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## Faith-Based Support for Alzheimer's Family Caregivers in Madison County, Alabama

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# Walden University

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2019

Abstract

Faith-Based Support for Alzheimer's Family Caregivers

in Madison County, Alabama

by

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MSW, Savannah State University, 2004

BA, Alabama A & M University, 2002

Dissertation Submitted in Complete Fulfillment of the  
Requirements for the Degree of  
Doctor of Philosophy in Public Policy Administration

Walden University

May 2019

## Abstract

Alzheimer's disease, the sixth leading cause of death in the United States, is incurable. Because of the extensive long-term care required for patients with Alzheimer's, the typical caregiver is often a middle-aged family member with his or her own health problems. The purpose of this quantitative cross-sectional study was to determine the extent to which there was a difference in the perception of quality of life between Alzheimer's family caregivers who receive tangible faith-based support compared to the Alzheimer's family caregivers who receive no social support. The theoretical basis was social support theory, which suggests that support buffers stress. The sample population consisted of Alzheimer's family caregivers ( $n= 42$ ) recruited through local organizations in a southern state, over a 3-month period. Faith-based support or no social support was the independent variable of dichotomous value, and perceived quality of life was the dependent variable measured by an ordinal scale. Perception of quality of life was determine using the World Health Quality of Life BREF-Survey Questionnaire. Five independent  $t$ -tests were used for statistical analysis. The study results showed the perception of physical health improved perception of quality of life when using faith-based support while the quality of life and general health, social relationships, psychological health, and environmental health null hypotheses were retained. This research contributed to positive social change by helping public policy administrators identify the impact of faith-based support on Alzheimer's family caregivers.

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## Dedication

I dedicate this dissertation to my parents Kenneth and Mary Alexander. To my mother who taught me at an early age, there is no such word as you *can't* complete a goal. To my father who always encourages me by saying *Money, you can do it*. Mathais, my brother, who cheered me on when focusing on my goals. To my husband, Reginald who motivated me throughout this journey. And to my sons, Randall and Reid, who keeps me humble every day.

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## Table of Contents

Chapter 1: Introduction to the Study.....	1
Introduction.....	1
Background.....	3
Problem Statement.....	3
Purpose of Study.....	5
Research Question and Hypotheses.....	5
Theoretical Framework for Study.....	8
Nature of the Study.....	9
Definition of Terms.....	9
Assumptions.....	11
Limitations.....	12
Scope of Delimitations.....	14
Significance of the Study.....	14
Summary.....	15
Chapter 2: Literature Review.....	16
Introduction.....	16
Literature Search Strategy.....	17
Social Support Theory.....	17
Summary and Conclusions.....	27
Chapter 3: Research Method.....	29
Introduction.....	29



Research Design.....	30
Study Population.....	32
Instrumentation-WHOQOL-BREF Survey Questions .....	33
Variables and Operationalization.....	34
Sampling and the Recruitment of Survey Participants .....	43
Survey Method.....	45
Statistical Methods.....	48
Threats to Validity .....	49
Ethical Procedures .....	50
Summary.....	51
Chapter 4: Results .....	53
Introduction.....	53
Data Collection .....	56
Survey .....	57
Scoring .....	62
Findings.....	63
t-Test Assumptions .....	64
Summary and Conclusions .....	67
Chapter 5: Discussions, Conclusions, and Recommendations .....	68
Introduction.....	68
Interpretation of the Findings.....	69
Limitations of the Study.....	74

Recommendations.....	78
Implications for positive social change.....	83
Conclusion .....	84
References .....	86
Appendix A .....	100

## Chapter 1: Introduction to the Study

### **Introduction**

Alzheimer's disease, the sixth leading cause of death in the United States, is incurable. A type of irreversible dementia, Alzheimer's disease is a degenerative disease, with a spontaneous onset, followed by slow deterioration and death (Dupuis, Epp, & Snale, 2014). Alzheimer's disease causes cognitive decline and aggressive behavior, affecting a person's basic needs such as bathing, toileting, and recall for daily routine activities (Centers for Disease and Control [CDC], 2015).

Because of the long-term care required for patients with Alzheimer's, family caregivers are often middle-aged family members who must juggle demands of the patient with Alzheimer's and their own responsibilities, such as caring for children, employment, and attending to their own quality of life (Family Caregiver Alliance, 2016). Alzheimer's family caregivers face the challenges of managing their own medications, responding to the patient with Alzheimer's aggressive behaviors, and paying bills for the patient with Alzheimer's (Alzheimer's Association, 2016). Moreover, Alzheimer's family caregivers face loss of income because of decreased work hours, money spent on personal care for patient with Alzheimer's, and ultimately, lost employment because of absenteeism (Family Caregiver Alliance, 2016). The caregiving responsibilities are so demanding that the quality of life and physical health of Alzheimer's family caregivers themselves often go unaddressed (White House Conference on Aging, 2015).

According to the World Health Organization, *quality of life* is the person's perception of status in society regarding his or her cultural values and how that perception relates to his or her view of their current life. (Gholami, Moosavi, Zarie, & Dehghan, 2013). With people living longer, public policy administrators need to examine programs that allow baby boomers to live longer and *age in place*, a phrase denoting people's desire to remain in their home despite needing assistance and depending on others.

Investing in baby boomers, who are typical Alzheimer's family caregivers, is important to public policy administrators in Madison County, Alabama. Faith-based support was one answer to the needs of Alzheimer's family caregivers in Madison County, Alabama. The U.S. Census Bureau (2010) found that 186,254 people live in Huntsville, the county's largest city. Madison County accounts for 48,000 baby boomers; a number predicted to rise to nearly 100,000 by the year 2040 (United Way of Madison County, 2014).

This study was designed to evaluate the effect of faith-based support on the quality of life and physical health of Alzheimer's family caregivers. This research contributed to positive social change by helping public policy administrators assist Alzheimer's family caregivers' needs for the long-term care of patients with Alzheimer's disease. I will discuss, in this chapter, background, problem statement, purpose of the study, research questions and hypotheses, theoretical framework, nature of the study, assumptions, limitations, scope of delimitation, and significance of the study.

## **Background**

Starting in 2000, state public policy makers focused on understanding Alabama family caregivers' needs, such as supplemental services to buy supplies for different levels of care for the patient, affording the equipment to modify the home environment, and improving skill deficit to care for patients (Family Caregiver Alliance, 2003). Alzheimer's family caregivers were found to need breaks from the demands of 24-hour care with the patient (Family Caregiver Alliance, 2003). Soon, aging in place was synonymous with home placements.

Many Alzheimer's family caregivers performed activities of daily living (ADLs), including housekeeping, bathing, toileting, and cooking. In 2006, the Reauthorization of Older Americans Act shifted the focus to Alzheimer's disease to address the growing number of Alzheimer's patients (U.S. Department of Human and Health Services, 2015). Alzheimer's disease, a type of dementia, causes aggressive behavior due to the loss of memory and changes in the way the brain processes information. Because of the cognitive damage, patients with advanced Alzheimer's do not recognize family members, which adds to the stress of the Alzheimer's family caregiver. Community conversations need to help Alzheimer's family caregivers upon whom patients depend for support with activities of daily living. (Keefe, Guberman, Fancey, Barylak, & Daphne, 2008).

## **Problem Statement**

Alzheimer's family caregivers need effective programs to assist with patients with Alzheimer's and the caregiver's health. Alzheimer's family caregivers are vulnerable to becoming recipients of care themselves when they provide services (Navaie-Waliser et

al., 2002). Sheets, Black, and Kaye (2014) argued that programs are needed for Alzheimer's family caregivers to expand the caregiver role from household activities to skilled nursing activities. The absence of household and skilled nursing programs put the Alzheimer's family caregiver at a greater risk of chronic diseases. Sheets et al. (2014) sought to evaluate caregiver services to include in-home, community-based, and evidence-based programs performed throughout the United States and abroad.

I researched faith-based support because of the absence of evaluations of faith-based organizations in Madison County, Alabama. Faith-based organizations are equipped to serve the most vulnerable and underserved populations through individualized services specific to the conditions of patients with Alzheimer's, instead of generalized services that provide a broad overview of a general population (Bielefeld & Cleveland, 2013). Sherman (2003) noted social programs such as faith-based support has limited research on evaluating intended outcomes. In many states, public policy administrators encouraged social programs because of the inevitable progression of Alzheimer's. Public policy administrators know that having assistance providing activities for daily living can assist family caregivers with the taxing demands they face. Anjos et al. (2015) evaluated faith-based support, as one kind of a social network support, for its effect on improving Alzheimer's family caregivers' perceived quality of life. Further research is needed to provide research outcomes of faith-based support (Anjos et al., 2015).

### **Purpose of Study**

In this quantitative study, I analyzed the effectiveness of faith-based support in addressing perception of quality of life and general health, physical health, psychological health, social relationships, and environmental health for Alzheimer's family caregivers through social support. I compared in this study those same factors for Alzheimer's family caregivers who receive faith-based support and those Alzheimer's family caregivers who receive no social support. I defined no social support as any support to Alzheimer's family caregiver to include public, private, or community support from organizations. The independent variable was having faith-based support or no social support. The dependent variable was the perceived quality of life. Faith-based organizations provide individualized support, including companionship, educational training seminars, transportation, respite services, financial support, and assistive devices to decrease behavioral safety concerns within the home environment for Alzheimer's family caregivers. Ozbay et al. (2007) found that social support is key to maintain their quality of life and to reduce morbidity and mortality.

### **Research Question and Hypotheses**

In the literature review, I suggested the need for a study to evaluate the quality of life and physical health for Alzheimer's family caregiver receiving faith-based support. I conducted the evaluation by using the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF) Survey. I designed the study to decide the outcome of the difference in the perception of quality of life between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social

support. The following are the five research questions, five null hypotheses and five alternative hypotheses.

Research Question 1 (RQ1): Is there a difference in the overall quality of life and general health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_01$ ): There is no difference in the perception of quality of life and general health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a1}$ ): Participants who receive faith-based support report a higher perception of quality of life and general health than participants who receive no social support.

Research Question 2 (RQ2): Is there a difference in the physical health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_02$ ): There will be no difference in the perception of physical health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a2}$ ): Participants who receive faith-based support will report a higher perception of physical health than participants who receive no social support.



Research Question 3 (RQ3): Is there a difference in the psychological health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_03$ ): There will be no difference in the perception of psychological health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a3$ ): Participants who receive faith-based support will report a higher perception of psychological health than participants who receive no social support.

Research Question 4 (RQ4): Is there a difference in the social relationships between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_04$ ): There will be no difference in the perception of social relationships between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a4$ ): Participants who receive faith-based support will report a higher perception of social relationships than participants who receive no social support.

Research Question 1 (RQ5): Is there a difference in the environmental health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_05$ ): There will be no difference in the perception of

environmental health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a5}$ ): Participants who receive faith-based support will report a higher perception of environmental health than participants who receive no social support.

The independent variable was the faith-based support, and the dependent variable was the perception of quality of life and general health, physical health, psychological health, social relationships, and environmental health.

### **Theoretical Framework for Study**

Derived from sociology and psychology, social support theory was the key theory for developing this study. Social support is the concept of providing support through social networks in the form of emotional, tangible, informational, and companionship supports (Hwang, Etchegaray, Sciamanna, Bernstam, & Thomas, 2011). Support for the family caregiver may be perceived or actually received. Southwick, Vythilingam, and Charney (2005) showed that the lack of social support influences life quality and physical health of family caregivers the same as it affects a person who smokes cigarettes, being overweight, having high blood pressure, or having a limited physical activity level. The effectiveness of faith-based support had not been evaluated for its effect on the quality of life for Alzheimer's family caregivers until this research study. Grounded on social support theory, in this study, I predicted Alzheimer's family caregivers receiving faith-based support would report greater personal resilience to withstand the taxing demand of

caring for a family member with Alzheimer's than those who receive no social support. Social support theory is discussed in more detail in Chapter 2.

### **Nature of the Study**

In this cross-sectional study, I gathered current evaluation data from Alzheimer's family caregivers living in Madison County, Alabama, to understand the quality of life level for those receiving faith-based support. I conducted this study by using the WHOQOL-BREF survey questionnaire, which measures the perceived quality of life through quantitative descriptive analysis. The WHOQOL-BREF survey questionnaire measured five domains: overall quality of life and general health, physical health, psychological health, social relationships and environmental health. The *About You* section of the survey began with five questions followed by the instructions for completing the survey questionnaire. These questions were followed by 26 questions in which Alzheimer's family caregivers were asked to rank their own quality of life within the last 2 weeks. The survey questionnaire used an ordinal scale to rank the perceived quality of life using a Likert-type scale from 1 to 5. Sample questions included (a) "How would you rate your quality of life?" (b) "How satisfied are you with your health?" (c) "To what extent do you feel your life to be meaningful?" Scores were then calculated according to the scoring guidelines (Gholami et al., 2013). The WHOQOL-BREF is discussed in more detail in Chapter 3.

### **Definition of Terms**

*Aging population:* is a group of individuals over the age of 50, typically the baby boomer generation.

*Alzheimer's disease:* is a debilitating condition causing cognitive decline and aggressive behavior due to a person's brain cells being destroyed.

*Companionship support:* is a form of social support associated with acceptance, belonging, and engagement.

*Emotional support:* is a form of a social support having the presence and sense of acceptance and affection.

*Family caregiver:* is a person providing in-home, unpaid care to a family member biologically related to them.

*Faith-based support:* is a form of tangible social support provided by faith organizations to improve the quality of life for family caregivers.

*Generalized services:* are services provided to a broader audience with a broad topic, not specific to everyone.

*Informational support:* is a form of social support offering suggestions or advice to solve a problem.

*Individualized services:* are services provided to family caregivers tailored to the caregivers needs to care for the Alzheimer's patient such as learning how to address aggressive behavior or skilled personal care training.

*Nonprofit organizations:* are organizations that function without receiving a profit and sometimes receive public funding.

*Public organizations:* are governed by public administrators to carry out the interest of people within a community.

*Quality of life:* is a person's perception of his or her position currently in life in the context of culture and values as it relates to goals, standards, expectations, and concerns.

*Social support:* is related to assistance provided through social ties.

*Tangible support:* is a form of social support offering material service such as financial support or completing task assistance from another person.

### **Assumptions**

Philosophical assumptions establish the guidelines used for making conclusions when interpreting data for quantitative research (Dazeley, Stone, & Images, 2015).

Guidelines are influenced by world views such as objectivistic world view which inquires humans about a phenomenon (Goduka, 2012). Two humans or people do not understand the investigative phenomenon in the same way (Goduka, 2012). To understand a universal truth, additional information must be inquired to establish distinct independent properties (Goduka, 2012). The fundamental issue with quantitative research is quantitative variables are a mental phenomenon or ontology and how this information can assist the researcher with the relationship of the mental phenomenon or epistemology (Gelo, Diana, & Benetka, 2008). I assumed an objectivistic world view when evaluating the quality of life for Alzheimer's family caregivers.

I assumed the positivist paradigm with an objective world view. The positivist paradigm derives from natural science testing the hypothesis developed from an existing theory (Goduka, 2012). In this study, I predicted five hypotheses which states: Participants who receive faith-based support will report a higher perception of quality of

life and general health, physical health, psychological health, social relationships, and environmental health than participants who receive no social support. Social support theory is the key theory for developing this study. This study was based on previous research suggesting individualized programs that include faith-based support should be evaluated due to the lack of evaluation of services provided by faith-based organizations. All guidelines followed methods protocol to ensure statistical analysis is valid.

Researchers use experiential designs to identify independent variables and dependent variables by making causal inferences about the relationship (Gelo et al., 2008). This cross-sectional experimental research design included a comparison group and a control group. The positivist paradigm is based on values of reason, truth and validity and empirically using quantitative methods consisting of surveys and experiments (Goduka, 2012). Furthermore, the positivist paradigm view of the world operates by laws of cause and effect with the key approach through direct manipulation (Goduka, 2012).

### **Limitations**

Gelo et al (2008) described the quantitative research as the relationship between a phenomenon that was generalized and made a prediction. Alzheimer's family caregivers generalizing faith-based support for spiritual support was one limitation affecting this study. By generalizing, the Alzheimer's family caregiver could think of spiritual support such as prayer and meditation when answering the survey questions. Spiritual support is defined as connecting to a broader sense of existence through religious activities, rituals, and beliefs (Gaventa, 2001). This study, I focused on tangible support from faith-based

organizations to include (a) time spent for companionship, (b) educational training seminars, (c) transportation, (d) respite services, (e) financial support, and (f) assistive devices.

Goduka (2012) explained study assumptions were based on a fair reality that only an independent researcher can verify data outcomes. As the researcher, I had no personal relationships with Alzheimer's family caregivers including community-based, familial birth, or social clubs. I had no professional relationships with Alzheimer's family caregivers including providing direct services to patients with Alzheimer's. When using epistemology, the researcher should avoid bias and forms of influence to receive honest data results (Goduka, 2012). I used a digital identifier to remain objective when collecting data from individual participants.

Another limitation was denoting factors affecting the family caregiver's quality of life such as age, family income, or geographical area. While the survey questionnaire asked questions about gender, date of birth, and health, participants had the option not to answer the questions and could leave them blank. Leaving the questionnaire blank was a limitation.

Internal validity was assuming only faith-based support experiences influence the perceptions of life quality and physical health of family caregivers. Creswell (2013) explained internal and external validity were identified and addressed to minimize potential threats. Threats to internal validity included Alzheimer's family caregivers' prior relationship with faith-based leaders or public and nonprofit staff. I measured external validity through generalizations that other Alzheimer's family caregivers, from

similar populations such as Madison County, will have faith-based support available to them.

### **Scope of Delimitations**

This study was limited to Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who do not receive faith-based support. Due to the limitation of focusing on Alzheimer's family caregivers in Madison County, Alabama, this study was limited to discovering faith-based support in a community of its size. The public and nonprofit organizations were identified using a community resource list. The organization provided a list of the sampling frame. The sampling frame included a list with the Alzheimer's family caregiver's name, address, and phone number. I recruited 3 months for the study from the start date of the first day of recruitment. I only used a quantitative study method through a nonprobability sampling frame provided by organizations in Madison County, Alabama. Alzheimer's family caregivers who referred other participants created a snowballing sample. The study was limited to data collection methods of a self-administered WHOQOL-BREF survey questionnaire completed by participants.

### **Significance of the Study**

I addressed a gap in the literature on faith-based support and the self-perceived quality of life and general health, physical health, psychological health, social relationships, and environmental health of Alzheimer's family caregivers. Public policy strategies are created with the local community to carry out a plan and to address the need for Alzheimer's family caregivers to have an improved quality of life while supporting



patients with Alzheimer's. Policy administrators' lack of research-based outcomes about faith-based support has created a barrier to seeking additional assistance and sharing insights to community leaders. This study may help further the national dialogue on ways to support Alzheimer's family caregivers through faith-based support by information, assistance, and supplemental services to decrease the demands of providing constant care to patients with Alzheimer's.

### **Summary**

How to best care for patients with Alzheimer's is important to public policy administrators. When an Alzheimer's family caregiver is not supported, the alternative is the patient with Alzheimer's living in an institutionalized nursing home for long-term care. Being institutionalized refers to living in a formally structured facility with activities for patients who are older and disabled, have recurring routines, and remain in the facility or nursing home (Wood, Lampe, Logan, Metcalfe, & Hoesly, 2017). Compared to institutions, home placements are more cost-efficient to state governments desiring to support and fund an aging population.

Public policy administrators address social problems that affect the public. Although public health issues must be widely communicated to the community (Harris, Choucair, Maier, Jolani, & Berhardt, 2014), little is known about the effectiveness of faith-based support for family caregivers of patients with Alzheimer's disease. In this study, I evaluated faith-based support and revealed the outcomes relating to Alzheimer's family caregiver quality of life and general health, physical health, psychological health, social relationships, and environmental health.

## Chapter 2: Literature Review

### **Introduction**

In the literature review, I establish the need for this study by evaluating the effect on quality of life and physical health for Alzheimer's family caregivers when receiving faith-based support in Madison County, Alabama. Over the last 20 years, researchers examined how physical health and caregiver burden can affect the Alzheimer's family caregiver. Rosee-Murphy et al. (2014) discussed one major point for improving the quality of life for Alzheimer's family caregivers was addressing the management of Alzheimer's behaviors. However, most studies have concluded that family caregivers must not become isolated or be without social support (Family Caregiver Alliance, 2016). The purpose of this study was not only to provide information to family caregivers but to understand the effect of quality of life and general health, physical health, psychological health, social relationships, and environmental health when faith-based support is used in Madison County, Alabama. Research has not been conducted about interventions such as establishing social support to increase Alzheimer's family caregiver longevity (Ozbay et al., 2007).

The quality of life for Alzheimer's family caregivers is a critical element to address the commitment to the in-home placements for a patient with Alzheimer's. Intervention such as faith-based support is helpful in improving perceived health (Mahendran et al., 2017). Furthermore, supporting Alzheimer's family caregivers may decrease the problem of scarcity involving institutionalized long-term care for the patient with Alzheimer's and acknowledge unrecognized assets such as social supports (Iris,

Berman, & Stein, 2014). This chapter includes information to include literature search strategy, social support theory, literature review, and summary.

### **Literature Search Strategy**

I searched the literature through several electronic databases to including BMC Open Access, Sage Journals, Medscape, ProQuest, and Google Scholar in the Walden University and the University of Alabama at Birmingham libraries. Keywords for journal search included *Alzheimer's family caregiver*, *social support*, *faith-based organizations*, *physical health*, and *quality of life*. The searched literature included years 1990–2017. This literature review includes a discussion of social support theory with the research emphasis on social support, quality of life and physical health, the impact on family caregivers, and impact of group social support.

### **Social Support Theory**

This dissertation is grounded in social support theory. Using concepts of psychology and sociology, social support theorists generally define social support as support for people to handle stressful situations. Social support refers to resources being available when people are most vulnerable; therefore, people can depend on others (Thoits, 1995). The person's perceptions of the availability of social support appear to be a much stronger influence on the quality of life and physical health than the actual acceptance of social support (Thoits, 1995).

Barnes, as cited in Thoits (1995) was the first to describe social connections through patterns of relationships with family, work, and social group support (Thoits, 1995). In the 1950s, when people accepted social support from others, the burden was

decreased. This concept was only explained by the social connections with others, having relationships to support one another. Later, Cassel (1976) found a person's physical health was protected from negative impact by relationships, and social support warded off a decrease in the quality of life (Glanz, Rimer, & Lewis, 2002).

The support network is built structurally by the size or availability (Huang, Musil, Zausziewski, & Wykle, 2006). Support can be made available by many means of connection, including in-person, by telephone call, or via the Internet. Structurally, social support can be received through family connections, work relationships, civic groups, or faith-based organizations. Family connections are kinship that people have with their family of origin in which they are born or legal family due to marriage or adoption. Work relationships are based on social interactions with people in the employment environment. Civic groups are social ties made by people through network association such as a society or league. Faith-based organizations are available churches, temples, synagogues, and mosques based on the religious preference of the person.

Functional support is the perception that support is available to someone if needed (Gallo et al., 2015). When a person is most vulnerable and needs support, functional support is provided through social support to include emotional, informational, tangible, or companionship (Hwang et al., 2011). Emotional support involves the presence of a person who conveys a sense of acceptance and affection. Informational support refers to advice and suggestions to solve problems. Acceptance, belonging, and engagement constitutes the third type of functional support, companionship support.

Finally, tangible support entails offering material services such as financial support and task assistance.

## **Literature Review**

### **Social Support**

There are several empirical studies on the impact of social support. Faw (2016) investigated how social support can buffer physiological health for caregivers of disabled children by collecting caregiver's baseline saliva, having the family caregivers receive conversation intervention with rest periods, and finally measuring another saliva collection. Using social support theory, Faw's (2016) research found that social support decreased physical health complaints of caregivers of disabled children, which led to an increase in quality of life. The saliva collection tested the increase in stress with of caregivers. This was measured by the correlation between the saliva collection and the decrease in physical complaints.

Basu, Hochhalter, and Stevens (2015) examined the effect of one informational support by giving the experimental group an intervention called Resources for Enhancing Alzheimer's Caregiver Health II (REACH II). The intervention measured perception of Alzheimer's family caregiver's quality of life post implementation. The intervention provided the family caregivers of Alzheimer's in the experimental group in-home sessions, telephone sessions, and educational sessions for 6 months (Basu et al., 2015)., The experimental group, at the conclusion of 6 months, showed a significant improvement in their overall perception of burden and levels of depression, compared with the comparison group who received no informational support.

Gitlin and Rose (2014) sought to assess the readiness of dementia family caregivers by a tangible support, nonpharmacological intervention. The intervention involved caregivers learning how to manage dementia patients' behavior through communication techniques and tangible environmental modification within the home (Gitlin & Rose, 2014). Using the transtheoretical model as a conceptual framework, caregivers' readiness was assessed using five stages: precontemplation, contemplation, preparation, action, and maintenance. After using the McNemar-Bowker test, Gitlin and Rose (2014) found 72% of caregivers were in action or ready to address the difficulty of caregiving, 28% in pre-action or becoming ready to address the difficulty in caregiving.

Thai, Barnhart, Cagle, and Smith (2015) evaluated the effect of quality of life for family caregivers of adults with disabilities over the age of 65. Thai et al. (2015) found family caregivers experienced a decrease in quality of life and physical health 52% of the time, from factors including the physical and emotional effect of the patient with a debilitating disease and the uncertainty of financial demands.

### **Quality of Life and Physical Health**

The most important factor in perceived physical health is improving quality of life. Using a single group repeated design, Lai, Lau Kan, Lam, and Fung (2017) found palliative care patients improve their healthcare concerns after a horticultural therapy intervention, which involves growing plants to promote well-being at the end of life. The improvement was measured by using the *End of Life Questionnaire*. Hong and Harrington (2016) found that an Alzheimer's family caregiver with a decreased support network had a higher burden and poorer perceived physical health. Supported by

conservation of resources theory, caregivers strive to retain, protect, and build resources such as friendships as an effort to offset lost resources (Hong & Harrington, 2016). The outcomes were based on secondary data from 2004 National Long-Term Care Survey, which found the correlation between long-term care family caregivers' perception of quality of life and family caregiver actual situation. The companionship support was considered broad, visible, or invisible networks used to improve caregiver companionship (Hong & Harrington, 2016).

Several researchers have monitored the impact of quality of life on physical health conditions. Hajli, Shanmugam, Hajli, Khani, and Wang (2015) indicated social media applications, positively improved health care by reducing transaction healthcare costs. The improvement was due to the emotional and informational support by using social media applications to give advice to patients on how to protect themselves from poor health. The improvement was measured through participant semi-structured interviews examining social support response. Tyrell, Paturel, Cadec, Capezzali, and Poussin (2005) found 60% of patients with end-stage renal disease were cognitively impaired, including being depressed. The increase in depression was found using several measurement tools including a quality of life scale, the Nottingham Health Profile, a cognitive scale, Mini-Mental State Examination, and a depression scale, the Montgomery-Asberb Depression Rating Scale.

One way to increase a person's quality of life is to reduce physical health symptoms. Shayan et al. (2016) found an increase in quality of life for patients with breast cancer engaged in stress management for physical health symptoms. The

experimental group completed a pretest before cognitive behavioral therapy for 2 hours, during nine sessions, and then a posttest. The control group only received pretest and posttest. Shin et al. (2017) studied how physical activity relates to the quality of life for survivors of breast cancer, noting a decrease in fatigue and pain when the routine physical activity occurred. Generalized linear model measured the quality of life using health-related quality of life survey. Shayan et al. (2016) concluded that the experimental group increased physical performance dimensions through quality of life in physical health.

### **Impact on Family Caregivers**

Caregiving experience is stressful and often negatively affects the caregiver's physical health, despite the intervention. Huang et al. (2006) explored the connection for dementia family caregivers on outcomes associated with health and social support using Epidemiological Studies-Depression Scale. Trivedi (2014) predicted caregiver problems would include daily hours spent caregiving, the patient's level of care, the caregiver's relationship with the patient with the long-term disability, the total duration of years caregiving, and major health problems of care patient. The prediction was measured by using Behavioral Risk Factor Surveillance System (BRFSS). Huang et al. (2006) found tangible support help did not buffer caregiver depressive symptoms, which may be a result of the caregiver needing greater tangible support and the impact on the family caregiver's health. Trivedi found that family caregivers of long-term disabled patients were more likely to have poor sleep habits and low mental health capabilities, which correlated to engaging in low social support.



Public policy administrators must learn how to improve in-home placements with family caregivers and decrease institutionalized care management for patients with Alzheimer's. Gibson, Gander, and Jones (2014) discovered common issues for patients with dementia moving into institutionalized care management and family caregivers sleep disturbances. Gibson et al. (2014) found common themes of sleep disturbances were age-related changes in sleep, changes in sleep timing, and factors affecting sleep in the night. Furthermore, family caregivers were worried and depressed from needing to care for the patient with dementia, which negatively affected their quality of life. Family caregivers needed time for themselves and less stress to decrease physical health, which worsened their quality of life (Gibson et al., 2014). Hazzan, Ploeg, Shannon, Raine, and Oremus (2015) addressed the need of learning how to assist family caregivers with in-home placements by assessing the relationship between quality of life and quality of care, using evidenced-based questionnaires. Intervention methods included group and individual interviews with family caregivers focused on the revision of the current questionnaire to serve as a guide to the future questionnaire. Hazzan et al. (2015) discovered caregivers preferred a questionnaire specifically for care management approach that recognized the increased demands for care for family caregivers. This included the uncertainty of level of care over time for patients with Alzheimer's.

The position of caregivers differs for spousal caregivers and adult child caregivers. Vellone, Piras, Venturini, and Alvaro (2012) evaluated caregiver support programs, comparing adult child caregivers to spousal caregivers. To measure the effects on family caregivers' health, Vellone et al. (2012) used phenomenological method

reflection before data collection. The data collection included interviewing each caregiver, researchers writing assumptions about the family caregivers, verbatim transcript interviews, and extensive interviews with family caregivers focusing on body language and tone of voice from the caregivers (Vellone et al., 2012). Likewise, Reed et al. (2014) used an 18-month observational study to evaluate the caregiver burden for Alzheimer's family caregivers in France, Germany, and the United Kingdom. In the study, the authors aimed to evaluate costs and resources associated with patients with Alzheimer's and caregivers by comparing spousal family caregivers and adult child family caregivers. Caregiver burden was measured with a self-reported tool at baseline and 6 months. Vellone et al. (2012) and Reed et al. (2014) study results showed spousal caregivers were lower than adult child caregivers in caregiver burden despite spousal caregivers spending more time with the patient with Alzheimer's.

Family caregivers experience more physical stress than their peers who are not family caregivers and tend to be in declining health condition. Berg-Weger, Rauch, Rubio, and Tebb (2003) discussed the effects of formal caregiving on adult daughter caregivers for elderly parents with Alzheimer's disease using the Medical Outcomes Study Short Form after the patient had died. The participants experienced an increase in physical health including functioning and role limitations associated with physical being. An increase in general health and bodily pain perceptions were included in the study results. Torisson, Stavenow, Minthon, and Londos (2016) found that family caregivers scored lower with symptoms associated with depression, cognitive impairment, and isolation before the death of the patient with Alzheimer's. Torisson et al. (2016) used the

13-item Quality of Life and Alzheimer's Disease Scale to compare an experimental group and comparison group of family caregivers of patients with Alzheimer's, discharging from the hospital over the age of 60. The participant experimental group was assigned a discharge liaison at hospital discharge, post-discharge telephone calls, and medication comprehension overview for six months. Alzheimer's family caregivers have better levels of quality of life and physical health when there are higher levels of social support. Using stress and coping theories Roth, Mittelman, Clay, Madan, and Haley (2005) hypothesized that lower responses to caregiver depression are associated with increased levels of social support, decreased stressfulness appraisal, and more adaptive coping responses. Lavela and Ather (2009) conducted a review of 10 years of literature and found one-third of the family caregivers over age 50 routinely cared for a disabled family member for more than a decade. Psychological health improved when the family caregiving role stopped, usually due to the death of the patient with a disability (Lavela & Ather, 2009). Family caregivers had cognitive impairments after caring for a family member at a greater frequency and magnitude over a period of time than their peers who were not caring for a family member. Cognitive impairments were seen more often in wives than husbands because wives were the primary dependents within the couples, and caregiving is a new role. Roth et al. (2005) randomly assigned family caregivers to the sample population, comparison or experimental groups; social support was measured using an intervention consisting of a comprehensive baseline assessment followed by counseling for one year. Eleven social support indicators were identified to include satisfaction with assistance, the total size of social network, and help with housework. The outcomes showed eight

out of 11 social support indicators improved for the experimental group. In contrast, the comparison group showed an improvement of only one out of 11 indicators of social support.

### **Impact of Group Social Support**

Family caregiver social support improves the longevity of supporting caregiver and decreases burdens. Social support can buffer stress thus improving the quality of life and physical health for the Alzheimer's family caregiver. Rosee-Murphy et al. (2014) found providing a home health care team strengthens the family caregiver social support and decreases caregiver burden. The multi-factor team theory intervention helped the home health team to learn how to decrease patients entering prematurely into institutionalized setting due to family caregivers' decline and inability to provide care in Spain. The experimental group received individualized sessions, family intervention, and group educational sessions. The comparison group continued to receive established home health programs, which were standard practice. Anjos et al. (2015) found that despite the socioeconomic status the family caregiver holds in society, there was moderate to severe correlation improvement between caregiver burden and time spent with social supports. The correlation would suggest social support does improve quality of life and physical health.

Community partnerships with family caregivers will help identify unmet needs when caring for patients with Alzheimer's. Ducharme et al. (2014) found that 70% of family caregivers wished to have more information about resources to decrease stress, to enjoy themselves despite taking on the role of family caregiver, and to have

individualized assistance specific to the caregiver's need. This was measured by the Family Caregivers Support Agreement (FCSA) tool as a mixed method approach which offers a more robust evaluation by assessing caregivers through survey and interviewing to emerging needs for mutual exchanges. Tompkins & Sorrell (2008) found that resources are available within members of the faith-based community and that clergy needs to encourage faith-based members who are health care professionals to use their skills to help family caregivers of patients with Alzheimer's. This further validates the partnership approach, which suggests all people are experts within reach of family caregivers.

### **Summary and Conclusions**

For more than 20 years, the caregiver research literature has focused more on symptoms of the poor quality of life, such as neglecting preventable diseases, rather than on how to improve the quality of life and general health, physical health, psychological health, social relationships, and environmental through interventions. Historically, family caregiver research supported a narrow group of focused interventions. Individualized programs for caregivers versus group treatment were important predictors for successful benefits and stronger outcomes (Roth et al., 2005). The research gap in knowledge was identifying how faith-based social support can affect family caregivers during an active caregiving role.

Meeting the needs of family caregivers of Alzheimer's patients is a rising societal problem in light of the predicted increase in Alzheimer's disease over the next 50 years (Brookmeyer, Gray, & Kawas, 1997). Current services are inadequate for long-term care

of patients with Alzheimer's. By 2047, 35% of the United States population will be more than over 65 years old. Therefore, Alzheimer's care issues, if not addressed by public policy, will have costly impacts on U.S. society (Brookmeyer et al., 1997). Without family caregivers, the care of the patients with Alzheimer's will rely on public services in institutionalized placements, such as nursing homes.

Patients living longer with Alzheimer's disease need a higher level of care, causing more support for family caregiver services (Brookmeyer et al., 1997). More research was needed to focus on having social supports to assist Alzheimer's family caregivers' quality of life. This study examined a family caregiver intervention designed to evaluate tangible improvements from faith-based support.

## Chapter 3: Research Method

### **Introduction**

In this study, I evaluated the quality of life between Alzheimer's family caregivers who receive faith-based support and their counterparts who receive no social support in Madison County, Alabama. For this study, the faith-based support is defined as support received from faith-based communities to include churches, temples, synagogues, and mosques. No social support referred to no support at all. Because of the growing cost of the public policy, family caregivers are pressured to identify their own social networks for support (Berwig et al., 2017).

Faith-based support was one of the various social network supports available in Madison County. Faith-based support lacked evaluation on Alzheimer's family caregivers' quality of life and general health, physical health, psychological health, social relationships, and environmental health. Located in the northern part of Alabama, Madison County is the third largest populated county in the state (United Way of Madison County, 2014). There are three major hospitals, three major universities, and over 1,000 faith-based organizations in the county.

In this study, I advanced the knowledge by understanding if there is a difference in the quality of life and general health, physical health, psychological health, social relationships, and environmental health with Alzheimer's family caregivers who receive faith-based support and those Alzheimer's family caregivers who receive no social support. In this chapter, I will discuss the research design, study population, survey method, instrumentation, the operationalization of variables, recruitment of survey

participants, survey method, instrumentation, recruitment of survey participants, statistical methods, threats to validity, and ethical procedures. The chapter concludes with a summary of the research method.

### **Research Design**

In this cross-sectional research design, I determined whether there is a difference in the quality of life and general health, physical health, psychological health, social relationships, and environmental health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support. I analyzed data information at the specific time the data was collected. The independent variable in this evaluation study was having faith-based support versus no support; the dependent variable is the perception of quality of life and general health, physical health, psychological health, social relationships, and environmental health by two groups of Alzheimer's family caregivers: one receiving faith-based support and the other receiving no social support.

The following null hypotheses and corresponding alternative hypotheses were tested.

Null Hypothesis ( $H_0$ ): There is no difference in the perception of quality of life and general health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a$ ): Participants who receive faith-based support report a higher perception of quality of life and general health than participants who receive no social support.



Null Hypothesis ( $H_02$ ): There will be no difference in the perception of physical health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a2$ ): Participants who receive faith-based support will report a higher perception of physical health than participants who receive no social support.

Null Hypothesis ( $H_03$ ): There will be no difference in the perception of psychological health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a3$ ): Participants who receive faith-based support will report a higher perception of psychological health than participants who receive no social support.

Null Hypothesis ( $H_04$ ): There will be no difference in the perception of social relationships between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a4$ ): Participants who receive faith-based support will report a higher perception of social relationships than participants who receive no social support.

Null Hypothesis ( $H_05$ ): There will be no difference in the perception of environmental health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_a5$ ): Participants who receive faith-based support will

report a higher perception of environmental health than participants who receive no social support.

Ozbay et al. (2007) found that social support could increase life quality and reduce morbidity and mortality. In this study, I limited faith-based support to tangible supports that faith-based organizations provide, including: (a) time spent for companionship, (b) educational training seminars, (c) transportation, (d) respite services, (e) financial support, and (f) assistive devices. When describing quality of life, it is assumed all people have the same construct, influenced by multiple factors (physical, mental, emotional, and environmental) and enhanced by social support (Cummins, 2005). Quality of life is enhanced by resources, a feeling of fulfillment, and a sense people care (Cummins, 2005). There were no time or resource constraints on this design choice.

### **Methodology**

In this section, I will provide the rationale of the study population and established instrumentation. The independent variable and dependent variable were described in detail. I will further align the variables, survey questions, and statistical methods.

#### **Study Population**

The participant population for this study were Alzheimer's family caregivers in Madison County, Alabama, over the age of 50. Huntsville, the largest city in the county, is named the *Rocket City* due to history of the United States space exploration (City of Huntsville, Alabama, 2015). However, in 2014, 20% of the people who received community social supports reported their largest source of income was Social Security (SS) or Supplemental Security Income (SSI; United Way of Madison County, 2014). SS

and SSI recipients are typically over the age of 50, receive social supports, and are predictive of receiving faith-based supports.

The study population target was Alzheimer's family caregivers who live in Madison County and 50 years old or over. Nearly half of school-age children living in Madison County are being raised by grandparents (United Way of Madison County, 2014). In Madison County, 48,000 people are baby boomers over the age of 50 living in both urban and rural settings (United Way of Madison County, 2014). Hence, there is recruitment for enough survey participants for statistical analysis.

The targeted population was an infinite or uncontrolled population. Although there were many Alzheimer's family caregivers in Madison County, it is impossible to identify how many patients with Alzheimer's have an Alzheimer's family caregiver due to multiple physician settings diagnosing Alzheimer's disease. However, the Alabama Department of Public Health (2013) reported between the years of 2009 to 2011, 266 patients with Alzheimer's disease and unspecified dementia died in Madison County. Thus, there was a sufficient number of Alzheimer's patients and Alzheimer's family caregivers. I accepted as many potential participants as possible without limiting the population to a specific number. The participants were only Alzheimer's family caregivers, not family caregivers of any kind of patient.

### **Instrumentation-WHOQOL-BREF Survey Questions**

The survey questionnaire questions focused on each Alzheimer's family caregiver's perceptions of quality of life and physical health. The data were collected by scoring 26 survey questions that are drawn from the original WHOQOL Survey, which

has been translated into many languages widely used with various survey samples. The original WHOQOL Survey covers 100 questions about the quality of life and physical health. Survey samples include hospital patients, caregivers, hospital staff, healthy subjects, psychiatric patients, and transgender women (Perera, Izadikhah, O'Connor, & McIlveen, 2016). Approval to use the WHOQOL-BREF questions was granted by Seattle Quality of Life Group, which distributes the English version of the survey questionnaire in the United States. Data was calculated from each completed survey questionnaire. Scores were calculated according to the survey questionnaire guidelines created by Seattle Quality of Life Group.

### **Variables and Operationalization**

**The independent variable.** The independent variable was the status with faith-based support. The first status was receiving social support through faith-based organizations. Lee and An (2013) defined faith-based organizations as a place where people adopt theological beliefs and spiritual practices such as prayer, singing, and meditation (Lee & An, 2013). Spiritual worship styles and fellowship are positively reinforced through attending churches, temples, synagogues, and mosques (Lee & An, 2013). The faith-based status included Alzheimer's family caregivers who received support from people in faith-based communities such as churches, temples, synagogues, and mosques. The second status was Alzheimer's family caregivers receiving no social support. This was a dichotomous measurement level consisting of two values.

Historically, faith-based organizations respond to vulnerable populations when communities have limited availability of formal supportive networks (Iris et al., 2014).

Receiving faith-based support referred to the current reception of receiving at least one of the following tangible faith-based social supports: (a) time spent for companionship, (b) educational training seminars, (c) transportation, (d) respite services, (e) financial support, and (f) assistive devices. The following describes several tangible social supports available from faith-based organizations in Madison County.

***Companionship.*** Time spent for companionship allows family caregivers dedicated time with peers for a cognitive outlet without the patient with Alzheimer's. Because of the isolation caused by caregiving, family caregivers experience negative effects including a deficit in well-being and social dysfunction (Weger, Racuh, Rubio, & Tebb, 2013).

***Educational training seminars.*** Experienced professionals provide Alzheimer's family caregivers with educational training seminars for guidance to address the higher skilled level of care for a patient with Alzheimer's. For example, as a result of brain decline, many times patients with Alzheimer's do not recognize the Alzheimer's family caregivers they have known for a lifetime (Alzheimer's Association, 2016). Educational training seminars prepare Alzheimer's family caregivers with patient signs and symptoms. Knowing how to address signs and symptoms such as wandering will improve how the Alzheimer's family caregiver responds in stressful situations (Family Caregiver Alliance, 2016).

***Transportation.*** Patients with Alzheimer's often experience disease-related losses in both mobility and income; they may have difficulty obtaining reliable transportation. Assistance for immediate needs for Alzheimer's family caregivers is available to mitigate

adverse effects on physical health (Monahan & Hooker, 1995). Transportation is important for Alzheimer's family caregivers to help them withstand the physical demand of physically moving the patient with Alzheimer's into a car for doctor's appointments.

***Respite services.*** Such services provide a needed break for Alzheimer's family caregivers to complete household maintenance tasks, such as grocery shopping. When receiving respite services, the primary benefit for the Alzheimer's family caregiver is a break from the caregiving role and a temporary return to socialization to which the Alzheimer's family caregiver is accustomed. Respite services benefit both the patient with Alzheimer's and family caregiver due to the Alzheimer's family caregiver being more attune when returning to his or her caregiver role (Bartfay & Bartfay, 2013).

***Financial support.*** Financial resources can change for the Alzheimer's family caregiver due to the loss of work hours, an increase in health care costs, and being on a fixed income. Financial strain is associated with the caregiver's perceived social support which can increase depressive symptoms (Monserud & Markides, 2017). Financial support is contributions to Alzheimer's family caregivers by parishioners of faith-based organizations.

***Assistive devices.*** Assistive devices help decrease behavioral safety concerns and increase intensive support within the home environment. With the increasing demand of patients with Alzheimer's living at home, assistive devices help Alzheimer's family caregivers to keep their homes safe and decrease stress associated with the steady progression of Alzheimer's disease (Hattink et al., 2014). Assistive devices include Hoyer lifts, motion sensors, calendar clocks, and wandering devices.

**Independent variables level of measurement.** There was one independent variable, the source from which the Alzheimer's family caregiver receives support which consists of two measurement values, faith-based organization and no social support. Two questions in the *About You* section of the WHOQOL-BREF survey focused on the independent variable. The first question asked, "How do you receive tangible support?" The participant could choose from (a) faith-based organization, (b) I don't receive social support, and (c) non-faith-based support. The participant chose (a) faith-based organization if they received support from people in a faith-based community such as churches, temples, synagogues, and mosques. The participant chose (b) I don't receive social support if the participant received no social support. When the participant responded (b) I don't receive social support, they were asked to go to Question 5. The participant chose (c) non-faith-based support; if the participant received support from a non-faith-based organization such as other family members or paid support services. When the participant responded (c) non-faith-based support, they were asked to stop answering the questions and leave the remaining survey questionnaire questions blank. This independent variable consisted of categorical measurement with only two groups, faith-based support and no social support. This aligned the categorical variables to quantitative data. This independent variable is a nominal categorical measurement, counting all responses the participant answers. The second question was, "Do you receive the following tangible support? Circle all that apply?" The participant will circle all that applies which includes (a) time spent for companionship, (b) transportation respite services, (c) assistive devices, (d) respite services, (e) educational training seminars, or (f)

financial support. This question was asked to determine the way the Alzheimer's family caregivers received faith-based support. The tangible support further clarified what type of social support received from faith-based support. The participant response was counted; the categorical measurement was converted by coding. The coding is as follows: (1) none, (2) at least one tangible support, (3) at least two tangible supports, (4) at least three tangible supports, (5) at least four tangible supports, (6) at least five tangible supports, or (7) all tangible supports. The source of support was dichotomous, tangible support was measured at the quantitative level but capped at seven.

**The dependent variable.** The dependent variable was the self-reported quality of life and general health, physical health, psychological health, social relationships, and environmental health of Alzheimer's family caregivers. Quality of life can be measured objectively and subjectively. Objective is qualified and measured by counting how many times a person experiences a situation at each specific time. Subjective quality existed through private consciousness the individual person can only verify by telling someone else (Cummins, 2005). The following described the five domains of the dependent variable that were measured using the WHOQOL BREF.

***Overall quality of life and general health.*** Overall quality of life and general health was the perception of how a person thinks they should be in life status according to childhood upbringing and adult societal influence. Overall health and wellbeing were reflected by the person who influences wellbeing and betrayed through another person's perception. When a person perceived having a sense of control over his or her quality of life, general illness and health problems were decreased (Thoits, 1995).



***Physical health.*** Physical health includes the physical body's reaction to behavior choices, such as neglecting physical health which causes pre-exposed genetic conditions. Perception of energy and fatigue can influence a person's ability to perform daily tasks (World Health Organization, 2012). Physical health domain defined the capacity to which the participants perceived their physical wellbeing in the last two weeks. Family caregivers' characteristics such as anger, anxiety, and hostility are related to high blood pressure and increasing morbidity and mortality (Monahan & Hooker, 1995).

***Psychological health.*** The third domain, psychological health, measured the intensity the participants perceived their emotional or intellectual state. This domain focused on a person's ability to concentrate on thoughts and make life decisions. Maintaining psychological health impacted the way a person responds to life circumstances. Things such as alertness, ability to learn and having memory intact influenced how a person address a difficult life situation.

***Social relationships.*** Personal relationships through companionship from established bonds constitute social relationships. Social relationships domain evaluated the extent to where there is social interaction or lack thereof. This domain focuses on sharing life experiences and having a connection with people emotionally and physically. The approval of social support depends on how a person received tangible support in a crisis (World Health Organization, 2012).

***Environmental health.*** Finally, environmental health domain quantified the condition of the physical environment and the accessibility of resources and support and referred to the space in which a person was living in the surrounding community. People

perceived their environments as being safe or unsafe in the home, neighborhood, and larger community. Furthermore, this domain involves financial resources that meet the needs of a healthy lifestyle (World Health Organization, 2012).

**Dependent variable level of measurement.** Twenty-six questions in the survey questionnaire measured the dependent variable, perceptions of quality of life to indicators of physical health along with the five domains: overall quality of life and general health, physical health, psychological health, social relationships, and environmental health. The first two domains, the overall quality of life and general health and physical health, measured both quality of life and physical health. The next three domains, psychological health, social relationships, and environmental health measured the quality of life only.

The responses to these 26 questions were measured using an ordinal scale. The ordinal scale measured the answers in rank-order, meaning the higher the number, the higher the perceived quality of life (Research Methods Knowledge Based, 2017). For example, for the question “Do you get the kind of support from others you need?” the participant answered *1 not at all to 5 completely*. If the participant answers *1 not at all*, the perceived quality of life was ranked lower.

The dependent variable questions were answered in nine semantic models. 1) *1 very poor to 5 very good*, 2) *1 very dissatisfied to 5 very satisfied* 3) *1 not at all to 5 an extreme amount* 4) *1 not at all to 5 completely* 5) *1 not at all to 5 extremely* 6) *1 not at all to completely*, 7) *1 very poor to 5 very well*, 8) *1 very dissatisfied to very satisfied*, and 9) *1 never to 5 always*. The nine semantic models allowed the participant to answer each

specific question by ranking how his or her quality of life and physical health were impacted.

**Demographic information.** The second question in the “About You” section provided more demographic information about the participant’s current health. The second question states, “Are you experiencing problems with your health?” The participant will circle all that applies which includes (a) diabetes, (b) high blood pressure, (c) arthritics, (d) glaucoma, (e) cancer, (f) heart problems, or (g) none. These medical conditions were included because they are typical medical problems (Monahan and Hooker, 1995). After each response from the participant was counted, the categorical measurement was converted by coding. The coding was as follows: (1) none, (2) at least one medical condition, (3) at least two medical conditions, (4) at least three medical conditions, (5) at least four medical conditions, (6) at least five medical conditions, or (7) all medical conditions. This aligned the categorical variables with quantitative data.

### **WHOQOL-BREF Scoring**

Twenty-six questions were answered by each participant about his or her perceptions of quality of life, as measured by five domains: overall quality of life and general health, physical health, psychological health, social relationships and environmental health with a maximum score of 130 (Seattle Group of Life Group, 2014). According to the World Health Organization Seattle Group of Life Group, when participants were unsure of a response to a question, the participant should choose the answer that appears most appropriate. In the instructions, participants were instructed to choose the answer that best answers the survey question, within the last two weeks

(Seattle Group of Life Group, 2014). All 26 statements for the participant were rated using a Likert-type ordinal scale from 1 to 5 (see appendix).

When more than 20% of the answers are missing from the survey questions, the survey should be discarded. According to the scoring guidelines, when a participant leaves only one answer blank to one survey questionnaire question in the social relationship domain of the survey, the domain score should be calculated by substituting the participant's average score across the completed domain, to the blank question (Seattle Group of Life Group, 2014). For example, there were three questions in the social relationship domain. If the question, "How satisfied are you with the support you get from your friends?" is the only blank question in the social relationship domain, the remaining two questions were added and divided to get the score for the one question that was blank. The physical health, psychological health, and environmental health domains can only be substituted if there are no more than two questions missing.

The scores were scaled in appositive order with lower scores signifying the lower perceived quality of life and higher scores signifying higher scores of quality of life (Seattle Group of Life Group, 2014). There were three questions that must be reversed before scoring "To what extent do you feel that physical pain prevents you from doing what you need to do, how much do you need any medical treatment to function in daily life, and how often do you have negative feelings such as blue mood, despair, anxiety, and depression?"

### **Sampling and the Recruitment of Survey Participants**

A sampling frame list was used to recruit individual participants from public and nonprofit organizations. The sampling frame was a list of individual Alzheimer's family caregivers who were identifiable by public and nonprofit organizations. Public organizations were governed by public policy administrators for carrying out the interest of people within a community. Nonprofit organizations, which sometimes receive funding from public entities, were governed by a board and did not operate for profit. Organizations were recognized by Alzheimer's family caregivers as helpful resources through television commercials, the internet, and word of mouth from peers. Therefore, Alzheimer's family caregivers in Madison County who have general questions about Alzheimer's communicated with these organizations.

There were four public and nonprofit organizations included in the recruitment of survey participants. When Alzheimer's family caregivers have general questions about community services, the family caregiver called the organizations. Each organization was recognizable through local television commercials as the "go to" to answer questions about patients with Alzheimer's. When the organization answered a general question for the Alzheimer's family caregiver via phone or in person, the Alzheimer's family caregiver was not committed to receiving social support including faith-based support. On average, each organization answered questions for 40 Alzheimer's family caregivers each month. Therefore, these organizations had access to potential participants in both the comparison and control groups.

Before the start of sampling, each organization was given the opportunity to sign a letter of cooperation which describes their specific role in the sampling stage of the study. Each organization's role in the sampling stage was to (1) comply with the organization's privacy rules when giving the researcher information about Alzheimer's family caregivers, (2) sign a letter of cooperation, and (3) commit to giving the researcher a list of Alzheimer's family caregivers. The sampling frame list included the Alzheimer's family caregiver's name, address, and phone number. After the sampling frame list was given to the researcher, the organization had no other obligations to the researcher.

The sampling method is nonprobability not involving a random sample (Research Methods Knowledge Based, 2017). The possibility of all Alzheimer's family caregivers living in Madison County being selected could not be calculated. Therefore, it was estimated at least 40 Alzheimer's family caregivers from the comparison group and control group would be in the study. This would be a total of 80 Alzheimer's family caregivers. The researcher contacted each Alzheimer's family caregiver via phone and offered the chance to participate in the study. A numerical identifier was created for the Alzheimer's family caregiver after agreeing via phone to participate in the survey questionnaire. The nonprobability sample was used to purposefully select as many participants who were eligible according to the description of the comparison and control groups (Burns & Grove, 2011).

After the Alzheimer's family caregiver decided to participate, the research protocol included: the researcher mailing an informed consent and a survey questionnaire to the participant's address with a self-addressed envelope, the participant completing the

survey questionnaire, and the participant mailing the survey questionnaire back to the researcher. The researcher matched the numerical identifier created for the participant to the survey questionnaire.

Each participant read the informed consent. The informed consent detailed the estimated minutes to complete the survey questionnaire and provided sample questions from the survey questionnaire. The participant was informed that his or her participation was voluntary. It was the participant's decision to participate or not to participate. The participant was informed that his or her decision would not affect his or her relationship with the public or nonprofit organization. The time frame for the sampling process and recruitment was three months.

Additionally, this was a convenient sample of relying on the connection that the Alzheimer's family caregivers had with other Alzheimer's family caregivers. I asked the nonprobability sample, Alzheimer's family caregivers, for referrals of other Alzheimer's family caregivers they knew; through their referrals, the study expanded the sample in a snowball manner. Snowballing was useful because I needed to reach populations that were inaccessible or hard to find. The same protocol was used for snowball sampling which included contacting potential Alzheimer's family caregivers via phone, creating a numerical identifier and mailing informed consent and survey questionnaires to the Alzheimer's family caregivers' homes.

### **Survey Method**

Each participant received the survey questionnaire through post office mailing, including informed consent. I budgeted \$400.00 for paper, envelopes, postage, copying

services, tape, staples, mailbox rental, pens, and return postage for the study. The budget was based on 40 participants from each group, comparison and control. The prices for the budget were based on prices from Staples.com (2017). The miscellaneous line item in the budget allowed for unexpected costs. Table 1 shows the budget for this study.

Table 1

*Budget*

Supply List	Number of items	Cost
Paper		15.99
Envelopes		25.99
Postage	.98 (cost) x 80 (number of participants=	78.40
Return Postage	.98 (cost) x 80 (number of participants=	78.40
Copying Services	.2 (cost) x8 (number of survey pages) x80=	128.00
Tape		8.99
Stapler		3.99
Mailbox Rental		19.00
Pens		5.99
Miscellaneous		35.25
		Total Budget \$400.00

The WHOQOL-BREF was paper-based and self-administrated. The participant read the instructions detailing the survey questionnaire information and how to answer



the survey questionnaire. The instructions explained to the participant that the purpose of the survey was to measure how the participant perceived his/her quality of life over the last two weeks. Participants were informed they might skip any survey question that they do not wish to answer. The participant exited the survey when he/she answers the last question of the survey or if he/she decides to leave the survey before completing all survey questions. The participants were given a designated phone number to call if he or she had any questions. Data was retrieved by the paper-based survey.

### **Data Collection**

The paper-based survey questionnaire was returned to an address at a local post office box. Only the researcher had the key to the post office box, and no one else could retrieve the survey questionnaires. The follow-up procedure included reviewing each survey questionnaire to ensure each question had been answered by the participant.

It is important to describe how to research information is disclosed and the time period for the destruction of the research information (Privacy Technical Assistance Center, 2014). After the information was retrieved and coded, the researcher destroyed the paper-based survey questionnaires three months after dissertation research ended. This included the sampling frame list of individual Alzheimer's family caregivers who were identifiable by the public and nonprofit organizations and any identifiable information given by nonprobability sample. The sampling frame lists and survey questionnaires were destroyed by a local paper shredding company.

## **Statistical Methods**

Once all the data was collected, five-independent sample *t* tests were used to compare the means of the comparison group and the control group. The independent variable is a dichotomous one with only two categories. Five independent sample *t* tests allowed the independent variables, having faith-based support or no social support, to be compared to the dependent variables' quality of life and general health, physical health, psychological health, social relationships, and environmental health for Alzheimer's family caregivers. Using five independent sample *t* tests as a statistical method assessed whether the means between the comparison group and control group were statistically different from each other.

Five independent *t*-tests were performed to specifically measure the five dimensions in the WHOQOL-BREF survey questionnaire. Using another statistical test such as MANOVA was not appropriate because this study had one independent dichotomous variable with only two categories.

SPSS calculated five independent sample *t*-tests. SPSS is a logical software allowing measurement for quantitative studies (SPSS Tutorial2018). The significant level for this study was .05 or that 95 out of 100 times each sample was tested, the population would receive the same result. This significant level tested each hypothesis that state participants who receive faith-based support will report a higher perception of quality of life and general health, physical health, psychological health, social relationships, and environmental health. Using statistical methods ensured the difference between the comparison group and the control group, study conclusion results were not a result of

random chance (Michell, 1997). Cronbach's alpha for the 26 questions was .70 in previous studies (Gholami et al., 2013).

### **Threats to Validity**

Several threats to internal validity were addressed. The first threat assumed only faith-based support experiences influence the quality of life and general health, physical health, psychological health, social relationships, and environmental health of family caregivers. The survey instructions clarified the importance of faith-based support or no support at all when evaluating the quality of life and general health, physical health, psychological health, social relationships, and environmental health. The second threat was Alzheimer's family caregivers' prior relationship with faith-based leaders or public and nonprofit staff. This threat decreased by having the WHOQOL-BREF be self-administrated. Additionally, family or cultural expectations about caregiving roles can also be a threat. Caring for family members holds value for female gender roles in some familial cultures (Family Caregiver Alliance, 2016), but in other cultures, gender roles are not clearly defined.

This study was open to men and women caregivers. The limitation was having no review of participants' past experiences related to caregiving, knowledge of whether the impact came before the study, or observation of change over a period of time (University of North Carolina, 2017). The causal inference made during data collection was that the participants perceived this type of quality of life and general health, physical health, psychological health, social relationships, and environmental health because of the experiences with caregiving at the time the data was collected. Therefore, participants

only answered survey questions thinking about their experiences in caregiving at the time the data was collected.

External validity was measured through generalizations. Generalizations involved drawing from broad conclusions from the information provided (Polit & Beck, 2010). One generalization for this study included Alzheimer's family caregivers from similar populations such as Madison County had faith-based support available to them. Faith-based support may not be accessible in other communities; however, other social networks may be accessible.

### **Ethical Procedures**

Even after considering bias and potential risks, researchers must acknowledge ongoing ethical concerns. I followed all instructions approved by Walden University Institutional Review Board (IRB). The IRB approval number was 01-24-18-0474171. Nonprofit organizations selected for this study were ethically governed by their specific boards. Each member of the board had a fiduciary responsibility to ensure that the written policy and procedures rule the public and nonprofit organizations services. Public organizations were ethically governed by public officials. Public officials were publicly sworn in office to uphold the law.

A letter of cooperation was reviewed and signed by each organization willing to provide information about family caregivers to include names, phone numbers, and addresses. Once the letter of cooperation was signed, each organization started distributing the information to the researcher. The decision whether to participate in the

study did not influence the participant's future relationship with the faith-based, public, or nonprofit organizations.

There were minimal ethical risks for participants in this study. The length of time it took to complete the survey questionnaire could seem daunting. Participants were encouraged to answer the survey on their own, at their own convenience. Also, answering survey questions about the quality of life could invoke some emotional response that was new to the participant. As such, the instructions explained to the participant that he or she could stop and withdraw from the survey at any time.

Mailing the survey questionnaire back to the researcher may have appeared to be cumbersome. Each participant received a self-addressed stamped envelope to return the survey questionnaire when completed. To protect the identities of the Alzheimer's family caregivers, each participant was assigned a digital identifier to protect survey response information. Each survey questionnaire was assigned the same sequential number. Each participant received informed consent detailing the procedures and risks involved in the study when he or she received the survey questionnaire.

### **Summary**

The cross-sectional research design evaluated the quality of life and general health, physical health, psychological health, social relationships, and environmental health for Alzheimer's family caregivers when receiving faith-based support. Sampling population was Alzheimer's family caregivers living in Madison County, Alabama. The nonprobability sample made referrals given by public and nonprofit organizations. The convenience sample was referrals from participants in the nonprobability sample. The

data was recorded by paper-based WHOQOL-BREF completed by Alzheimer's family caregivers.

Data collected from the WHOQOL-BREF was coded in Microsoft Excel for analysis. Data analysis was completed using SPSS. The independent variable was faith-based support status having faith-based support or having no social support. The dependent variable was the perception of quality of life and general health, physical health, psychological health, social relationships, and environmental health. The quality of life was recorded on an ordinal scale, rated on a 5-point Likert scale. The survey results provided perceptions of quality of life and general health, physical health, psychological health, social relationships, and environmental health on an ordinal scale, indicated in each domain. The higher the score, the higher of quality of life and general health, physical health, psychological health, social relationships, and environmental health. Understanding tangible supports from the faith-based organization helped further the national conversation to meet the long-term needs of Alzheimer's family caregiver goals (Levin, 2014). In Chapter 4, I will report the results of the data analysis.

## Chapter 4: Results

### **Introduction**

In this cross-sectional study, I intended to evaluate the effect of faith-based support on the quality of life and general health, physical health, psychological health, social relationships, and environmental health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support. Faith-based organizations provide individualized tangible support, including companionship, educational training seminars, transportation, respite services, financial support, and assistive devices to decrease behavioral safety concerns within the home environment for Alzheimer's family caregivers. In this study, I define no social support as any support given to an Alzheimer's family caregiver to include public, private, or community support from organizations.

I used the WHOQOL BREF Survey to determine the perceived quality of life and general health, physical health, psychological health, social relationships, and environmental health for Alzheimer's family caregivers. The analysis included an independent variable with dichotomous value consisting of only two groups: faith-based support and no social support. The dependent variable used an ordinal scale measuring the answers in rank-order, meaning the higher the number, the better the perceived quality of life. All 26 survey statements for the participant were rated using a Likert-type ordinal scale from 1 to 5.

Driving this study is answering the five research questions.

Research Question 1 (RQ1): Is there a difference in the overall quality of life and general health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_01$ ): There is no difference in the perception of quality of life and general health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a1}$ ): Participants who receive faith-based support report a higher perception of quality of life and general health than participants who receive no social support.

Research Question 2 (RQ2): Is there a difference in the physical health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_02$ ): There will be no difference in the perception of physical health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a2}$ ): Participants who receive faith-based support will report a higher perception of physical health than participants who receive no social support.

Research Question 3 (RQ3): Is there a difference in the psychological health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_03$ ): There will be no difference in the perception of



psychological health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a3}$ ): Participants who receive faith-based support will report a higher perception of psychological health than participants who receive no social support.

Research Question 4 (RQ4): Is there a difference in the social relationships between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_{04}$ ): There will be no difference in the perception of social relationships between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a4}$ ): Participants who receive faith-based support will report a higher perception of social relationships than participants who receive no social support.

Research Question 1 (RQ5): Is there a difference in the environmental health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support?

Null Hypothesis ( $H_{05}$ ): There will be no difference in the perception of environmental health between participants who receive faith-based support and participants who receive no social support.

Alternative Hypothesis ( $H_{a5}$ ): Participants who receive faith-based support will report a higher perception of environmental health than participants who receive

no social support.

Each Alzheimer's family caregiver based his or her specific response on the perception of quality of life and physical health. Perception of quality of life is subjective thoughts and exists through self-consciousness that can only be answered by the Alzheimer's family caregivers (Cummins, 2005). In this chapter, I will explain the study results of the data analysis using SPSS including the data collection, demographic survey questions, independent variable questions, dependent variable questions, scoring, *t*-test assumptions, findings, and results.

### **Data Collection**

The Seattle Group approves the administration of the World Health Organization surveys in the United States. I contacted the Seattle Group and received approval # 84f37631eaff9129ee7dc6eae3d3a688 to use WHOQOL BREF. Four organizations were all contacted to invite Alzheimer's family caregivers who were potential participants in the study. One organization declined to participate. After contacting another organization, nothing was finalized to invite Alzheimer's family caregivers. One organization offered to advertise on Facebook only. I declined the organization's offer. And the last organization agreed to assist with this study. As a result, all participants were recruited through one organization.

Following the IRB approval of the proposal for this study, I received written permission from one organization to receive the names and phone numbers of the Alzheimer's family caregivers who contacted their office about Alzheimer's questions. The organization provided the information list of potential participants in a hard copy,

and I did not photocopy the list. I called the Alzheimer's family caregivers on the list using a telephone script approved by IRB. Once a caregiver agreed to participate, I asked the caregiver about other Alzheimer's family caregivers I can call about participating in the study. This helped to expand the sample in a snowballing manner. Finally, I mailed the consent form and paper survey questionnaire to those consenting to participate with a self-addressed return envelope. The return address for the survey was a confidential post office box that I rented, and I was the sole person with access. I mailed the survey packet to 93 caregivers over a period of 97 days between January 23, 2018 to April 30, 2018, 53 surveys were returned, 42 were usable for data analysis; of those excluded, seven were receiving non-faith-based support, and four were incomplete in survey responses.

The information was mailed to respondents and returned to me during the data collection period. I instructed the respondents to review the consent form and contact me if they had specific questions. I received five calls with questions about the survey, and most asked to clarify the meaning of non-faith-based support. The respondents receiving non-faith-based support were instructed to mail back the survey questionnaire with unanswered questions.

## **Survey**

**Demographics.** The survey questionnaire began with the section entitled *About You*, which included questions about demographics and the independent variable. The demographic information included the respondents circling male or female for their gender, writing their date of birth, and circling any health problems they were experiencing. The majority of respondents were over the age of 60, 20 respondents

(48%); followed by the next highest age group of 50-54 years, 10 respondents (22%). The 55-59 age group included 5 respondents (12%). Surprisingly, 7 respondents were under the age of 50 (19%). Women from both groups represented most respondents, 32 (76%), and there were 10 male respondents (24%). The usable survey questionnaire was answered by 24 respondents (57%) receiving faith-based support and 18 respondents (43%) receiving no social support. (See Table 2).

Table 2

*Distribution of sample demographics and support status (N=42)*

		Participants
		Number (%)
Age	Under 50	7 (19%)
	50-54	10 (22%)
	55-59	5 (12%)
	60+	20 (48%)
Gender	Male	10 (24%)
	Female	32 (76%)

Table 2

(continued).

## Support Status

Faith-Based Support	24 (57%)
No Social Support	18 (43%)

---

The average age of the faith-based group was 62, and the average age of the no social support group was 58. When reviewing the information, I observed a difference between female and male respondents. In the faith-based support group, women were two times more likely to receive faith-based support than men. In the no social support group, men were two times more likely not to receive social support at all than women. (See Table 3).

Table 3

*Distribution of mean/SD, support status, (N=42)*

	With Faith-Based Support (N=24)	Without Social Support (N=18)
Age (Mean/SD)	62 (6.17)	58 (3.8)
Sex (%)		
Female	75	25
Male	28	72

---

The fifth question in the *About You* section states, “Are you experiencing problems with your health?” The respondents circled all that applies which include (a) diabetes, (b) high blood pressure, (c) arthritics, (d) glaucoma, (e) cancer, (f) heart problems, and (g) none. Of the faith-based respondents’ group, 75% reported experiencing health problems to including nine respondents experiencing at least (1) health problem, five respondents experiencing at least two health problems, three respondents experiencing at least three health problems, and one respondent experiencing at least four health problems. In comparison, 55% of the no social support respondents reported experiencing health problems including four respondents experiencing at least one health problem and six respondents experiencing at least two health problems.

More than half of the respondents in both groups reported health problems. Faith-based respondents reported high blood pressure as the most common health problem. In comparison, no social support respondents reported heart problems as the most common. In sum, the group receiving faith-based support was 20% more likely to have health problems than those receiving no social support. (See Table 4).

Table 4

*Health Problems of the Respondents (N=28)*

Support status	Have a health problem N= 18	No health problem N=10
		%
Receiving faith- based support	75	25

Table 4  
(continued).

55 45

Receiving No  
Social Support

---

**The Independent variable: Faith-based support.** The survey had two questions; one measures whether the respondents receive faith-based support. The question was “How do you receive social support?” with responses of (a) faith-based support, (b) no social support, or (c) non-faith-based support. If the respondents answered faith-based support, they were asked to continue answering the questions as listed. If the respondents answered no social support, they were asked to go to Question 5. The respondents who answered receiving non-faith-based support were asked to stop taking the survey and mail the survey questionnaire back with no responses.

The second question regarding the independent variable helped clarify which type of tangible support the respondents were receiving from the faith-based organization. Tangible supports included (a) time spent for companionship, (b) transportation, (c) assistive devices, (d) respite services, (e) educational training seminars, or (f) financial support. Of the 24 respondents having faith-based support, 18 participants reported receiving tangible support. This included 11 respondents reported receiving at least one tangible support, six respondents reported receiving at least two tangible supports, and two respondents reported receiving at least three tangible supports. The respondents reported the most common tangible supports were educational seminars and companionship. The non-faith-based support respondents were excluded from the comparative analysis in this study. The respondents receiving faith-based support or no

social support were asked to reflect on the last 2 weeks of their lives when answering the survey.

**The Dependent variable: Family Caregiver's Perceptions.** There were 26 questions: two were related to quality of life and general health, seven about physical health, six about psychological health, three about social relationship, and eight about environmental health.

### Scoring

The survey answers were entered into the Excel spreadsheet starting with the demographics, independent variable and dependent variable. Then, I typed the number scores into the Excel spreadsheet of answers to all 26 questions, respectively. The scores were scaled according to the World Health Organization scoring form to include in apposite direction with a perceived higher quality of life measured with a higher score.

The apposite direction responses included nine semantic models; all were measured on an ordinal scale: a) *1 very poor to 5 very good*, b) *1 very dissatisfied to 5 very satisfied*, c) *1 not at all to 5 an extreme amount*, d) *1 not at all to 5 completely*, e) *1 not at all to 5 extremely*, f) *1 not at all to completely*, g) *1 very poor to 5 very well*, h) *1 very dissatisfied to very satisfied*, and i) *1 never to 5 always*. The results of the following three survey questions were reversed to achieve a consistent direction on the measurement scale. They were: "To what extent do you feel that physical pain prevents you from doing what you need to do?", "How much do you need any medical treatment to function in daily life?", and "How often do you have negative feelings such as blue mood, despair, anxiety, and depression?"



## Findings

The analysis compared the responses of the two groups in five perceived areas: a) quality of life and general health, b) physical health, c) psychological health, d) social relationships, and e) environmental health. The results of the study were analyzed using five independent sample *t*-tests to reject or accept the null hypotheses. I considered Levene's test for equality of variance when reporting the independent sample *t*-tests. Independent sample *t*-tests are commonly used to test the statistical difference between the means of two groups (Kent State University, 2018). Furthermore, the dependent variable must be continuous, the independent variable must have two or more category groups, and respondents cannot be in the same group (Statistics and Risk Management, 2018).

## Hypotheses

On average, those receiving faith-based support perceived physical health higher ( $M=25.2$ ,  $SD=17$ ) than those with no social support ( $M=22.1$ ,  $SD=3.8$ ). The difference was statistically significant:  $t=2.0$ ,  $P<.05$ . I reject the null hypothesis. None of the independent sample *t*-test results performed on the other four types of health domains showed a significant difference. Therefore, based on the study's findings, I cannot reject the null hypotheses and found no difference between the two groups in psychological health, social relationships, environmental health, and overall quality of life and general health. (See Table 5).

Table 5

*Results of independent-sample t-test (N=42)*

Perception Score	Faith-Based Support (N=24)		No Social Support (N=18)		<i>t</i> -Test
	Mean	SD	Mean	SD	
Physical Health	25.2	6.17	22.1	3.8	2.0*
Psychological	22.3	4.76	20	4.37	1.8
Social Relationships	11.0	2.11	10.1	2.37	1.3
Environmental	31.8	4.96	29.3	4.88	1.5
Quality of Life and General Health	3.72	.90	3.68	.81	.14

\**P* (2-tailed)=.05

#### ***t*-Test Assumptions**

I performed independent sample *t*-tests in testing the five null hypotheses; the tests compared the five average composite scores of the family caregivers with faith-based support and those without social support. There were four assumptions made when performing independent sample *t*-tests to trust the conclusion information. The assumptions included (a) the applied scale of measurement followed a continuous, ordinal scale, (b) the homogeneity of the variance, (c) the distribution of results should approach a normal bell-shaped curve, and (d) the results were in a normal distribution (Maverick, 2018). This study followed the four assumptions.

First, the data follows a continuous ordinal scale. In this study, the data followed an ordinal scale from a range of 1 to 5 when answering 26 dependent variable survey questions. Second, the *t*-test assumption homogeneity of variance exists (Maverick, 2018). A Levene's Test for Equality was performed on each *t*-test to verify the homogeneity of variance. The results are follows as: physical health  $p = .073$ , psychological health  $.597$ , social relationships  $.136$ , and environmental health  $p = .858$ , and quality of life and general health  $p = .877$ . Because the *p*-value is greater than 0.05, the groups were treated as equal.

Third, the results were in a normal distribution which is a bell-curve data value that tends to be around the mean. Fourth, the distribution of results should approach a normal bell-shaped curve. I performed a visual inspection of the histograms. Normal Q-Q plots and box plots showed the data were distributed equally for both Alzheimer's Family Caregivers who receive faith-based support and Alzheimer's Family Caregivers who do not receive faith-based support in the physical health domain. The physical health *t*-test met the normal distribution and normal bell-shaped. However, the remaining four *t*-tests did not meet normal distribution and normal bell-shaped curve. Figure 1 and 2 starts on the next page illustrating normal distribution.

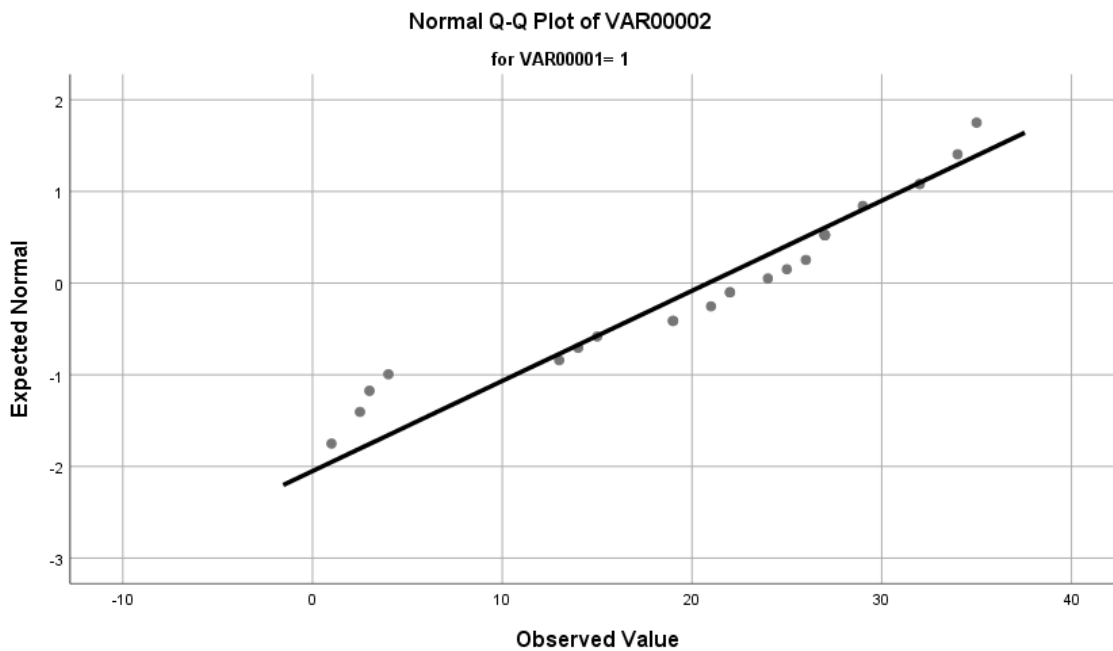
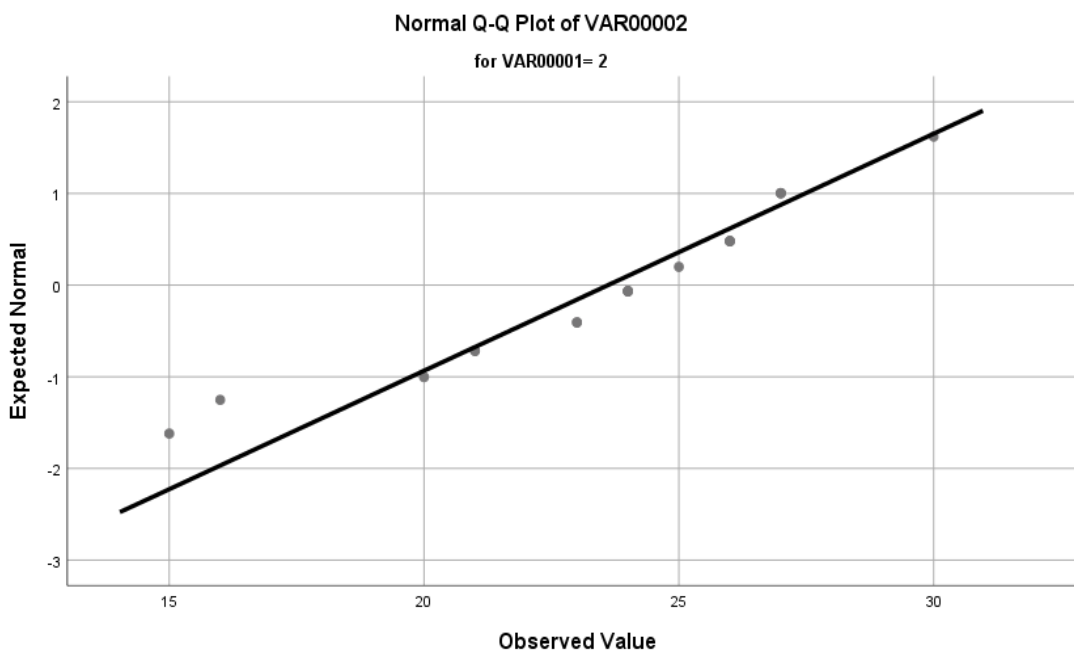


Figure 1. Normal Distribution Graph for faith-based caregivers. This figure illustrates the normal distribution for perceived physical health.



*Figure 2.* Normal Distribution Graph for no social support caregivers. This figure illustrates the normal distribution for perceived physical health.

### **Summary**

This chapter presented the descriptive results and detailed the five independent sample *t*-tests outcomes. Only one of the five showed a significant difference between perceptions of Alzheimer's family caregivers receiving faith-based support and no social support. Tables were presented providing the statistical analysis conducted to answer the research questions. During data collection, 93 surveys were mailed to respondents from January 23, 2018 to April 30, 2018; of these, 53 surveys were returned, 42 were used for data analysis, and seven were excluded for receiving non-faith-based support, and four were excluded due to incomplete responses.

The independent sample *t*-test results showed that of the five areas of perceptions between Alzheimer's family caregivers with faith-based support and those with no social support, a significant difference was observed only in physical health. I will discuss the results in Chapter 5, along with recommendations and findings.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this cross-sectional study was to examine whether there is a difference in the quality of life and general health, physical health, psychological health, social relationships, and environmental health between Alzheimer's family caregivers who receive faith-based support and Alzheimer's family caregivers who receive no social support. I used the WHOQOL BREF Survey was used to determine the perceived quality of life and physical health of Alzheimer's family caregivers when receiving faith-based support or no social support.

In 2014, Alzheimer's disease cost the United States 214 billion dollars, and the cost continues to grow higher as the complex disorder affects 5.2 million American people (Jones-Davis & Buckholtz, 2015). Public and non-profit organizations continue to offer resources to assist Alzheimer's family caregivers with this taxing demand. However, the evaluation of these programs continues to be a hindrance to understanding the perceived quality of life for Alzheimer's family caregivers' longevity in caring for a patient with Alzheimer's.

This study provided results comparing the Alzheimer's family caregivers who receive faith-based support and those family caregivers who receive no support. In this study, statistical evidence showed the Alzheimer's family caregivers who received faith-based support perceived their physical health to be better than those who did not receive any social support. The study results showed the perceived quality of life and general health, social relationships, psychological health, and environmental health had no

evidence of statistical change between Alzheimer's Family Caregivers who received faith-based support and those who received no support. Nonprofits such as faith-based communities have a great responsibility to share resources with all Alzheimer's family caregivers and to make a culture shift, addressing the need for Alzheimer's family caregivers. This vision is synonymous with the National Plan to treat Alzheimer's Disease by preventing or curing people from Alzheimer's disease by 2025 (Jones-Davis & Buckholtz, 2015). No previous studies compared perceived quality of life and general health for Alzheimer's family caregivers in Madison County, Alabama. Therefore, the findings from this study provided new and valuable insight into the effect of faith-based support for Alzheimer's family caregivers in an area of its size. This is beneficial to provide information regarding trends of services which Alzheimer's family caregivers need. In this chapter, I will explain the interpretation of the findings, limitations of the study, recommendations, implications for positive social change, and conclusion.

### **Interpretation of the Findings**

#### **Theory**

The theoretical foundation for this study was social support theory and the idea that social support decreases health problems and increases ways of handling stressful situations. Perceived social support is more influential than the actual support received (Thoits, 1995). Social support can be measured structurally, by the size of the social network in one's life, and functionally by the perception of available support. In this study, Alzheimer's family caregivers who received faith-based support reported a better perception of physical health than those who received no social support.

## **Gender**

Table 2 (in Chapter 4) showed an interesting difference: Female caregivers in this sample were 1.6 times more likely than male caregivers to receive faith-based support. Cameron, Wells, and Hobfoll (1996) found that women are more accepting of social networks than men. Of the women who responded to this study, 15% reported receiving educational seminars as tangible support. My findings were consistent with previous studies which note that female respondents care more for their family members. Lahaie, Earle, and Heymann (2012) discovered, for example, that 69% of family caregivers are women.

In addition to caregiver responsibilities, women must accommodate work responsibilities such as time off and decreased work hours, which cause financial strain, or even worse, unemployment. Still, women play a significant role in caring for a family member while juggling their other responsibilities, such as their own healthcare (Lahaie et al., 2012). As reported in this study, 37% of women responded that they had high blood pressure.

In contrast, only one-fourth of the male caregivers responded as receiving faith-based support. Men were almost 2 times more likely than women to have no social support. Educational seminars made up 50% of the types of tangible support male respondents received. Meanwhile the other 50% of male caregivers did not explain the type of tangible support they received from faith-based support. This alarming percentage can further explain how male caregivers perceive different kinds of faith-based support offered.



One hundred percent of the male respondents reported having high blood pressure. Reinhard, Given, Petlick, and Bemis (2008) found that high blood pressure, cardiovascular disease, and increased insulin levels over time will increase a caregiver's chances of dying prematurely because 40% of caregivers spend 5 or more years in the caregiving role. Such data may further help us understand why there were a lower number of male respondents in this study. Men caregivers were unavailable to answer the survey because they experienced more health problems as family caregivers than women.

### **Age**

This study focused on Alzheimer's family caregivers over the age of 50. However, 19% of respondents reported being under the age of 50. The average age of both faith-based support and no social support respondents was 60. Respondents 50 years and over reported health problems 63% of the time. Huang et al. (2006) examined the demographic characteristics and caregiver stress on general health. When the older caregivers receive minimal social support there was a low perception in general health (Huang et al., 2006). The surprising finding in this study was the oldest age group population, 60 and older. Of those respondents with health problems, 84% reported receiving tangible faith-based support. With those descriptive statistics, this study showed that most family members with health problems utilize faith-based support.

### **Health Problems**

In this study, Alzheimer's family caregivers who received faith-based support reported more health problems than the no social support group. This finding can be interpreted as Alzheimer's family caregivers being more aware of health problems

because of the support they receive from faith-based support. Now more than ever, faith-based approaches are being used to address public health problems such as obesity, hypertension, and diabetes (Kim, Linnan, Campbell, Brooks, Koenig, & Wiesen, 2008). Therefore, due to Alzheimer's family caregiver's health problems, they have to seek support. Faith-based support provides tangible assistance such as educational training seminars, highlighting the importance for family caregivers to maintain healthy habits. When caregivers are isolated or receive no support, awareness is generally lower about things such as being attentive to their health.

### **Physical Health Domain**

Based on the statistical results presented in Chapter 4, the physical health null hypothesis was rejected. I interpreted as faith-based support helping respondents become more aware perception of physical health, such as general health problems or pain among Alzheimer's family caregivers. One of the things that influence the family caregiver's pain is lifting the patient with Alzheimer's when they have no help such as assistive devices. Assistive devices provided by faith-based support include Hoyer lifts, motion sensors, calendar clocks, and wandering devices to help improve the patient with Alzheimer's safety concerns in the home environment.

### **Psychological Health Domain**

The psychological health domain comprises a person's positive feelings of contentment, balance, peace, and enjoyment in life (World Health Organization Quality of Life Group, 2016). The null hypothesis was accepted as all Alzheimer's family caregivers reported the same self-esteem, body image, appearance, accomplishments,

self-concept, and acceptance of any bodily impairment. Questions associated with enjoying life and family meaningfulness in life did not influence the perception of whether a family caregiver had received faith-based support or no social support.

### **Social Relationships Domain**

Social relationships are gained by people intimately connecting with others to share moments in close relationships, marriages, and partnerships (World Health Organization Quality of Life Group, 2016). This domain overlaps with sexual activity. In this study, however, tangible social support was defined only as companionship, as it relates to social relationships, not as sexual relations. This null hypothesis was accepted and further explained, in this study, that participants of faith-based support receiving companionship only, whereas no social support respondents may have had some higher social relationships within sexual relationships, further validating the null hypothesis.

### **Environmental Health Domain**

Physical safety and security refer to the person's sense of comfort within their environment. The environmental health null hypothesis was accepted and showed that there was no difference when faith-based support was given to Alzheimer's family caregivers. The survey questions were framed to give a person the opportunity to respond that they live without constraints and felt safe. The survey questions were sensitive to people who felt unsafe (The World Health Organization Quality of Life Group, 2016). Faith-based support and no social support respondents reported the same sense of freedom and safety, despite the differing type of support.

### **Quality of Life Domain**

In the domains of overall quality of life and general health, the null hypothesis was accepted. The overall quality of life defines the well-being and perception of overall life. This includes the general health which can vary for Alzheimer's family caregivers due to their perception of preventable health problems such as high blood pressure or diabetes. Having high blood pressure was reported 43% of the time by all Alzheimer's family caregivers. Furthermore, the first two questions were based on what the respondent perceived his or her current status of quality of life to be.

### **Limitations of the Study**

This study compared having faith-based support to no social support. Six limitations must be taken into consideration when interpreting the results. These are (a) no social support (b) small sample size, (c) geographic location, (d) population, (e) WHOQOL BREF survey, and (f) controls factors.

### **No Social Support**

Four null hypotheses were accepted, stating that faith-based support has minimal influence on Alzheimer's family caregivers. In this study, I did not take into account other forms of social support, such as family support. Wilks and Croom (2008) explain that forms of social support such as family and friends provide a protective factor of resilience. The possibility exists that having any support may influence perceptions of Alzheimer's family caregivers, not just faith-based support.

**Small Sample Size**

The recruitment period for this study was 3 months. I anticipated receiving caregiver information from four organizations to mail the survey to potential respondents; however, only one organization agreed to provide names. The anticipation of the sampling frame was a valid conclusion based on the latest Alzheimer's disease death rates. According to the Alabama Department of Public Health, in 2 years, between 2009 to 2011, 266 deaths were due to Alzheimer's disease and unspecified dementia-related issues in Madison County, Alabama. This study had 93 respondents in the sampling list, of whom 42 qualified for completing the study. Initially, I did not consider social media for this study due to the sample population for this area, which is historically accustomed to answering surveys via phone and mail. In future studies, it would be helpful to open recruitment through other means such as Facebook and to other surrounding counties with similar resources.

**Geographic Location**

The local organization serves a broader geographic location than explained initially in Chapter 3. According to the United States census in 2016, the metro Huntsville Area, which is the largest city in Madison County, includes Limestone County, Alabama (Huntsville Chamber of Commerce, 2016). There is a possibility that the respondents live outside of the Madison County area, based on the greater metro Huntsville area, providing services to a larger geographic location.

Despite this, faith-based support within the organization service area and the surrounding counties are comparable to those in Madison County, Alabama. All of the

Alzheimer's family caregivers have access to call the local organization and receive information on faith-based support. This includes tangible support such as companionship, educational training seminars, transportation, respite services, financial support, and assistive devices to decrease behavioral safety concerns within the home environment for Alzheimer's family caregivers.

### **Population**

This study was limited initially to Alzheimer's family caregivers over the age of 50. However, when the survey was returned to me, some of the survey respondents in this study identified as being under the age of 50. According to the Alzheimer's Association (2016), the forgotten Alzheimer's family caregivers are those family members ages 35 years to 50 years old (2016). The Family Caregiver Alliance (2016) said that caregivers could be found across middle age from 35-64 years old. Nevertheless, the Alzheimer's family caregivers in this study who identified as being under the age of 50 responded to the survey questions in the same matter that caregivers over the age of 50 did. For example, family caregivers under the age of 50 also reported having similar health problems such as high blood pressure, diabetes, and heart problems.

### **WHOQOL BREF survey**

I chose WHOQOL BREF for this study based on its use in other studies by researching the perceived quality of life of caregivers. The survey began with respondents answering demographic questions about their gender, date of birth, and health problems. After receiving the responses from the surveys, those demographic questions became usable answers from respondents. However, there was a limitation due

to respondents not having a fill-in-the-blank option to improve responses to the questions. For example, out of 24 respondents who received faith-based support, 18 responded to a specific type of faith-based support according to answers to Question #4 on the survey. Therefore, there were six respondents who answered as receiving faith-based support, but the kind of faith-based support was unknown. Next, two participants did not respond to the quality of life and general health questions. The unanswered questions caused only 40 surveys (24 with faith-based support and 16 with no social support) to be entered for the quality of life and general health domain.

A total of 5 out of 42 respondents answered the survey questions with the help of someone else. This study was primarily based on the perception of quality of life for Alzheimer's family caregivers. Those who responded to the survey questions this way could convey the interpretations of the assisting person rather than the respondents' own. This method had the potential to be mistranslated from the respondent to the person who is helped, as the survey questionnaire was based on the perception of the respondent. I took the survey questionnaire information as written even when the respondent received help with the survey questionnaire.

### **Lack of Control Variables**

Because this study did not control factors affecting the caregiver's quality of life there is a limitation. Such factors include family income, the perception of where the caregiver thinks he or she should be in life, and the caregiving role identified by the family's values. Huang et al. (2006) found that when caregivers can pay an in-home assistant, the caregiver's perceived quality of life was better. Also, caregivers who

experience family integrity associated with the family caregiving norm, tend to view caregiving, as a positive outcome of overall satisfaction and embrace the demand for caregiving. However, caregivers who are alienated tend to feel helpless (Guerra, Figueiredo, Patrao, & Sousa, 2016). My study was based solely on the perception of quality of life for the respondent and did not control for potentially influencing factors.

### **Recommendations**

My study contributes to Alzheimer's family caregivers' perceived physical health associated with faith-based support compared with no social support. In my study, when Alzheimer's family caregivers used faith-based supports, perceived physical health was improved. This study failed to reject the null hypothesis associated with quality of life and general health, psychological health, social relationships, and environmental health between Alzheimer's family caregivers who receive faith-based support. Many studies focus on improving the outcomes of care for Alzheimer's family caregivers. Previous studies proposed creating interventions that go beyond the description of Alzheimer's disease to the development of a personalized response to the family's caregiver (Davis et al., 2014). Further research is recommended to address (a) accepting faith-based support, (b) no social support (c) using other social supports, (d) male caregivers, and (e) the research approach.

### **Accepting Faith-Based Support**

A surprising finding in this study was that 43% of respondents did not reach out to faith-based organizations for support. An implication for further research is a better understanding of why Alzheimer's family caregivers do not seek faith-based support or



help from nonprofit organizations. The study focused primarily on faith-based support, assuming that Alzheimer's family caregivers were amenable to receive tangible support from the faith-based community. The assumption was inferred primarily due to the study taking place in the Southern region of the United States, also known as the *Bible belt*. The Bible Belt denotes the United States region where religious customs, specifically those of the Anglican Church in the 18<sup>th</sup> Century, influence politics, culture, and social practices (World Atlas, 2018). Two cities in Alabama, Birmingham and Huntsville, are considered the *Buckle* of the Bible Belt. Historically, Baptist, Methodist, Jewish, and Adventist founded community support institutions such as hospitals (Levin, 2014). It is vital to study barriers to accepting faith-based supports as it relates to community-based outreach from the faith community. There may be several conclusions, including acceptance of membership in a faith-based community, lack of accessibility, and help as a family norm.

### **No Social Support**

This study compared faith-based support to no social support. No social support or non- faith-based support can translate to informal support as resources that assist in everyday activities. Any form of social support for caregivers can lower stress, improve confidence, and increase problem-solving skills (Wilks et al., 2008). In this study, caregivers who reported no social support reported the same health problems as faith-based support.

In addition to the health problems listed in this study, depression was written in by one no social support respondent. Uncovering other health problems, such as depression, is due to a paradigm shift; instead of focusing on caregiver stress as a deficit-

focused perspective, it was focus on an obstacle to overcome (Wilks et al., 2008). The quality of life survey focuses on the perception of caregivers, opening a dialog on how to implement strategies for caregivers to endure patients with Alzheimer's physical symptoms such as failure to remember words, unpredictable responses, or agitation. Having other forms of social support should be evaluated in future studies.

### **Using Other Social Supports**

Natural supports are personal, and community supports, created from mutual relationships that have little structure but are reciprocal in nature when asking for help (Department of Developmental Services, 2008). For example, an Alzheimer's family caregiver can meet another Alzheimer's family caregiver in the doctor's office and start talking about the struggle to transfer the patient with Alzheimer's from the hospital bed to the portable toilet. The other Alzheimer's family caregiver can share her experience with transporting, creating natural support.

Online social support helps Alzheimer's family caregivers affirm decisions and receive reassurance and emotional support. Scharett et al. (2017) that found 26% of online posts from Alzheimer's family caregivers were related to Alzheimer's symptoms. A total of 45.56% pertained to caregiver well-being, with emotions ranging from heartbreak to intense anger. Scharett et al. (2017) suggest that psychological health is very important when addressing the needs of caregivers.

### **Male Caregivers**

Only 24% of caregivers in this study were male, with one-fourth of males receiving faith-based support and one-fifth receiving no social support. Male caregivers

take on a family role that historically has not been recognized by doctors, nurses, and other health professionals: men caring for their family members. The male caregiver population increased by 50% between 1984 and 1994, with male caregivers engaging in complex tasks like their female counterparts (Reinhard et al., 2008). The complex tasks included helping with personal care, addressing defiant behaviors, and managing finances. Male caregivers are less likely to express their emotions due to societal expectations (Hubbell & Hubbell, 2002). In addition, males are less likely to identify themselves with caregiving roles, thus decreasing their participation rates in this study.

Male caregivers accept assistance from social support that is task oriented or features problem-solving strategies. Geiger, Wilks, and Lovelace, (2015), who included 138 male caregivers in the sample population, found that emotion or avoidance focus strategies were less effective. Thus, male caregivers have less depersonalization and fewer masculine traits when an emotional and affectionate relationship with the patient exists prior to the onset of Alzheimer's disease (Hubbell et al., 2002). It is possible that I received an unrepresented sample of males in this study. Theoretical findings need further studies with larger samples to ensure that the difference in this study is a pattern based on sex.

### **Research Approach**

In this research, the quantitative research approach was chosen to align with the World Health Organization BREF. The WHO BREF survey has been widely used to determine the perceived quality of life for many populations including hospital patients and transgender women. However, the WHO BREF is a survey with a Likert scale, so

respondents only circle responses 1-5. To improve the response rate, I would suggest continuing a quantitative study appropriate for the Alzheimer's family caregiver population and recommending more options for respondents to fill in the blanks to write answers. Respondents writing the answers will help clarify specific types of faith-based support.

Six respondents did not list the type of faith-based support they had received. Not listing the type of support is due to respondents not being aware of the specific tangible faith-based support listed in this study. However, the six respondents identified themselves as receiving support, which implies that the assistance they received from the faith-based organization was helpful. Other skills taught through faith-based support include caregiver management styles. There are three caregiver management styles: adapters, strugglers, and care managers. Adapters tend to take on the caregiver role thinking about how to adapt to the certain decline in the future behavior of the patient with Alzheimer's. Meanwhile caregivers in the struggler position, do not think about the future of patients with Alzheimer's, but instead face one crisis situation at a time. The third caregiver management style, care manager, puts a limit on the amount of time of caring for a loved one, such as 2 months or 2 years (Davis et al., 2014). Nevertheless, these six respondents are functionally receiving faith-based support or perceive that support is available. This concept supports the theoretical basis, of social support theory, which states that the caregiver's perceived support improves his or her quality of life.

### **Implications for Positive Social Change**

This research contributes to limited positive social change as associated with faith-based assumptions. Four out of five null hypotheses were accepted. Despite this, public policy administrators need to assist the needs of Alzheimer's family caregivers in the long term. The longevity of Alzheimer's family caregivers is critical to public policymakers. After the study, the results showed that the perception of physical health improved when Alzheimer's family caregivers received faith-based support. Despite this, only 57% of the respondents in this survey rely on faith-based support. With only 57%, there is a way to assist Alzheimer's family caregivers before they become the secondary patient. A secondary patient or hidden patient denotes family caregivers who need protection and guidance from the demands of caregiving, which places family caregivers at high risk for adverse events (Reinhard et al., 2008).

I suggest using other social supports, such as advocacy through nonprofits. Each year during the general session, organizations visit the state's capital in Montgomery to advocate for more money allocated to supporting policies to assist patients with Alzheimer's. Given the public policy advocacy, on May 21, 2018, Governor Kay Ivey signed into law the Silver Bill, which allows first responders to search for a lost patient with Alzheimer's who have wandered away from their family immediately, instead of waiting the usual 24-hour period for the family to file a missing person's report (Martin, 2018). The Silver Bill further demonstrates how public policy makes a positive social change.

Positive social change can come by improving the opportunities for Alzheimer's family caregivers to receive the help they need to maintain their caregiver role. While this study shows that faith-based support is a reliable resource of tangible support to improve physical health, it is ultimately up to the caregivers to receive the help they need to address the taxing demand of caregiving.

### **Conclusion**

Perception of quality of life and general health for Alzheimer's family caregivers continues to be a challenge because of the increased need to care for the patient with Alzheimer's and the decreased self-care of the Alzheimer's family caregivers. Faith-based support is one of the social support methods used in Madison County, Alabama. This study provides public policy administrators with a greater understanding of how the quality of life is affected when a family caregiver is caring for a patient with Alzheimer's.

Many forms of public policy have been widely used throughout history to improve conditions. Jane Addams, a social worker, co-founded Hull House to address the need of immigrants in Chicago in the 1880s (National Association of Social Workers, 2004). Addams took a different approach by believing that all people need assistance instead of previous practices, which would make a decision of aid based on which person was worthy of help (National Association of Social Workers, 2004). Therefore, Addams solved the public problem of food, homelessness, employment, and poor education. The Nobel Peace Prize was rewarded to Jane Addams in 1931.

The study results confirm that when Alzheimer's family caregivers in Madison County, Alabama received faith-based support, perceived physical health is better. This

study contributes to research by helping public policy administrators identify the effects that faith-based support has on Alzheimer's family caregivers. Future research should focus on a) male caregivers, b) accepting faith-based support, c) using other social supports, and d) the research approach.

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## Appendix A: WHOQOL-BREF Survey

## About You

Before you begin we will like to ask you to answer a few general questions about yourself by circling the correct answer or by filling the space provided.

1. What is your gender?                      Male                      Female
2. What is your date of birth?                                 /            /             
Day                      Month                      Year
3. How do you receive tangible social support?
  - (a) Faith-based organization                      (c) Non-faith based organization
  - (b) I don't receive social support

If you answer non-faith based organization, please stop taking the survey and mail in your responses.

If you answer I don't receive tangible social support, please go to question 5.

4. Do you receive the following tangible social support? Circle all that apply
  - (a) time spent for companionship                      (d) respite services
  - (b) transportation                      (e) educational training seminars
  - (c) assistive devices                      (f) financial support
5. Are you experiencing problems with your health? Circle all that apply
  - (a) Diabetes                      (e) Cancer
  - (b) High Blood Pressure                      (f) Heart Problems
  - (c) Arthritics                      (g) None
  - (d) Glaucoma

## Instructions

This survey asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

	Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
How would you rate your quality of life?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others.

	Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
How would you rate your quality of life?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

	Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
How would you rate your quality of life?	1	2	3	4	5

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

	Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
1. How would you rate your quality of life?	1	2	3	4	5
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very Much	An extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5



	Not at all	A little	A moderate amount	Very Much	An extreme amount
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5
10. Do you have enough energy for everyday life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Have you enough money to meet your needs?	1	2	3	4	5
13. How available to you is information that you need in your day to day life?	1	2	3	4	5

14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
	Very Poor	Poor	Neither Poor Nor Good	Well	Very Good
15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

	Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
	Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
18. How satisfied are you with your capacity for work?	1	2	3	4	5

19. How satisfied are you with yourself?	1	2	3	4	5
	Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5

25. How satisfied are you with your mode of transportation?	1	2	3	4	5
	Never	Seldom	Quite Often	Very Often	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?  
(Please circle yes or no)

Yes

No

How long did it take to fill out this form?

\_\_\_\_\_

Thank you for your help