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Social Support, Gender, and Burden in Caregivers of Patients with Alzheimer's Disease

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Walden University

College of Social and Behavioral Sciences

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Jennifer Wisneski

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

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Walden University 2018

Abstract

Social Support, Gender, and Burden in Caregivers of Patients with Alzheimer's Disease

by

Jennifer Lynne Wisneski

MS, Walden University, 2014

MA, University of the Rockies, 2011

BS, Binghamton University, 2007

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Clinical Psychology

Walden University

May 2018

Abstract

There are 15.9 million adults in the United States providing care to a family member diagnosed with Alzheimer's disease. Family member caregivers experience detrimental physical and mental health stress because of their caregiving role. The purpose of this study was to determine if the independent variables of marital status, perceived social support, and gender of family member caregivers of patients with Alzheimer's disease were related to the dependent variable of caregiver burden. The variables were examined through the lens of John Bowlby's attachment theory using archival data (n = 586) from the REACH II program. The results of the analysis of variance indicated that marital status did not affect level of burden. The outcome of a correlational analysis indicated a positive linear association between burden and social support. The result of an independent samples t test was that females reported higher burden than males. The outcome of a linear regression identified marital status, social support, and gender as predictors of caregiver burden. Positive social change implications of this study include contributing to scholarly literature, providing information for families to consider when implementing a plan for long-term care, and encouraging caregivers to seek professional support to minimize burden and maximize quality of life for themselves and the care receiver. Female caregivers with many social supports were identified as high risk for severe burden, an important factor for clinicians, agencies, and healthcare providers who work with family caregivers to consider. Identifying factors that contribute to burden and developing strategies to manage these factors may reduce severity of burden and improve quality of life for both caregivers and care recipients.

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Dedication

I dedicate this work to my family and friends who have believed in me and cheered me on since the beginning of this journey. I appreciate the positivity I have received from all of you. To my husband, Matthew Wisneski, for his unwavering support and encouragement. You have reminded me of the silver linings, made me laugh during challenging times, and kept me focused on crossing the finish line. To my best friend, Emily Fairchild, who was always there to celebrate small victories and partake in adventures when I needed time to relax and recharge. To my parents, Alan and Trishia VanGorden and Diana Osterhoudt for instilling amazingly strong work ethic and determination in me. I am appreciative for the drive to fulfill my dreams and the sense of humor to get me through this process.

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I would also like to thank the staff at the United Way of Tarrant County and the Alzheimer's Association – North Central Texas Chapter. I appreciate the opportunity to work together in a common area of interest and provide support to caregivers of patients diagnosed with Alzheimer's disease.

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Chapter 1: Introduction to the Study

As of 2012, there were 43.1 million individuals in the United States who were 65 years of age and over (Administration on Aging, 2013). This equates to one senior for every seven people. It is anticipated that there will be 92 million individuals 65 years and older in the United States by the year 2060 (Administration on Aging, 2013).

Approximately 5.2 million, or 11%, of Americans age 65 and older have been diagnosed with Alzheimer's disease (Alzheimer's Association, 2017). A significant percentage of these individuals require long-term care services on a daily basis (Family Caregiver Alliance, 2015). As of 2015, between 5.8 and 7 million people provide care to a family member or friend who requires assistance with daily activities (Family Caregiver Alliance, 2015).

This is an important topic because the number of people 65 years and older with Alzheimer's disease requiring a caregiver is expected to more than double by the year 2050 and in turn the number of informal family caregivers is expected to increase tremendously (Family Caregiver Alliance, 2015). Caregiver burden impacts the physical and mental health of both the caregiver and care recipient (Iavarone, Ziello, Fasanaro, & Poderico, 2014; Kamiya, Sakurai, Ogama, Maki, & Toba, 2014; Krull, 2013; Mausbach et al., 2014). Additional information is necessary to understand which factors influence burden to minimize burden for family caregivers (Conde-Sala et al., 2014; Kamiya et al., 2014; Mausbach et al., 2014; Monin, Zhou, & Kershaw, 2014; Reed et al., 2014). This study may have positive social change implications by contributing to the existing

scholarly literature on the important topic of caregiver burden. It may potentially provide helpful information to caregivers and professionals working with caregivers.

In this chapter, I will explain the background of the study, identify the problem and purpose of the study, and provide the research questions and hypotheses. In addition, this chapter will briefly discuss the theoretical framework, nature of the study, important definitions, assumptions, limitations, and significance of the study.

Background

The topic of caregiver burden is a broad, highly researched topic (Iavarone et al., 2014; Kamiya et al., 2014; Krull, 2013; Mausbach et al., 2014; Schulz et al. 2014). The research relevant to this study can be narrowed down to seniors, the need for long-term care services, transitioning an individual to a nursing home, caring for a patient who has been diagnosed with Alzheimer's disease, and caregiver burden. As the population of people 65 years of age and older increases, demand for long-term care services also increases, and there are not enough resources available to fill this demand (Hudson, 2014). The lack of resources to provide long-term care can pressure families to place the patient in a nursing home, an event likely to take a toll on the physical and mental health of the patient and caregiver (Krull, 2013; Mausbach et al., 2014).

The duties of caring for an individual become more challenging when the patient has a disease such as Alzheimer's (Iavarone et al., 2014). The caregiver must have an understanding of the symptoms associated with the disease, and a caregiver with little knowledge is likely to experience higher levels of burden (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010b; Kamiya et al., 2014). Additional

research is necessary to understand how social support for caregivers of patients with Alzheimer's disease may improve care and minimize burden (Raggi Tasca, Panerai, Neri, & Ferri, 2015).

Caregiver relationship to the patient and caregiver gender may also impact caregiver burden. Research on relationships between caregivers and care receivers has suggested that the ability of spousal caregivers to manage burden is dependent on many factors, such as attachment style, caregiver health, and the dynamics of the marital relationship (Chappell, Dujela, & Smith, 2014; Conde-Sala et al., 2014; Mausbach et al., 2014; Monin et al., 2014). Factors such as attachment style, personality, and severity of patient illness contribute to the ability or inability to manage symptoms of burden (Conde-Sala et al., 2014; Monin et al., 2014). In addition to caregiver relationship to the patient, caregiver gender may impact caregiver burden. Female caregivers often report higher levels of burden based on the amount of time providing care, physical and developmental factors, and social activity, whereas male and female caregivers report similar severity of emotional burden (Kim et al., 2016; McDonnell & Ryan, 2013).

Gap in the Research Literature

Many contributing factors may limit the severity of caregiver burden experienced by a family member caregiver. Literature discussing caregiver burden is lacking empirical research on specific factors that may affect severity of burden, such as social support, marital status, and gender of caregivers (Conde-Sala et al., 2014; Dam, Vugt, Klinkenberg, Verhey, & Boxtel, 2013; Mausbach et al., 2014). The gap in current research on caregiver burden that I explored in this study was the impact of social

support, marital status, and gender on severity of burden. Continuing to gather information on caregiver burden in family member caregivers is important for several reasons. First, the population of 65 and older in the United States is rapidly growing (Family Caregiver Alliance, 2015). In turn, the number of family member caregivers will increase. Alleviating burden can improve quality of life for both the caregiver and care recipient. Burden needs to be managed in order to reduce the negative impact on the health and quality of life of both caregiver and patient (Kamiya et al., 2014; Mausbach et al., 2014; Shankar, Hirschman, Hanlon, & Naylor, 2014; van der Steen, Deliens, Ribbe, & Onwuteaka-Philipsen, 2012). This study was necessary because it may potentially contribute to scholarly literature on the relationship between social support and severity of caregiver burden. It is important to expand research on factors that influence burden to promote quality of life for both caregivers and care recipients (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012).

Problem Statement

Most family member caregivers of patients with Alzheimer's disease experience some level of burden (Mausbach et al., 2014). Caregiver burden has a negative impact on the quality of care a caregiver provides, limiting the quality of life for the care recipient (Iavarone, 2014). Caregiver burden is experienced by most caregivers in the form of physical, psychological, or emotional stress (Iavarone, 2014). Caregivers often lack a plan of action for the instance when their family member requires a higher level of support than the caregiver can provide (Krull, 2013). In fact, many times the patients and family members are unaware of their options for long-term care or what steps they need

to take to initiate the transition process (Krull, 2013). Making this change so abruptly can be devastating to the patient and family (Koplow et al., 2015). The patient has experienced a significant life change and may require a great amount of support from the family. This can be problematic if primary caregivers are preoccupied with their own distress. This is important considering that there are 45.3 million family caregivers in the United States providing care to individuals over 50 years of age, 15.9 million of whom care for an individual who has been diagnosed with Alzheimer's disease or another form of dementia (Alzheimer's Association, 2017). When family members are able to control their stress, be involved in the treatment plan, and actively communicate with nursing home staff, the patient tends to experience a higher quality of care (van der Steen et al., 2012).

Research related to this topic has been focused on improving the quality of care for the patient who has been admitted to a nursing home. Ryan and McKenna (2013) explored the challenge that patients and caregivers experience during the transition into a nursing home, with the primary goal of the study being to improve overall health of senior patients entering nursing homes and their caregivers. In a longitudinal study, Arling et al. (2013) examined the quality of health in nursing home patients for the first year after admission. The results indicated that patients are less likely to return to the community after residing in a nursing home more than 90 days (Arling et al., 2013). Vandervoort, Houttekier, Stichele, van der Steen, and Van den Block (2014) explored the process of advance care planning for end of life. The results of their study confirmed that nursing home residents who had an advance care plan experienced less emotional distress

at the end of their life than those without a plan in place. It is important to encourage advance care planning and to provide high quality care for a patient recently admitted to a nursing home in order to protect the patient's physical and mental health (Arling et al., 2013; Brownie, Hortsmanshof & Garbutt, 2014; Ryan & McKenna, 2013; Vandervoort et al., 2014).

In the past decade, researchers have become more focused on caregiver burden of family caregivers to identify opportunities to improve quality of care for new nursing home patients. Tremont et al. (2013) explored the use of interventions to address caregiver burden after the patient was admitted to a nursing home. They conducted the study to gather information on physical and mental stress on caregivers of people diagnosed with dementia during the transition process. Van der Steen et al. (2012) found a relationship between the quality of care in nursing homes, family involvement during care, and overall health of the patient; for example, when the family is involved in care planning and had regular communication with facility staff, patient health was better. Dillman, Yeatts, and Cready (2013) found that patients who had family members living close to the facility reported a higher quality of care because their family members were more actively involved with the staff and visited often. The researchers also found that family members who perceived the nursing home as having a residential feel were more comfortable leaving the patient in a facility (Dillman et al., 2013). An issue for caregivers is that they do not have a support system to assist them in transitioning from being responsible as the patient's caregiver to allowing the nursing home to assume this role (Krull, 2013). Caregivers may experience feelings of burden, depression, and guilt,

impairing ability to focus on their family member's transition into the facility (Naden et al., 2013). This could restrict the quality of care a patient receives if the caregiver is physically unable to care for the patient due to deteriorating health (Iavarone, 2014). If the caregiver is feeling mentally or emotionally drained, that person may find it difficult to keep track of patient needs such as administering medication at the proper times or maintaining a schedule of the patient's medical appointments (Iavarone, 2014).

Research on caregiver burden has focused on basic risks including psychological stress, decrease in physical health, and financial health (Iavarone et al., 2014). Krull (2013) stated that caregivers often struggle to meet their personal obligations because of the amount of time they must dedicate to caring for a senior family member. According to Mausbach et al. (2014), caregivers of patients diagnosed with dementia and Alzheimer's disease tend to experience extremely high levels of stress and depression, often prompting the caregiver to consider placing the family member in a long-term care facility. There are many opportunities for further research to understand how caregiver burden can be controlled in order to increase quality of care for the patient. For example, Mausbach et al. (2014) suggested that further studies be conducted to examine the relationship of marital status and quality of social relationships on caregiver burden. Shankar et al. (2014) indicated that further research is necessary to explore interventions that target caregivers of patients with Alzheimer's and dementia. Kamiya et al. (2014) explored characteristics of the patient that impact caregiver burden and suggested that future studies expand on characteristics that are directly related to the caregiver, such as marital status and gender. Friedemann and Buckwalter (2014) conducted a study to

explore the relationship between caregiver perceived roles based on gender, workload, burden, and help from other family members. Limitations identified in this study indicated that the sample did not include enough ethnic minorities, and that information on support from other family members was lacking (Friedemann & Buckwalter, 2014).

It is important that researchers continue to empirically examine ways to alleviate caregiver burden prior to the transition of the patient into a nursing facility because caregiver burden impacts caregivers, the caregiver's family and friends, as well as seniors and disabled individuals who require care to live in their home (Fukahori, Yamamoto-Mitani, Sugiyama, Sugai, & Kai, 2010; Krull, 2013; Mausbach et al., 2014). This study measured the effect of social relationships on caregiver burden, an issue that had been identified as a gap in the literature. If social support was identified as a factor that influences severity of burden, it could encourage positive social change by suggesting that further research focus on building social support for family caregivers to reduce burden. Reducing factors that contribute to caregiver burden is likely to improve quality of life for both the caregiver and the care recipient (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012). This is why social support is a meaningful gap in the literature of caregiver burden. Although past research has shown that the majority of family caregivers experience some level of burden, alleviating caregiver burden can improve patient quality of life, and that factors such as patient health and personal obligations of the caregiver can impact ability to cope with burden, it is unclear whether caregivers' social relationships impact their ability to cope with the burden of caring for loved ones (Kamiya et al. 2014, Mausbach et al., 2014; Shankar et

al., 2014; van der Steen et al., 2012). This issue is important because the number of seniors in the United States is expected to almost double by the year 2050, and in turn the family caregiver population will significantly rise (Family Caregiver Alliance, 2015). This study examined the relationship of social support, marital status, and caregiver gender to the severity of caregiver burden in family caregivers of patients with Alzheimer's disease. These three factors have not been previously studied among caregivers of patients diagnosed with Alzheimer's disease. Approximately 52 million, or one in five adults in the United States, serve as informal caregivers to a disabled family member over the age of 18 (Family Caregiver Alliance, 2015). Twenty-eight percent of this population is caring for an individual diagnosed with Alzheimer's disease, making it important to contribute to research on caregiver burden (Family Caregiver Alliance, 2015). In addition to benefiting the caregiver and care recipient, advances in research on burden may potentially benefit public healthcare in the United States (Family Caregiver Alliance, 2015). There has been a national trend to switch long-term care services from skilled nursing facilities to community-based treatment in the patient's home (Family Caregiver Alliance, 2015). This shift occurred after the Supreme Court upheld the rights of people to receive care in their home rather than a nursing home in the 1999 case referred to as the Olmstead Decision (Family Caregiver Alliance, 2015). Patients who remain in their home to receive long-term care are often happier, have more contact with family and friends, feel they are able to maintain their dignity, and experience a higher quality of life than patients residing in a nursing home (Dillman et al., 2013; Iavarone et al., 2014; Mausbach et al., 2012; Naden et al., 2013).

Purpose of the Study

A nonexperimental, quantitative design method was employed to explore the independent variables of marital status, perceived social support, and gender of caregivers of patients with Alzheimer's disease to determine if these factors were related to the dependent variable of caregiver burden. I chose this approach because I was using archival data, there were no control groups or manipulation of variables, and data were collected at one time when participants chose to enroll in the REACH program (Alzheimer's Association, 2017; Frankfort-Nachmias, Nachmias, & DeWaard, 2014; Schulz et al., 2001).

Research Questions and Hypotheses

The following research questions guided the study, with the following hypotheses to test in statistical analysis:

RQ1: Is there a significant difference in reported caregiver burden as measured by the burden interview scale (see Appendix C) between caregivers who are single, married, widowed, or divorced?

 H_0 1: There is no significant difference in reported caregiver burden among caregivers who have never been married, are currently married, widowed, or divorced.

 H_a 1: There is a significant difference in reported caregiver burden among caregivers who have never been married, are currently married, are widowed, or divorced.

- RQ2: Is there a relationship between caregiver burden as measured by the burden interview scale (see Appendix C) and caregiver perceived social support as measured by the social support scale (see Appendix B)?
- H_02 : There is no significant correlation between caregiver burden and perceived social support.
- H_a 2: There is a significant correlation between caregiver burden and perceived social support.
- RQ3: Is there a significant difference in reported burden as measured by the burden interview scale (see Appendix C) between male and female caregivers?
- H_03 : There is no significant difference in reported caregiver burden among male and female caregivers.
- $H_{\rm a}3$: There is a significant difference in reported caregiver burden among male and female caregivers.
- RQ4: Is there a significant interaction between caregiver marital status, social support, and gender on caregiver burden as measured by the burden interview scale (see Appendix C)?
- H_0 4: There is no significant interaction between caregiver marital status, social support, and gender on caregiver burden.
- H_a 4: There is a significant interaction between caregiver marital status, social support, and gender on caregiver burden.

Theoretical Framework for the Study

In this study, I employed the concepts of John Bowlby's attachment theory (1988) to examine the data. Attachment behavior refers to the act of an individual seeking security from another in order to cope with stress (Bowlby, 1988). This theory was first applied to the relationship between an infant and parent (Bowlby, 1988). Attachment theory has been applied to recent research of caregiver burden (Chen et al., 2013; Monin & Schulz, 2010; Monin, Schulz, & Kershaw, 2013; Monin et al., 2014; Morse, Shaffer, Williamson, Dooley, & Schulz, 2012). For example, Monin and Schulz (2010) used attachment schemas to evaluate emotional reactions of caregivers. Attachment theory has been utilized when evaluating caregiver depression, response to stress, and attachment orientations of patients with Alzheimer's disease and spousal caregivers (Monin et al., 2013; Monin et al., 2014; Morse et al., 2012). Attachment theory has also been utilized to evaluate the differences in response to the caregiving role by male and female caregivers and ability of caregivers to cope with stressful events based on gender (Apiknar, Kucukguclu, & Yener, 2011; McDonnell & Ryan, 2013; Monin et al., 2013; Monin et al., 2014; Stewart et al., 2016).

Attachment theory may provide some insight as to how caregivers cope with stress based on the variables of marital status, perceived social support, and gender. Based on this theoretical framework, it was expected that caregivers with secure attachment schemas would report lower severity of caregiver burden due to support from a spouse and strong social supports, and caregivers with a negative attachment schema would report the opposite (Bowlby, 1988; Monin et al., 2013; Monin et al., 2014; Morse

et al., 2012). Male and female caregivers with secure attachment schemas may report similar amounts of social support and severity of burden, whereas female caregivers with a negative attachment schema may rate severity of burden much higher than males in the same category (McDonnell & Ryan, 2013). The application of attachment theory to the variables of perceived social support, marital status, gender, and severity of caregiver burden will be discussed in further detail in Chapter 2.

Nature of the Study

A quantitative design was employed to measure the statistical relationship between variables with the intent to reach a specific conclusion with numerical values (Frankfort-Nachmias et al., 2014). The independent variables in this study were perceived social support, marital status, and gender of the caregiver. The dependent variable was caregiver burden. Archival data from the REACH II program conducted by the Alzheimer's Association - North Central Texas Chapter were used. The three instruments in the REACH II study providing necessary information for the current study were the Burden Interview (see Appendix C), the Caregiver/Care Recipient Sociodemographic Information (see Appendix A), and the Social Support (see Appendix B) scale. I analyzed data using Statistical Package for the Social Sciences (SPSS) version 23.0 for Windows to conduct an analysis of variance (ANOVA).

Definitions

Adult child caregiver: A care recipient's child who is age 18 or older and provides direct care to the patient on a daily basis (Conde-Sala et al., 2014).

Advance care plan: A written directive that identifies goals and desired direction of care in the event the patient is unable to make decisions (Vandervoort et al., 2014). This plan includes directives for treatment decisions such as do-not-resuscitate, use of life-prolonging treatments, do-not-hospitalize, and withholding or withdrawing artificial foods or fluids (Vandervoort et al., 2014).

Alzheimer's disease: A specific form of dementia. This degenerative disease causes abnormalities within the brain, leading to a loss in functions such as memory, reasoning, language, decision making, judgement, and other skills necessary for an individual to live independently (Family Caregiver Alliance, 2015).

Caregiver burden: The overwhelming feelings of exhaustion, psychological stress, economic burden, and restricted social activities that may result from caring for an incapacitated loved one (Fukahori et al., 2010).

Emotional contagion: Mimicking or mirroring another individual's emotions through behavior, expressions, or verbalizations (Monin et al., 2013).

Family member caregiver: An immediate family member such as a spouse or child who is 18 years of age or older and provides direct care to the patient on a daily basis (Schulz et al., 2001).

Quality of life: The overall health and well-being of an individual (Shankar, 2014). The factors impacting quality of life include patient comfort, independence, overall health, ability to understand the diagnosis, and support from family (Bern-Klug, 2014).

Senior: A person who is aged 65 years or older.

Social relationships: The relationships with family members, friends, and neighbors (Schulz et al., 2007).

Social support: The psychological and sometimes physical support given to caregivers with regard to decision-making about their loved one, completing caregiving tasks, discussing the challenges of caregiving, or assisting in handling difficult situations (Schulz et al., 2001).

Assumptions

It was assumed all participants understood the questions being asked and were truthful in their answers on the Burden Interview, Caregiver/Care Recipient

Sociodemographic, and Social Support scales during participation in the REACH II program (Alzheimer's Association, 2017). These assumptions are necessary because of the limitations of the current study. The intention of this study was to examine cross-sectional archival data collected by the Alzheimer's Association - North Central Texas

Chapter (Alzheimer's Association, 2017). The data were drawn from self-rating scales on burden severity and perceived social support, and a demographics questionnaire

(Alzheimer's Association, 2017). With use of archival data, there was no opportunity to conduct further interviews with participants to verify they understood each question or to ensure participants answered each question truthfully.

Scope and Delimitations

The intentions of the REACH II program align with the task of the current study.

The REACH II program was implemented to collect data about family member caregivers of patients diagnosed with Alzheimer's disease and care receivers in order to

collect further information about caregiver burden and the implementation of an intervention to support caregivers (Schulz et al., 2001). The primary goals of the REACH II were to identify and reduce risk factors of family caregivers, improve wellbeing of caregivers, and enhance quality of life for care recipients (Schulz et al., 2001). Similar goals and the availability of data on the variables of burden, perceived social support, marital status, and gender made the REACH II program an appropriate source of archival data for the current study. The Alzheimer's Association - North Central Texas Chapter replicated REACH II with the intention to provide specialized education and counseling to family member caregivers and to collect data to monitor success of the program (Alzheimer's Association, 2017). The target population of the REACH II program is family member caregivers of patients diagnosed with Alzheimer's disease in northern Texas. Both female and male caregivers over the age of 19 participated in the program (Alzheimer's Association, 2017). During the past 7 years of the REACH II program, 77 % of participants have been female and 23% have been male. Most of the participants have been Caucasian; however, African American, Asian, and Hispanic ethnicities were also represented in the data (Alzheimer's Association, 2017). Further information about ethnicity was not collected from participants. This means that data obtained from the REACH II program cannot be used to determine if burden varied among ethnicity.

The process of recruitment and locations in which participants were recruited had an impact on generalizability. Participants for the REACH II program were recruited from northern Texas. Limiting recruitment of participants to one area limits the ability to

adequately represent both rural and metropolitan regions. Methods of recruitment to the REACH II program include a telephone helpline, inquiries made via the United Way of Tarrant County and Alzheimer's Association - North Central Texas Chapter websites, support groups, case managers, partnering agencies, home health agencies, and the Aging and Disabilities Resource Center (Alzheimer's Association, 2017; Lykens, Moayad, Swati, Reyes-Ortiz, & Singh, 2014). The methods of recruitment include use of technology and in-person contact, increasing diversity of participants by using multiple methods of recruitment (Lykens et al., 2014). However, there may be caregivers who are not actively receiving support from one of the local agencies involved in referring participants. Use of additional sources of advertising, such as radio, television, community events, and mailings could have increased the number of participants and expanded the types of populations represented in the data.

The inclusionary data for caregivers were that the participant had to be at least 21 years of age, be a family member of the care recipient, provide care to the recipient for at least 6 months for a minimum of 4 hours direct care daily, and reside with the recipient in a home sharing at least a common kitchen (Schulz et al., 2001). Caregivers were required to have a telephone, reside in the recruitment region for at least 6 months, were expected to participate in the REACH II intervention, and required to complete a follow-up assessment (Schulz et al., 2001). Individuals were excluded if unable to speak English or Spanish, participating in cancer treatment, expected to place the care recipient in a nursing home within 6 months, or answered four or more questions incorrectly on the Short Portable Mental Health Status Questionnaire (Pfeiffer, 1975). The inclusionary

data for care recipients were a diagnosis of dementia or cognitive impairment by a primary physician, or a raw score under 24 on the Mini Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975). Exclusionary data for care recipients were the inability to speak English or Spanish, participation in REACH I, a history of Parkinson's disease or stroke, actively receiving cancer treatment, or having three or more acute hospitalizations in the year prior to participation in the study (Schulz et al., 2001).

Limitations

Due to the use of archival data, there were several limitations on the current study. There were limitations on procedures, interviewing process, data collection, data coding, and data cleaning because these steps had already been done by the researchers at the time of the study. The REACH II program conducted by the Alzheimer's Association -North Central Texas Chapter was a replication of the REACH II program conducted by Schulz et al. (2001). To promote consistency during the implementation of REACH II in Texas, two dementia care specialist staff members from the Alzheimer's Association were trained by an investigator from the original REACH team (Lykens et al., 2014). The 2-day training covered use of the resource book, role-playing, and proper response to ideas and concerns brought up by caregivers (Lykens et al., 2014). The fact that training was done in 2 days is a limitation. During the original REACH studies, field interviewers were given extensive training on professionalism, handling difficult situations, responding to caregiver requests, dealing with emergencies, recording participant responses, and implementing both baseline and follow up assessments (Schulz et al., 2001).

Culture, family beliefs, education, and experience are all factors that could impact a participant's perception of the caregiving role. Secondly, there is a risk of recall bias and trying to provide more socially desired answers. Individuals who accept caregiving as an expectation in their culture and have support from family members may report a lower level of burden (Friedemann & Buckwalter, 2014; Lykens et al., 2014; Schulz et al., 2001). These biases may have an impact on self-reporting when participants were rating severity of burden and perceived social support. Caregivers with more education and experience are likely to report a lower level of burden (Friedemann & Buckwalter, 2014). However, the way questions were presented to participants in the questionnaires limits this bias (Schulz et al., 2001). When asked about social support and burden, participants were directed to report based on their experiences within the month prior to completing the survey (Schulz et al., 2001). Questions required participants to rate their experience based on the number of people actively assisting with caregiving tasks and to identify how often they neglected other personal responsibilities due to caregiver tasks (Schulz et al., 2001). The REACH II data provided limited information on ethnicity, only identifying White, Black, Asian, and Hispanic populations. To address limitations by expanding the sample of participants, the REACH II program utilized several methods of advertisement to reach more individuals (Alzheimer's Association, 2017). The agency utilized referrals from a 24-hour telephone helpline, case managers, partnering agencies, support groups, inquiries made via the agency website, and home health agencies in North Texas (Lykens et al., 2014).

Significance

The current research study was significant because it advanced knowledge in the discipline and may potentially contribute to advancements in practice and policy. This study addressed a gap in research by providing information about the effects of social support, marital status, and gender on caregiver burden for family caregivers of patients diagnosed with Alzheimer's disease. Expansion of the literature on this topic may provide insight to the target population of family member caregivers providing care to an individual diagnosed with Alzheimer's disease, which is approximately 15.9 million people in the United States (Alzheimer's Association, 2017; Conde-Sala et al. 2014; Dam et al., 2016; Family Caregiver Alliance, 2015; Friedemann & Buckwalter, 2014; Kamiya et al., 2014; Krull, 2013; Mausbach et al., 2014; Shankar et al., 2014). Previous research has indicated the need to examine specific factors thought to influence caregiver burden as an area requiring additional research (Conde-Sala et al. 2014; Dam et al., 2016; Friedemann & Buckwalter, 2014; Kamiya et al., 2014; Krull, 2013; Mausbach et al., 2014; Shankar et al., 2014). Identifying that these variables negatively affect severity of burden would suggest the importance of further research in the discipline and encourage implementation of methods to increase social support for caregivers to decrease burden, improve well-being of caregivers, and enhance quality of life for care recipients (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012).

This study may promote positive social change for caregivers and patients diagnosed with Alzheimer's disease. It may provide helpful information to psychologists and other professionals working with caregivers to understand the impact of marital

status, social support, and gender on severity of burden and prepare caregivers for handling burden with these variables in mind. Specifically, this study may potentially contribute to advancements in practices and policy by raising awareness among the target population about factors that may increase severity of burden and compromise quality of life for the caregiver and care receiver. This study may encourage development of strategies to address concerns surrounding caregiver perceived social support, marital status, and gender in order to limit or alleviate burden. Lowering severity of burden may improve quality of life for caregivers and care receivers. Implementation of interventions to limit burden could also allow care receivers to delay the need to transition into a nursing home (Krull, 2013; Mausbach et al., 2014; Shankar et al., 2014).

Summary

Although caregiver burden is a highly-researched topic, there are many opportunities to conduct research and contribute to gaps in the literature (Iavarone et al., 2014; Kamiya et al., 2014; Krull, 2013; Mausbach et al., 2014; van der Steen et al., 2012). Specifically, the current study may provide information about impact of social support, marital status, and gender on severity of caregiver burden. It is important to continue researching factors that may impact burden because decreasing severity of burden has a positive impact on quality of life for the caregiver and care recipient (Iavarone et a., 2013). Archival data from the REACH II program conducted by the Alzheimer's Association - North Central Texas Chapter were utilized in this nonexperimental quantitative design. Through the lens of attachment theory, I explored the research questions, which were about the effect of marital status, social support, and

gender on severity of burden in family member caregivers of patients diagnosed with Alzheimer's disease. This study may promote social change by potentially offering information on the impact of social support, marital status, and gender on caregiver burden that may prove helpful to caregivers, care recipients, and professionals assisting caregivers in preparing for the burden they may experience.

In Chapter 2, I will expand on several points mentioned in Chapter 1 such as the problem statement, purpose of study, and theoretical framework. I will also discuss in detail the nature and significance of the study and provide an extensive review of the relevant literature.

Chapter 2: Literature Review

There are 65.7 million family caregivers in the United States, which is about 29% of the adult population (Family Caregiver Alliance, 2015). Approximately 15.9 million of these caregivers provide care to a person who has been diagnosed with Alzheimer's disease or dementia (Alzheimer's Association, 2017). The problem addressed with this study was that most caregivers experience some level of caregiver burden, which can influence the quality of care that is provided to the patient. This in turn impacts the quality of life for the patient. The purpose of this study was to examine the relationship of marital status, social support, and gender to the burden of family caregivers of patients with Alzheimer's disease.

This chapter will provide a description of the process used to obtain sources of information for the literature review, with the majority of the research coming from peer-reviewed articles published within the past 5 years. I will also explain the use of attachment theory as the theoretical framework for the current study and how this theory applies to social support, marital status, gender, and severity of burden. Topics discussed in recent literature that are relevant to the current study and to attachment theory include the emotional reactions of informal caregivers, depression and stress response in caregivers, and attachment orientations among spousal caregivers (Monin & Schulz, 2010; Monin et al., 2013; Morse et al., 2012).

To provide an understanding of the effects of marital status, social support, and gender on caregiver burden, in this literature review, I will discuss studies related to the increasing need for long-term care for the aging population, maintaining quality of life

when transitioning to a nursing home, family caregiver stress, and caring for an individual with Alzheimer's disease. Most caregivers experience some level of chronic stress, which is also referred to as "caregiver burden" (Iavarone et al., 2014). In caregivers of patients with Alzheimer's disease, chronic stress often appears as depression, clinical anxiety, and a major decline in physical health (Iavarone et al., 2014). Predictors of caregiver burden that have been explored in past research include race, socioeconomic status, level of education, employment, mental health, and physical health (Friedemann & Buckwalter, 2014; Kim, Chang, Rose, & Kim, 2012; Mausbach et al., 2014; Monin et al., 2013; Shankar, 2014; Vandervoort et al., 2014). Recently, researchers discussing caregiver burden indicated a need to continue research on the factors that may contribute to severity of burden (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012). This is because burden has a negative impact on well-being of caregivers and limits quality of life for the care recipient (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012). If the task of caregiving becomes too overwhelming for the caregiver, the patient usually transitions into a nursing home to receive proper care (Krull, 2013, Kwak & Polivka, 2014). This abrupt and significant life change usually causes a large amount of physical and mental stress on both the caregiver and patient (Dillman et al., 2013; Krull, 2013; Muller, Lautenschlager, Meyer, & Stephan, 2017; Naden et al., 2013, Ryan & McKenna, 2013; Tremont et al., 2013). Researchers have identified several factors that influence burden; however, additional research is necessary to determine if social support, marital status, and gender have an effect on severity of caregiver burden

(Friedemann & Buckwalter, 2014; Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014).

Literature Search Strategy

To search for literature, I used several electronic databases in the psychology and nursing subjects of the Walden University Library databases: ProQuest Central, ProQuest Dissertations, ESCOHOST, Academic Search Complete, PsycInfo, SocIndex, CINAHL, and Google Scholar. I completed searches using various combinations of the following key terms: caregiver burden, caregiver stress, Alzheimer's, Alzheimer's disease, nursing home, nursing facility, long-term care, marriage, marital status, husband or wife, adult child, social relationships, social support, friends, social groups, gender, REACH II, REACH study, attachment theory, and John Bowlby. The scope of the literature review for the theoretical framework ranged from 1980 to present and included peer-reviewed articles and literature written by John Bowlby related to attachment theory. For the search of literature on the topic of caregiver burden, the literature search focused on articles from 2000 to 2017 with a majority of the research coming from peer-reviewed articles published between 2012 and 2017.

Theoretical Foundation

I employed the concepts of attachment theory (Bowlby, 1988) to examine the relationship of perceived social support, marital status, and gender to caregiver burden. Attachment behavior is the act of a person seeking security from another person as a way to cope with stress (Bowlby, 1988). Based on the concepts of attachment theory, it is likely for caregivers with a secure attachment schema to pursue sources of social support

and rely on help from a spouse with caregiving tasks. These individuals may rate their perceived social support as high. Participants who have a negative attachment schema are expected to find it difficult to pursue social support or request help from a spouse and are expected to rate their perceived social support as low (Bowlby, 1988; Monin et al., 2013; Morse et al., 2012). In addition, female caregivers with a negative attachment schema are expected to perceive caregiving as more of a burden than males with a negative attachment because females tend to add more of an emotional-oriented approach to the task, whereas males are more task oriented (Apiknar et al., 2011; Bowbly, 1988; Kim et al., 2016; McDonnell & Ryan, 2013).

This theory was first applied to the relationship between an infant and parent, indicating that the infant looks to the parent for the resources necessary to survive (Bowlby, 1988). Attachment theory has been applied in research on patient stress and caregiver burden (Chen et al., 2013; Monin & Schulz, 2010; Monin et al., 2013; Morse et al., 2012). Research has supported the idea that attachment orientation may impact the emotional response of caregivers to patient stress, the amount of caregiver burden reported, and the ability of caregivers to cope with emotions related to burden (Chen et al., 2013; Monin & Schulz, 2010; Monin et al., 2013; Morse et al., 2012; Salcuni, 2015). Key studies by Monin and Schulz (2010), Monin et al. (2013), and Morse et al. (2012) showed how attachment theory has been applied to caregiver burden in past research. These researchers used attachment theory to evaluate emotional reactions of caregivers, measure caregiver depression and response to stress, and determine if spousal caregivers with positive attachment behavior had better coping skills to manage burden.

Attachment Orientations

There are two types of attachment orientations: positive or secure attachment and negative or avoidant attachment (Bowlby, 1988). Individuals with a secure attachment schema receive the support and reinforcement from his or her parents (Bowlby, 1988). This fuels confidence, the ability to manage physical and emotional reactions to stressful circumstances, and the ability to depend on others when necessary (Bowlby, 1988). A negative or avoidant attachment schema forms when an individual does not receive support and encouragement from his or her parents during infancy and childhood, causing the individual to struggle when faced with stressful circumstances and to find it difficult to depend on others (Bowlby, 1988).

Similar Use of Attachment Theory in Other Research

Emotional reactions of caregivers. Monin and Schulz (2010) reviewed literature to evaluate emotional reactions of caregivers using three theories: the model theory of emotional regulation (Gross, 2001), attachment theory, and the functionalist perspective on emotion. Specifically, the researchers conducted a review of literature on the connection between declining caregiver health and the emotional reactions to witnessing his or her partner experience chronic illness (Monin & Schulz, 2010). It was expected that caregivers would react in many different ways to the family member's experience with chronic illness. Some caregivers displayed emotional contagion, a form of mimicking their partner's emotions (Monin et al., 2013). Other caregivers empathized with the patient (Monin et al., 2013). Monin et al. (2013) used attachment theory to explain these different emotional responses through two models: the sense of self and the

sense of others. Caregivers who responded to the stress of the care receiver or patient with anxiety were identified as having an avoidant schema, meaning that the individuals found it difficult to rely on others and were afraid to be rejected by others (Monin et al., 2013). Attachment theory was also used by Monin et al. to explain how caregivers with positive behavior could react negatively to the family member's stress when already experiencing distress. Therefore, when caregivers felt insecure in the relationship with the patient, the caregiver was more likely to be affected by the distress. Monin et al. suggested that future research should be done to understand how attachment theory applies to late-life relationships when one is in the caregiver role, and the other is experiencing chronic illness.

Caregiver depression and response to stress. Morse et al. (2012) used attachment theory to evaluate caregiver depression and responses to stress. The purpose of this study was to gather more information on attachment styles of Black and White older adults as part of the Family Relationships in Late Life 2 study (Morse et al., 2012). Data were collected at the University of Georgia, the University of Pittsburgh, and the University of Alabama in Tuscaloosa from caregivers and care recipients who were residing together (Morse et al., 2012). To qualify to participate in the study, the caregiver had to be providing unpaid care for at least one daily living activity to an individual over the age of 60 who had either cognitive or physical impairment (Morse et al., 2012). The final sample consisted of 430 caregivers who had participated in the Family Relationships in Late Life 2 study. Researchers utilized the Bartholomew and Horowitz scale (Bartholomew & Horowitz, 1991) to gather information on caregiver attachment

behavior, the Center for Epidemiological Studies Depression scale (Radloff, 1977) to measure depressive symptoms, an 11-item scale to identify exemplary care behavior, the Conflict Tactics Scale (Straus, 1979) to measure potentially harmful caregiver behavior, and the Multidimensional Functional Assessment Questionnaire (Fillenbaum, 1988) to gather information on activities the caregiver was required to conduct for the patient (Morse et al., 2012). Data were analyzed in three different ways. Bivariate Pearson correlation coefficients were used to identify correlations between caregiver attachment schemas and caregiving responses, and a regression analysis was completed to determine if there were interactions between caregiver responses based on demographics, race, kinship, and type of attachment behavior. The third data analysis was an independent samples t test to compare the mean differences between Black and White caregivers (Morse et al., 2012). The results of the study indicated that participants modeling attachment avoidant behaviors were more likely to experience depression and provide inadequate care. Younger caregivers who possessed a negative avoidant schema reported higher levels of depression than older participants who possessed a negative avoidant schema when expected to do numerous daily living tasks (Morse et al., 2012). Results of the comparison between White and Black caregivers indicated that Black caregivers were younger, less likely to be spouses than White caregivers, had more depressive symptoms, completed a limited number of tasks for the patient, and received lower scores on the Bartholomew and Horowitz scale (Bartholomew & Horowitz, 1991; Morse et al., 2012). Morse et al. presented this as a difference between races; however, it appears that several

other factors could have influenced the outcome of this study including culture, socioeconomic status, age, and social support.

Attachment orientations of patients with Alzheimer's disease and spousal caregivers. Monin et al. (2013) chose to use attachment theory to examine how caregivers manage their emotions and reactions to caring for a chronically ill spouse. The hypotheses were that the attachment schema of an individual with dementia would affect self-reported symptoms, the attachment orientation of spousal caregivers would influence perceptions of their spouse's symptoms, and the caregiver's attachment schema would influence the patient's self-reported symptoms (Monin et al., 2013). Researchers recruited participants through the Alzheimer's disease Research Center at the University of Pittsburgh. The final sample consisted of 58 participants diagnosed with Alzheimer's disease and their spousal caregivers (Monin et al., 2013). The instruments used to measure data included a 12-item version of the Experiences in Close Relationships Scale (ECR; Brennan et al., 1998), and two scales to collect information on the physical and psychological symptoms of the patient from the view of the patient and from the view of the spouse (Monin et al., 2013). Data were analyzed using four different multiple regression models and with a linear regression model. The Monin et al. concluded that patients with a more negative attachment orientation reported more health symptoms, particularly when the caregiver also had a negative attachment orientation. Likewise, caregivers reported physical symptoms in patients who had a negative attachment orientation. These results support the use of attachment theory in explaining the reaction of caregivers and patients to physical symptoms of Alzheimer's disease, supporting the

use of this theory in examining reported caregiver burden in caregivers of patients with Alzheimer's disease.

Relationship of Attachment Theory to This Study

The theory of attachment suggests that caregivers with a secure attachment schema are able to cope with the stress of caregiving better than caregivers with an avoidant attachment schema (Bowlby, 1988; Monin et al., 2014; Morse et al., 2012). It was expected that female caregivers without a spouse whom lack strong social supports would demonstrate avoidant attachment behavior and report higher levels of caregiver burden. Likewise, it was expected that male caregivers whom are married and have significant social supports would demonstrate positive attachment behavior and have adequate coping abilities to control caregiver burden.

Literature Review Related to Key Variables and Concepts

Caregiver burden is a frequently researched topic. However, further information is needed on the relationship of marital status and social support for the caregiver to the level of caregiver burden experienced (Shankar et al., 2014, Mausbach et al., 2014, Kamiya et al., 2014). For the current study, the dependent variable was caregiver burden. The independent variables were marital status, social support, and gender. Research conducted in the past decade has focused on causes of caregiver burden such as type and severity of patient illness, demographics, and some other characteristics of the caregiver and patient. However, research is lacking in the area of social impact on ability of the caregiver to cope with burden (Kamiya et al., 2014).

Accommodating the Aging Population: Long-Term Care

Long-term care is necessary when the patients become unable to complete daily tasks on their own (Family Caregiver Alliance, 2015). These tasks include activities of daily living (ADLs) which are personal care tasks such as getting bathed or dressed and instrumental activities of daily living (IADLs) which include preparing meals, managing finances, buying groceries, cleaning the house, and taking medications (d'Orsi et al., 2014; Family Caregiver Alliance 2015). The inability to complete ADLs without support is often due to a physical impairment, whereas difficulty completing IADLs indicates moderate cognitive impairment usually due to a condition such as Alzheimer's disease or other type of dementia (d'Orsi et al., 2014). The amount of limitations a person has on ADLs and IADLs, the availability of family members to assist with care, and the availability of agencies to provide long-term care are usually key factors in determining if the patient is able to continue living in his or her home, must move in with a family member, or needs to be placed in a long-term care facility (Family Caregiver Alliance, 2015; Iavarone, 2014; Krull, 2013; Mausbach et al., 2014; Tremont et al., 2013). Longterm care services may be provided by friends and family or by professional agencies (Family Caregiver Alliance, 2015).

The task of providing long-term care to a relative is challenging because families do not usually have a plan in place for providing care (Krull, 2013; Kwak & Polivka, 2014). The need for long-term care often happens quite abruptly, often after a sudden illness or injury that requires hospitalization, and is usually required for several years (Koplow et al., 2015; Krull, 2013; Kwak & Polivka, 2014). There are professional

caregivers within personal care agencies who can provide care in the patient's home and adult daycare services to assist with care when family members are unavailable (Hudson, 2014). However, establishing care services takes time and money, and in some areas home care services are in high demand and lack enough resources to fulfill demand as the aging population continues to grow rapidly (Hudson, 2014).

Preparing for the Transition Into a Nursing Home

About two-thirds of patients diagnosed with Alzheimer's disease are receiving informal care in a private residence instead of in a nursing home (Family Caregiver Alliance, 2015). On average, family member caregivers provide care for about five years before pursuing professional care, which usually results in transition of the patient to a nursing home (Muller et al., 2017; Tremont et al., 2013). The decision to transition an individual into a nursing home usually occurs after a drastic change in physical or mental health. It is based on factors such as health of the patient, health of the potential caregiver, proximity of the caregiver to the patient's home, amount of care required on a daily basis and the caregiver's employment status (Krull, 2013). Admittance into a nursing home may be a temporary or permanent plan for long-term care, depending on if the patient needs short-term rehabilitation services or if the patient has had a permanent decline in health that makes it unsafe for the patient to reside in a community setting even with care in the home (Arling et al., 2013). If an individual resides in a nursing home more than 90 days, it is unlikely that the patient will return to a community setting, even if the intent was for short-term rehabilitation (Arling et al., 2013).

The first few months after being admitted into a nursing home is critical for the physical and mental health of the patient (Brownie et al., 2014). During this time, the patient has to accept the reality of leaving home, adjust to a new environment, and in some instances, deal with recent changes in health (Brownie et al., 2014; Ryan & McKenna, 2013). Patients may fear losing independence and privacy and may feel their dignity has been compromised (Naden et al., 2013; Schulz et al., 2014). Researchers have indicated family involvement in care planning during the process of transitioning a patient to a nursing home improves patient health (Dillman et al., 2013; Rose & Lopez, 2012). Providing families with a nurse to assist in the transition process may improve caregiver confidence in decision making and enhance communication between the family and nursing home (Rose & Lopez, 2012). Patients are likely to experience better overall health if their family visits often and provides emotional support during the transition into a facility (Iavarone 2014). This is why it is so important that the caregiver is able to manage the burden in order to focus on supporting the patient during this difficult time to minimize the negative impact on the patient's overall health.

The ultimate goal for most nursing homes is to provide acceptable care to improve or maintain the quality of life for patients (Bern-Klug, 2014). There are many steps nursing home staff can take to achieve this goal. One of the biggest concerns for individuals who require long-term care is maintaining dignity (Naden et al., 2013). Experiencing limitations in ability to complete daily living tasks and losing control of some aspects of life are challenging concepts for aging individuals to accept. Strategies to maintain dignity for these individuals include adequate communication with them

about their care, involving the patient in decision-making, allowing the patient to maintain some level of privacy, and being courteous and respectful (Naden et al., 2013). These strategies can be used by family or professional caregivers before and after the patient transitions to a facility.

Caring for an Individual with Alzheimer's Disease

In the year 2011, there were almost 15 million people in the United States providing care for a patient with Alzheimer's disease in an informal setting, meaning the caregiver was not a paid professional (Family Caregiver Alliance, 2015). Having a family member diagnosed with Alzheimer's disease presents many challenges, impacting the family members physically, psychologically, and financially (Iavarone et al., 2014). The most common health concerns for caregivers of patients with Alzheimer's disease are anxiety, depression, and a decline in physical health (Iavarone et al., 2014). This is because the effects of Alzheimer's disease are debilitating to the patient, impacting primary functions such as reasoning, language, decision making, judgment, and the ability to complete daily living tasks (Family Caregiver Alliance, 2015; Iavarone et al., 2014). In addition, as the patient's health declines, the individual is likely to experience a loss of interest in hobbies, difficulty with social interactions, aggressive behavior, trouble sleeping, and incontinence (Kamiya et al., 2014). Caring for a person who has been diagnosed with Alzheimer's disease can be particularly challenging for someone who has little knowledge of the disease. It can be surprising to witness such changes in behavior, particularly when the caregiver is a close family member such as a spouse or adult child of the patient (Conde-Sala et al., 2010a).

In recent years, researchers have focused in on burden of caregivers for patient diagnosed with Alzheimer's disease. One recent study was conducted by Kamiya et al. (2014) to investigate the factors that influence burden in caregivers of patients with Alzheimer's disease. The Zarit Burden Interview (ZBI; Zarit et al., 1985) was used to gather information on severity of caregiver burden (Kamiya et al., 2014). This was compared to data collected using several scales to identify the level of impairment experienced by the patient (Kamiya et al., 2014). Results identified a higher burden scale in caregivers whose family member had a higher level of cognitive impairment (Kamiya et al., 2014). Kamiya et al. (2014) did state that there were several limitations in the study. Further studies should be done to explore a more diverse group of participants, explore the impact of physical illness of the patient, environmental factors, financial status, and social support available for the caregiver (Kamiya et al., 2014). A similar study was facilitated by Raggi et al. (2015) to determine if there was a correlation between severity of burden and impairment experienced by the patient. The specific impairments identified in this study were cognitive, physiological, behavioral, and motor skills (Raggi et al., 2015). Findings indicated that there was a positive correlation between level of caregiver burden reported and the severity of impairments of the patient being cared for. However, Raggi et al. (2015) stated that caregivers with successful coping methods reported lower levels of burden, suggesting that further research needs to be conducted on caregiver burden in patients with Alzheimer's disease specifically on types of coping methods and available support from family and friends. Based on the

information from these two recent studies, additional research is needed to explore social support for caregivers of patients with Alzheimer's disease.

Caregiver Burden in Family Caregivers

Caregiver burden refers to the stress a person experiences due to the responsibilities of being a caregiver (Shankar et al., 2014). This chronic stress may have a negative impact on the caregiver's physical and psychological health, social life, and personal finances. Burden may be displayed as depression, anxiety, guilt, frustration, failing to complete the important tasks of caregiving (Brownie et al., 2014; Naden et al., 2013; Iavarone, 2014). Caregiver physical or mental health may decline due to caregiver burden (Brownie & Horstmanshof, 2014; Conde-Sala et al., 2014; Naden et al., 2013; Reed et al., 2014; Shankar et al., 2014). If the caregiver's overall health declines, it can limit the quality of life experienced by the patient (Shankar et al., 2014). For example, if the caregiver is not able to dedicate adequate time and focus to caregiving, he or she may forget important tasks such as giving the patient medications, taking the patient to doctors' appointments, or preparing balanced meals (Iavarone, 2014).

In previous research on caregiver burden, many different characteristics of the caregiver have been used to explain the caregiver's ability or inability to cope with the stress of being a caregiver. Some of these characteristics include gender, race, age, employment, education, and support from friends and family. To understand how marital status and social support are related to caregiver burden of patients with Alzheimer's disease, it is important to review research on the increased demand for long-term care for the aging population, maintaining quality of life when transitioning the patient to a

nursing home, caregiver stress in family member caregivers, and caring for an individual with Alzheimer's disease. Most caregivers experience some level of chronic stress, also referred to as caregiver burden (Iavarone et al., 2014). In caregivers of patients with Alzheimer's disease, chronic stress often appears as depression, clinical anxiety, and a major decline in physical health (Iavarone et al., 2014). The purpose of this study was to identify the relationship of marital status and social support to the burden of family caregivers of patients with Alzheimer's disease.

Relationship to the Patient

Spouse of the patient. There has been research conducted to determine if there was a correlation between the relationship of the caregiver to the patient and severity of burden (Pietromonaco & Beck, 2015). Attachment theory has been applied to romantic relationships because adult romantic relationships display traits similar to an attachment relationship between an infant and parent (Pietromonaco & Beck, 2015). Some researchers have stated that a caregiving spouse of the patient is at higher risk of experiencing burden than another adult caregiver (Conde-Sala et al., 2014; Monin et al., 2014; Pietromonaco & Beck, 2014). This is because the spouse had previously relied on the patient for support and partnership. When placed in a caregiver role, the spouse must find other means of support while coping with the reality that the patient has experienced an extreme change in overall health (Conde-Sala et al., 2014; Monin et al., 2014; Pietromonaco & Beck, 2014). It is also common for spouses to experience health issues that limit the quality of care they can provide (Reed et al., 2014). Specifically, spouses of patients with Alzheimer's disease tend to experience increased emotional stress and

decreased physical well-being when caring for their spouse (Mausbach et al., 2014). These issues usually improve if the patient is placed in a long-term care facility (Mausbach et al., 2014). Mausbach et al. (2014) does expand on this by stating that it may be common for burden to decrease after the patient is placed in a nursing home. However, there are several factors that contribute to the spouse's coping skills, personal mastery of daily tasks, physical health, prescribed medications, participation in therapy, and participation in social activities (Mausbach et al., 2014).

Chappell et al. (2014) bring contrasting information with their research, stating that the spouse of the care receiver may be a better caregiver than an adult child or other family member because they may be able to invest more time and energy into providing care. This is because the spouse may be older, possibly retired, and have fewer commitments to maintain than an adult child who may have his or her own children, family commitments, and employment in addition to providing care to a patient (Chapell et al., 2014). Cary, Rubright, Grill, and Karlawish (2015) suggest spouses of the patient have a more positive outlook than adult children caregivers. In a study conducted in 2010, adult children had better physical health, reported high levels of social burden, psychological stress, and guilt (Conde-Sala et al., 2010b). The spousal caregivers scored higher on emotional well-being and perceived a more positive outcome for the patient than the adult children (Conde-Sala et al., 2010b). In another study conducted by Conde-Sala et al. (2010a), researchers identified factors of burden associated with either spouse or adult child caregivers. The outcome of the study was that burden levels of each group

were not affected by age, physical health, or mental health of participants (Conde-Sala et al., 2010a).

Adult child caregiver. Researchers have suggested that additional research be conducted to compare the severity of caregiver burden between spousal caregivers and adult child caregivers (Conde-Sala et al., 2014; Reed et al., 2014; Cary et al., 2015). Conde-Sala et al. (2010a) facilitated a study to determine if there were variables that differentiate caregiver burden between spouse and adult child caregivers. Variables that the researchers examined include the caregiver's perception of the patient's well-being based on factors such as health, energy, memory, ability to complete physical activities, and socialization (Conde-Sala et al., 2010a). The researchers found adult caregivers had a more negative perception of patient health, and that particularly female adult children based perception of patient health on the severity of burden experienced and the level of depression witnessed in the patient (Conde et al., 2010a). Spousal caregivers reported a more positive outlook on patient health, particularly in spouses who had more education and witnessed greater functional autonomy in the patient (Conde-Sala et al., 2010a).

Pillemer and Suitor (2014) focused on caregiver burden in adult children of patients diagnosed with dementia. The results of this study expanded on the findings from the Conde-Sala et al. (2010) study by examining variables that may influence the burden experienced by adult children caregivers. Participants who had full-time employment or a job with limited flexibility reported higher levels of stress, caregiver burden, and depression than participants who worked part-time jobs with more flexibility or were unemployed (Pillemer & Suitor, 2014). Caregivers who were married, had

children, and lived further away from the care receiver reported more stress in the caregiving role than participants living in closer proximity with fewer social roles (Pillemer & Suitor, 2014). Although this study does identify possible risk factors for caregiver burden, this study does not explore the same factors in spouse caregivers. Therefore, further research should be done to determine if full-time employment leads to higher stress in all categories of caregivers, or if social support and type of relationship to the patient are related to severity of burden experienced. This study may yield information on the potential relationship of social support and relationship to the patient to severity of burden.

Gender

In a review of several studies on caregiver burden and gender differences, it was concluded that men report fewer signs of physical stress than women caregivers (Kim et al., 2016; McDonnell & Ryan, 2013). Severity of psychological stress was comparable among male and female caregivers (Kim et al., 2016; McDonnell & Ryan, 2013). Female caregivers are also more likely to report distress on their social lives due to the time invested in providing care (McDonnell & Ryan, 2013). McDonnell and Ryan (2013) and Robinson et al. (2014) suggested that the reason males report lower levels of stress because they approach caregiving in a task-oriented manner. Females report higher stress because they add an emotional value to the caregiving role (Kim et al., 2016; McDonnell & Ryan, 2013; Robinson et al., 2014). This may provide a simple explanation to gender differences in reported caregiver burden, however, it is possible that there were many other factors that impacted severity of burden among males and females. Equal

representation of gender has been an ongoing concern in research of caregiver burden because of the low percentages of male participants (Friedemann & Buckwalter, 2014; McDonnell & Ryan, 2013; Upson, Flynn, Haynes, Sancho, & Glendon, 2015; Robinson et al., 2014; Schulz et al., 2007).

Gender roles of adult children caregivers. A comparative study was conducted by Akpinar et al. (2011) to determine if gender of a caregiver affects severity of burden among caregivers of individuals diagnosed with Alzheimer's disease. Variables used in this study include age, amount of time providing care each day, education level of the caregiver, employment status of the caregiver, and scores of the patient for a MMSE (Akpinar et al., 2011). Female caregivers scored significantly higher than male caregivers for caregiver burden based on the variables of time dependence, physical and developmental factors, and social activity. The only variable in which female and male caregivers scored similarly was on emotional burden. Akpinar et al. stated that family values and gender roles could affect caregiver burden among male and female adult children and suggested further studies be done to explore this.

McDonnell and Ryan (2013) conducted a review of several studies on caregiver burden to develop a better understanding of gender differences that may impact severity of caregiver burden. One conclusion drawn from this review was that son caregivers reported less burden than daughter caregivers because of the types of tasks they took responsibility for. Son caregivers provided fewer hours of care, and they handled transportation, finances, shopping, and housekeeping tasks (McDonnell & Ryan, 2013). Son caregivers were more likely to seek help in direct care tasks from other family

members or professional agencies (McDonnell & Ryan, 2013). Daughter caregivers took responsibility for more direct care hours, were less likely to seek help in caregiving tasks, and statistically reported a higher number of hours dedicated to care on a weekly basis (McDonnell & Ryan, 2013). Part of the difference in burden reported among male and female caregivers may be explained by the relationships sons and daughters hold with their parents along with the family's view of gender roles (Apiknar et al., 2011; McDonnell & Ryan, 2013). In some cases, the son takes on tasks related to finances and housekeeping rather than direct care tasks because he has been designated to take over a family business. This is more common in rural areas when a family owns a farming business or when the family owns a large amount of property that will require intense maintenance (McDonnell & Ryan, 2013; Stewart et al., 2016).

Comparison of men and women providing care in home versus nursing home care. Both men caring for their wives and sons caring for a parent have indicated less stress, guilt, and depression when providing care in the family home than when the patient is living in a nursing home (McDonnell & Ryan, 2013). Men caring for a wife diagnosed with dementia whom had less education, more social interactions, and good health were better at coping with burden (McDonnell & Ryan, 2013). They were also less likely to focus on the strain they experienced due to caregiving duties (McDonnell & Ryan, 2013).

Women caregivers, whether spouse or daughter of the patient, report more physical and emotional stress when providing care in the family home than when the patient is living in a nursing home regardless of personal health, experience, and

education (McDonnell & Ryan, 2013; Silverman, 2013). Women caring for an immediate family member diagnosed with dementia often neglected personal needs and other responsibilities to complete caregiver tasks (McDonnell & Ryan, 2013; Silverman, 2013). They are less likely to request help from others when overwhelmed with caregiver tasks, and were more likely to report guilt if unable to complete all tasks (Ericksson, H., Sandberg, J., & Hellstrom, I., 2013; McDonnell & Ryan, 2013; Silverman, 2013).

Additional research is needed to understand if there is a relationship between gender and severity of caregiver burden. This study may provide information on the relationship between gender and caregiver burden. As in other studies of caregiver burden, the ratio of male to female participants in the REACH II program is about 1 male for every 3 females. Male participants were not equally represented in the study, limiting generalizability (Friedemann & Buckwalter, 2014; McDonnell & Ryan, 2013; Robinson et al., 2014; Schulz et al., 2007; Upson et al., 2015). Additional research is necessary to collect more data on gender differences among caregiving roles. Research has not equally evaluated gender differences while evaluating all factors that may influence burden, such as age, experience, education, ethnicity, socioeconomic status, and family dynamics.

Summary and Conclusions

As previously stated, the problem addressed in this study was that most caregivers experience some level of burden, which in turn can compromise the quality of care the caregiver is able to provide to the patient (Iavarone, 2014). The major themes that were

important to this research include providing long-term care to the aging population, caring for a patient with Alzheimer's disease, and caregiver burden experienced by an immediate family member caregiver. There is strong evidence in the literature to support the need for additional research of caregiver burden as the aging population continues to grow. Specifically, Alzheimer's disease is a debilitating disease that affects millions of individuals in the United States and may increase the symptoms of burden that caregivers experience (Conde-Sala et al., 2014; Kamiya et al., 2014; Reed et al., 2014). Caregiver burden is a problem that may not be avoidable; however, with the correct tools, it may be possible to limit caregiver burden and maintain overall health of the caregiver. By limiting caregiver burden, both the caregiver and the patient will experience a higher quality of life.

There is a substantial amount of research supporting the idea that coping skills can be utilized by caregivers to manage burden (Conde-Sala et al., 2014; Fukahori et al., 2010; Kim et al., 2012; Shankar et al., 2014; Krull, 2013). Fukahori et al. (2010) discussed the importance of conducting screenings on family member caregivers to measure symptoms of burden. This can identify areas of strength and weakness for the caregiver and guide professionals in choosing the best method of treatment for burden based on the individual (Fukahori et al., 2010). It is evident from past research that burden does not only affect the caregiver (Kim et al., 2012). Caregiver burden also affects the patient being cared for, impacting long-term care and end-of-life planning (Kim et al., 2012; Krull, 2013; Shankar et al., 2014; Vandervoort et al., 2014). There were several characteristics of family member caregivers and caregiver burden that need

to be explored in future research. Specifically, further research needs to be done to understand if there is a relationship of social support and severity of caregiver burden (Kamiya et al., 2014; Mausbach et al., 2014). Social relationships refer to caregiver marital status, support from other family members, friends, and neighbors (Schulz et al., 2007; Shankar et al., 2014; van der Steen et al., 2012). Additional research is needed to determine if there is a relationship between gender and severity of burden (Friedemann & Buckwalter, 2014; Kim et al., 2016; McDonnell & Ryan, 2013; Upson et al., 2015; Schulz et al., 2007). This is the gap in the literature that was examined in this study. In Chapter 3, I will discuss methodology for the current study. To explore this gap in the literature, I used a nonexperimental quantitative design to examine the causal relationship between social support, marital status, and gender on caregiver burden. Archival data from the REACH II program conducted by the Alzheimer's Association - North Central Texas Chapter and the United Way of Tarrant County was used in cross-sectional data analysis to address the research questions to explore these variables in relation to the gap in the literature.

Chapter 3: Research Method

The purpose of this study was to explore marital status, perceived social support, and gender of family caregivers of patients with Alzheimer's disease to determine if these factors were related to caregiver burden. This chapter provides an explanation of the research design and rationale for the design. I will discuss the target population, sampling method, procedures, and the use of archival data. This chapter will also include information on the data analysis, validity, and ethical procedures.

Research Design and Rationale

The independent variables in this study were marital status, social support, and gender of the family caregiver. The dependent variable was the severity of caregiver burden reported. The research method selected for this study was a nonexperimental quantitative design method. This was the most appropriate method because the study measured the causal relationship between variables with the intent to reach a specific conclusion (Frankfort-Nachmias et al., 2014). A qualitative design would not accommodate the numerical comparison of data required in this study (Frankfort-Nachmias et al., 2014).

Methodology Using Archival Data

Population, Sampling, and Sampling Procedures

The target population for this study was family caregivers of individuals diagnosed with Alzheimer's disease. As of 2016, there were 15.9 million people in the United States in this category (Family Caregiver Alliance, 2015). For the current study, I used archival data obtained from the REACH II program conducted by the Alzheimer's

Association - North Central Texas Chapter and the United Way of Tarrant County (Alzheimer's Association, 2017). This agency serves Tarrant County and surrounding counties in northern Texas (Alzheimer's Association, 2017). Data obtained by the REACH II program was collected using a convenience sample. This method of sampling was used because the Alzheimer's Association - North Central Texas Chapter was only able to recruit participants in the area served by their chapter (Alzheimer's Association, 2017). One of the goals of this agency is to provide the REACH II program to as many participants as possible. Utilizing a different sampling method would have interfered with this mission.

Caregiver Inclusion Criteria

The REACH II program delivered by the Alzheimer's Association – North Central Texas Chapter used the caregiver and care recipient criteria as published in the original REACH II study (Lykens, 2014; Schulz et al., 2001). To be included as a caregiver participant, each individual had to be at least 21 years of age, be the family member of the care recipient, provide care for the recipient for more than 6 months, provide a minimum of 4 hours of direct care each day, and reside with the care recipient or share a common kitchen area (Schulz et al., 2001). Caregivers were required to have a telephone compatible with the Computer Telephone Integration System and expected to reside in the recruitment area for 6 months after the baseline assessment for implementation of the intervention and follow-up assessment (Schulz et al., 2001). All participants were required to complete a risk screening tool and have a score of at least 1

for the first three questions and a score of at least 2 for the last six questions (Schulz et al., 2001).

Caregiver Exclusion Criteria

Individuals were excluded from the REACH II program if they were unable to speak English or Spanish, if they were actively enrolled in cancer treatment, if they had participated in the REACH I study, or they were expected to place a family member in a nursing home or with another care provider within 6 months. Recruits who missed four or more questions on the Short Portable Mental Health Status Questionnaire (Pfeiffer, 1975) were also excluded (Schulz et al., 2001).

Care Recipient Inclusion/Exclusion Criteria

There were also criteria for each care recipient to participate in the REACH II study. In order to participate, the patient needed to have diagnosis of dementia or cognitive impairment by his or her primary physician (Schulz et al., 2001). If no diagnosis, the individual was given the MMSE (Folstein, Folstein, & McHugh, 1975), and the individual was able to participate if the raw score was under 24. Care recipients were excluded from participating if they were unable to speak English or Spanish, had participated in the REACH I study, had a history of Parkinson's disease or a stroke, received cancer treatment during the study, or had more than three acute medical hospitalizations within the past year (Schulz et al., 2001). Additional exclusionary criteria for care recipients included having schizophrenia or another severe mental illness, dementia secondary to head trauma, and blindness or deafness prohibiting completion of data collection. Individuals were also excluded if they had participated in REACH

interventions, obtained MMSE results of 0 and were bedbound, or if they planned to be placed in a nursing home within 6 months.

Power Analysis

A power analysis is necessary when conducting a quantitative study to determine the probability that the null hypotheses will be accurately rejected, which is referred to as the power of the statistical test (Faul, Erdfelder, Lang, & Buchner, 2007). The G*Power (Erdfelder, Faul, & Buchner, 1996) software was used to calculate an adequate sample size to conduct an ANOVA with 24 groups for this study. A standard power level of .80 and an alpha level of .05, indicating a medium effect size, were used to conduct the analysis (Faul et al., 2007). The outcome of the analysis was that the sample size should be at minimum 128 participants. There were 586 participants in the REACH II program conducted between January 2015 and December 2016, making the sample size more than adequate to reach the desired power level of .80 (Alzheimer's Association, 2017).

REACH II Procedures

The facilitators of the REACH II program used many forms of advertising to recruit participants to the REACH II program in northern Texas including referrals from a 24-hour telephone helpline, case managers, partnering agencies, support groups, the Aging and Disabilities Resource Center, and home health agencies in northern Texas (Lykens et al., 2014). The trained counselors of the REACH II program went to participant homes for the initial interview, and they provided follow up either in person or via telephone (Lykens et al., 2014). During these interview sessions, REACH II counselors provided participants with a packet of information similar to the informational

packets used in the original REACH II study by Schulz et al. (2001). Counselors also provided training on topics of home safety, stress management, behavioral skills training, and information that catered to the needs of each participant (Lykens et al., 2014). Data were collected between July 2015 and June 2016 (Alzheimer's Association, 2017). The follow-up interviews were conducted 6 months after the baseline assessment (Alzheimer's Association, 2017).

Procedure for Gaining Access to the Data Set

The United Way of Tarrant County provided funding for the REACH II program data collection, and the Northern Central Texas Chapter of the Alzheimer's Association managed data collected during implementation of the REACH II program. The United Way of Tarrant County has granted permission to the Alzheimer's Association to share data from the REACH II program for use in the current study. The staff facilitating the REACH II program de-identified data to protect confidentiality of all participants.

Instrumentation

Caregiver/Care Recipient Sociodemographic Information

The Intake Form (Alzheimer's Association, 2017) is a questionnaire used to collect basic descriptive data about the caregivers and care recipients during the baseline interviews. The questions are about the participant's marital status, employment, race, ethnicity, and gender, as well as the caregiver's relationship to the care recipient and the care recipient's date of diagnosis and health care provider (Alzheimer's Association, 2017).

Burden Interview

The original ZBI (Zarit et al., 1985) instrument is a 22-item scale in which caregivers rate each item on a 5-point Likert scale ranging from 0 (*never*) to 4 (nearly *always*) with overall scores ranging from 0 (*no burden*) to 88 (*highest level of burden*). In the study conducted by Zarit et al. (1985), the Spearman's rho correlation was used to determine construct validity of caregivers for patients diagnosed with dementia in relation to health, finances, and social life (Zarit et al., 1985). The outcome of the Spearman's rho correlation indicated good construct validity with correlation of .32 for activities of daily living, .32 for social life restrictions, .41 for the Brief Symptoms Inventory, and .71 for the global index of burden (Zarit et al., 1985). In review of reliability, there was excellent internal consistency with results of the Cronbach's alpha of .83 and .89 and test-retest reliability of .71.

In the REACH II study, a 12-item brief version of the ZBI (Bedard et al., 2001; Zarit et al., 1985) was administered to all caregiver participants. The caregivers rated each item on a 5-point Likert scale ranging from 0 (*never*) to 4 (nearly *always*; Schulz et al., 2001). Scores ranged from 0 which indicated no burden to 48, indicating the highest level of burden (Schulz et al., 2001). Bedard et al. (2001) developed the shorter version of the ZBI (Zarit et al., 1985) as a screening tool functional across diagnostic groups of cognitively impaired older adults with the intention that the scale could be used in cross-sectional, longitudinal, and intervention studies. In a study to examine validity and reliability of the 12-item ZBI (Bedard et al., 2001), internal consistency was calculated using Cronbach's alpha with a result of .88 (Bedard et al., 2001). Correlations between

the full ZBI (Zarit et al., 1985) and the brief ZBI (Bedard et al., 2001) were between .92 and .97, indicating that the brief version has a strong prediction rate compared to the full scale. The ZBI (Zarit et al., 1985) has been used primarily among the aging population; however, this scale has been used with all adult caregivers 18 years or older (Schulz et al., 2001; Zarit et al., 1985). There are translated versions of this scale in Arabic, Chinese, French, Japanese, Portuguese, and Spanish (APA, 2017b; Bachner, 2013; Goncalves-Pereira & Zarit, 2014; Tang et al., 2016).

Social Support

The social support (NIA/NINR-REACH II, 2002) questionnaire was administrated to all caregiver participants to determine the perceived amount of social support each caregiver reported. This was a hybrid questionnaire created by the REACH investigators (Schulz et al., 2001). The four categories addressed in this tool were received support, social interaction, negative interaction, and satisfaction with support (Cho, Ory, & Stevens, 2016; Schulz et al., 2001). The questions related to received support, satisfaction with support and negative interaction were obtained from the modified version of the Inventory of Social Supportive Behaviors (ISSB; Barrera, Sandler, & Ramsey, 1981; Krause, 1995; Krause & Markides, 1990). The questions about social network were adapted from the Lubben Social Network Index (Lubben, 1998). The scale created by Krause (1995) has a Cronbach's alpha of .70, indicating an acceptable level of internal consistency (Krause, 1995). The 6-item Lubben Social Network Scale (Lubben, 1988) scores range from 0 or no support to 30 or high support. This scale has an overall internal reliability of .83 with reliability of family questions

ranging from .84 to .89 and non-kin questions ranging between .80 and .82 (Lubben, 1988). As for validity, low scores have been correlated with mortality, all-cause hospitalizations, mental health issues, physical health issues, and lack good health practices (Lubben, 1988). This scale has been used to rate social support among male and female adults 18 years and older of varying race, including White, Black, Hispanic, and Asian (Krause, 1995; Lubben, 1988; Schulz et al., 2001). It has been used to evaluate perceived social support in various situation, including caring for a family member, coping with health problems, natural disasters, and during bereavement (Schulz et al., 2001).

Data Analysis

Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 23.0 for Windows. Preliminary analyses were conducted to analyze demographic information and to determine if all assumptions were met for each statistical test.

Demographic information collected on the demographic questionnaire included caregiver race, ethnicity, age, and marital status. Data cleaning and screening was completed by the REACH II program evaluators. Data were transferred from paper records to the data management software using a coding system. Each participant was assigned a unique participant identification number to protect participant identities (Alzheimer's Association, 2017). The data management software was used to identify inconsistencies, and records containing errors were excluded from the study (Alzheimer's Association, 2017). Data were provided to me by the Alzheimer's Association - North Central Texas Chapter as a Microsoft Excel document. I transferred data to SPSS to conduct the

analyses. To address the first research question, a one-way ANOVA was done to determine if marital status had a significant effect on burden. For the second research question, a correlation analysis was used to determine if there was a linear association between social support and burden. An independent sample *t* test was utilized to identify if there was a difference in burden between male and female caregivers, addressing the third research question. Finally, I conducted a multiple linear regression model for the fourth research question. This statistical test was used to determine if there was a significant interaction between marital status, social support, and gender on severity of caregiver burden.

Research Questions and Hypothesis

RQ1: Is there a significant difference in reported caregiver burden as measured by the burden interview scale (see Appendix C) between caregivers who are single, married, widowed, or divorced?

 H_0 1: There is no significant difference in reported caregiver burden among caregivers who have never been married, are currently married, widowed, or divorced.

 H_a 1: There is a significant difference in reported caregiver burden among caregivers who have never been married, are currently married, are widowed, or divorced.

RQ2: Is there a relationship between caregiver burden as measured by the burden interview scale (see Appendix C) and caregiver perceived social support as measured by the social support scale (see Appendix B)?

- H_02 : There is no significant correlation between caregiver burden and perceived social support.
- H_a2 : There is a significant correlation between caregiver burden and perceived social support.
- RQ3: Is there a significant difference in reported burden as measured by the burden interview scale (see Appendix C) between male and female caregivers?
- H_03 : There is no significant difference in reported caregiver burden among male and female caregivers.
- $H_{\rm a}3$: There is a significant difference in reported caregiver burden among male and female caregivers.
- RQ4: Is there a significant interaction between caregiver marital status, social support, and gender on caregiver burden as measured by the burden interview scale (see Appendix C)?
- H_04 : There is no significant interaction between caregiver marital status, social support, and gender on caregiver burden.
- H_a 4: There is a significant interaction between caregiver marital status, social support, and gender on caregiver burden.

Threats to Validity

There were some aspects of the REACH II program that threaten validity. The first factor that limits validity was the use of a sample of convenience. The facilitators of the REACH II program relied on mostly referrals from local agencies to recruit participants. The agency did not have a minimum number of participants required to run

the program because the agency's focus is on providing educating and supporting caregivers. The agency did not conduct the REACH II program strictly for research purposes. In addition, the sample was limited to people in northern Texas, limiting how well the sample population accurately represents the target population (Alzheimer's Association, 2017). Validity could also be compromised if an investigator failed to follow the script, influenced participant answers, or if participants gave answers they assumed were social desired. The REACH II program utilized scales published in the REACH II study by Schulz et al. (2001). These scales were evaluated by an external review team during the REACH II study (Schulz et al., 2001). The REACH II validity and reliability on outcomes of caregiver quality of life and prevalence of caregiver clinical depression were rated as 3.5 and 4.0 out of 4.0 respectively (Schulz et al., 2007). Instruments were psychometrically sound and backed by research (Schulz et al., 2007). A detail-oriented approach was utilized when creating the manual to limit investigator influence on participant answers (Schulz et al., 2007). There were some limitations to external validity because the sample was drawn from one region and focused on specifically caregivers of patients diagnosed with Alzheimer's disease. However, these limitations were addressed by using many methods to recruit participants, such as networking with other agencies and utilizing the internet. The sample obtained by the Alzheimer's Association (2017) includes participants from both metro and rural areas, a variety of ethnicities, male and female, a large range of ages, and caregivers from different levels of education and employment experience. The brief version of the ZBI (Bedard et al., 2001; Zarit et al., 1985) was developed for use with all caregivers, making this method applicable to other populations of caregivers. Both social support and caregiver burden scales have good external reliability because both were designed to be used with caregivers, not specifically for only caregivers of patients diagnosed with Alzheimer's disease (Krause, 1995; Schulz et al., 2001, Zarit et al., 1985).

Ethical Procedures

I obtained the archival data for this study from the Alzheimer's Association -North Central Texas Chapter. Data were screened and coded to ensure confidentiality of all participants during the REACH II program (Alzheimer's Association, 2017). Each participant was assigned an identification number to utilize on all documents where data were collected. This prevents confidential or identifying information from being compromised during and after the completion of the REACH II program (Alzheimer's Association, 2017). Only designated management staff at the Alzheimer's Association -North Central Texas Chapter have access to the data, which was saved electronically (Alzheimer's Association, 2017). Due to the lack of confidential information, there were no plans for data to be destroyed. These policies ensure record keeping and data management was compliant with Ethical Standards 6.01 and 6.02 which regulate documentation and record maintenance of scientific research (APA, 2017a). There was no need to obtain informed consent or new agreements from participants prior to conducting this study. According to Ethical Standard 8.05, when utilizing archival data which does not include confidential information of the participants, it is acceptable to conduct research without obtaining informed consent (APA, 2017a). Walden University required approval from the Institutional Review Board (IRB) prior to conducting this

study. I submitted an application for IRB approval prior to completing the study, and the IRB did grant permission to conduct the study. The approval number was 07-14-17-0126856.

Summary

In this chapter, I explained the research design and rationale for this study, the target population, and the use of archival data. In addition, I provided a detailed explanation of the sampling method and procedures of the REACH II program from which data were obtained to conduct the current study. This chapter concluded with a discussion of validity, ethical considerations, and the process for complying with the IRB at Walden University.

In Chapter 4, I will present the process for data collection and data analysis of the independent variables of marital status, perceived social support, and gender of family member caregivers of patients with Alzheimer's disease to determine if these factors were related to the dependent variable of caregiver burden. An interpretation of the results will also be provided in Chapter 4.

Chapter 4: Results

The purpose of this study was to quantitatively examine if caregiver marital status, perceived social support, and gender of caregivers of patients with Alzheimer's disease were related to caregiver burden. The research questions and hypotheses were as follows:

RQ1: Is there a significant difference in reported caregiver burden as measured by the burden interview scale (see Appendix C) between caregivers who are single, married, widowed, or divorced?

 H_01 : There is no significant difference in reported caregiver burden among caregivers who have never been married, are currently married, widowed, or divorced.

 H_a 1: There is a significant difference in reported caregiver burden among caregivers who have never been married, are currently married, are widowed, or divorced.

RQ2: Is there a relationship between caregiver burden as measured by the burden interview scale (see Appendix C) and caregiver perceived social support as measured by the social support scale (see Appendix B)?

 H_02 : There is no significant correlation between caregiver burden and perceived social support.

 $H_{\rm a}2$: There is a significant correlation between caregiver burden and perceived social support.

RQ3: Is there a significant difference in reported burden as measured by the burden interview scale (see Appendix C) between male and female caregivers?

 H_03 : There is no significant difference in reported caregiver burden among male and female caregivers.

 H_a 3: There is a significant difference in reported caregiver burden among male and female caregivers.

RQ4: Is there a significant interaction between caregiver marital status, social support, and gender on caregiver burden as measured by the burden interview scale (see Appendix C)?

 H_04 : There is no significant interaction between caregiver marital status, social support, and gender on caregiver burden.

 H_a 4: There is a significant interaction between caregiver marital status, social support, and gender on caregiver burden.

In this chapter, I will summarize the data collection procedures, demographics of the participants, and the results of the main analyses addressing the four research questions.

Data Collection

The target population for this study was family caregivers of individuals diagnosed with Alzheimer's disease. I obtained archival data from the REACH II program facilitated by the Alzheimer's Association - North Central Texas Chapter using a convenience sample. Participants had to meet caregiver inclusion criteria, provide care to an individual who met care recipient inclusion criteria, and be enrolled in the REACH II program between January 2015 and December 2016. Field interviewers collected data during the initial face-to-face interview conducted within 1 month of enrollment into the

REACH II program with the Alzheimer's Association - North Central Texas Chapter.

Program facilitators assigned each participant an identification number to be used on all documentation to protect participant identity. The Alzheimer's Association removed any identifying information prior to sharing the archival data. Data were produced by the Alzheimer's Association in a Microsoft Excel spreadsheet. There were no discrepancies with the data collection plan discussed in Chapter 3.

There were 586 caregiver participants included in this sample. The sample consisted of 77.5% females and 22.5% males. In this sample, 81.4% of participants identified as White, 16.7% as African American, 0.9% as Asian, 0.3% as multiple race, 0.2% as Native American, 0.3% as American Indian or Alaska Native, and 0.2% did not identify a race. A total of 79.2% of participants indicated their ethnicity was Hispanic or Latino, 11.9% did not identify as Hispanic or Latino, and 8.9% did not indicate an ethnicity. Caregivers ranged from 21 to 92 years of age, with the majority of caregivers falling between 50 and 79 years of age. A total of 63.7% of participants reported marital status as married, 12.5% as single, 5.3% as divorced, 1.5% as widowed, 0.5% as other, and 16.5% did not provide a response. Table 1 illustrates these demographics.

Table 1
Frequencies: Demographics of Caregiver Participants

	_	
	n	%
Gender		
Female	454	77.5
Male	132	22.5
Race		
White	477	81.4
African American	98	16.7
Asian	5	0.9
Native American	1	0.2
American Indian	2	0.3
Multiple races	2	0.3
No response	1	0.2
Ethnicity		
Hispanic/Latino	464	79.2
Non-Hispanic/Latino	70	11.9
No response	52	8.9
Age		
21-29	2	.3
30-39	13	2.2
40-49	53	9.0
50-59	148	25.3
60-69	135	23.0
70-79	138	23.6
80-89	91	15.6
90-99	6	1.0
Marital status		
Married	373	63.7
Single	73	12.5
Divorced	31	5.3
Widowed	9	1.5
Other	3	0.5
No response	97	16.5

There were some limitations to external validity because a nonprobability convenience sample was used. This means each group did not have an equal chance of being represented in the sample (Field, 2013). The limitation to external validity was addressed by the facilitators of the REACH II program by using several methods to recruit participants, such as networking with other agencies, collecting referrals from websites, recruiting from support groups, and obtaining referrals from a telephone helpline (Alzheimer's Association, 2017; Lykens et al., 2014). Participants came from both rural and metropolitan regions in northern Texas (Alzheimer's Association, 2017). According to the Alzheimer's Association (2017), roughly 65% of caregivers in the United States are female and 34% of caregivers are aged 65 or older. In this study, 77.5% of participants were female, and 62.2% were aged 60 or older. About 62% of caregivers in the United States identify their race as White and 13% as African American, and 6% as Asian American (Family Caregiver Alliance, 2015). In this study, 81.4% identified as White, 16.7 identified as African American, and less than 1% as Asian American. While there were some similarities between the target population and sample used in this study, there were some limitations that impact generalizability. Researchers should consider these limitations when conducting future research.

Results

Preliminary Analysis

The archival data were provided by the Alzheimer's Association-North Central Texas Chapter in a Microsoft Excel spreadsheet. I transferred data from the spreadsheet to SPSS in order to conduct the analyses. There were no errors in the data. Some

missing values were found, and I excluded those participants from the main analyses. The sample size was still adequate to exceed the minimum of 128 participants recommended to achieve a statistical power level of .80 and alpha level of .05 as discussed in Chapter 3.

Tests of assumptions were run for each research question. For RQ1 the assumptions for a one-way ANOVA were met for a continuous dependent variable, independence of observations of groups, outliers, normality, homoscedasticity, and homogeneity of variances (Field, 2013). A Levene's test for homogeneity of variances was used to determine if variances of each population of the sample was equal (Field, 2013). As shown in Table 2, the results of the Lavene's test indicated equal variances across the samples, F(4,484) = 1.275, p > .05.

Table 2

RQ1 Assumptions: Levene Statistic

Lavene Statistic	df1	df2	p
1.275	4	484	.279

For RQ2, the assumptions for a Pearson Correlation were assessed. Both variables were continuous, and a linear relationship existed between variables (Field, 2013). There were no significant outliers, and variables were normally distributed. Assumptions for a Pearson's correlational analysis were met for RQ2.

For RQ3, assumptions were evaluated for an independent samples t test. The assumptions for normality of the dependent variable and homogeneity of variance were met. As shown in Table 3, results of the Lavene's test indicated equal variances across samples (F = 1.035, p > .05).

Table 3

RQ3 Assumptions: Levene Statistic

Source	F	Sig.	T	Df
Equal Variances Assumed	1.035	.309	3.636	584
Equal Variances not Assumed			3.816	229.580

For RQ4, assumptions were assessed for a linear regression model. Preliminary analysis confirmed there was a linear relationship between the independent and dependent variables, no issues with outliers, normality across variables, and no multicollinearity of variables (Field, 2013). Additionally, there were no signs of autocorrelation, and homoscedasticity was met (Field, 2013). Assumptions for all research questions were met prior to conducting the main analyses.

Main Analyses

RQ1: Is there a significant difference in reported caregiver burden as measured by the burden interview scale (see Appendix C) between caregivers who are single, married, widowed, or divorced?

A one-way ANOVA was used to analyze if marital status had a significant effect on the caregiver burden. As shown in Table 4, marital status had five groups; 373 identified as married, 73 single, 31 divorced, three indicated marital status as other, and nine widowed. Because the F-test statistic was 1.697 with a p value of 0.149, I failed to reject the null hypothesis at the $\alpha = 0.05$ level of significance. See Table 5. This means that there was no significant difference across marital status groups in terms of their mean caregiver burden. Post hoc comparisons are conducted to confirm differences between groups when significant results are identified in a one-way ANOVA (Field, 2013). RQ1

was the only one-way ANOVA. Post hoc comparisons were not analyzed for RQ1 because significant differences in the means were not found.

Table 4

Descriptive Statistics of Marital Status

Marital status	N	M	SD	SE	95% CI
Married	373	18.96	10.245	.530	[17.92, 20.01]
Single	73	20.25	11.273	1.319	[17.62, 22.88]
Divorced	31	21.16	9.798	1.760	[17.57, 24.76]
Other	3	32.33	6.506	3.756	[16.17, 48.50]
Widowed	9	19.89	7.424	2.475	[14.18, 25.60]
Total	489	19.39	10.355	.468	[18.47, 20.31]

Table 5

ANOVA: Marital Status and Burden

Source	SS	df	MS	F	P
Between groups	723.828	4	180.957	1.697	.149
Within groups	51602.785	484	106.617		
Total	52326.613	488			

RQ2: Is there a relationship between caregiver burden as measured by the burden interview scale (see Appendix C) and caregiver perceived social support as measured by the social support scale (see Appendix B)?

A correlation analysis was used to determine if there was a significant linear association between caregiver burden and social support. As shown in Table 6, the correlation coefficient between caregiver burden and perceived social support was 0.159 with a p-value less than 0.0001. As a result, the null hypothesis was rejected. This sample gives sufficient evidence that there was a significant positive linear association between caregiver burden and social support.

Table 6

Correlation Between Burden and Social Support

Variables	Burden	Social support
Burden		
Pearson Correlation	1	.159**
Sig. (2-tailed)		.000
N	586	586
Social Support		
Pearson Correlation	.159**	1
Sig. (2-tailed)	.000	
N	586	586

Note. **p > .01.

RQ3: Is there a significant difference in reported burden as measured by the burden interview scale (see Appendix C) between male and female caregivers?

An independent sample *t* test was analyzed to determine if there was a significant difference in the caregiver burden between males and females. Statistical information for gender of caregivers is shown in Table 7. The null hypothesis was rejected because the t-test statistic was 3.636 with a p-value less than 0.0001. See Table 8. This means that this sample gives sufficient evidence that there was a significant difference between males and females in terms of caregiver burden.

Table 7

Caregiver Burden Among Male and Female Caregivers

Gender	N	M	SD	SEM	p
Female	454	20.02	10.893	.511	.309
Male	132	16.17	9.977	.868	

Table 8

Independent Samples t Test: Burden Among Males and Females

Source	T	df	Sig. (2-tailed)	95% CI
Equal variances assumed	3.636	584	.000	[1.769, 5.923]
Equal variances not assumed	3.816	229.580	.000	[1.860, 5.831]

RQ4: Is there a significant interaction between caregiver marital status, social support, and gender on caregiver burden as measured by the burden interview scale (see Appendix C)?

A multiple linear regression model was analyzed to determine what the best predictors of caregiver burden were. Marital Status, social support, and gender were all included in the model as explanatory variables. As shown in Table 9, the regression model was significant (F = 5.023, p < 0.0001).

The parameter estimates and corresponding test statistics are included in Table 9. Each group of marital status (except Divorced, p = 0.056), social support, and gender were all found to be significant predictors of caregiver burden because all t-test statistics were significant and p-values less than 0.05.

The beta coefficients were significant for married, single, and widowed participants. Severity of burden ranged from highest to lowest among the married, widowed, and single groups respectively. The divorced group was not a significant predictor of burden. Gender had a beta coefficient that was negative and indicated that males had lower caregiver burden scores than females. Finally, social support had a

positive beta coefficient of 0.174, as seen in Table 10. This means that the model predicted that for every one point increase in social support, caregiver burden can be expected to increase by 0.174 points.

Table 9

ANOVA: Predictors of Burden

Model	SS	df	MS	F	Sig.
Regression	3079.412	6	513.235	5.023	.000
Residual	49247.202	482	102.173		
Total	52326.613	488			

Table 10

Coefficients of Marital Status

	Unstandardized coefficients		Standardized coefficients		
Model	B	SE	Beta	T	p
Constant	30.887	5.856		5.274	.000
Married	-13.664	5.883	562	-2.323	.021
Single	-12.345	5.970	425	-2.068	.039
Divorced	-11.743	6.121	277	-1.918	.056
Widowed	-13.698	6.752	178	-2.029	.043
Sex	-4.204	1.097	171	-3.831	.000
Social support	.174	.058	.133	2.995	.003

Summary

The first research question assessed if caregiver marital status had an effect on severity of burden. The results of the one-way ANOVA indicated that marital status did not have a significant effect on severity of burden. The second research question asked if there was an association between caregiver perceived social support and burden. The results of the correlation analysis indicated that there was a significant positive association between caregiver perceived social support and burden. The third research

question asked if gender influenced caregiver burden. The results of the independent sample *t* test indicated there was a significant difference in burden among male and female caregivers. Female caregivers reported higher severity of burden than male caregivers. The final research question assessed the interaction between caregiver marital status, social support, and gender on burden. The results of the multiple linear regression model identified marital status, social support, and gender to all be significant predictors of severity of caregiver burden.

In Chapter 5, there will be an overview of the research study, summary of key findings, and interpretation. In addition, limitations identified in the study, recommendations for further research, and implications for positive social change will be discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this nonexperimental quantitative study was to examine whether marital status, perceived social support, and gender had an effect on burden as reported by family member caregivers of individuals diagnosed with Alzheimer's disease. I conducted this study to address a known gap in the literature by contributing to scholarly research on the effect of social support, marital status, and gender on severity of burden in caregivers of patients diagnosed with Alzheimer's disease (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al., 2012). Archival data from the REACH II program conducted by the Alzheimer's Association - North Central Texas Chapter was used. Participants were immediate family members of individuals diagnosed with Alzheimer's disease. Data were collected using the Burden Interview (see Appendix C), the Caregiver/Care Recipient Sociodemographic Information (see Appendix A), and the Social Support scale (see Appendix B). The research questions of this study were discussed in Chapters 1, 3, and 4.

According to the results of this study, marital status did not have a significant effect on burden. Therefore, I failed to reject the null hypothesis for the first research question. Results indicated a significant positive association between social support and burden for the second research question. The null hypothesis was rejected. For the third research question, data analysis indicated a significant difference in burden among male and female caregivers. The null hypothesis was rejected. The results of the final research question identified marital status, social support, and gender collaboratively to be significant predictors of caregiver burden. Therefore, the null hypothesis was rejected.

Interpretation of the Findings

Findings of the Literature Review

Research on caregiver burden has shown that caregiver characteristics such as age, education, career, overall health of both caregiver and patient can influence the severity of burden experienced by caregivers (Dillman et al., 2013; Iavarone et al., 2014; Krull, 2013; Mausbach et al., 2014; Raggi et al., 2015; Tremont et al., 2013; van der Steen et al., 2012). This study built on the research analyzed in Chapter 2, in which I discussed the importance of providing support to family member caregivers of patients diagnosed with Alzheimer's disease to improve overall health of both the caregiver and patient. Researchers have indicated that caregiver burden can negatively impact a person's overall health, put strain on interpersonal relationships, and complicate finances for the caregiver (Brownie & Horstmanshof, 2014; Conde-Sala et al., 2014; Iavarone, 2014; Naden et al., 2013; Shankar et al., 2014). As caregiver burden increases, the patient's quality of life tends to decrease (Iavarone, 2014; Shankar et al., 2014). This study addressed a gap in the literature by examining the effect of caregiver marital status, perceived social support, and gender on severity of burden in caregivers of individuals diagnosed with Alzheimer's disease.

Marital status of the caregiver. Previous research on caregiver burden has presented conflicting information on the impact of a spousal relationship between caregiver and care receiver. Pietromonaco and Black (2015) suggested that a caregiving spouse is at a higher risk of experiencing burden than other caregivers because the caregivers relied on their spouse to provide support and assist in decision-making

(Pietromonaco & Black, 2015). However, Chappell et al. (2014) stated that a spouse is more willing to provide care as part of his or her role in marriage. In addition, spousal caregivers are more likely to be retired and may not have young children (Chappell et al., 2014). This means spousal caregivers may have fewer commitments to other responsibilities, making them available to serve as the patient's primary caregiver (Chappell et al., 2014).

Results of this study indicated that marital status did not have an effect on severity of caregiver burden. There were several factors that may have influenced this result. First of all, approximately 63.7% of participants in the sample used for this study identified themselves as married. This study did not identify how many of these married participants were married to the care receiver. It should also be considered that this study did not identify if any of the single, divorced, or widowed participants had a partner who provided support similar to a marital relationship (Monin et al., 2013). Other factors such as length of marriage, length of time since becoming divorced or widowed, and amount of social support received from other individuals could also influence the outcome of this analysis (Conde-Sala et al., 2010; Hudson, 2014; Iavarone et al., 2014; Kamiya et al., 2014). Further research to closely examine these aspects of marital status in relation to severity of caregiver burden could be helpful.

Perceived social support. Researchers who discussed social support suggested that individuals who are able to build positive relationships and have more social support are more likely to report lower levels of caregiver burden (Kamiya et al., 2014; Mausbach et al., 2014; Morse et al., 2012). As well, caregivers who had assistance from other

family members in decision making and providing care were less likely to report depression and other health issues (Arling et al., 2013; Dillman et al., 2013; Krull, 2013; Rose & Lopez, 2012). Conflicting research suggested caregivers with more social support may rate severity of burden as high (Akpinar et al., 2011; Pillemer & Suitor, 2014). This is because caregivers may have less time to dedicate to interpersonal relationships due to the task of caregiving, or because the care receiver used to be one of the caregiver's primary social supports prior to becoming ill (Akpinar et al., 2011, Pillemer & Suitor, 2014).

In the correlational analysis completed for the current study, social support and severity of burden had a positive linear relationship. The perceived level of social support and severity of caregiver burden rose simultaneously. This result contradicts the research that suggested higher levels of social support would help minimize burden (Kamiya et al., 2014; Mausbach et al., 2014; Morse et al., 2012). The results of this study aligned with past research indicating caregivers with more social support report higher levels of burden (Akpinar et al., 2011; Pillemer & Suitor, 2014). When caregivers have to balance personal responsibilities and caregiving tasks, they may withdraw from social activities and hobbies (Akpinar et al., 2011; Iavarone et al., 2014; Pillemer & Suitor, 2014). This may be due to depression associated with burden, or feelings of guilt about designating time for personal activities instead of fulfilling responsibilities (Akpinar et al., 2011; Iavarone et al., 2014; Pillemer & Suitor, 2014).

Gender of the caregiver. Research on caregiver gender suggested that female caregivers would report higher levels of burden than male caregivers (Kim et al., 2016;

McDonnell & Ryan, 2013; Robinson et al., 2014). According to McDonnell and Ryan (2013), female caregivers tend to report higher psychological and physical stress and strain on interpersonal relationships than male caregivers. In addition, female caregivers often take on more responsibilities by themselves (McDonnell & Ryan, 2013). Male caregivers strictly focus on the basic needs such as transportation, finances, and shopping, and seek assistance from family or professional agencies to complete direct care tasks (McDonnell & Ryan, 2013). In this study, the results were as expected based on the literature review. Female caregivers reported higher severity of burden than male caregivers. When female caregivers have to balance caregiving tasks, interpersonal relationships, and other responsibilities, they may associate how well they balance these tasks as a reflection of their character because of the emotion-focused view on being a caregiver. They may be reluctant to ask others for help and more likely to experience severe physical and psychological strain. Male caregivers are more likely to approach caregiving in a strategic manner, identify tasks they can complete on their own, and seek assistance from others to ensure all tasks are completed. They are less likely to experience strain to physical and psychological health. In addition, male caregivers are less likely to report difficulty balancing interpersonal relationships, caregiving roles, and other responsibilities because of their task-oriented approach.

The Interaction between marital status, social support, and gender on burden. A linear regression model was conducted to determine if there was an interaction between the three dependent variables on caregiver burden. The results of this analysis identified all groups of the dependent variables as significant predictors of

caregiver burden, except for the divorced group. This study did not collect information that may have influenced results such as length of time participants were divorced or whether the participant had a significant other to provide support. Additional factors such as the responsibility to maintain a job, the task of caring for children, level of education, age, and other sources of social support beyond immediate family members may also impact the results of this analysis (Kamiya et al., 2014; Mausbach et al., 2014; Morse et al., 2012; Shankar et al., 2014). From the results from RQ4, I have identified a relationship between marital status (except for divorced), gender, and perceived social support. This means that there was a relationship between these variables. When marital status, gender, and perceived social support were examined together, these variables were significant predictors of severity of caregiver burden.

Findings of the Theoretical Framework

This study was viewed through the scope of attachment theory as founded by Bowlby (1988). Based on the concepts of attachment theory, it was hypothesized that caregivers with a positive attachment schema who were married would seek support form a spouse, and report burden lower than caregivers who were not married (Monin et al., 2013; Morse et al., 2012). The results of this study did not confirm what was expected based on attachment theory. There was no significant difference in burden among participants who were married, single, divorced, or widowed. Based on the concepts of attachment theory and the results of this study, I concluded that marital status was not an accurate way to identify participants with positive and negative attachment schemas. It is possible that participants with different attachment schemas experienced different levels

of burden, however, marital status should not be used to identify individuals who are at risk for higher levels of caregiver burden.

Secondly, based on the concepts of attachment theory it was expected that caregivers who perceived social support as high would report lower severity of burden (Bowlby, 1988; Monin et al., 2013; Morse et al., 2012). The results of this study did not support the expectation that caregivers reporting higher support would indicate lower severity of burden. In fact, the positive correlation between burden and social support indicates that burden actually increased as perceived social support increased. These results conflicted with the theoretical propositions. One explanation for this result is that caregivers with more sources of social support may have more social responsibilities because of their many social roles. The more expectations a person feels obligated to fulfill, the more physical and psychological stress he or she is going to experience. Participants with a greater number of social supports have increased expectations and reported higher severity of burden than caregivers with fewer social supports.

Lastly, female caregivers were expected to report higher severity of burden than male caregivers. This is because females are more likely to be emotional-oriented to the task, whereas males are more likely to be task-oriented (Kim et al., 2016; McDonnell & Ryan, 2013). As expected, female participants reported higher severity of burden than male participants in this study. These findings support the theoretical propositions that females were emotionally connected to their task as a caregiver, less likely to seek assistance with their responsibilities, and more likely to assign themselves more responsibilities without consideration of their other social roles. Due to this approach to

the task of caregiving, females experienced higher levels of physical and psychological stress, and reported higher burden than male participants. Male participants were more likely identify tasks to be completed and create a plan to finish all tasks. They focused on completing the most important tasks for patient survival, and may have asked for assistance from others to complete caregiving responsibilities. This approach led male participants to experience less strain on physical and psychological well-being. For this reason, male participants reported less burden than female participants.

Limitations of the Study

There were several limitations associated with this study. Archival data were obtained from the REACH II program facilitated by the Alzheimer's Association - North Central Texas Chapter. For the current study, I was not able to control or monitor the interviewing processes, data collection methods, coding of data, or region from which participants were recruited. The REACH II program team replicated the REACH II study conducted by Schulz and colleagues (2001). This was a limitation because the REACH II program facilitated by the Alzheimer's Association – North Central Texas Chapter had different intentions than the original REACH II study conducted in 2001. The purpose of the study by Schulz and colleagues (2001) was to evaluate the effectiveness of multiple interventions and examine the pooled effect of the REACH interventions (Schulz et al., 2007). The purpose of the REACH II program is to offer the services to as many families in the region as possible (Alzheimer's Association, 2017). Pertinent information about effectiveness of the program was collected for all participants at enrollment and after program completion. This information was used to report the outcome(s) of the REACH

II program to the public, and has been used in some research studies (Cho, Thorud & Stevens, 2016; Lykens et al., 2014). The Alzheimer's Association – North Central Texas Chapter did not make an attempt to address limitations of the REACH II study identified by Schulz and colleagues (2001). These limitations included a limited representation of minority groups and males in the REACH II study sample, use of 1 follow-up assessment, and the control group had access to a limited treatment program (Schulz et al., 2007). A convenience sample was used because the goal of the Alzheimer's Association – North Central Texas Chapter was to provide REACH II program services to as many people in the region as possible. Participation in the REACH II program was voluntary and specific inclusion and exclusion criteria for both the caregiver and care receiver had to be met prior to enrollment. For these reasons, generalizability of the results may be limited.

Culture, family beliefs, caregiver education, and prior experience as a caregiver were all confounding factors that could have impacted perception of the caregiving role (Friedemann & Buckwalter, 2014; Lykens et al., 2014, Schulz et al., 2001). Participants who were expected to become a caregiver because of their culture or family beliefs may have reported lower severity of burden (Friedemann & Buckwalter, 2014). As well, participants with more experience and education in caregiving and the patient's diagnosis may have rated severity of burden lower (Lykens et al., 2014; Schulz et al., 2001). Another limitation of this study was the use of self-reporting measures. When using these measures, there was a risk of response bias, social desirability bias, recall bias, and self-report bias (Lykens et al., 2014; Schulz et al., 2001). Response or survey bias occurs

when participants are not truthful with their answers or participants answer questions a certain way based on the way the question was asked (Field, 2013). Participants may display social desirability bias by choosing answers they feel are favorable, such as overreporting desired behaviors and under-reporting undesired behaviors (Field, 2013; Schulz et al., 2001). Another limitation is recall bias, which occurs when participants forget or overlook important details of a situation, hindering their ability to provide an accurate recollection of past events (Field, 2013; Lykens et al., 2014; Schulz et al., 2001). When self-reporting measures are used, participants may not be completely honest with questions that ask about their personal traits, specific attitudes or values, or behavior that some may consider unusual or questionable (Field, 2013). Caregivers who identified their role as an expectation within their culture may have reported lower severity of burden (Friedemann & Buckwalter, 2014; Lykens et al., 2014). This is because they were doing what was expected of everyone in a culture that highly values caregiving (Friedemann & Buckwalter, 2014; Lykens et al., 2014). Finally, internal validity of this study may be limited if other factors that influenced severity of burden were not included in the data analysis (Field, 2013).

Recommendations

In this study, I revealed a correlation between social support and burden, a significant difference in burden among male and female caregivers, and an interaction between marital status, social support, and gender on caregiver burden. However, this study also revealed there was not a significant relationship between marital status and caregiver burden. In addition, the correlation between social support and burden was

reversed from what was expected. Further research is necessary to understand how the variables of marital status and social support affect severity of caregiver burden.

Additional research may also provide information about other factors that could influence burden, such as culture, family values, and education.

To increase understanding of social support, future researchers may want to utilize additional instruments. The social support measure used in this study was created to evaluate social support perceived by caregivers, individuals experiencing natural disasters, and during periods of bereavement (Schulz et al., 2001). The scale collected information on received support, satisfaction with support, positive interactions, and negative interactions (Schulz et al., 2001). Other instruments would gather additional information about social support that may be useful. A few suggestions are the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981), Interpersonal Support Evaluation List (Cohen, Mermelstein, Kamarck, & Hoberman, 1985), and Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983). These three instruments have high ratings for test-retest reliability, validity, and internal consistency (Heitzmann & Kaplan, 1988). The Norbeck Social Support Questionnaire is used to collect information on functional properties of social support, duration and frequency of relationships, and recent losses (Norbeck, Lindsey, & Carrieri, 1981). The Interpersonal Support Evaluation List consists of four subscales covering tangible support, sense of belonging, self-esteem, and appraisal to measure participant perceptions of available support (Cohen et al., 1985). The Social Support Questionnaire requires participants to

create a list of individuals in their support network and then rate overall satisfaction with support received based on the list (Sarason et al., 1983).

Future researchers may also find it beneficial to use additional instruments when collecting data on caregiver burden. The brief ZBI (Bedard et al., 2001) used in this study was intended for use with aging caregivers, although it has been used with adult caregivers 18 years or older (Bedard et al., 2001; Schulz et al., 2001). The brief ZBI (Bedard et al., 2001) is used to collect self-reported information about personal strain and role strain (Schulz et al., 2001). There are other instruments that may provide a more comprehensive report on caregiver burden, such as the Caregiver Burden Inventory (CBI; Novak & Guest, 1989). This instrument provides information on time dependency, developmental issues, physical health, emotional health, and social relationships (Novak & Guest, 1989). The CBI (Novak & Guest, 1989) has good reliability and construct validity (Family Caregiver Alliance, 2015). Another instrument that may be used to measure burden is the Montgomery Borgatta Caregiver Burden Scale, which also has good reliability and construct validity. This instrument has two subscales to measure quality of the relationship between the caregiver and patient, and a scale that measures consequences of caregiving (Montgomery et al., 1985). Future researchers may want to compare several burden inventories to ensure they are collecting relevant and accurate information from participants.

It may be beneficial for future researchers to examine other factors that could influence severity of burden. This study examined the effect of marital status on burden. However, it may be helpful to examine more groups within married individuals, such as

care givers who are spouses of the care receivers and caregivers whose spouse is not the care receiver. This study did not examine other variables that could influence severity of burden, such as caregiver culture, family values, education, and experience. Future researchers may want to consider exploring the relationship between these factors and caregiver burden. Researchers may want to use a qualitative approach to gather information on other factors influencing burden. This may allow researchers to identify influential factors on severity of burden that have not been identified in the literature.

I recommend that future studies address the limitations identified in this study. Future researchers may want to consider the limitations experienced in this study because archival data was used. For this study, I used a convenience sample from one region of Texas. Future studies should strive to achieve a sample that more accurately represents the target population of caregivers residing in the United States caring for a family member diagnosed with Alzheimer's disease. The sample was likely an accurate representation of caregivers of family members diagnosed with Alzheimer's disease in northern Texas. Limiting a sample to one region may compromise generalizability to the target population of caregivers in the United States. Researchers may address this limitation by recruiting participants from a larger region or several regions throughout the United States. A study that expands the variables beyond marital status, social support, and gender may obtain more accurate information about how these factors influence severity of caregiver burden. The results of the analysis conducted to determine if marital status had a significant effect on burden indicated there was no significant difference across marital status groups in terms of burden. The final analysis was

conducted to examine the interaction between gender, marital status, and social support on caregiver burden. It identified all marital status groups as significant predictors of burden, except for the divorced group. It is possible that additional factors are influencing severity of burden reported by caregivers. These factors may include caregiver education, caregiver employment status, and the extent of support the patient requires to complete daily living tasks (Friedemann & Buckwalter, 2014; Kim et al., 2012; Mausbach et al., 2014; Monin et al. 2013; Shankar et al., 2014; Vandervoort et al., 2014). Expanding the variables beyond marital status, social support, and gender may provide useful information about how these factors influence severity of caregiver burden. It may, however, be difficult to explore so many potential predictors of burden in one study.

Implications

This research highlighted an issue which impacts approximately 15.9 million people in the United States (Alzheimer's Association, 2017). This study promotes positive social change for individuals, families, and society by broadening the knowledge of factors that may impact severity of caregiver burden in family member caregivers of patients diagnosed with Alzheimer's disease. Specifically, the study addressed a gap in the literature by examining the effect of marital status, social support, and gender on severity of burden in caregivers of patients diagnosed with Alzheimer's disease. The results of this study identified female caregivers and caregivers with higher perceived social support as experiencing higher levels of burden. These caregivers may benefit from having supports outside of their family and friends to manage caregiving tasks.

Positive Social Change for Individuals, Families, and Society

Potential implications for social change include providing individuals and families with a better understanding of the risks involved in taking on the role of a caregiver. Factors such as marital status and gender cannot be changed; however, individuals and family members are encouraged to seek professional supports such as counseling, caregiver support groups, education about Alzheimer's disease and fulfilling the role of a caregiver (Administration on Aging, 2013, Alzheimer's Association, 2017; Family Caregiver Alliance, 2017). It is important for individuals and families to know that there are organizations that can provide this support and that being proactive in minimizing severity of burden will likely improve overall health and quality of life for the caregiver and patient (Administration on Aging, 2013, Alzheimer's Association, 2017; Family Caregiver Alliance, 2017).

This study added information about the factors that impact severity of caregiver burden. Professionals and organizations are encouraged to utilize this knowledge and recognize the importance of supporting caregivers of patients diagnosed with Alzheimer's disease. Many services are currently available via private and public agencies (Administration on Aging, 2013; Family Caregiver Alliance, 2015). However, as the number of caregivers continues to rise, the demand for resources and support is likely to increase (Family Caregiver Alliance, 2015).

Advancements in Practices and Policy

This study also encourages advancements in practices and policy by highlighting factors that impact severity of burden and identifying a need for further research on

variables that effect burden. Psychologists and other professionals may find this information useful when working to support clients who are caregivers for patients diagnosed with Alzheimer's disease. When conducting individual therapy, professionals may identify risk factors associated with higher levels of burden, identify signs of burden when conceptualizing a case, and consider burden when creating a plan for treatment (McDonnell & Ryan, 2011; Monin et al., 2014). For example, female patients who rate their social support high are more likely to need assistance in managing caregiver burden (McDonnell & Ryan, 2011). Professionals may also consider facilitating group therapy sessions for caregivers of patients diagnosed with Alzheimer's disease to provide caregivers with support from others sharing similar experiences (Kim et al., 2016; Krull, 2013).

Public and private agencies who support caregivers may want to consider expanding the resources they have available to caregivers and offer services specifically for caregivers of patients diagnosed with Alzheimer's disease. Offering literature and education seminars may be successful in raising public awareness about risk factors that lead to caregiver burden (Administration on Aging, 2013; Family Caregiver Alliance, 2015; McDonnell & Ryan, 2011). Encouraging caregivers to include their spouse or immediate family members in the support groups and educational activities may be helpful (Koplow et al., 2015; Monin et al., 2014). Expanding the availability of emergency resources such as 24-hour phone lines, walk-in clinics, and respite services may be useful supports for caregivers experiencing high severity of burden (Alzheimer's Association, 2017; Schulz et al., 2014). Providing additional ways for caregivers to

communicate with agency staff would allow caregivers to balance caregiving responsibilities while seeking support (Tremont et al., 2013). Such services could include communication via an online platform such as secure email or instant messaging applications.

I recommend that health care agencies train staff on warning signs and risk factors of caregiver burden. Both home-based health services and traditional facilities should consider how often they serve family caregivers or patients diagnosed with Alzheimer's disease receiving care from a family member (Koplow et al. 2015; Krull, 2013). Staff may assume female caregivers appearing to have many social supports are experiencing less burden (McDonnell & Ryan, 2011). However, the results of this study suggest the opposite. If agency staff members are properly trained and able to identify a caregiver with severe burden, they may be able to refer caregivers to agencies who can provide additional support (Krull, 2013; Muller et al., 2017). Staff members may also be able to suggest additional services their agency can provide to alleviate some of the caregiver responsibilities (Muller et al., 2017).

This study may encourage advancements in practices and policy by identifying the importance of developing and implementing strategies to address concerns of social support, marital status, and gender in caregivers as an attempt to limit burden. If caregivers perceive minimal social support, it is important that they can identify other means of receiving support and limit burden. Decreasing severity of caregiver burden can improve overall health and quality of life for both the caregiver and care receiver (Kamiya et al., 2014; Mausbach et al., 2014; Shankar et al., 2014; van der Steen et al.,

2012). Making burden more manageable for the caregiver also may delay or prevent the need to place the patient in a nursing home. While placing the patient in a nursing home may be a successful method to alleviating caregiving burden, transitioning an individual to a nursing facility can be a traumatic event for both the patient and the patient's family members (Iavarone, 2014; Naden et al., 2013). The process causes physical and psychological stress for the patient and caregiver (Iavarone, 2014; Mausbach et al., 2014). This is because families tend to experience financial strain, difficulty finding appropriate placement for the patient, the task of moving the patient's belongings, and maintaining communication between the facility and other health providers to ensure a smooth transition (Arling et al., 2013; Iavarone, 2014; Naden et al., 2013; Vandervoort et al., 2014). Patients who remain in their home instead of moving to a nursing facility are often healthier, happier, have more contact with family and friends, feel they are able to maintain their dignity, and experience a higher quality of life than patients residing in a nursing home (Dillman et al., 2013; Iavarone et al., 2014; Mausbach et al., 2012; Naden et al., 2013).

Conclusion

The number of individuals in need of long-term care in the United States continues to rise (Family Caregiver Alliance, 2015). Currently, there are at least 15.9 million people in the United States providing care to a family member who has been diagnosed with Alzheimer's disease (Alzheimer's Association, 2017). This number is expected to double by the year 2050 (Family Caregiver Alliance, 2015). Conducting research on factors that contribute to severity of caregiver burden is a relevant and

valuable focus for society. The physical and psychological stress placed on a caregiver will negatively impact quality of life for both the caregiver and patient if burden is not properly managed. This study addressed one gap in the research by examining the effects of marital status, perceived social support, and gender on severity of caregiver burden. The results of this study indicated marital status did not affect severity of burden, levels of social support and burden simultaneously rise, and female caregivers report higher burden than male caregivers. In this study, I identified that when the variables marital status, social support, and gender were grouped together, they were identified as predictors of severity of caregiver burden. It is strongly recommended that future research be conducted to further examine factors that may influence severity of burden in caregivers of family members diagnosed with Alzheimer's disease so that we as a society may continue to better the lives of the growing numbers of Alzheimer's patients and their caregivers.

From the results of this study, I concluded that female caregivers with many social relationships were at a higher risk of experiencing severe caregiver burden.

Raising awareness and encouraging professionals to implement strategies to support this at-risk population may lead to positive social change by providing caregivers with the resources they need to manage caregiver burden. As a result, caregivers and care receivers may experience improved quality of life. This shift would also align with the nationwide initiative to lower public healthcare costs by maintaining long-term care within the community instead of public institutions.

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Appendix A: Sociodemographic Questionnaire

~REACH~

Resources for Enhancing Alzheimer's Caregiver Health

		Inta	ake Form		
Completed	ke:by:b months prior		Referral Sou CG SS# Yes □ No PW	urce:	
CG:	•		CR•		
Date of Birt	h:		Date of Birt	h:	
Age:			Age:	11.	
Gender:	,		Gender:		
English as F	PL:		English as F	PL:	
Ethnicity:	Hispanic/L Non Hispan	atino		Hispanic/La Non Hispanic	tino
Race:	African Âm Caucasian Hispanic	,	Race:	African Ame Caucasian Hispanic	
Address:			Address		
City/Zip:			City/Zin:		
Email:			Home Phon	e:	
Home Phon	e:			or N Wartime	
Cell Phone:				gnosis:	
Marital Stat	us:		Marital Stat	us:	
Current Emp	ployment Stat	us:	Marital Status:CR's Health Provider:		
Relationship Notes	to Care Reci	pient:			
Directions_					
	completed?	Y or N	Confirmed recei	ipt of MASR?	Y or N
CM Referral	Made?	Y or N	Confirmed CM	Contact?	Y or N

Appendix B: Social Support

Social Support: REACH Composite Score

☐ Not at all

☐ A little

Next, I will ask you questions about support you receive from those around you. 1. Do you have someone to comfort you, listen to your feelings, etc.? ☐ Never ☐ Sometimes ☐ Always 2. Do you feel isolated from your family and friends? □ Never ☐ Sometimes ☐ Always 3. Overall, how satisfied have you been in the past month with the help you've received from family members, friends, or neighbors? ☐ Not at all ☐ A little ☐ Moderately ☐ Very 4. How many relatives, friends, neighbors, other than (Care Recipient), do you see or hear from at least once a ☐ None \Box 1 □ 5-8 ☐ 9 or more \square 2 □ 3-4 5. How many relatives, friends, neighbors, other than (Care Recipient), do you feel you can call on for help with chores, transportation, etc.? ☐ None \Box 1 \square 2 □ 3-4 □ 5-8 ☐ 9 or more 6. When other people you know have an important decision to make, do they talk to you about it? □ Never ☐ Seldom ☐ Sometimes ☐ Often ☐ Very Often ☐ Always 7. In the past month, how often has someone, such as a family member, friend, or neighbor, other than (Care Recipient), provided transportation or pitched in to help you do something that needed to get done, like household chores or yard work and/or helped you with shopping? □ Never ☐ Once in a While ☐ Fairly Often ☐ Very Often 8. In the past month, overall, how satisfied have you been with the help you have received with transportation, housework, yard work and shopping? ☐ Not at all ☐ A little ☐ Moderately ☐ Very 9. In the past month, how often has someone been there with you (physically) in a stressful situation, provided comfort to you, or expressed concern about your well-being? ☐ Once in a While ☐ Fairly Often ☐ Very Often 10. In the past month, how satisfied have you been with the support, comfort, interest and concern you have received from others?

☐ Moderately

☐ Very

Appendix C: Burden Interview

Burden Interview

Subject ID

BURDEN INTERVIEW

Now I am going to ask you some questions regarding your feelings about caring for (CR).

Do you feel:	Never	Rarely	Sometimes	Quite frequently	Nearly always	Unknown	Refused
1.FNOTMthat because of the time you spend with (CR) that you don't have enough time for yourself?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
2.FSTRE stressed between caring (RC24) for (CR) and trying to meet other responsibilities (work/family)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
3.FANGRangry when you are (RC24) around (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
4.FRLTN that (CR) currently affects your relationship with family members or friends in a negative way?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
5.FSTRA strained when you are (RC24) around (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
6.FHSUF that your health has (RC24) suffered because of your involvement with (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
7.FNOPRthat you don't have as (RC24) much privacy as you would like because of (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
8.FNOSL that your social life has suffered because you are caring for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
9.FLCNT that you have lost control of your life since (CR)'s illness?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
0 FUWDO uncertain about what to (RC24) do about (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
11.FSDOM you should be doing (RC24) more for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()
12.FSDOByou could do a better job (RC24) in caring for (CR)?	0 ()	1 ()	2 ()	3 ()	4 ()	-3 ()	-4 ()