EXPLORING THE RELATIONSHIP OF KNOWLEDGE AND PERCEPTIONS/ATTITUDES OF ALZHEIMER’S DISEASE (AD) WITH PERCEIVED EXPERIENCES OF WORKING WITH AD PATIENTS AMONG CAREGIVERS AT LONG-TERM CARE FACILITIES

This study examined how knowledge and perceptions/attitudes of Alzheimer’s disease (AD) are associated with experiences of caregivers working with AD patients at long-term care facilities in the United States. A total of 100 caregivers participated in a cross-sectional paper-pencil survey of the study. The results showed positive relationships between the perceived experiences of the AD caregivers and all the three variables, while these relationships were not statistically significant. The findings of the study provided implications for social work practice, policy, and research.
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CAREGIVERS AT LONG-TERM CARE FACILITIES

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LIST OF ABBREVIATIONS

AD- Alzheimer's Disease
PE-Perceive Experience
K-Knowledge
P-Perception
A-Attitudes
CHAPTER I

INTRODUCTION

Alzheimer’s disease (AD) is a serious illness that affects the well-being of people, particularly those aged 65 years and above (McKhann et al., 2011). In this population, AD is a primary cause of dementia. People diagnosed with AD are likely to experience significant memory loss, the deterioration of language and problem-solving skills, and reduction in the functioning of cognitive tasks that influence how they perform everyday activities (McKhann et al., 2011). Furthermore, much capital and social costs are associated with AD, which is diagnosed predominantly in people over the age of 65 years. An analysis of the situation by the Alzheimer’s Association in 2012 established that over 200 billion dollars were paid annually for the treatment of the disease (Alzheimer’s Association, 2013). This prohibitive cost indicates that there is a huge effect on families regarding retirement savings, food budget, and restricted health spending on other preventive medical practices. This indication raises concerns about understanding and preventing dementia-related costs that stem from AD (Alzheimer’s Association, 2013).

In 2016, AD was estimated to be attributed to the deaths of approximately 130,000 people in the state of Georgia. According to a report by the Alzheimer’s Association (2016), in this state, 50,000 people aged 85 years and above were diagnosed
with AD in 2016. This number reflects almost 38% of the total elderly population in the state of Georgia (Alzheimer’s Association, 2016). The projected statistics showed that by 2020, the number of AD patients in the state of Georgia will increase by 15.4%; by 2050, 46.2% of the population will be affected by AD (Alzheimer’s Association, 2015). In the US, it is estimated that 5.4 million Americans have AD, and this number is expected to grow rapidly to the point that by 2050, a new case of AD will be diagnosed every 33 seconds (Alzheimer’s Association, 2016).

Because of the significant burden on older people, there is an urgent need for health professionals to examine the outcomes and factors associated with AD (Prince et al., 2015). Furthermore, there is a need to understand how the quality of care provided by caregivers of AD patients influences their health outcomes. Caregivers are persons who directly interact with AD patients at care facilities (Allen, Dublin, & Kimmerly, 2012). This chapter examined AD and its impacts on patients as well as on the caregivers working with these patients.

**Statement of the Problem**

AD is common among the aging population of people over 65 years in the US, but it is not a distinctive characteristic of the aged (Karasek, 2004). In its initial stage, AD starts on one side of the brain. It then slowly extends to other parts, including sections that are dedicated to the retention of the memory (Whitehouse et al., 1982). Even though medication does not cure this disease, it helps in improving its destructive consequences
by reducing its progression and relieving patients from some severe symptoms (Citron, 2002).

Research has shown that AD is associated with various negative health outcomes. Over time, CAD causes nerve cells to be disconnected from the brain, leading to its shrinkage (Weiner & Frenkel, 2006). During the final phase of AD, this shrinkage is evident throughout the whole brain, and its tissues appear to shrink to significantly low numbers (Weiner & Frenkel, 2006). Memory loss is especially pronounced among AD patients. It had negative consequences for the victims, as they develop many problems, such as getting lost, taking unusually long times to complete simple tasks, and repeating statements and questions (Alzheimer’s Association, 2016). Memory loss may also lead to forgetting people, paranoia, hallucinations, and the inability to learn new things (Kotilinek et al., 2002). In addition, the loss of brain tissue tends to influence the language function of a patient and how he or she constructs meaning when communicating with others. At the last stage, the brain shuts down completely, and the patient is forced to stay in bed (Albert et al., 2011).

Another factor associated with AD is age; AD is a kind of dementia that mostly affects the elderly (Bertram & Tanzi, 2011). Although AD is a form of dementia, it is not necessarily like other forms of mental disintegration, such as delirium. Dementia leads to the loss of the mental and intellectual abilities, intelligences, and social skills. Studies showed that about 10% of people who suffer from dementia are in “dementia pre-aging” or prehensile dementia (Bertram & Tanzi, 2011). If the patient is over the age of 65 years, it is called “senile dementia.” However, the existing literature reports the importance of
lifestyle, which is a primary factor associated with AD among older people. Research showed that AD is associated with the diet, social engagement, and physical activities of older people, and maintaining a healthy lifestyle is likely to decrease the risk of developing and suffering from AD (Bertram & Tanzi, 2011).

Social relationships have been found to affect the health of an individual. According to Cohen, (2004) maintaining a good relationship helps an elderly patient maintain a healthy life for a prolonged time. Good relationships indicate better care for ailing relatives, hence increasing their chances of feeling better or recovering from the effects of the disease. Good relationships also help the patient retain positive memories, and it increases their possibility of feeling better and being responsive to treatment (Kawachi & Berkman, 2001).

Furthermore, many studies have highlighted the significant impact of the quality of care delivered by caregivers on the health outcomes of AD patients, especially at long-term care facilities. These caregivers are especially burdened in caring for AD patients because of the associated memory loss (Etters, Goodall, & Harrison, 2008). Caring for a close relative with AD-associated dementia means that they do not even recognize him or her, which causing a psychological trauma in the caregiver. If they are not informed about what to expect with an AD patient, they might withdraw from caring for them. Most caregivers of AD patients have been diagnosed with anxiety and depression, especially when the patient is a close relative (Mahoney, Regan, Katona, & Livingston, 2005) As suggested by Bourgeois, Schulz and Burgio (1996), the caregivers of AD patients should be equipped with the knowledge of the disease in order to raise their
awareness of caring for the patients and increase the quality of their interaction with them.

**Purpose of the Study**

This study aimed to explore the knowledge, perceptions, and attitudes toward AD among caregivers working with AD patients and their working experiences at care facilities. In particular, this study investigated the ways in which the knowledge, perceptions, and attitudes toward AD among these caregivers are associated with their working experiences at the facilities. According to earlier studies, maintaining healthy social relationships enhances the memories of the elderly; therefore, maintaining healthy social relationships aids in lowering their chances of suffering from the disease.

**Research Questions**

The following two research questions are based on the study’s purposes:

1. What are the levels of knowledge, perceptions, and attitudes toward AD and the levels of the perceived experiences of AD caregivers?
2. Are the perceived experiences among AD caregivers associated with their knowledge, perceptions, and attitudes toward AD?
Hypotheses

In this study, the hypotheses were generated to test the associations among caregivers’ knowledge, perceptions, and attitudes toward AD and perceived experiences of working with the AD patients among caregivers at long-term care facilities:

$H_1$: Caregivers working with AD patients have high scores of knowledge, perceptions, and attitudes toward AD.

$H_2$: The caregivers’ high scores of knowledge, perceptions, and attitudes toward AD are correlated with their positive experiences of working with AD patients at long-term care facilities.

Significance of the Study

Researchers have found a dramatic increase in AD among older people. Previous studies showed the multiple negative impacts of AD on the quality life of older people (Prince et al., 2015). These elderly AD patients also face many psychological problems (Whitehouse et al., 1982). Researchers have also shown that AD is increasing at a high rate, and it is expected to continue to increase in the near future. Based on these findings, this study is significant because it offers information about strategies for the diagnosis, prevention, and treatment of AD. The government spends billions of dollars each year on AD. In the state of Georgia, the current expenditures are approximately $183 billion per year (Albert et al., 2011). This study is also significant because the financial resources expended by the government to deal with AD will diminish, which will directly influence
the quality of care for AD patients and their families. This study is also significant because it addresses the importance of the knowledge, perceptions, and attitudes toward AD for improving the quality of care among caregivers and the quality of life among AD patients and their families.

To overcome all the problems associated with AD, there is a need for continual research throughout medical, allied medical, psychiatric-psychological, and sociological disciplines as well as social work to involve all of them in multidisciplinary and interdisciplinary approaches to improving the quality of care for AD patients. This study aimed at increasing the knowledge about AD in today’s society in order to contribute to the continued search for better recommendations and knowledge about the disease. Furthermore, understanding how communities and patients deal with AD is important in developing the content of health education about the disease (Mastwyk et al., 2002).

Because there are many myths and misconceptions about AD, there is a need to conduct a study that removes many of these illogical assumptions, such as having a relative with AD does not necessarily mean that a person will develop the disease. People will gain knowledge about the risk factors associated with AD, such as diabetes, hypertension, drinking alcohol, and smoking cigarettes. By delineating the known risk factors, this research will help people adjust their lifestyles and reduce or eliminate many known risk factors. Because there was currently no remedy, this study will also help people learn about the symptoms associated with the disease and recognize the significance of early detection and diagnosis. Finally, the study expands the knowledge
that people have about AD. Having an increased base of knowledge will allow people to have new and meaningful ways to protect themselves against this disease (Fowler, 2001).

**Chapter Summary**

This study examines the relationship of knowledge, perceptions, and attitudes toward AD with the perceived experiences of caregivers who work with AD patients. Chapter 2 discusses the literature related to AD and the Afrocentric perspective, which provide the theoretical framework for the study. Chapter 3 describes the research methodology used to address the specific aim of the study and answer the research questions. Chapter 4 reports the results of the study. Chapter 5 discusses the study’s findings and limitations, provides suggestions for future research, and describes the study’s clinical implications for social work.
CHAPTER II
REVIEW OF LITERATURE

Research has shown that Alzheimer’s disease (AD) seriously impacts our society. According to statistics (Allen, Dublin, & Kimmerly, 2002), in the US, a person is diagnosed with AD every 70 seconds. Moreover, the baby boomer generation is estimated to contain nearly 10 million new AD patients (Allen, Dublin, & Kimmerly, 2002). Furthermore, as the number of elderly has been gradually increasing in the state of Georgia, AD is expected to become a public health concern in this state (Allen, Dublin, & Kimmerly, 2002). People with AD need a large amount of care. However, the burden of care is placed mainly on female caregivers, including spouses and children (Hoffman & Mitchell, 1998). The quality of care delivered by caregivers is important because it influences the quality of life and the health outcomes of people with AD (Brodaty & Donkin, 2009).

Historical Perspective

AD was identified for the first time by Alois Alzheimer (Glickstein, 1997). He identified the disease in 1906 by observing the mental and physical degeneration of one of his patients who showed symptoms of paranoia, psychological changes, and loss of memory. During the autopsy of the patient, Dr. Alzheimer observed the shrinkage of the
patient’s brain cells, especially those around the brain column. However, despite Alzheimer’s discovery, no treatment was available to Alzheimer’s patients. Because Alzheimer’s patients usually lose memory, AD was considered a natural process, a process of aging that happens to every individual. During this time, the word senility was used to denote Alzheimer’s disease, and it was thought that AD was a new kind of mental disorder (Glickstein, 1997).

According to Schmid (2008), a German psychiatrist named Emil Kraepelin first used the term Alzheimer’s disease. In 1974, the National Institute on Aging (NIA) was established by Congress to support research related to AD. During the 1970s, Robert Katzman found that AD was a prevalent form of dementia. Karasek’s discovery showed the world that Alzheimer’s disease is not a consequence of age, and he demonstrated that AD is not a natural consequence of aging (Karasek, 2005).

Leonard et al. (2016) found that “Georgia is leading the country with increases of AD cases” (p. 34). They also projected that in the following ten years, the frequency of Alzheimer’s disease in Georgia would increase by 48.1%. One element that could precipitate the increase might be Georgia’s expanding prevalence as a retirement destination. This developing pattern has increased the financial load on the state and its citizens. Georgia’s Senate Bill 14 included a formal acknowledgment by the General Assembly of the gravity of Alzheimer’s disease throughout the country. It noted the significance of leveraging assets from the private, public, and non-profit segments to enhance the state’s capacity to battle all types of dementia, especially AD.
Relatives might need to research the availability of classes at senior neighborhood facilities or adult care offices. Poor vision in many patients should be addressed in every aspect of the home. Additionally, relatives can implement strategies that might help AD patients live better lives at home, such as purchasing furnishings that clearly distinguish other objects from dividers and floors and that will maintain a strategic distance from objects that cause depth recognition issues. For instance, a restroom that is painted white might be troublesome for the vision of AD patients. A caregiver could help resolve this issue by placing a deeply hued cover or pad on the toilet seat, which would act as a solid visual marker for the patient (Glickstein, 1997).

About $1.8 billion in the costs of adult care centers in non-institutional settings and $16.6 billion in nursing costs are attached to the nursing home (Albert et al., 2011). The absence of a precise AD is a noteworthy obstruction to the care of patients in the current period (Albert et al., 2011). Recent evaluations showed that only a portion of all people with AD are ever diagnosed, and the picture is far worse for African-Americans, who tend to be diagnosed later if at all (Albert et al., 2011). The nonexistence or critical deferral of a diagnosis forces patients to travel to obtain comprehend their condition and treatment choices, which is a convoluted, costly, and financially depleting process (Albert et al., 2011).

Research has shown that AD is associated with various negative health outcomes. Over time, AD causes nerve cells to be disconnected from the brain, leading to its shrinkage (Albert et al., 2011). During the final phase of AD, this shrinkage is evident throughout the whole brain, and its tissues appear to shrink to significantly low numbers.
Memory loss is especially pronounced among AD patients. It has negative consequences for the victims because they develop problems with becoming lost, taking unusually long times to complete simple tasks, and repeating statements and questions (Albert et al., 2011). Memory loss also may lead to forgetting people, paranoia, hallucinations, and the inability to learn new things (Albert et al., 2011). In addition, the loss of brain tissue tends to influence the language function of the patient and how he or she constructs meaning when communicating with others. At the last stage, the brain shuts down completely, and the patient is forced to stay in bed (Albert et al., 2011).

Dependent Variable: Perceived Experiences of AD Caregivers

AD includes weaknesses in memory, cognizance, and consideration. AD patients show slow intellectual and functional decay over time. Giving essential care to a relative with AD needs extraordinary measures of vitality, time, and assets. As the malady advances, the AD caregiver is subjected incessantly to a progression of stressors that prompt physiological and psychological reactions. The AD guardian must deal with stressors that can have numerous causes, including the need to be constantly accessible and give close supervision to the AD patient. Other stressors are the absence of family and social help, the search for and securing of resources, and the conduct and correspondence issues of AD patient (Arevalo-Flechas, 2008).

Research has shown that language and culture can also have a significant impact on the caregiver’s perception of the experience of caregiving. Because the caregiving experience is physically challenging, emotionally draining (e.g., companionship loss,
relinquishment of social activities, and feeling of isolation) and financially detrimental, it can affect the caregiver’s perceived experience of caring for the AD patient (Arevalo-Flechas, 2008).

In Janevic and Connell’s study (2001), white caregiving figures tended to report more prominent misery and the assisted provision of care as more distressing than African American guardians did. The findings were mixed with respect to contrasts in adapting and social help. However, it was found that minorities might not have as much accessible help as whites did.

Independent Variable: Caregivers’ Knowledge and Perceptions/Attitudes toward AD

It has been estimated that more than 30 million people live with AD worldwide, and this figure is estimated to double every 20 years (Arevalo-Flechas, 2008). People living with AD require high levels of care, which is often provided by nursing and family caregivers. However, despite the prevalence of AD, the healthcare experiences of individuals with the AD and their caregivers are often considered a complex and dynamic process that needs to be addressed (Arevalo-Flechas, 2008). Therefore, there is a need to incorporate the health care experiences of both the caregivers and the patients in health service provision to ensure that their needs are met, and that person-centered care is provided. According to Janevic and Connell (2001), the healthcare experience of the caregivers is often considered stressful, and the evaluation of information regarding their
perceived experiences in service delivery is important to understand the preferences for improved patient outcomes.

**Knowledge of AD**

Although the knowledge of and attention to AD is increasing among both family members and patients, there has been little information regarding the public’s understanding of the disease (Johnson, 2015). According to Kleinman et al. (1978), the knowledge of AD often involves the process of providing explanations of both the biomedical and cultural models. According to Smyth et al. (2013), the quality of life, as well as the functional status of individuals with AD, is often affected by the quality of care in healthcare environments. It is perceived that adequate knowledge of AD among caregivers are critical to the provision of quality care, diagnosis, and the subsequent implementation of quality care interventions (Barrett et al., 1997). Therefore, there is a need to evaluate the knowledge of AD among both patients and their caregivers.

**Perceptions/Attitudes toward AD**

Concerns regarding AD have increased significantly in recent years, mainly in western societies. The impact of the disease on caregivers has resulted in various social attitudes. People with AD are often stigmatized and discriminated against because of the attitudes of people toward individuals suffering from this disease (Arevalo-Flechas, 2008). AD patients often fail to inform their family members and friends about their condition because they fear that they will react negatively. Most negative attitudes toward
the disease often are based on the cultural perspectives that people have regarding the disease. For example, according to some African cultures, the disease in individuals is a sign that they are possessed by evil spirits or are being punished for their sins (Arevalo-Flechas, 2008). Moreover, other studies have indicated that people often associate the disease with old age, and the occurrence of the disease during old age is considered a normal phenomenon (Corner & Bond, 2004). However, in other communities, such as in western societies, there is little, or no stigma attached to AD; however, it is conceptualized as accompanied by a combination of stress and worry. The process of providing care to the AD patients is often considered stressful. The patients and the family members consider the disease to cause the loss of memory and intellectual ability, which are often incurable. Hence, these perceptions and attitudes drive the need to understand the attitudes toward AD in society.

AD impacts not only the people diagnosed with AD but also their caregivers who are in charge of taking care of them. About 80% of the care for AD is provided by unpaid guardians who are mainly close family members (Arevalo-Flechas, 2008). Compared to professional caregivers, including nurses and nursing aids that work for AD patients, the caregivers of family members are likely to lack knowledge about AD, including its causes, symptoms, progression, treatments, and interventions, which is important in taking care of AD patients (Arevalo-Flechas, 2008). Therefore, it is important to assess the knowledge of AD among the caregivers of AD patients and then educate them.

According to Haghighat (2001), mental illness is a stigmatized topic in most cultures. People who suffer from mental illness are often subjected to further stress. This
stigma tends to have negative impacts on individuals with AD and on their caregiver’s social, physical, and emotional well-being. Nonetheless, there is a lack of literature available on how the caregivers of AD patients perceive this disorder.

Haghighat (2016) investigated the attitudes of caregivers with people with a mental illness such as AD. Their findings showed that the attitudes of the caregivers differed according to educational status, gender of the patient and the caregiver, marital status, the caregiver’s relationship with the patient, occupation, and the use of different treatment modes. In a cross-sectional study conducted in Greece, Haghighat (2011) found that the caregiver’s attitudes and perceptions regarding AD heavily depended on how the disease progressed.

Afrocentric Perspective

Afrocentricity is a worldview held by African individuals. It declares that research should re-declare a feeling of organization with a specific end goal to accomplish rational soundness. In the 1960s, educated African-Americans in the recently developed black studies departments at colleges started to plan novel methods for analyzing data. These new ways involved examining data from “a black viewpoint” instead of the “white point of view” used to analyze most data in American educational institutions (Green et al., 2002).

Afrocentricity is an innovative and a stimulating concept that has gradually emerged in the last few decades in studies related to African people. The concept holds that any authentic and meaningful study of people of African descent must have Africa at
its center instead of on the periphery. Furthermore, according to this concept, people of African descent are viewed as subjects, not objects. This concept aims to challenge Eurocentric scholarship against which all other cultures are measured. As a result, their individuality is destroyed. The present study focuses on the Afrocentric perspective to examine African culture with specific regard to AD. This perspective does not assume that Europe’s history, concepts, research, and traditions related to AD are the same as those of Africa. This study does not generalize the conditions of AD and its caregivers in Africa, and it seeks to examine the area from an Afrocentric perspective.

Ten basic concepts are specific to the Afrocentric perspective: humanistic values, autonomy, strengths, matrix roles, spiritual balance, collective view of self, the universalistic and particularistic significance of self-knowledge and personal experience, and the validation of linear logic, circular logic, and intuition.

In the Afrocentric perspective, the term humanistic values refer to the idea that values related to eliminating all human oppression and enhancing human potential should be prioritized. The concept holds that humanistic values must be put above all other values. Afrocentricity generally holds a humanistic philosophy. Morality as an important part of spirituality is highly valued in the Afrocentric world view, which reflects the emphasis on humanistic values. This humanistic thought process differs from western psychological process. In the African concept of humanistic values, the relationship between humans and God is maintained. A human being’s ability to be caring and moral is related to God’s model of care and morality (Green et al., 2002).
In contrast, the strengths perspective refers to the identification of group characteristics that can be favorably conceived and are sources of human advancement and resiliency. In social work, the strengths point of view has been developed as an option to the typical pathological emphasis on helping clients. Instead of concentrating on customers’ issues and shortcomings, the strengths viewpoint focuses on clients’ capacities, abilities, and assets (Schiele, 1994).

According to Green et al. (2002), AD is more pervasive in the African American community than in the white community. Estimates suggest that 15% more African-Americans are impacted by the disease, it has been found that it is more noteworthy in families, and African-Americans are at higher risk for the disease. Genetic and related environmental components might be combining to cause this disease in African-Americans. In the relative places, African-Americans with AD have a higher aggregate risk of dementia than whites with AD do. The dementia is persistent as a chronic mental disorder that distorts mental procedures and results in brain injury or disease that is manifest in impaired reasoning, personality changes, and memory disorders. Age is a main risk factor for AD. It is related to most racial background. More than 10% of the total population and more than 66 and almost 50% of this provided more than 80 have faced this disease (Green et al., 2002). The number of African-Americans with AD aged 66 years and older will increase from 2.8 million in 1995 to 7.1 million by 2033 (Green et al., 2002).
**Family Systems Theory**

Dr. Murray Bowen introduced family systems theory according to individuals need to be understood as a part of a family, and any attempts to understand them in isolation are wrong and futile (Eshbaugh, 2016). As indicated by Bowen, a family is a framework of principles in which every member has a part to play. In this framework, individuals are relied upon to react to each other positively according to their part, which is dictated by relationship agreements. Inside the limits of the framework, designs are created as a relative’s conduct is caused by and influences other relative’s practices in a predictable way. Although maintaining a behavioral pattern in a framework may prompt a balance in the family, it may also contribute to dysfunction. For instance, if a spouse is depressive and recover, the wife may need to take the responsibility and move on. The adjustment may preserve dependability in the relationship, yet it might also push the family toward an alternate state of equilibrium. This new state of equilibrium may prompt brokenness, as the spouse will most likely be unable to keep up his demanding part over a long period. The same could be the case in AD patients and their primary caregivers. When the patients’ caregivers are pushed to perform several duties that they otherwise would not do, it may have a negative impact on their perceived experiences with the patient (Eshbaugh, 2016).

The same could be the case with the AD patients and their primary caregivers. When the patients’ caregivers are pushed to perform several duties that they otherwise were not performing, it may have a negative impact on their perceived experiences with the patient. Overburden and caregiving stress in addition to increased duties on the part of
the caregiver could have an adverse impact on the perceived experiences of the AD caregivers and also their attitudes that is the independent variable. So according to the family system theory there is a link between the dependent and independent variable in terms of perceived experiences of caregivers of AD and what is the knowledge and attitudes of AD in caregivers.

**Theoretical Model of Caregiver Stress**

Lazarus and Folkman (1986) presented their theoretical model of caregiver stress and experiences with AD patients. Dementia care provision is usually the model for analyzing the impacts of chronic burden and stress on the person’s mental and physical well-being. The most well-known hypothetical model of caregiver stress experienced by dementia caregiving figures is Lazarus and Folkman’s (1986) transactional anxiety and adapting model. This model emphasizes that circumstances or encounters are not naturally unpleasant but rather are experienced as distressing after a two-level evaluation or appraisal process by the person. Initial evaluations or appraisals are affected by background, past encounters, culture and ethnicity, and identity. Secondary evaluations include choosing whether an individual is fit to deal with the anxiety and to determine a strategy for adaptation. This auxiliary procedure depends on circumstances more than the underlying examination does, and it is by and large the objective of interventions. Evidence confirms that among dementia caregivers dynamic adapting procedures prompt lower levels of stress than avoidant adapting procedures do (Tremont, 2011).
It is evident through this theory that the individual characteristics of the caregiver such as their attitudes, knowledge, perceptions about AD that is the independent variable are directly linked to caregiver stress and their perceived experiences with the patient that is dependent variable.
CHAPTER III

METHODOLOGY

The present study aimed to explore how knowledge, perceptions, and attitudes of Alzheimer’s disease (AD) are associated with experiences of caregivers working with AD patients at long-term care facilities in the United States. Understanding the relationships is important to provide a quality of healthcare services for optimal health outcomes among AD patients.

This chapter discussed the study’s design and sampling, the instruments used for measuring the dependent and independent variables, and analysis of data obtained from a cross-sectional survey. Moreover, this chapter discussed also the limitations this study has which might influence the findings of the study.

Study Design

This study employed a cross-sectional paper-pencil survey to collect the data. The survey asked participants to self-report quantitative information as to socio demographics, knowledge, perceptions, and attitudes (independent variables) of AD, and perceived experiences (dependent variable) of caregivers working with AD patients at long-term care facilities.
This study focused on assessing caregiver’s knowledge, perceptions, and attitudes regarding AD and how they are associated with the caregivers’ experiences in working with the AD patients. Therefore, participants were included in this study if they were staff or adult volunteers who had ever provided care services to AD patients for more than one year at a long-term care facility in the state of Georgia. The participants who however failed to meet these specific requirements were excluded from the study. This study sought at least 100 participants to ensure statistical analysis of the relationships between dependent and independent variables. Data collection occurred between June and July 2017 at various long-term care facilities, including nursing homes, nursing placement agencies, and non-profit organizations serving AD patients in the state of Georgia.

**Sampling Procedure**

Convenient sampling was used to recruit participants for this study. The researcher identified local long-term care facilities which serve AD patients in community through searching websites. The researcher contacted an administrative manager at the facility via phone to request permission of recruitment for study participants. With verbal permission of the facility administrator, the researcher contacted potential participants via phone or email, briefly introducing this study. For data collection at their facility, the researcher set up a schedule for a meeting with the potential participants interested in this study. During the meetings with the potential participants at the facility, an informed consent form was administered. Immediately after obtaining the consent form from the participants interested in this study, survey
questionnaire was administered. The completion of the survey took about 20 minutes on average. The Clark Atlanta University Institutional Review Board approved this study.

**Measures**

The cross-sectional, self-reported survey consists of a total of 29 questions of dependent and independent variables and a total of 11 questions regarding socio demographics. These questions used a five-point Likert scale, with the following answers: “Strongly Agree,” “Agree,” “Neutral,” “Disagree,” and “Strongly Disagree.” The questions for the dependent and independent variables are dispersed throughout both questionnaires in order to ensure that question grouping did not have an influence participants’ data, as the ordering of questions can create bias in the data (Quelhas et al., 2011).

**Perceived Experiences of Caregivers (Dependent Variable)**

The perceived experiences of caregivers were collected from the 15-item Perceived Experience Scale, with the responses ranging from 1 (“strongly disagree”) to 4 (“strongly agree). Examples of the statements include: “Since working with my Alzheimer’s patient(s), I have been able to maintain my social life.” and “I feel an appreciation for my life’s purpose.” In this study, Cronbach’s alpha value was 783.

**Knowledge of AD (Independent Variable)**

One of the independent variables in this study was knowledge of AD. This scale consists of 13 items designed to assess the knowledge of people concerning AD An
example of a statement on this scale is “Most caregivers are familiar with Alzheimer’s disease in terms of prevention methods and causes.” In this study, Cronbach’s alpha value was .755.

**Perception of AD (Independent Variable)**

The second independent variable in this study was perceptions of AD among caregivers of AD patients. The perception of AD was measured by the 6-item statements ranging from 1 (“strongly disagree”) to 4 (“strongly agree). The higher score of the sum of responses indicates more positive perception of AD. Examples of the statements include: “People under 65 aren’t diagnosed with Alzheimer’s disease.” and Alzheimer’s patients need special care.” In this study, Cronbach’s alpha value was .823.

**Attitude toward AD (Independent Variable)**

The third independent variable in this study was attitude toward AD. This scale reflects the participants’ attitudes toward their own professional competency in the care for AD patients. Providing advocacy (“Since working with my Alzheimer’s patient, I have been able to become an advocate for Alzheimer’s care”) could imply a positive attitude toward the self and one’s own personal power to affect patients with AD. In this study, Cronbach’s alpha value was .743.
Demographic Characteristics

The demographic information included race, age, educational level, the length of employment.

Data Analysis

Descriptive analysis was conducted to describe characteristics of the participants. Pearson correlation test was implemented to measure the relationships between independent and dependent variables. The Statistical Package for the Social Sciences (SPSS) 21 version was used for data analysis.

Limitations of the Study

This study had some limitations in terms of methodology used. Firstly, the present study used a cross-sectional survey. Findings of this study are limited to temporal characteristics of the study variables and their relationships. Future studies need to employ longitudinal and experimental design which helps better understand casual-effect relationships between the variable of interest. Secondly, due to reliance on participants’ self-report on the measures, the findings might be influenced by systematic error, including social desirability bias or acquiescent response set bias among the participants. Upcoming studies should consider cultural norms related to study participants in selecting or developing survey questions to avoid the bias. Finally, the other limitation in this study involves the type of sampling that was selected. Convenient sampling method was selected in this particular study, which might have added up the as a limitation to the
sample selected. This is primarily because a small sample is subject to increasing in errors and thus the results will not be illustrative of the whole population.

**Chapter Summary**

This particular chapter was primarily focused on the specific research methods that aimed at getting a deeper understanding of the knowledge, perceptions, and attitudes of Alzheimer’s disease (AD) and the perceived experiences of caregivers working with the AD patients. The main research method that was adopted in this study was the quantitative method, with the cross-sectional survey employed to collect data from 100 participants who took part in the study. Besides, through the use of SPSS 21 version, the data was analyzed to get an in-depth analysis of the various variables in the study.
CHAPTER IV

PRESENTATION OF FINDINGS

The purpose of this study is to identify the associations of knowledge, perceptions, and attitudes of AD with perceived experience of caregivers working with AD patients. Research questions of this study are as follows:

1. What are levels of knowledge, perceptions, attitudes, of AD and levels of perceived experiences of AD caregivers?
2. Are perceived experiences among AD caregivers associated with knowledge, perceptions, and attitudes of AD.

Sample Characteristics

Table 1 shows description of the sample characteristics. A total of 100 adult caregivers aged between 20 and 80 years participated in a cross-sectional survey. Out of the participants, 91 percent \((n = 91)\) were female, while only 9 percent \((n = 9)\) were male. The participants’ mean age was 34.5 years old. The analysis of age sub-groups revealed that 32\% \((n = 32)\) were between the ages of 30 to 39, while 7\% \((n = 7)\) were between the age of 70 and 79. For relationships with AD patients, 51 percent \((n = 51)\) were close relatives, 23 percent were medical health professionals, ten were spouses,
eight were local community members, seven were distant relatives, and one participant was family member. In respect to hours per week spent working for AD patients, 30% spent 1 to 5 hours and 20 hours or above, respectively, while about 20% \((n = 22)\) spent 5 to 10 hours. This study also asked participants to report a number of the patients for whom they had cared. While most of the participants \((n = 28)\) had cared for 7 or more Alzheimer patients prior to the current assignment, an almost equal number were on their first assignment \((n = 25)\). On the other hand, 22 and 25 participants had taken care for 1-3 and 4-7 patients, respectively, prior to their current assignment. Most people prefer an inpatient work setting \((n = 35)\) compared to those who like outpatient settings \((n = 3)\). A higher prevalence also goes for those who like working within a client relative’s home \((n = 20)\) rather than in the client’s residence \((n = 20)\). A small percentage \((n = 10)\) indicated they prefer other work settings. Most of the participants \((n = 58)\) completed their technical school (certificates or associates), while 23 had accomplished the 11th grade or below and eight participants had completed their bachelor’s degree. Over 70 percent of the participants were African Americans, while 20 percent were White Americans. Only five \((5\%)\) of them were Asian American while Hispanic Latino, American Indians, and other races were 1, 3, and 1 respectively. When asked what gender of the patients that the respondents had previously taken care of, most of the respondents \((n = 50)\) had cared for both males and females. While 22 had no preference, 22 had only female clients while 4 had only male clients. However, when asked what gender of Alzheimer patients they would prefer to take care of, 50 participants said they had no preference, 21 said female
only, 12 said males only and 17 said both male and female patients. These demographics are shown in Table 1.

Table 1

**Sample Demographic**

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>91</td>
<td>91.0</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>9.0</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>16</td>
<td>16.0</td>
</tr>
<tr>
<td>30-39</td>
<td>32</td>
<td>32.0</td>
</tr>
<tr>
<td>40-49</td>
<td>21</td>
<td>21.0</td>
</tr>
<tr>
<td>50-59</td>
<td>14</td>
<td>14.0</td>
</tr>
<tr>
<td>60-69</td>
<td>10</td>
<td>10.0</td>
</tr>
<tr>
<td>70-79</td>
<td>7</td>
<td>7.0</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American/Black</td>
<td>7</td>
<td>70.0</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>20</td>
<td>20.0</td>
</tr>
<tr>
<td>Asian American</td>
<td>5</td>
<td>5.0</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>1, 3</td>
<td>1,3.0</td>
</tr>
<tr>
<td>Variable</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Alzheimer’s patient you rather be assigned:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females only</td>
<td>50</td>
<td>50.0</td>
</tr>
<tr>
<td>Males only</td>
<td>50</td>
<td>50.0</td>
</tr>
<tr>
<td>Some mix of females and males</td>
<td>22</td>
<td>22.0</td>
</tr>
<tr>
<td>No preference</td>
<td>22</td>
<td>22.0</td>
</tr>
<tr>
<td>Relationship with client:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>23</td>
<td>23.0</td>
</tr>
<tr>
<td>Spouse</td>
<td>10</td>
<td>10.0</td>
</tr>
<tr>
<td>Close Relative</td>
<td>51</td>
<td>51.0</td>
</tr>
<tr>
<td>Distant Relative</td>
<td>7</td>
<td>7.0</td>
</tr>
<tr>
<td>Community Member</td>
<td>8</td>
<td>8.0</td>
</tr>
<tr>
<td>Other (family member)</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Working Hours with Client per week:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 hours</td>
<td>30</td>
<td>30.0</td>
</tr>
<tr>
<td>5-10 hours</td>
<td>22</td>
<td>22.0</td>
</tr>
<tr>
<td>10-15 hours</td>
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<tr>
<td>15-20 hours</td>
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<td>9.0</td>
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<tr>
<td>Variable</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
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</tr>
<tr>
<td>Alzheimer’s patient you rather be assigned:</td>
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<td></td>
</tr>
<tr>
<td>Females only</td>
<td>50</td>
<td>50.0</td>
</tr>
<tr>
<td>Males only</td>
<td>50</td>
<td>50.0</td>
</tr>
<tr>
<td>Some mix of females and males</td>
<td>22</td>
<td>22.0</td>
</tr>
<tr>
<td>No preference</td>
<td>22</td>
<td>22.0</td>
</tr>
<tr>
<td>Relationship with client:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>23</td>
<td>23.0</td>
</tr>
<tr>
<td>Spouse</td>
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<td>10.0</td>
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<tr>
<td>Close Relative</td>
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<td>51.0</td>
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<tr>
<td>Distant Relative</td>
<td>7</td>
<td>7.0</td>
</tr>
<tr>
<td>Community Member</td>
<td>8</td>
<td>8.0</td>
</tr>
<tr>
<td>Other (family member)</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Working Hours with Client per week:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 hours</td>
<td>30</td>
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<tr>
<td>5-10 hours</td>
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<td>22.0</td>
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<tr>
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<tr>
<td>15-20 hours</td>
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</tr>
<tr>
<td>20+ hours</td>
<td>30</td>
<td>30.0</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>5.0</td>
</tr>
</tbody>
</table>
Descriptive Analysis of Variables

The primary variables for this study were perceived experiences of AD caregivers (PE) and knowledge (K), perceptions (P), and attitudes (A) of AD. Table 2 shows the mean score of perceived experiences (dependent variable) of caregivers was 1.98 ($SD = .232$). For the knowledge of AD, the mean score was 1.75 ($SD = 0.932$). Furthermore, the mean score of the perception scale was 1.17 ($SD = 1.172$). Finally, the mean score of the attitude scale was 1.95 ($SD = .722$).

Table 2
Descriptive Statistics of Primary Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>PE</td>
<td>1.98</td>
<td>.232</td>
</tr>
<tr>
<td>K</td>
<td>1.75</td>
<td>.932</td>
</tr>
<tr>
<td>P</td>
<td>1.17</td>
<td>1.172</td>
</tr>
<tr>
<td>A</td>
<td>1.95</td>
<td>.723</td>
</tr>
</tbody>
</table>
Correlation Analysis among Variables

The Pearson correlation coefficients were calculated to examine the relationships between the perceived experience of caregivers (dependent variable) and independent variables. The correlation analysis showed that PE is positively correlated with all independent variables, respectively (see Table 3). The correlation coefficient value was the highest between PE and P ($r = 0.5$, $p > .05$), while it was the lowest between PE and K ($r = .340$, $p > .05$). No significant relationship between dependent variable and each independent variable was found in the tests.

Table 3

Correlation of Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>1. PE</th>
<th>2. K</th>
<th>3. P</th>
<th>4. A</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Perceived Experiences (PE)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Knowledge of AD (K)</td>
<td>.340</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Perceptions of AD (P)</td>
<td>.489</td>
<td>.634*</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>4. Attitudes toward AD (A)</td>
<td>.443</td>
<td>.678*</td>
<td>.635</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: Correlation is significant at the 0.05 level (2-tailed).

*p < .05.
CHAPTER V

CONCLUSION

This study aimed to examine the associations of perceived working experience of AD patient caregivers with their knowledge, perceptions, and attitudes of Caregivers. This study used a self-report cross-sectional survey to obtain the data. The findings of the data analysis provided critical information for social work practice, policy, and research.

Summary of the Study

In this study the typical caregiver was a middle-aged female (30-39 years.), 91%. In the past studies, some other factors have been studied in regard to Alzheimer’s disease – such as how perceived burden relate to perceived spiritual support (Martin et al., 2000; Wilks & Vonk, 2008). In these studies, the majority of caregivers were the care recipients’ spouse. In contrast, this study identified the majority of caregivers as the female 32%. Over 70 percent of the participants were of the African American race while another 20 percent were Caucasian/white respondents. Only five (5%) of them were Asian American while Hispanic Latino, American Indians, and other races comprised of 1, 3, and 1 respectively.

The study also involved demographic analysis of the participants involved in the survey by gender, age, education, and race. With a cohort of 100 study cases, 91% were
female and only 9% were male. Majority of groups were concentrated in 30 to 39 years. The study found that most of the caregivers spent more than 20 hours caring for AD patients.

In regard to perception, when asked if AD is another definition of madness (dementia), a central mean score of 2.53 was reported. Surprisingly on the correlation analysis, it was found that perception was leading effect on the perceived experiences amongst AD caregivers, with a correlation of .49. This suggests that perception have the highest impact on the perceived experiences amongst the AD caregivers. Apparently the more the respondents were perceptive, their perceived experiences increased concurrently.

Overall, a positive correlation was found among the three study relationships: i.e., the correlation between perception and perceived experience, attitude and perceived experience, and knowledge and perceived experience, respectively. This result showed positive relationship between the perceived experience of the AD caregivers and all the three variables, while the relationships were not significant.

This helps us answer the questions such as, in the context of social impact in relation to perceived experiences amongst AD caregivers: Caregivers working with AD patients will have high scores of knowledge, perceptions, and attitudes about AD What are levels of knowledge, perceptions, attitudes, of AD and levels of perceived experiences of AD caregivers? This part of research study explores the level of knowledge, perceptions, attitudes, influence the level of perceived experiences of AD caregivers. Caregivers give advice to the Alzheimer’s patient’s family members. From
the responses, it was found that by enhancing the bond of relationship with a patient suffering from Alzheimer, by taking in advice from other caregivers, and by performing as an advocate for Alzheimer’s care, caregivers would overcome the misunderstandings held by the non-informed individuals on how Alzheimer affects a patient.

Are caregivers able to have a socio-emotional connection regarding their work with Alzheimer’s patients? From analysis presented above, it can be said that caregivers are capable to be socio-emotionally connected with respect to their care to Alzheimer’s patients. Their working experience, preference, and education connect these caregivers to their Alzheimer’s patients. The result of this part able to answer the research question raised in the first chapter properly.

How do factors such as gender and work experience with Alzheimer’s patients impact the quality of the patient-caregiver relationship? Analysis given above shows that the gender factor has some impact on the quality of a relationship between patient and caregiver because when asked about what the preferred gender of Alzheimer patient a respondent would rather be allotted, 50 out of 100 participants responded that they have no preference, 21 responded that they have preference for female only, 12 responded with the males only, and 17 participants responded of a combination of the patients for female and male. Likewise, when asked what a gender of the patients is they care for most; 50 of the participants said combined females and males, 24 responded with a preference for the female only, 4 responded with males only, and only 22 responded that they do not have any preference regarding the gender of patients. Work experience of caregivers also
affects the way they treat their customers. So, this part of the research study was able to answer the research question in an appropriate manner.

**Implications for Social Work**

There are numerous implications concerning the knowledge and perceptions of Alzheimer’s Disease (AD) and the experiences of the caregivers in providing services to the AD patients. This research study brought into light the impact of the various misunderstandings regarding the Alzheimer’s Disease to the process of providing care to the AD patients. This particular study provides the caregivers with information on how to deal with the various misunderstanding by the non-informed individuals about the AD. Through these misunderstandings the patients are perceived to be critical in ensuring that social workers should educate the people regarding the disease and in the process, provide efficient services to the AD patients. The results of the study are also crucial to the caregivers given that it provides critical information that can be used by the social work caregivers, educators, and the policy makers in understanding the causes of other related factors of the Alzheimer’s Disease.

Firstly, for social work practice, findings are crucial in providing avenues through which the social workers can be able to provide better services to their patients. The persons with AD require more attention and intensive care from both the caregivers and the family members and thus the information from this study would help the caregivers to prepare for better delivery of services since they would have a better understanding of the patient. Through the information above, the health care system would also be better
equipped in terms of the services that they provide and also the policies that they institute.

As social workers meet with caregivers at individual level, they should be aware that each individual possess their own perceived experiences, knowledge, perception, and attitude. The goal of a social worker is to help the caregivers cope with the challenges of caring for loved ones with AD. Therefore, social workers should be aware of the findings of this study–how knowledge, attitude and perception relate with the caregivers’ perceived experiences–so as to able to assist a client (e.g., students) using perceived experiences as a factor which determines the kind of care they offer to the AD patients.

Social work trainers must be aware of the positive correlation reported in the study for caregivers’ perceived experiences in relation with knowledge, perception and attitude. The main goal of a social work educator is to prepare social work students to be able to take care for a wide array of AD patients. A well-prepared student should be confident in their knowledge of AD and their patients’ knowledge level. Also, a student should be aware of attitude and perception effect. This ultimately prepares a wholesome social worker capable of taking care of diversified AD patients.

Secondly, for social work policy, findings are useful to the social workers given that it would help them in creating awareness programs in the society to reduce the numerous misconceptions about the Alzheimer’s Disease. It has been seen that the misunderstandings about AD is also due to the insufficient knowledge of the health care givers which has greatly contributed to the perpetuation of the misconceptions. Therefore, education should be aimed at groups which are accessible and homogenous to
the AD patients. The institution of the necessary policies would be quite essential in ensuring that the welfare of both the Alzheimer’s disease patients and the caregivers are well taken care of. Besides, the policies would help establish the promotion of satisfactory environment that would promote the wellbeing of the patients and the social workers.

Finally, for social work research, findings suggest that there is a need to support the design, evaluation, and implementation of the integrated approaches to the caregiver services and how policy, media and training approaches might impact upon Alzheimer disease related to misconceptions, including the changes in AD perspectives, attitudes, and emotional experiences. Besides, there is the need to conduct research that primarily explores the nature of relationships between the patients with Alzheimer disease and those who are living around them such as the local community, neighbors, and the family. This is primarily because the service providers have been seen to have a personal experience of Alzheimer disease and the potential effect that it might have in the provision of services. This kind of research would help in bringing into light how perceived misunderstandings of the diseases and its components would affect the social constructs and interactions in effective care of the patients.

The obligation of majority of social work practitioners, especially those caring for AD patients is to be there for them and help them deal with the crisis. Despite this being the case the perceived experiences of the caregivers are of interest since it ultimately affects the kind of care AD patients receive. Perceived experiences are studied in relation to knowledge, perception, and attitude. A positive correlation was reported on the three
relations, which leads to conclusion, as the positive knowledge kicks in amongst the caregivers, positive perceived experience is gained, as caregivers embrace positive attitude towards the AD patients, positive perceived experience kicks in, and also likewise as perception improves positively.

This study concluded as positive knowledge, attitude and perception is reported among the caregivers, positive perceived experience is also reported. This shows the importance of caregiver’s knowledge, perception and attitude in determining the kind of experience they offer their patients and themselves.

**Conclusion**

Alzheimer’s disease has robbed millions of lives since it was first diagnosed in Alois Alzheimer and long before then, today, millions of families are affected by Alzheimer’s disease, and it’s a stressing, time-consuming and expensive process taking care of loved one living with the disease. Families experience the agony of the disease slowly robbing their loved ones of each memory, brain and body functions, and ultimately the patient’s personality (Logsdon, 2008) But the whole experience is hugely perceived by the caregivers of the patients. The caregivers are presented with a pool of experiences during this process and it’s important for them to be aware how the whole experience can be affected by one’s knowledge, perception, and attitude. Having a positive approach in the three disciplines can greatly have a profound positive impact on caregiver’s perceived experience, as attested by the findings of this study. If the caregiver
has a positive perception towards Alzheimer’s disease, perceived experience outcome will ultimately be positive.

Alzheimer’s disease and caregiving are expensive and demanding responsibilities and it takes a collective social responsibility to be able to manage—in terms of medical bills and time spent with patients. Social workers need to professionally prepare a caregivers and caregivers needs to be aware of factors that may influence their care-giving abilities. Since Alzheimer’s disease is a terminal illness, it’s only obvious that the caregiving process is the only comfort the society can offer the patients, this being the case a lot of intensive care-giving research should be encouraged, so as to improve the kind of experience caregivers and their patients offer each other.
APPENDIX A
INFORMATION LETTER

Date

Dear Potential Research Participants,

You have been selected to participate in a research study that looks at the status of Alzheimer’s disease and how it affects your daily interactions with people and healthcare providers. My name is Ohud Alsulami, I am a graduate student at Clark Atlanta University who is training to become a Clinical Social Worker. I wish to study the effects of Alzheimer’s disease on older Americans residing in an urban community in the State of Georgia.

The testing packet includes:

- This introduction letters
- A letter of informed consent (which allows the researcher permission to use your answers
- A demographics form (10 background questions)
- A questionnaire with 5 answer choices
- The Barthel Index questionnaire

These surveys should take no more than 20-30 minutes of your time.

Your personal information will be kept anonymous and your names will not be released to anyone other than the researcher. Each packet will contain an Identification
Code, the researcher will not share this information with any advertisers or public agencies. Your participation in this research study could help Social Workers and Social Work students better prepare to work with and meet the needs of clients who are living with Alzheimer’s.

Thank you for your support,

Ohud Alsulami, MSW student. Seokwon Jin, Ph.D., M.S.W.,M.A.

Principle Researcher Assistant Professor of Social Work
Clark Atlanta University Clark Atlanta University
APPENDIX B

CONSENT FORM

Exploring the Relationship of Knowledge and Perceptions/Attitudes of Alzheimer’s disease with Perceived Experiences of working with the Alzheimer’s disease Patients Among caregivers at long-term Care Facilities.

Please Note: Unless required by your research sponsor, EXEMPT research does NOT require a CONSENT FORM for participants. However, a “Letter to Participants”, informing them about their participation, and including the issues covered in this consent form template, must be developed and submitted at the time of the IRB application.

You are invited to be in a research study to look at the experience of being a caregiver to Alzheimer’s patients. You were selected as a possible participant because you currently or recently worked or volunteered with Alzheimer’s patients in the Atlanta Metropolitan area. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study will be conducted by Ohud Alsulami at the School of Social Work at Clark Atlanta University.

Background Information:

The purpose of this study is,

The purpose of the study will be to explore the relationship of knowledge and perceptions/attitudes of Alzheimer’s disease with perceived experiences of working with the AD patients among caregivers at long-term care facilities:
1. How do caregivers respond to the misunderstandings held by non-informed people on how Alzheimer’s affects the patient(s). The researcher will ask questions based on common misperceptions held about Alzheimer’s that have been showcased on television or in news articles in the past.

2. Are caregivers able to have a socio-emotional connection regarding their work with Alzheimer’s patients? The researcher will ask questions to measure the level of comfort the caregiver has with the work they do and how they believe they are able to maintain stability in their lives.

3. How do variables such as gender and work experience with Alzheimer’s patients impact the quality of the patient-caregiver relationship? The researcher will look at the results to see if there are differences in the responses given for caregivers that have worked longer in the area or if the gender of the patient or caregiver has an influence on the connection between the caregiver and patient.

Procedures:

If you agree to be in this study, we would ask you to do the following things. The participants will be given a small packet containing the informed consent form, two questionnaires and a demographics sheet. The entire packet should not exceed 20 minutes in length. The testing will be arranged in available meeting areas in the facilities.

Risks and Benefits of Being in the Study:

The risks of participants in this study will be minimal. The participants will be asked to provide their thoughts of experience of working with Alzheimer's disease patients. The data obtained will help the research community to understand the areas of improvement and support for the caregivers of Alzheimer’s patients in the Atlanta Metropolitan area.

The benefits to participation are:

The answers generated will help the research community to understand the areas of improvement and support for the caregivers of Alzheimer’s patients in the Atlanta Metropolitan area.
Confidentiality.

The records of this study will be kept private. In any sort of report, we might publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file; only the researchers will have access to the records. After 2 years, all of the survey packets will be properly destroyed, and your personal information will not be shared with others.

Voluntary Nature of the Study.

Your decision whether or not to participate will not affect your current or future relations with the researcher, or Clark Atlanta University [or with other cooperating institutions, insert names]. State the voluntary nature of the research participation, the freedom to withdraw at any time without affecting those relationships previously identified. If at any time you feel uncomfortable with the survey questions, you may withdraw from the study. You will just need to return your packet to the researcher. The information you completed will not be included with the survey and in 2 years all the information gathered will be properly discarded.

Contacts and Questions:

The primary researcher conducting this study is Ohud Alsulami. You may ask any questions you have now. If you have questions later about the research, you may contact the researcher at: Phone: 404-509-4321, Email: Doody.a.2011@hotmail.com. My academic advisor is Dr. Seokwon Jin, Ph.D., M.S.W., M.A. at: Phone: 404-880-880-6703, Email: sjin@cau.edu.

If you have any questions now, or later, related to of the research, the rights of research subjects, you are encouraged to contact Dr. Georgianna Bolden at the Office of Sponsored Programs (404) 880-6979 or Dr. Paul I. Musey, (404) 880-6829 at Clark Atlanta University.

You will be given a copy of this form to keep for your records.

Statement of Consent: I have read the above information. I asked questions and have received answers. I consent to participate in the study.
Signature ____________________________________________________ Date: ______

Signature of Investigator ______________________________________ Date: ______

NOTE: Children under the age of eight (8) require the permission of their parent(s) or legal guardians to participate in any type of research; those over the age of eight (8) require permission from their parent(s)/legal guardian, in addition to their Assent to participation.

PLEASE consider the attainment of informed consent as a process within the research design that requires your attention. The consent/assent forms that are approved by the IRB committee will be stamped as such and returned to the researcher and must be utilized throughout the research study.
APPENDIX C
QUESTIONNAIRE

Part I: Demographics

Please answer the following background information questions

1) What is your gender?
   a. Female
   b. Male

2) What is your current age?
   a. __________

3) What is your relationship to the client living with Alzheimer’s
   a. Contracted medical/mental health professional
   b. Spouse / Partner
   c. Close Family Relative
   d. Distant Family Relative
   e. Local Community Member
   f. Other______________________________

4) How long do you spend time with the client living with Alzheimer’s per week?
   a. 1-5 hours
   b. 5-10 hours
   c. 10-15 hours
   d. 15 or 20 hours
   e. 20 or more hours
   f. Other______________________________

5) Please list any and all specialty certifications, licenses, or training you use in your work with clients living with Alzheimer’s?
   a. ______________________________________________________________
   b. ______________________________________________________________
   c. ______________________________________________________________

6) How many clients living with Alzheimer’s have you cared for before this current assignment?
   a. 0, this is my first assignment
   b. 1-3
   c. 4-7
   d. 7 or more
7) Please circle your typical work settings?
   a. Outpatient Treatment Facility
   b. Inpatient Treatment Facility
   c. In the Client’s personal residence
   d. In the residence of the client’s relative
   e. Other ________________________________

8) What is your highest level of education?
   a. Grade School (11th grade education or below)
   b. High School (Diploma or GED)
   c. Technical School (Certificate or Associates)
   d. College (Bachelor’s degree)
   e. Graduate School (Master’s degree and above)

9) How do clients contract your services?
   a. Through an assistance/placement agency
   b. Personal advertisement
   c. Word of mouth
   d. Insurance referral service
   e. Other ________________________________

10) What is your race?
    f. African American/ Black
    g. Caucasian/ White
    h. Asian American
    i. Hispanic/ Latino
    j. American Indian/ Pacific Islander
    k. Other ________________________________

10) What is the gender of the patient or most of the patients in your care?
   a. Female only
   b. Male only
   c. Females & Males combined
   d. No preference

11) What is the preferred gender of an Alzheimer’s patient you rather be assigned?
    a. Females only
    b. Males only
    c. Some mix of females and males
    d. No preference
Part II: Knowledge and Perceptions/Attitudes toward AD

Directions: The following questions are based on the ideas others have about Alzheimer’s. Please indicate your level of agreement and select only one response for the corresponding questions.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Alzheimer’s disease affects older people more than younger people.</td>
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<td>2) Hypertension strongly affects Alzheimer’s disease.</td>
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<td>3) Alzheimer’s is another definition of madness &amp; dementia.</td>
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<td>4) High cholesterol is a leading cause of Alzheimer’s disease.</td>
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<td>5) Alzheimer’s patients need special care.</td>
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<td>6) There is a specific gene that leads to Alzheimer’s disease.</td>
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<td>7) Taking pressure medications can delay or control Alzheimer’s disease.</td>
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<td>8) The daily practice of game crossword puzzles has a clear role in avoiding Alzheimer’s disease.</td>
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<td>9) Eating healthy foods does not have signs of Alzheimer’s disease.</td>
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</table>
10) The level of higher education greatly influences the strengthening of the brain and thus helps to avoid the disease.

11) Most people are familiar with Alzheimer’s disease in terms of prevention methods and causes.

12) One of my relatives suffered from Alzheimer’s disease.

13) I can handle an Alzheimer’s patient professionally, if I am placed in a position where I must work with them.

14) Every person over the age of 70 has Alzheimer’s disease.

15) People under 65 aren’t diagnosed with Alzheimer’s disease.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since Working with my Alzheimer’s Patient(s) I have been able to:</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>

Part III: Experiences of Working with AD Patients

The following questions ask you to tell the researcher about your experience working with Alzheimer’s patient(s).
1) Offer advice to others who are working with a family member who is living with Alzheimer’s.

2) Find the answers to medical questions from the patient’s assigned Doctors, Nurses, and Specialist.

3) Feel an appreciation for my life’s purpose.

4) Improve the bond of my relationship with the Alzheimer’s patient.

5) Maintain healthy eating habits.

6) Feel discouraged about the future.

7) Find support from other caregivers in the community.

8) Maintain my social life.

9) Become an advocate for Alzheimer’s care.

10) Find support from religious organizations in the community.

11) Receive mental health assistance.

12) Maintain a balance in my home and work.

13) Maintain a support system of friends and coworkers who can
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<td>offer me advice when I have concerns.</td>
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<td>14) Feel appreciation from others for the work I do with the patient(s)</td>
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REFERENCES


