was measured by caregiver ability to obtain annual cholesterol check-up, annual flu shot, and annual doctor visits, and the ability to manage household tasks (e.g. shopping and paying bills.). In this study I sought to fill a gap in the literature regarding the relationship, if any, between caregiver burden, which may impact caregiver general health, and exacerbation of caregiver stress caused by a lack of use of support services for the caregiver (Kim et al., 2012).

This section provides an explanation of the research design and rationale, methodology, target population, and sample size. Power analysis determined sample size. Determining the sample size for this study assured an adequate analysis to detect statistical significance (see Cohen, 1977). The section also includes information on data analysis, validity, and ethical procedures.

Research Design and Rationale

The selection of a research design should be based on the nature of the research problem or issue being addressed, the researchers' personal experience, and the audiences for the study (Creswell, 2009). I used a quantitative correlational study to examine the relationship between the study's independent and dependent variables. I retrieved secondary data from the 2017 NYSDOH/BRFSS database. I analyzed data by using logistic regression. Results from this study may inform healthcare administrators and New York State Alzheimer disease policy makers regarding the health and stress burden on AD caregivers. The knowledge from this study may help change policy to improve the physical and mental health of both AD caregivers and AD patients.

Methodology

I analyzed the New York State 2017 BRFSS secondary data using logistic regression to examine the relationship, if any, among the variables. Logistic regression analysis aids in proving the existence of a linear relationship, if any, between the dependent variable and the independent variables. The dependent variable for this study was hours per week the AD caregiver spends caring for the AD/dementia family member, and the independent variables were age, gender, and ethnicity of the caregiver; self-reported general health of the caregiver; and self-reported level of stress of the caregiver. I used the NYSDOH 2017 BRFSS data to verify and validate the hypothesis that AD caregivers are vulnerable to caregiver burden arising from day-to-day daily care demands and that they experience deterioration in their ability to perform activities of daily living as the AD progresses. I measured caregiver general health by caregiver ability to obtain annual cholesterol check-up, annual flu shot, and annual doctor visits and the ability to manage household tasks, (e.g., shopping and paying bills). Gellert et al. (2018) emphasized the SBM of social support by pointing out that it reduces the impact of negative life experiences as well as reduces the impact of negative relationships. Gellert et al. posited that the stress-buffering framework can be applied to caregivers of individuals with Alzheimer/dementia.

Population

The Alzheimer's Association (2018) has estimated that 5.7 million Americans of all ages are living with Alzheimer disease dementia. There are an estimated 5.5 million people over the age of 65, and approximately 200,000 are under the age of 65 (Alzheimer's Association, 2018). BRFSS sample population for this study looked at individuals who were unpaid informal caregivers who provided regular care to a family member or friend with AD. The population of 95 caregivers was subdivided by caregiver age, gender, and race/ethnicity. The final size of this sample was 95 participants. The study year for this population was from January 2017, through December 2017, which was the most recent period published by the New York State BRFSS commission.

Sampling Design and Power Analysis

According to Creswell & Creswell (2018), power analysis is the probability of rejecting the hypothesis; they suggested that a standard power should be at least 80%, which refers to an 80% chance of finding results that are significant within the study population. For this study, 0.80 was used as the minimum acceptable level of power when estimating the sample size needed; the alpha level that was used for this analysis was $p < .05$ (Fraley & Vazire, 2014). The guidelines for power analysis for logistic regression (Lipsey & Wilson, 2001) and G* Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2013) were used to calculate the sample size is 71 cases for a small effect size (odd ratio = 1.50) and the minimum sample size is 81 cases for a large effect size (odds ratio = 4.30).

Data Collection and Management

Data collection is a critical first step in responding to caregiving as a public health issue and allows for appropriate intervention (Schulz & Eden, 2016). The data collection was in collaboration with the NYSDOH and BRFSS. I used the BRFSS data collection tool to generate variables in relation to the number of Alzheimer caregivers. Participants completed the BRFSS telephone survey questionnaire that included caregiver sociodemographic of age, gender, and relationship to the care-recipient from January 2017, to December 2017. The raw data that was collected was publicly available. I downloaded the raw data from the BRFSS database, cleaned it for the population of those who care for Alzheimer family members, and inputted it into the IBM SPSS v 2.0 (2013) software to be analyzed.

Operational Definitions of Variables

Table 6 represents the operational definitions of variables that I used in the data analysis. The variables that I used were caregiver age, gender, hours providing care, race/ethnicity, AD support services and caregiver stress, self-reported general health, management of personal time, household tasks, annual flu shot, and doctor visits. Nominal and dichotomous variables were categorized by either 0,1, or 2. The variables are in Table 6.

Table 6

Operational Definitions and Variables

Name	Measurement	Values of Variables
Caregiver Age	Interval	1. 55 and older 0. 18-54
Gender	Nominal	0. Male 1. Female
Hours providing care	Interval	0. 0-19 hours per week 1. 20 or more hours per week
Race/ethnicity	Nominal	0. White-non-Hispanic 1. White
AD Support Services	Nominal	0. No 1. Yes
Manage Personal Time	Nominal	0. No 1. Yes
Annual Cholesterol Check	Nominal	0. No 1. Yes
Household Tasks (shopping, paying bills)	Nominal	0. No 1. Yes
Annual flu Shot	Nominal	0. No 1. Yes
Self- Reported Days Mental Health Not Good	Ordinal	0 Days 1-13 Days 14 or more days

Data Analysis

I analyzed the data from the 2017 NYSDOH/BRFSS secondary dataset tool using IBM SPSS Statistics v. 22.0 (2013) statistical software. For nominal variables, frequencies were computed, and a logistic regression analysis technique was conducted to test each research question. For the auxiliary analysis, I applied descriptive statistics to all continuous variables. I generated a histogram with demographics and scatterplot to assess the normality for the linear regression analysis.

Data Cleaning

Prior to analyzing the research question, I performed data cleaning and data screening to ensure that the variables under study satisfied the appropriate statistical assumptions. The use of the code 9999 allowed for the given dataset for any errors and mistakes and verified and updated any missing data information in the dataset. Data cleaning is the process of detecting and correcting errors and inconsistencies in a data set to improve its quality (Van den Broeck, Cunningham, Eeckels & Herbst, 2005). Participants who did not have all the variable points filled in were not used. I conducted statistical Analysis using IBM SPSS Statistics v. 22.0 (2013) statistical software to analyze the sample size for the secondary data collected from the BRFSS public data set.

Research Questions

The following research questions were adopted for this study:

RQ1: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver?

$H_0$1: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

H_a1: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

RQ2: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed?

H_{02}: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

H_a2: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

RQ3: What is the relationship, if any, between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services?

H_0 :There is not a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

H_a3:There is a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

Analysis Techniques

For the three research questions, logistic regression analyses were used. The first and second research question will each have three independent variables and the third research question will have four independent variables. Logistic regression analysis was conducted to examine the extent to which changes in one variable are predictive of changes in the dependent variable (Lakhani & Sakatkar, 2016).

To interpret the results of the study the *p*-value for each analyses and regression coefficient was set at .05 (Howell, 2009, Rencher, 2002) to determine the significance of each hypothesis test and to examine if each regression coefficient was statistically significant. This allowed me to deduce that the results were not due to chance. Finally, in Section Three confidence intervals for each logistic regression coefficient were produced to determine that each coefficient was statistically different from zero.

Threats to Validity

A threat to validity refers to the occurrence of events that could alter the results of a study (Fraenkel, Wallen& Hyn (2012). Archival data was obtained for this study, and therefore comparing groups, selection history, maturation, test, instrumentation, and mortality threats does not apply to this study (Trochim, 2006a). *Internal* threat was limited to the availability and accessibility of recent data related to AD caregivers. Conclusions from this study may be generalized and applied to other contexts in the field of informal caregivers. Basic principles maybe misleading. Researcher bias may occur when there was deviation from truth in data collection, data analysis and interpretation causing false results of the study (Simundic, 2013). The validity of the finding was enhanced by being aware of the personal feelings of caregivers of AD patients. Caregivers who continuously care for AD patients may often experience considerable stress and risks for mental and physical health issues (Fernández-Calvo et al., 2016). As the AD progresses, providing care to a family member becomes progressively demanding, exposing the caregiver to increase emotional and physical demands that may negatively impact the health of the caregiver. I chose an appropriate research design that helped control other threats to internal validity. The uniqueness of the experience and decisions of the AD caregiver are aligned with the study questions. *External validity* provides the scope and method in which the results of an experiment can be generalized to different variables and tests (Candioti, DeZan, Ca’mara, & Goicoechea, 2014). To ensure the generalizability in this study, the sample was drawn from the specific population from the BRFSS secondary dataset thus, avoiding a potential threat to data retrieved. A significant question was whether the research findings are generalizable to larger populations and whether the findings may be applied to various social and political settings.

Ethical Procedures

Permissions

The 2017 NYSDOH/BRFSS is a public database therefore, there was no direct contact with participants in this study. Permission to obtain and use this data was provided by the NYSDOH, data released April 4, 2019 (see Appendix A). The issue of confidentiality and data storage was important to the conduct of research in that personal information may be exposed to the public, thereby, compromising participant information. As a researcher, the ethics of confidentiality and data security are important. To alleviate research bias, only data gathered from a public database was used for this study.

Treatment of Data

BRFSS is a public dataset that was used in this study without personal identifiers, to avoid ethical breach. To avoid any breaches, the standard procedure is to save data on an encrypted USB flash drive, stored in a safe deposit box, for five years, a requirement of Walden's Institutional Review Board (IRB) approval is required prior to the collection of archival data (Walden University, 2015).

Ethical Concerns

Ethical concerns in research are essential. Ethical standards prevent untruth or falsifying of data. Ethical behavior was of vital importance for collaborative work, encouraging an environment of trust, accountability, and mutual respect among researchers (Grady, 2010). The usage of secondary data was an ethical practice that maximized the value in previously collected data, reduced the burden on the part of the participant ensures replicability of study outcomes and had greater transparency of research methods and the reliability of research work (Grinyer, 2009). The secondary data collected for a research study was used to determine if a correlation existed between the dependent and independent variables.

Summary

Section 2 presented research procedures, populations, research design, sample size, sampling procedures, data collection of secondary data materials, and use of power analysis to determine sample size. This section identified software that was used for analyses, provided an explanation of data cleaning and screening procedures appropriate for this study, and described threats to external, internal and validity and any ethical concerns and agreements regarding ability to gain access to secondary data set, if appropriate. Section 3 will provide the interpretation of the results of the data, results, and findings, and summarize answers to research questions.

Section 3: Presentation of the Results and Finding

Introduction

The purpose of this quantitative correlational study was to inform health care administrators in New York State who oversee AD programs about the variables that impact the health outcomes of AD caregivers. I retrieved the sample of participants from the 2017 NYSDOH/BRFSS, a large national sample, and used logistic regression for the primary analysis for this research. The research questions for this study were:

RQ1: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver?

$H_0$1: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

H_a1: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

RQ2: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed?

$H_0$2: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

*H*a2: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

RQ3: What is the relationship, if any, between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services?

$H_0$3:There is not a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

*H*a3:There is a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

Data Collection of Secondary Data Set

I used the BRFSS for this study, which is a collaborative project between all the states in the United States, participating U.S. territories, and the CDC. The BRFSS is administered and supported by the CDC's Population Health Surveillance Branch under the Division of Population

Health at the National Center for Chronic Disease Prevention and Health Promotion. The BRFSS is a system of ongoing health-related telephone surveys designed to collect data on health-related risk behaviors, chronic health conditions, health care access, and use of preventive services.

The BRFSS was initiated in 1984 with 15 states collecting surveillance data on risk behaviors through monthly telephone interviews. During 2017, all 50 states including the District of Columbia, Guam, and Puerto Rico collected BRFSS. I customized the BRFSS raw data collection tool for NYS to collect pertinent information related to the doctoral study. The target population for this study was caregivers of family members with AD. The data collected for the variables were age, gender, ethnicity, hours worked, self-reported general health, annual cholesterol check, annual flu shot, and personal doctor visits. Data was produced from the NYSDOH/BRFSS in a Microsoft Xcel spreadsheet. The timeframe of the NYSDOH/BRFSS data was from January 2017, through December 2017. I analyzed the sample for frequency, standard deviation, average, percentage, mean, mode, sum, and differences in male and female caregivers. As a requirement and to comply with the ethics of this research, permission to proceed with the research was granted from the Walden Institutional Review Board (IRB). The IRB approval number for this study is 01-15-20-0354072. The analysis of data retrieved from the 2017 NYSDOH/BRFSS is presented in this section.

Assumptions

I used logistic regressions to assess which independent variables predicted hours per week the caregiver cares for the family member. I coded hours per week as a binary variable in which 0 represented 0 to 19 hours worked per week and 1 represented 20 or more hours per week. As a result, logistic regression was the appropriate statistical analysis because it permits the examination of the odds of membership in one of the two outcome groups (i.e., 0 to 19 hours, 20 or more hours). I examined the $\chi 2$ omnibus test of model coefficients to assess whether adding the independent variables significantly increased the ability to predict hours per week the caregiver cares for the family member. Additionally, I inspected the Nagelkerke R^2 to assess the percent of variance accounted for by the independent variables, and finally, I determined the predicted probabilities of an event occurring by the odds ratio. Before proceeding, I conducted preliminary analyses of the dataset to determine if the assumptions of logistic regression were met.

Next, I examined multicollinearity to ascertain if the independent variables were highly correlated with one another. I calculated a tolerance statistic using linear regression. Higher tolerance values represent lower levels of collinearity; preferably, values of .2 or higher are ideal (Menard, 2010). Finally, to confirm that substantial standard errors did not occur, I analyzed the ratio of cases to variables to ensure that there were not too few cases to the number of variables in the model. Too few cases could result in the model not converging. (Tabachnick & Fidell, 2013).

Participants

Participants in the data set included 95 caregivers. Using the software package G* Power, which is a statistical power analysis software, I conducted priori power analyses (see Farley & Vazire, 2014) and the minimum number of participants was equal to or greater than 95.

The majority of participants had an income of $75,000 or more (see Table 7). Most (66.3%) caregivers were female (see Table 8), and the largest age cohort of the participants was

65 years old or older (35.8%). Most identified as White only (78.9 %), 42.1% were employed for wages, and 51% had attained a four-year degree or higher. Finally, the majority (31.6%) of caregivers provided care for their mothers (see Table 7).

Table 7

Demographic Frequencies

Variables	Categories	*N*	%
Education			
	College 1 year to 3 years (Some college or technical school)	19	20
	College 4 years or more (College graduate)	48	50.5
	Grade 12 or GED (High school graduate)	24	25.3
	Grades 1 through 8 (Elementary)	2	2.1
	Grades 9 through 11 (Some high school)	1	1.1
	Refused	1	1.1
Employment			
	A homemaker	12	12.6
	A student	4	4.2
	Employed for wages	40	42.1
	Out of work for 1 year or more	1	1.1
	Retired	26	27.4
	Self-employed	8	8.4
	Unable to work	4	4.2
Income			
	Less than $10,000	3	3.2
	Less than $15,000 ($10,000 to less than $15,000)	2	2.1
	Less than $20,000 ($15,000 to less than $20,000)	3	3.2
	Less than $25,000 ($20,000 to less than $25,000)	9	9.5
	Less than $35,000 ($25,000 to less than $35,000)	6	6.3
	Less than $50,000 ($35,000 to less than $50,000)	7	7.4
	Less than $75,000 ($50,000 to less than $75,000)	11	11.6
	$75,000 or more	46	48.4
	Don't know/Not sure	5	5.3
	Refused	3	3.2
Providing Care For			
	Child	2	2.1
	Father	10	10.5
	Father-in-law	2	2.1
	Grandfather	3	3.2
	Grandmother	10	10.5
	Husband	14	14.7
	Mother	30	31.6
	Mother-in-law	8	8.4
	Other relative	5	5.3
	Sister or sister-in-law	5	5.3
	Unmarried partner	1	1.1
	Wife	5	5.3
Race			
	American Indian or Alaskan Native only, Non-Hispanic	1	1.1
	Black only, non-Hispanic	5	5.3
	Hispanic	11	11.6
	Multiracial, non-Hispanic	2	2.1
	White only, non-Hispanic	75	78.9
	Don't Know/Not Sure/Refused	1	1.1
Self-Reported Days Mental Health Not Good			
	0 Days	61	65.6
	1-13 Days	19	20.4
	14 or more days	13	14

Research Question 1: Results

RQ1: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver?

$H_0$1: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

H_a1: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the age, gender, and ethnicity of the caregiver.

I used a logistic regression to examine the relationship between the number of hours per week and (a) age, (b) gender, (c) and ethnicity of the caregiver. First, I examined the assumptions. The multicollinearity tolerance values for the independence values ranged from 0.96 to 0.99, which exceeded the preferred value of at least 0.2 or higher (Hosmer & Lemeshow, 2000). Next, inspection of the data (see Table 7) confirmed that the ratio of cases to variables was adequate. I conducted the Hosmer and Lemeshow (2000) Goodness-of-Fit test to test the null hypothesis that the data fit the specified model, $\chi 2(5) = 5.84$, $p = .322$, and the test was not statistically significant.

As a result, the null hypothesis was retained. In the next step, I examined the Omnibus Tests of Model Coefficients. The Omnibus Test measures how poorly the model predicts the decisions using chi-square tests by analyzing the -2 Log-Likelihood where lower values reflect improved ability to predict (Field, 2013). These tests are statistical tests that are designed to detect any of a broad range of departures from a specific null hypothesis (Salkind, 2010). By adding in the three independent variables, the -2 Log-Likelihood was reduced by 12.89 from an initial value of 119.99. The results suggest that the ability to predict hours per week the caregiver cares for the family member improved with the addition of the independent variables.

In predicting hours per week an AD caregiver spends caring for a family member with AD/dementia, the three independent variables explained 17.7% (Nagelkerke *R2*) of the variance for hours per week the caregiver cares for the family member and correctly classified 76.6% of the cases. Because there is a logistic regression, confidence values of ± 1 equal statistical significance at the .05 level. The only statistically significant variable in hours per week the caregiver cares for the family member was age, where those who were aged 55 or older had 5.22 (95% *CI*: 2.05 – 13.30) times higher odds of providing care of 20 hours or more per week, as compared with those who were 54 or younger. Therefore, a positive relationship exists between age and the dependent variable. As a result, for $H_0 1$, the null hypothesis was rejected, and the alternative hypothesis was accepted. Finally, the odd ratio of 5.22 indicated a large effect size as it exceeded the 4.30 large effect guideline. Age had a large effect on hours per week an AD caregiver spends caring for a family member with AD/dementia. The results are presented in Table 8.

Table 8:

Logistic Regression Analysis of Hours per Week the Caregiver Cares for the Family Member with OR, 95% CI, Wald and p *Values*

	N	%	OR	95% CI		Wald	*P*
Variables				Lower	Upper		
Males	32	33.7	1.00				
Females	63	66.3	1.08	0.40	2.94	0.03	0.869
White	75	78.9	1.00				
Non-White	20	21.1	1.11	0.34	3.59	0.03	0.860
18 - 54 years	61	64.2	1.00				
55 years or older	34	35.8	5.22	2.05	13.30	12.02	0.001

Note. (*N* = 91).

Research Question 2: Results

RQ2: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed?

$H_0$2: There is not a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

H_a2: There is a statistically significant relationship between number of hours per week an AD caregiver spends caring for a family member with AD/dementia and the self-reported general health of the caregiver as measured by annual cholesterol check, annual flu shot, and personal doctor visits, as needed.

Logistic regression was used to examine the relationship between the number of hours per week and (a) annual cholesterol check, (b) annual flu shot, (c) and personal doctor visits. Cholesterol Check and flu shot were coded as 0 for no and 1 for yes. Personal doctor visit(s) was coded as 0 for doctor's visit(s) more than one year and between two and five years and 1 for doctor's visit(s) within the last year. Listwise deletion was used to remove participants with missing data. As a result, personal doctor's visit(s) was eliminated due to the variable being a constant.

The multicollinearity tolerance values for the two predictor variables was .90. Next, inspection of the data (see Table 9), confirmed that the ratio of cases to variables was not adequate. To test the null hypothesis that the data fit the specified model, the Hosmer and Lemeshow (2000) Goodness-of-Fit test was conducted, $\chi2(1) = 0.121$, $p = .728$, and the test was statistically significant. As a result, the null hypothesis was retained.

In the next step, the Omnibus Tests of Model Coefficients was examined. By adding in the two independent variables, the -2 Log-Likelihood was reduced by 0.265 from an initial value of 46.66. The results suggest that the ability to predict hours per week the caregiver cares for the family member only slightly improved with the addition of the independent variables. The two independent variables explained .01% (Nagelkerke *R2*) of the variance for hours per week the caregiver cares for the family member and correctly classified 55.9% of the cases. Neither annual flu shot, or cholesterol check significantly predicted hours per week worked. As a result, because there is not a statistically significant relationship, I failed to reject the null hypothesis. The results are presented in Table 9.

Table 9

Logistic Regression Analysis of Hours per Week the Caregiver Cares for the Family Member with OR, 95% CI, Wald and p *Values*

	N	%	OR	95% CI		Wald	*p*
Variables				Lower	Upper		
Flu shot (No)	8	8.4	1.00				
Flu shot (Yes)	26	27.4	0.75	0.14	4.16	0.11	0.746
Cholesterol check (No)	7	7.4	1.00				
Cholesterol check (Yes)	88	92.6	0.69	0.05	9.58	0.08	0.784

Note. (*N*= 95).

Research Question 3 Results

RQ3: What is the relationship, if any, between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services?

$H_0$3: There is not a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

H_a3:There is a statistically significant relationship between number of hours per week the AD caregiver spends caring for a family member with AD/dementia and the ability of the caregiver to manage personal time, perform household tasks such as shopping and paying bills, and use AD support services.

A logistic regression was used to examine the relationship between the number of hours per week the caregiver care for the family member and (a) management of personal time, (b) performing household tasks, (c) and utilizing of AD support services (e.g., counseling, support groups). Managing personal time and performing household tasks were coded as 0 for no and 1 for yes. The utilization of support services was coded 0 for no and 1 for yes. The multicollinearity tolerance values for the three-predictor variables ranged from 0.88 to 93. Next, upon inspection of the data (see Table 10), the ratio of cases to variables was adequate. The Hosmer and Lemeshow (2000) Goodness-of-Fit test results, $\chi 2(4) = 0.211$, $p = .995$, indicate the data fits the specified model.

The Omnibus Tests of Model Coefficients was examined in the next step. By adding in the three independent variables, the -2 Log-Likelihood was reduced by 27.432 from an initial value of 117.73. This suggests that the ability to predict hours per week the caregiver cares for the family member improved with the addition of the independent variables.

The three independent variables explained .35% (Nagelkerke *R2*) of the variance for hours per week the caregiver cares for the family member and correctly classified 70.2% of the cases. Neither utilization of support services, managing caregiver's personal time nor performing household tasks for the family member which produced a substantial standard error, predicting hours per week the caregiver cares for the family member. Managing personal time of the family member was the only statistically significant variable in predicting hours per week the caregiver cares for the family member. It is important to note that there was a very low response for caregiver's personal time so it can be assumed that caregivers had less time to for personal time. A test was performed for personal time of the caregiver. Those who managed the personal time of their family member with AD/dementia had 7.87 (95% *CI*: 2.08 – 29.79) times higher odds of providing care of 20 hours or more per week, compared with those who did not manage personal time. Therefore, there was a positive relationship between managing personal time of the family member and the dependent variable. In other words, caregivers who managed the personal time provided more hours in care than those who did not. As a result, for $H_0 1$, the null hypothesis was rejected, and the alternative hypothesis was accepted. The results are presented in Table 10.

Table 10

Logistic Regression Analysis of Hours per Week the Caregiver Cares for the Family Member With OR, 95% CI, Wald and p *Values*

	N	%	OR	95% CI		Wald	*P*
Variables				Lower	Upper		
Support services (No)	68	71.6	1.00				
Support services (Yes)	26	27.4	1.35	0.47	3.83	0.31	0.578
Perform household tasks (No)	16	16.8	1.00				
Perform household tasks (Yes)	79	83.2	480621246.42	0.00	0.00	0.00	0.998
Manage personal care (No)	39	41.1	1.00				
Manage personal care (Yes)	56	58.9	7.87	2.08	29.79	9.22	0.002

Note. (*N* = 95).

Auxiliary Analysis

For RQ3, managing caregiver's personal time was removed due to the responses were low. An additional analysis test was performed to look at caregiver's self-reported physical health, mental health, and the caregiver's ability to exercise. An additional RQ4 was created to include the additional variables.

RQ4: What is the relationship, if any, between the number of hours per week an AD caregiver spends caring for a family member with AD/dementia and self-reported general health, self-reported mental health, and self-reported exercise of the caregiver?

A multiple linear regression was used to examine the self-reported general health *(M* = 3.46, *SD* = 1.13) as measured on a six-point Likert scale from ‘poor’ to ‘excellent’ could be predicted by number of hours per week an AD caregiver spends caring for a family member (e.g., 0-19 hours, 20 or more hours), the number of days self-reported mental health not being good (i.e., 0 days, 1-13 days, 14 or more days), and exercise activity (*M* =1.67, *SD* = 1.13) as measured on a six-point Likert scale from ‘insufficiently active’ to ‘highly active’. The data met linearity and homoscedasticity assumptions as exhibited in the studentized residuals versus unstandardized predicted values plot as presented in Figure 2.

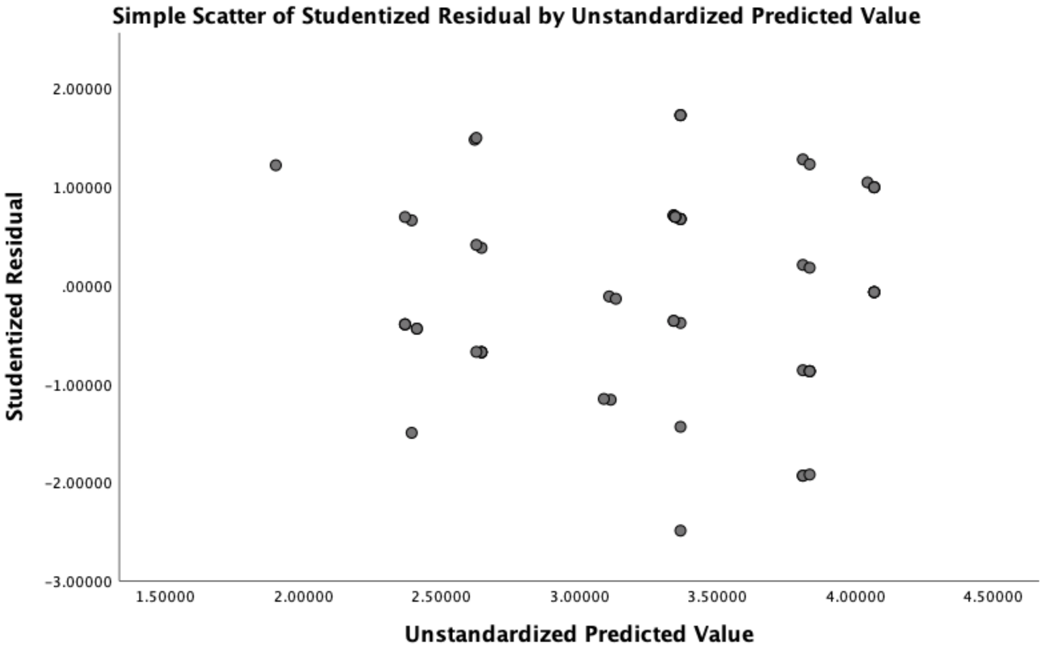

Figure 2. Scatterplot assessing linearity between independent variables and self-reported general health.

Additionally, there was independence of residuals, as assessed by Durbin-Watson statistic of 1.06 and the model exhibited no multicollinearity, as evaluated by tolerance values greater than 0.1 for all the predictor variables. Also, the analysis showed that no leverage values than 0.2, and values for Cook's distance above 1.

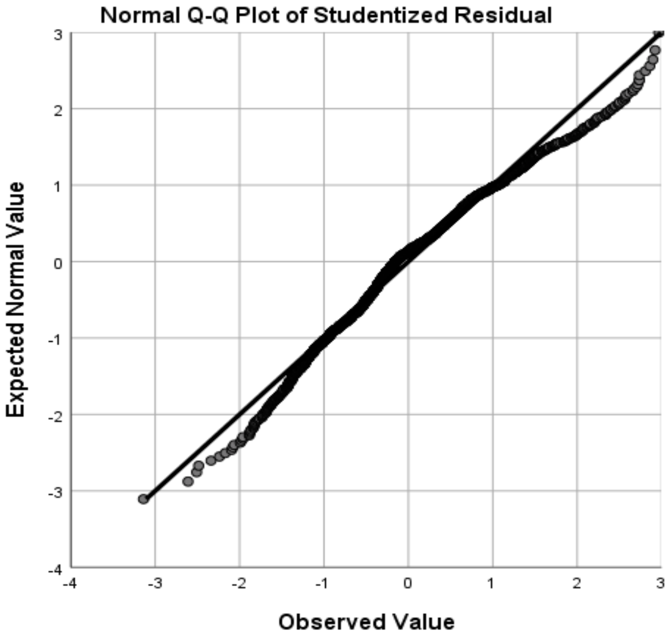

Figure 3. Q-Q plot assessing normality for independent variables and self-reported general health.

The assumption of normality was met, as assessed by a Q-Q plot as presented in Figure 3 and a histogram of the residuals as presented in Figure 4.

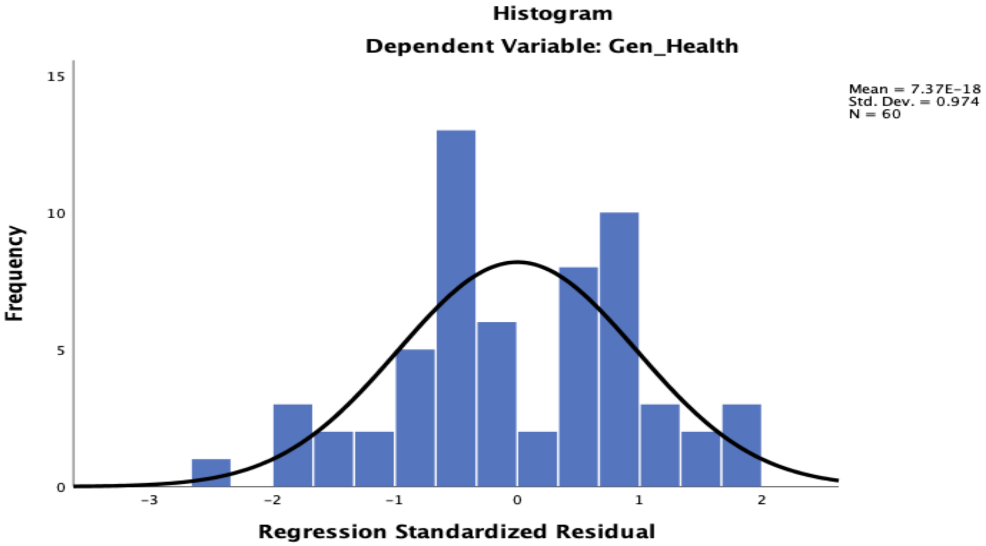

Figure 4. Histogram assessing normality between independent variables self-reported general health.

The multiple regression model statistically significantly predicted self-reported general health, F (3.56) = 7.31, p>.001, R2 = .28. Holding all variables in this model constant mental health and exercise were significant predictors of self-reported general health. The results indicated that holding all variables in this model constant, for every standard deviation unit increase in number of days of self-reported mental health not being good (β = -0.50, *p* <.001) self-reported general health decreased by 0.50 units. Additionally, for every standardized deviation unit increase in exercise (β = -0.28, *p* <.05) self-reported general health decreased by 0.28 units. The results are presented in Table 11.

Table 11

Linear Regression Analysis of Hours Per Week Worked with 95% CI and p *Values*

Variables	B	SE	β	Lower	Upper	*p*
Constant	4.07	0.24		3.58	4.56	0.001
Mental health	-0.72	0.17	-0.50	-1.06	-0.39	0.001
Exercise	-0.23	0.10	-0.28	-0.42	-0.04	0.017
Hours	-0.02	0.27	-0.01	-0.57	0.52	0.929

Note. (*N* = 95).

Summary

The validity of this research was to exclude alternative explanations of the results that were measured using quantitative variables. The secondary data collected for the research study was used to determine if a correlation exists between the dependent and independent variables. The study is to inform health care administrators in New York State who oversee AD about the variables that impact the health outcomes of AD caregivers.

Conducting this quantitative study validates the need for current and future studies to assist leaders of healthcare organizations to create a sustainable plan to alleviate caregiver’s burden, reduce caregiver stress, and improve caregiver’s quality of life, forgetfulness and decrease in participation in work or social functions (Rebekić, Lončarić, Petrović, & Marić, 2015).

Respondent data from 95 caregivers were used for analysis in this study. A logistic regression analysis was used to evaluate the three research questions. For each regression, the predictors included measures of the caregiver’s background (age, gender, income, managing personal time of family member, household tasks, ethnicity, utilization of support services), and the numbers of hours per week the caregiver cares for the family member. An additional analysis was performed using the test for caregiver's self-reported physical health, mental health, and exercise.

In examining which factors made a significant impact on hours per week the caregiver cares for the family member. Those aged 55 years or older were caregivers who managed the personal time of their family member significantly predicted hours per week the caregiver cares for the family member. Gender, the ethnicity of the caregiver, annual cholesterol check, annual flu shot, support services, and performing household tasks for the family member did not significantly predict hours per week the caregiver cared for the family member. To assess the magnitude of the effect of the significant variables on hours per week the caregiver cared for the family member, the guidelines of Chen, Cohen, and Chen (2010) were used where the OR=1.68, 3.47, and 6.71 are equivalent to Cohen's *d*= 0.2 (small), 0.5 (medium), and 0.8 (large) effect sizes. Caregivers who were 55 years or older had an odds ratio of 5.22, which is more than 3.47 and less than 6.71; this translates into a medium effect size. Caregivers who managed the personal time of their family member had an odds ratio of 7.87, which translates into a large effect size. The results of the 2017 NYSDOH/BRFSS Survey, was used to examine the variables that were most influential in predicting the number of hours per week a caregiver spends caring for a family member with AD/dementia.

In this section, the results of a secondary data analysis were presented. The 2017 NYSDOH/BRFSS was analyzed using SPSS® version 24 (IBM Corp., 2016). The analysis was validated by using the validation functions within SPSS® version 24. Descriptive analysis of the variables was conducted, recoded as necessary to ensure proper alignment with the research questions. This section also provided the data collection of secondary data set, assumptions, interpretation of the results of the data, results and findings, research question results. The next section provides an interpretation of findings, limitations, recommendations for additional study exploration will be further discussed. Finally, I will share my experience as a DHA student.

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

Introduction

The purpose of this quantitative correlational study was to inform health care administrators in New York State who oversee AD programs about the variables that impact the health outcomes of AD caregivers. AD and related dementias are increasingly becoming a worldwide concern. The study advances professional practice by informing administrators and health care policy makers regarding necessary support services for AD caregivers, which may enhance the mental and physical health of the caregiver and quality of care for the patient.

Evidence from this research informs administrators, healthcare professionals, and hospital leaders regarding the importance of providing support services to AD caregivers. Awareness and new knowledge from this study may help caregivers find solutions that will allow for better care of their health while caring for the individual with AD. This study will also help bring social change by informing administrators, health care professionals, and hospital leaders about providing support services to AD caregivers.

Interpretation of the Findings

The three research questions were posed to evaluate the relationship between hours a caregiver spends caring for a family member with AD/dementia. The sample of 95 participants were retrieved from the 2017 NYSDOH/BRFSS. To interpret the analyses of the results, I used logistic regression for RQ1 to determine if there is a statistically significant relationship between (a) number of hours per week caring for a family member with AD/dementia, (b) age, (c) gender, and (d) ethnicity of the caregiver. Table 7 confirmed that the ratio of cases was adequate. The only statistically significant variable in hours per week the caregiver cares for the family member was age. For RQ2, I used logistic regression to determine if there is a statistically significant relationship between (a) number of hours per week caring for a family with AD/dementia, (b) annual cholesterol check, (c) annual flu shot, and (d) personal doctor visits. Personal doctor's visit(s) was eliminated due to the variable being a constant. Neither annual flu shot, nor cholesterol check significantly predicted hours per week worked. For RQ3, I used logistic regression to determine if there is a statistically significant relationship between (a) number of hours per week caring for a family with AD/dementia, (b) managing personal time, (c) managing household tasks, and (d) use of AD support services. Neither utilization of support services, managing caregiver's personal time, nor performing household tasks for the family member produced a substantial error of predicting hours per week the caregiver cares for the family member. Managing personal time of the family member was the only statistically significant variable in predicting hours per week the caregiver cares for the family member.

An auxiliary analysis was performed to produce an additional RQ4 was created to include additional variables. For RQ4, I used multiple linear regression to examine the self-reported general health as predicted by number of hours per week a caregiver spends caring for a family member, the number of days self-reported mental health not being good and exercise activity. The multiple regression model statistically significantly predicted self-reported general health; holding all variables in this model constant, mental health and exercise were significant predictors of self-reported general health.

Methodological, Theoretical, and Empirical Implications

A quantitative correlational research design for this study was to examine the relationship between the independent variables age, gender, and ethnicity; self-reported general health of the caregiver, and dependent variable hours per week the AD caregiver spends caring for the AD/dementia family member. The independent and dependent variables were appropriate for this study.

The theoretical framework used to guide this quantitative research study was the SBM developed by physician and epidemiologist J. Cassel and psychiatrist S. Cobb (1976). The SBM highlights that social support reduces the impact of negative relationships (Gellert et al., 2018). I analyzed the sample for frequency, standard deviation, average, percentage, mean, mode, sum, and differences in male and female caregivers. The model was created on the premise that certain resources aid in minimizing the implications of negative life events on a person’s health (Gellert et al., 2018). The sample of participants came from the BRFSS, a large national sample, and logistic regression was the primary analysis used for this research.

Limitations of the Study

The limitations of this study are defined according to the boundaries set by a statistical analysis, by handling of secondary data, and the sample (Burkholder, Cox, Crawford, 2016). The validity of this research was to exclude alternative explanations of the results that were measured using quantitative variables. The first action was to select parameters that could only be interpreted with a single reason ideally obtained from the sample. Answering the research questions have only one interpretation, which would be that the independent variables are responsible for the changes in the dependent variables through the application of statistical analysis rules for secondary data statistics. The results of this study were obtained from analysis of data from the secondary database of the 2017 NYSDOH/BFSS with a population of caregivers aged 18 years and older, which were gathered through telephone interviews.

The BRFSS relies on information reported directly by the respondent. This may be significant to several sources of possible error. The way questions are worded may elicit responses in a certain way that can also result in what can be referred to as a measurement error (Behavior Risk Factor Surveillance System: Centers for Disease Control and Prevention, 2017). The findings of the study may be generalized to the U.S. population due to the sample being drawn from the 2017 NYSDOH/BRFSS. Despite being representative of the population, the use of the BRFSS survey tool has its limitations.

Recommendations

While caregiving can bring families together, it also places a demand and burden on the caregivers who have minimal time for their own physical, emotional, and cognitive needs (Chakrabarti, 2013; Marimbe et al., 2016). As reported in the previous section, the impact of caregiving is moderated by race, gender, age, and ethnicity. Females (66.3%) and males (33.7%) provide informal care respectively with many being 55 years or older and (35.8%) and the vast majority being Caucasian at (78.9%). An aspect of caregiver stress that I investigated also addressed the effect of support services; self-reported general health as measured by annual cholesterol checks, annual flu vaccine, management of personal time; and overall caregiver well-being. Caregivers should be mandated yearly as with any other profession to complete an annual health survey, receive an annual flu vaccine, and participate in their own yearly physical. The caregiver may also be attached to social services with a social worker to routinely, at least annually, participate in a mental health and social well-being survey. As reported in the available literature, female caregivers experienced greater effects of caregiver burden. To address the gender difference, it may be important to encourage women caregivers to have routine mammograms and annual gynecological appointments.

Researchers indicated that the risk of negative impacts on physical health increase over time with the increase in caregiver responsibilities and patients' demands (Roth et. Al., 2015). As the aging population continues to live longer, there will be a need to have more support groups and implementation of new programs such as respite care, which gives transient help to essential primary caregivers. It may be orchestrated for an evening or a few days or weeks. Care can be given at home, in a healthcare facility, or an adult day care center, (U.S. Department of Health and Human Service, 2019). Conducting an exploratory case study would give participants the chance to discuss their individual experiences as informal caregivers. These results would enable the healthcare community to provide active interventions that are evidence-based.

At the point when informal caregivers start to overwhelm healthcare centers, medical providers, and clinics with stress related issues as a result of caring for a chronically ill family member, clinical pioneers will have the chance to direct on-going research on caregiver burden. Another recommendation that future research is that this study should be replicated by choosing a wider scope and by changing populations to include specific cultures (due to cultural diversity); disorders such as cardiovascular accidents, Parkinson's disease, stage IV various cancers; and veteran caregivers in an attempt to generalize the findings of this study.

In the face of the current world-wide Covid-19 (coronavirus) pandemic, and the stay-at-home restrictions in New York State, future research is needed to survey AD/Dementia caregivers and the impact of social and mental changes. Looking at stress, personal care, and general health of this population, may inform health care policy makers in New York State of additional needs to caregivers above and beyond the findings in the BRFSS (COVID-19 Response & Prevention, 2020).

Implications for Professional Practice and Social Change

Professional Practice

Implications for professional practice may include knowledge useful for healthcare administrators, policy makers, healthcare professionals, and healthcare researchers in search improving family members' underlying health issues to bring relief to the overall situation and assist with lowering the stress of the caregiver. Probably the greatest difficulties confronting informal caregivers is the coordination of resources to help patient care beneficiaries in the home or as they transition from one care setting to another. Caregivers may need to arrange roles among family members who differ on care alternatives such as nursing homes and senior care facilities and identify significant accessible administrative health services, evaluate caregiver qualification requirements, and convey and negotiate with health professionals and insurance companies. Health professionals with detailed knowledge of and experience with health care systems can coordinate care for patients and provide help locating these services, which may be challenging (Division of Behavioral and Social Sciences and Education, 2010).

Planning care is especially risky for caregivers providing support to older individuals. The range of formal support options available to care recipients and caregivers is expansive, complex, and disarranged, with various access points and qualification criteria. Access to data about alternatives for care—for example, respite services, adult day care, support groups, meals on wheels, transportation services, and financial assistance—is one of the major neglected needs of informal caregivers (Olson, 2015). This is especially problematic among African American, Asian American, and Hispanic parental figures, who are considerably more likely than white caregivers to state they need assistance obtaining, processing, and understanding health information (Olson, 2015).

The unpredictability of identifying and accessing health and social service alternatives that may be valuable to caregivers is overwhelming. The average layman has minimal chance of optimizing formal support services to limit the complexity of providing care (Olson, 2015). Healthcare administrators can adopt a serving leadership model guided by the need to assist informal caregivers to succeed in their roles (Parand et al.,2014). Leaders can provide proactive caregivers with access to counseling programs, health programs, or other programs that will assist them to maintain their health (Parand et al., 2014). Results from this study may help professionals in educating caregivers about where to access the resources, help, and support needed in providing quality of care.

Positive Social Change

Walden defines positive social change as a deliberate process creating and applying ideas, strategies, and actions that promote the worth, dignity, and development of individuals, communities, even to experienced organizations, and societies. Positive social change results in the improvement of human and social conditions (Walden, 2017). Long-term care is the reduction in professional care provided at home and firm criteria for admission to assisted living and nursing home facilities resulting in an increased *need for informal care* among older adults (Broese van Groenou & De Boer, 2016). Given the projected aging population over 80 in the coming decades (Broese van Groenou & De Boer, 2016), more people will stay at home and need personal care, nursing care and other types of care. Specifically, individuals with AD, dementia, cancer, or other physical impairments will need intensive and long-term home care. As the need for in home care grows, and people in need of complex care, will contribute to an increased number of people providing informal care due to the ageing of the population (Broese van Groenou & De Boer, 2016).

This study highlighted an issue impacting informal caregivers of AD family members in New York State. The study promotes positive social change for AD caregivers, AD care-recipients and society by the knowledge of factors that impact the severity of caregiver. Findings showed that race, is among the significant structural factors that moderate the effect of caregiver burden on individuals. Researchers argue there is a close link between race and cultural norms that determine expectation regarding caregiving (Namkung et al., 2017).

Implications for positive social change may include knowledge useful for health care administrators, leaders in policy and other health care professionals as well as healthcare researchers in search to improve caregiver resources. To effectively examine positive change, it is important to explore how healthcare providers will address culture and language of caregivers. There is a growing awareness needed for culturally and linguistically competent health care. Additional implications for social change include enhancing the quality of services within the communities that are underserved and culturally diverse (Cultural and Linguistic Competence Policy Assessment, 2006). The Cultural and Linguistic Competence Policy Assessment (CLCPA) tool focuses on healthcare professionals, community health centers, and organizations in achieving cultural competence and approaches to eliminate health disparities. Understanding key factors regarding predictors and health related issues for informal caregivers can help advance research in long-term home care.

Conclusion

Caregivers undertake caregiving responsibilities over a long period of time, the burdens placed on them could lead to undue stress and affect their health. The burden of AD/dementia will increase as the aging population increases. The study may inform healthcare administrators/researchers regarding the gaps in utilization and the effectiveness of support services measured by self-reported physical and social burden of the AD caregivers, so that training courses can be developed and implemented. This research contributes to the growing body of knowledge that addresses the burden of the informal caregivers' experience.

The significance of this quantitative study can guide health care administrators, health policy and programs that provide resources to address caregiver burden. Administrators and health care providers can become advocates for AD caregivers resulting in a change in attitudes towards those family members and in social support to manage AD persons with advancing AD at home. Evidence collected and data analyzed from this study may assist and educate caregivers about where to access the help and support they need to provide quality of care.

This doctoral study has helped me to reflect on my own growth and development and patience throughout this process of creating, evaluating, and understanding the burden and the coping strategies in persons who care for AD/dementia individuals. During my research I have found that there is no difference between caring for AD individuals or caring for any other medical modalities. I became more aware of the need to find coping mechanisms and resources for the informal caregiver. We seem to think that informal caregivers whether they be a spouse, adult child , family member or friend that they we are supposed to care for this individual, identifying as a bonafide caregiver (should be inclusive) should immediately turn our minds to a certain set of understanding and principles. These principles should be founded on the understanding that our minds should then immediately transition our thoughts from the understanding that we are caring for someone to the fact and reality that in turn we need to find time to pay attention to ourselves.

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Appendix A: Permission to Use the Dataset

Permission to use NYS BRFSS Data

About this Dataset

Updated

Metadata Last Updated
April 4, 2019

Date Created
March 14, 2019

Data Provided by
New York State Department of Health
Dataset Owner
Open Data NY - DOH

Contact Dataset Owner

Dataset Summary

Office/Division	Division of Chronic Disease Prevention
Program Owner	Bureau of Chronic Disease Evaluation and Research
Time Period	2017
Posting Frequency	Yearly
Dataset Owner	Bureau of Chronic Disease Evaluation and Research
Coverage	Statewide
Granularity	Statewide and DSRIP regions. County data are available upon request.