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ABSTRACT

Alzheimer's is a devastating disease that affects nearly 50 million people worldwide and will continue to increase exponentially with the aging of the population. The current work is an attempt to identify the needs of a subset of Alzheimer's patient caregivers who have placed their family member to help identify the specific psychosocial needs the family member may have. This will help agency staff to tailor specific plans in their interactions with both the patient and family member to help reduce identified caregiver burden. Due to the COVID-19 restrictions only a limited number of family members ($n=5$) were contacted and able to participate in the current study. Levels of patient needs were evaluated by head nurse by use of the Global Deterioration Scale. Family concerns were determined by having participants complete the Family Caregiver Well-Being Assessment results found that caretaker needs were not always consistent with the level of patient needs. Findings support the importance of the current agency program that helps identify and tailor staff interactions and education with family needs.

What Interventions Should Be Utilized with Alzheimer's Patients to Increase
Quality of Life?

A Thesis

Presented to

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In Partial Fulfillment

Of the Requirements for the Degree

Master of Science in Social Work

By

Laci Bach

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Master of Science in Social Work

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CHAPTER I

INTRODUCTION

Society is facing an aging population that is larger than ever before. This has not been viewed as a significant concern in the past; however, if interventions are not in place to treat, address and handle the influx of individuals with an Alzheimer's diagnosis, a major social problem will arise. The Alzheimer's Association estimates that 9.5 million Americans are living with an Alzheimer's Disease (AD) diagnosis in the United States (Biogen and Eisai, 2020). In Texas, 390,000 people aged 65 and older have AD (Texas Department of State Health Services, 2019).

Research completed on the effects of AD on patients and their families by Barbara Grabher in 2018 discovered that for the first time in history, the number of older people will outnumber children younger than five years of age. In the next 25 years, the number of people older than 65 will double. AD ranked sixth among leading causes of death in the United States, meaning that one in three elderly die with AD. This would mean that within the population of the United States someone develops AD every 65 seconds, and AD kills more individuals than breast cancer and prostate cancer combined (Grabher, 2018).

Statement of the Problem

The term "Silver Tsunami" was coined when the projections from the U.S. Census Bureau pointed out that baby boomers are reaching their senior years and acknowledged the increased senior populations (Grabher, 2018). AD is a devastating

disease that affects more than 46.8 million people worldwide and will continue to increase exponentially as time progresses. According to the Texas Department of State Health Service's 2019 Facts and Figures Report, in 2017 there were 9,545 deaths from AD; 5,824 people on hospice with a primary diagnosis of AD; and 1,451 emergency department visits per 1,000 people with dementia. The negative impact on the diagnosed individual, their families, and the entire health care system as a whole are astonishing.

Significance of Study

Alzheimer's disease is an illness that impacts brain activity due to nerve cells dying within the central nervous system. This affects the individual's ability to remember things, think clearly, and make sound judgment. Early signs of the disease begin with having a challenging time remembering things, asking the same questions repeatedly, not remembering directions to and from familiar locations, misplacing items, or placing items in unusual locations. In the disease progression, normal daily activities are forgotten such as combing hair, toileting, brushing teeth, and bathing. Disorientation about time, date, family members, friends and places are frequent. Inability to recall household items such as a desk, bed, etc., and wandering away from home are also common symptoms (National Institute on Aging, 2015).

This study emphasizes the need to utilize interventions that are proven to be effective in caring for an AD patient. Clinical trials are essential to advancing research due to the baby boomer population reaching older age. There has yet to be a cure found for this disease, so it is imperative to utilize the interventions already in place in addition to continuing to research this disease.

In conversations with families of loved one experiencing memory deficits, a common question raised regards the difference between AD and dementia. Dementia is a comprehensive term for symptoms synchronous to AD. Dementia is not a disease itself but is instead an underlying condition and type of AD. The cause of AD has yet to be discovered, and it is unknown why some individuals get it and others do not. The disease starts slowly, usually without the individual having knowledge they have it. The first sign of having the disease are memory deficits that become more frequent and complex. As the disease progresses, there is greater negative impact in day to day living such as forgetting daily tasks, cooking, cleaning, paying bills, driving a car, and routine task such as hygiene care, getting lost easily, experiencing confusion in simple tasks, and forgetting things. This often causes frustration, anger, and anxiety in the individual (Reisberg et. al, 2019)

CHAPTER II

CONCEPTUAL FRAMEWORK

Researchers continue to study how to prevent symptoms, slow the disease progression, and reduce symptoms. Right now there is no cure; however, AD is the second most feared diagnosis behind cancer. Clinical trials on treatment medication; early detection; healthy lifestyle choices; protecting head from trauma; not using tobacco; alcohol or other substances; staying socially active; participating in challenging brain activities; and practicing stress relief are proven to reduce the risk and symptoms of the disease process (Reisberg et al, 2019). Reisberg's research has found commonalities among individuals with a diagnosis of AD, such as age, family history and genetics. Research has also proven that those who have a sibling or parent with AD are more likely to develop the disease than others who do not have immediate family with the diagnosis, and the risk increases if more than one family member is diagnosed.

As the disease progresses, most people with the diagnosis need a full-time caretaker to assist with daily needs such as feeding, bathing and dressing. There are two options in this case: live-in caretaker within the home, or admission to a memory care facility within a nursing home. Both options are expensive, adding financial strain to the individual or family. Research for Alzheimer's care is priority due to the astronomical cost associated with caretaking. Individuals with an AD diagnosis have longer stays in the hospital and are the largest sources of disability. Caregivers remain involved up to the advanced stage of the illness, which may be up to seven years after the initial diagnosis.

Supportive Interventions

Research shows that there would be an impact on the effects of AD progression if education and training were provided on supportive interventions for families, which could result in increased visit frequency from families, prolonging the quality of life for patients who are diagnosed. A single group repeated measures design was used to research effectiveness of therapists using individualized multicomponent intervention to address the needs for comfort, social interaction and sensory stimulation (B'edard et al., 2011). The research was conducted by using 30-minute sessions during a time of day when behaviors were more prevalent within the group. The frequency and duration of verbal aggression were measured through direct observation and collecting data multiple times before, during and after the intervention. The findings indicate that need-based intervention is proven to be worthwhile. This result was limited to the specific times during which the intervention was being practiced. Half of the participants (54%) demonstrated significant behavioral improvement during the intervention, 50% reduction of symptoms. Some interventions are scientifically proven to lead to a better quality of life in late-stage dementia that are under-utilized within facilities and the family system.

The symptoms and behaviors of those who have frequent visits from family compared to those who do not have family participation over their lifespan after diagnosis are significant. Family participation, in collaboration with the Interdisciplinary team (IDT) contributes to comprehensibility in the diagnosed individual (B'edard et al., 2011). Alzheimer's disease could potentially be managed in a way that delays symptoms through interrupting degenerative brain changes and implementing combative interventions for symptoms found in early screening. Interventions have been formulated

to slow the disease process down such as music therapy, engaging in cognitive activities, diet, reminiscence and validation therapies, physical exercise, and memory stimulation. Research has also proven to recognize signs and utilizing early screening would be beneficial. Prevention methods could be used to prolong impacts of disease progression and prevent symptoms as long as possible (B'edard et al., 2011).

The Alzheimer's Association has also conducted research that shows the benefits of healthy nutrition, stating that, "A regular, nutritious meal may become a challenge for people with dementia. As a person's cognitive function declines, he or she may become overwhelmed with too many food choices, forget to eat or have difficulty with eating utensils"(Alzheimer's Association, 2020). Proper nutrition is important to keep the body strong and healthy. For a person with Alzheimer's or dementia, poor nutrition may increase behavioral symptoms and cause weight loss. Eliminating distraction, eating meals with the individual to ensure they eat a well-balanced diet, keeping table settings simple, making sure food is at correct temperatures, etc., are some of the protective measures that can be used to combat this problem ("Food & Eating", 2020).

CHAPTER III

REVIEW OF THE LITERATURE

Review of the literature indicated the effectiveness of using the GDS and other evidence-based interventions while caring for a loved one with AD; however, studies of the role of social work in healthcare settings and education for families is limited, underlining the importance of research in this area. In review of current literature, the need for further research is evident to fully grasp the processes of caring for a loved one with AD. Evidence on the effectiveness of identifying where a diagnosed individual is on the GDS and Family Caregiver Well-Being assessment is evident in the literature; however, evaluating the implementation of using this scale and the Family Caregiver Well-Being Assessment are scarce. The literature review further outlines a summation of the effects on the family system before, during and after diagnosis; social support during the care for both the diagnosed and the caregiver; the population affected; the role of caretaker and social work in care; prevalence of medications; and the economic burden associated with AD.

Effects on the Family System

Family support has been shown to benefit patients by decreasing the effects of stressful events in the disease process and behavioral disorders; however, supporting the caregiver is just as crucial as caring for the patient (Falcao et al., 2016). Caring for a loved one with AD is generally carried out by one person within the family system, which results in difficulty in managing home, family, personal and work life. When the

caretaker within the family reaches out to other members of the family for help, it often causes controversy, and results in an unresolved conflict within the family system.

The effects on the family system when an individual is diagnosed with AD are multifaceted and complex. There is a need to prepare families for the changed behaviors/personality as the disease progresses. Maintaining relationships with loved ones means having altered relationship dynamics. Assistance is needed to keep, restore, or enhance the skills families need to better deal with the diagnosis.

Social Support During Care

For the caregivers, the greatest difficulty that was reported on the Caregiver Well-being Assessment was lack of social support during the care process for the elderly. It would be beneficial for the social worker in the health care setting to invest time increasing the physical and mental well-being of the caregivers themselves to improve their quality of life, which would in turn improve the quality of life for the elderly diagnosed with AD (Silva et al., 2018). The quality of life for the caregiver of a family member with AD is altered. Further, many caregivers experience an absence of professional, social, and family support as well as a lack of education about AD, causing caregiver overload. (Silva et al., 2018).

Families have the potential to enhance the quality of life for Alzheimer's patients; however, families are not always able or willing to provide this type of care. In some cases, families do not come to see individuals living with AD because they do not know how to interact with them, and they do not think they will remember them or their visit. They often do not realize the potential power they have in enhancing the sense of connection. If families are not educated on what to expect or why their loved one is

presenting with behaviors that are new and different than what they have always been, it results in fewer visits, frustration, depression and sometimes even anger (Thomson & Lipp, 2012). The research completed shows a lack of incorporating proven effective interventions in care, such as sensory stimulation, storytelling, music therapy, cognitive engagement, diet changes, etc. A barrier presents itself when determining whose role it is to execute a plan in engaging the individual in available interventions. Family involvement may be lacking not because the desire is not there, but rather, the knowledge of how to have productive visits with their loved one is absent.

Education and Knowledge

According to Nilsson and Olaison (2019), a common theme with AD is family members having a thirst for education and knowledge on the disease itself and the most supportive methods to enhance success in managing the diagnosis. Limited research has been completed on how clinicians engage couples with a new diagnosis in therapy with a new diagnosis together openly and how to have resilience in the face of the unknown challenges ahead. A study was conducted that uses video-recorded interviews with 15 couples between the ages of 60 and 83 living with the effects of dementia. Two researchers interviewed the spouses and the couples were asked about their lives together, their experiences with dementia, and their current life jointly. Background information was gathered through questionnaires with regard to children, the longevity of the marriage, and career paths. The answers reflected that either or both spouses were interested in education about the progression of dementia; the spouses without dementia expressed distress regarding to not knowing what the future would look like and concerns about barriers in communication (Nilsson & Olaison, 2019).

Barrier to Care

The social problem is formulated in this population due to the lack of a strong support system that educates on the most effective ways to manage symptoms at both the micro and macro levels results in a social problem. In most general cases, this results in families leaving the patient in long-term care settings that are not specifically focused on the demands of the AD, which results in their needs not being met. A lack of family involvement results in increased feelings of isolation present that decrease meaningful interactions and decrease the quality of life for the individual (Lillekroken et al, 2017).

When an individual is diagnosed with dementia, the amount of care the individual needs is multiplied. There is a lack of understanding from the family when there is a new set of behaviors present, and the medical community has barriers to being adequately equipped to meet their needs. Research conducted by Lillekrocken, Hayue, and Slettebos (2017) states that dementia care requires focus on maintaining a sense of significance in the individual with dementia by recognizing and valuing the person for who they were and still are. They introduce the concept of “slow nursing” to address individuals with dementia in a manner that honors and respects the residents as individuals while validating their emotional reality, maintaining their dignity and integrity, and supporting their lived experiences. In managing care with this perspective, the care the nurses provided honored the residents’ choices and maintained a sense of pleasure in being a part of something that provided a sense of satisfaction and belonging that created meaningful connections in everyday life. The barrier is that medical facilities are not trained in “slow nursing,” nor does time allow for adequate care to be given.

The increasing pleasure in the patient being a part of something that provides a sense of satisfaction and belonging created meaningful connections in everyday life decreasing isolation. Some interventions that medical facilities are not currently utilizing are proven to be beneficial, such as the use of heart rate variability (HRV) to measure increase/decrease of agitation and gauge effectiveness in using music therapies, pharmaceutical medications and storytelling with others. To avoid disrupting an already vulnerable population, the study was performed on ten healthy university students before using HRV on the individual with the dementia diagnosis. HRV was used on the students by wearing sensors during an individualized music intervention that would be used in the study. The research concluded that music therapy has the potential to be effective in reducing agitation with dementia patients. Using HRV to detect stimulation allows for gathering data through more than visual cues. Music can be used to give dementia patients the gift of reminiscing through music therapy. Although HRV was not used with dementia patients, it still serves as an intervention that is worthy of being studied (Falcão et al., 2016).

Supportive Management

Numerous forms of supportive management have proven to be effective in alleviating some of the AD symptoms and prolonging the patient's ability to perform functions of daily living but are not currently being utilized in long-term care facilities in the present day. Enhancing the comprehensibility of time and space is vital. Having a caring approach and addressing the barriers of carrying out that approach is worth the time and effort. There are evidence-based practices that have been proven to be effective that decrease verbal agitation in individuals with dementia. There is a gap in care when it

comes to providing training that adequately equips the IDT in medical communities to practice these interventions (Grabher, 2018).

Medical facilities that are prepared for the increased flux of the baby boomer generation in their aging processes are already in high demand. This is going to affect the economy, and facilities are not prepared to accommodate the needs of this increasingly growing population. Funding and building facilities that are specifically made to house individuals with this disease are something we can no longer avoid. Individuals with AD are housed within long-term care facilities that are not specifically equipped to meet their needs.

CHAPTER IV

METHODOLOGY

In this research project, I randomly selected five existing records to review from the Meridian of Temple nursing facility in Temple, Texas. The director of nursing ran a report that gathered diagnoses as well as psychiatric and behavior data and removed any personal information that could be used to identify the patient in accordance with Safe Harbor (no dates of service, no patient IDs, etc.). This report was encrypted and has no HIPAA-protected info on it. Age, diagnosis, family demographics, and noted interactions with patient visitation behaviors were reviewed. Qualitative assessment of the level of family involvement and visitation practices was reviewed. There was not a specific survey of identification of qualitative data in advance of this process. The purpose of this work was two-fold: (i) to identify observations that help to identify family behaviors towards the patient; and (ii) to develop an intervention program for the facility that will identify needs, gaps, and how agencies and families may help to improve interactions with AD diagnosed individuals.

A descriptive, quantitative approach was used to score the needs identified through the patient profile summary. The GDS, (Figure 1) and the Family Caregiver Well-Being Assessment (Monnot et al., 2005; see Appendix B) were administered and scored. The scoring was calculated based on where the diagnosed individual was on the GDS regarding signs, symptoms and behaviors. The Family Caregiver Well-Being Assessment was scored by assessing the caregiver on a Likert self-report scale from 1 to

5 in regards to the impact of both subjective caregiving burden and the impact of caregiving (strongly disagree=1, disagree=2, neither agree nor disagree=3, agree=4, agree strongly=5).

The Global Deterioration Scale (GDS) is a standardized approach that creates an assessment that sharply defines symptoms as a means to gauge where an individual is in the disease progression (see Figure 1). This was created by Dr. Barry Reisberg as a means for health care professionals and families that provides an overview of the stages of disease progression that aims to measure where one is at in the disease process (Reisberg et al, 2019). The higher the score on the GDS, the higher the level of care an individual requires. This serves as a tool to help families prepare for the future, understand the present and cope with changes in behaviors.

Table 1

Global Deterioration Scale

Stage 1: No cognitive decline
Stage 2: Very mild cognitive decline
Stage 3: Mild cognitive decline
Stage 4: Moderate cognitive decline.
Stage 5: Moderately severe cognitive decline
Stage 6: Severe cognitive decline.
Stage 7: Very severe cognitive decline.

The GDS is an assessment tool used in long-term care settings that has been proven to be reliable and effective in providing a summation of stages of the disease advancement (Reisberg et al., 2019). It was created to measure functional decline for individuals suffering degenerative disease and consist of seven stages with each stage defined by clinical presentation based on memory, ability to recall objects or learn new

things, communication, sleep, incompetence, and mental and social impairment. This also serves as a guide to assist family members in understanding the future level of care the individual will require and what disease progression looks like (Doran, 2015).

GDS Scoring

In stage one, no cognitive decline, clinical presentation is with little to no memory deficits or cognitive impairments. The individual is still able to complete all activities of daily living (ADL) sufficiently without assistance. Brain changes start long before symptoms are noticeable. Deterioration may be subtle and indirect lasting over a longer period of time throughout several years.

In stage two, very mild cognitive decline, a person presents with subjective complaints of forgetfulness most commonly in areas of object misplacement and/or inability to recall names of personal contacts such as family or friends in one's social network. The individual is able to maintain employment and engage in social settings and function within normal limits. Family and friends will begin to notice some changes in behaviors and raise valid concern regarding their brain functioning.

In stage three, mild cognitive decline the individual presents with earliest obvious observable symptomatic behaviors. The individual may be unable to return to home after traveling to an unfamiliar location and/or may notice a decline in ability to perform job duties, decline in vocabulary where deficits are noticeable to family and friends while engaged in conversation, and/or decline in ability to learn and retain new information, such as meeting new people. Anxiety is increased or experienced for the first time in the individual and/or family due to noticeable changes in behavior and onset of symptoms.

In stage four, moderate cognitive decline, clinical behavior is shown in symptoms, such as decreased knowledge of reality and current events. Often the individual becomes a poor historian on their own life. The individual becomes unable to effectively manage finances, shopping, preparing meals, or traveling. While still able to recall person, place, situation, date and time, the individual presents with flat affect and tends to withdraw from situations that may be challenging.

In stage five, moderately severe cognitive decline, the individual is unable to maintain safety independently within the home setting without some assistance that requires cueing for proper clothes to wear or maintaining ADLs appropriately. Inability to answer assessment questions due to disorientation to time, date, and season; and recalling major life events, such as marriage or divorce, graduations, previous employment, etc. An inability to recall names of spouse, grandchildren or other intimate relationships becomes evident. Personal information such as phone number, address, social security number, driver's license number, etc. is challenging to recall.

Stage six is severe cognitive decline. If the individual has a spouse that is cognitively intact, the spouse is most likely to have become the primary caretaker in this process of the diagnosis. Occasionally the individual will be unable to recall their own name, or their spouse's name, or communicate effectively. If an individual does not have a spouse, they will need another individual upon whom they are entirely dependent for survival. In most cases this requires long-term care settings due to increased level of care for the following: incontinence; lack of orientation to time, date, persons, etc.; increased fall risk; wandering that deems them a threat to self; total dependence on others for physical care and decreased nutrition; and safety risk in general. Personality changes and

behavioral issues are common such as delusional, obsessive/compulsive, agitative, aggressive and anxious behaviors. The individual struggles with maintaining thought processes that result in their intended course of action.

In stage seven, very severe cognitive decline, dysphasia (difficulty swallowing) and agraphia (inability to read or write) are present. Weight loss, frequent falls, wandering, disorientation and agitation are daily occurrences. Few words are understandable, and the ability to walk becomes a deficit as this stage evolves. Ability to carry out ADLs is completely lost as the brain is no longer able to communicate with the body.

Family Caregiver Well-Being Assessment

The Family Caregiver Well-Being Assessment created by Monnot et al., in 2005 was modified to perform this study. It is a compilation of seventeen questions assessing how caregiving has impacted the individual providing care. The questionnaire was designed to assess overall deficits in health and mental well-being, social activities, happiness and self-satisfaction, energy level, personal relationships, and financial means of the caregiver.

The questionnaire is divided into two parts, subjective caregiver burden and impact of caregiving. The categories measured for subjective caregiving were evaluated on level of impact caregiving has in regards to leading to mental and physical health suffering because of the care required, feelings of isolation, not being able to give care much longer, losing control of life, being tired, nervous and depressed, feeling trapped, facing high care demands, financial stress and feeling resentful of other relatives who could help out, but do not. The categories measured for the impact of caregiving were

wishing caregiving could be left for someone else, decline is socialization because the care given, time spent giving care and not having enough time for yourself, inability to plan ahead when the diagnosis needs are unpredictable, patients' needs determining how days are spent, and asking for more help than necessary.

Population and Sample

The skilled nursing facility at Meridian of Temple provides a comprehensive health care screening to patients that serves as an overview of the stages of cognitive function for those suffering from a degenerative dementia and AD. The director of nursing randomly selected a group of caregivers to screen the patients seen during the May 2018 to May 2019. The screening occurred during the admission intake process using the GDS. If patients had a diagnosis of AD or showed signs of cognitive decline, the staff administered the GDS on the patient and the Family Caregiver Well-Being Assessment to the primary caregiver in the family and assessed for all seventeen categories.

CHAPTER V

RESULTS

The five individuals that completed the family caregiver survey had family members that were placed in Meridian of Temple nursing facility. The level of cognitive decline of the patient, as measured by the GDS scale are reported in Table 1. Given the small number of individuals, an overall comparison was reduced to two scales for purposes of later comparison. The severe range of patient need was measured by combining families 1-3 into a severe range of need, and families 4-5 into moderate need.

Table 2

GDS Score

	Family 1	Family 2	Family 3	Family 4	Family 5
Stage 1: No cognitive decline					
Stage 2: Very mild cognitive decline					
Stage 3: Mild cognitive decline					
Stage 4: Moderate cognitive decline				X	
Stage 5: Moderately severe cognitive decline					X
Stage 6: Severe cognitive decline		X			
Stage 7: Very severe cognitive decline	X		X		

The Family Caregiver Well-Being Assessment was reported by two subscales: subjective caregiver burden (Table 2) and impact of care (Table 3). Only fatigue, feelings of being trapped, and not enough money for care were found to be areas of concern (see

Table 2). There was no concern about their health, they did not feel isolated and alone, nor did they report being nervous and depressed, or being angry at the individual. Now that the individual was placed in a facility, they were neutral about their ability to care for the individual, nor did they feel as if they had lost control of their life, believe that they were the only ones that could now care for the patient, or feel resentful of the patient's needs.

Table 3

Subjective Caregiver Burden by Family

	Family 1	Family 2	Family 3	Family 4	Family 5	Overall Mean
Health will suffer	2	1	3	1	3	2.0
Isolated and alone	2	3	4	2	2	2.6
Unable to give care much longer	3	4	4	3	5	3.8
Lost control of your life	2	4	5	2	5	3.6
Tired	2	5	5	4	5	4.2
Nervous and Depressed	3	2	3	2	3	2.6
'Trapped'	4	5	4	4	4	4.2
Angry at individual	1	3	3	1	3	2.2
Only one they can depend on	1	4	5	2	5	3.4
Not enough money to care	5	4	4	3	5	4.2
Resentful	4	2	3	3	3	3.2

There was a somewhat different picture that emerged with their subjective impact of their caregiving (see Table 3). Even though the individual was placed, they still believed that they did not have enough time for themselves and that the patient's needs still determined how their days were spent. They did not feel that the individual asked for more help than was necessary and were only marginally impacted by having left the care to others and experiencing a negative impact on their social life. They did report having problems planning because of patient care needs.

Table 4*Subjective Impact of Caregiving*

	Family 1	Family 2	Family 3	Family 4	Family 5	Overall Mean
Leave caregiving to others	2	4	4	3	5	3.6
Social life has suffered	3	4	4	2	5	3.6
Not enough time for yourself	2	4	5	4	5	4.0
Hard to plan because care needs are so unpredictable	4	3	5	2	5	3.8
Patient needs determine how your days are spent	4	4	5	2	5	4.0
Ask for more help than necessary	1	2	3	1	4	2.2

When the subjective care burden perception was compared by severity of need, the only agreement found was that not enough money to care for the individual was associated with the higher level of need (see Table 4). Those in the moderate range of need still reported having a higher level of concern of being unable to care for the individual much longer, and feelings of being trapped. All other comparisons of burden were similar for the two groups.

Table 5*Mean Comparison of Subjective Caregiver Burden by Severity of Patient Illness**

	Mean score of moderate level need (n=2)	Mean score of severe level of need (n=3)
Health will suffer	2.0	2.0
Isolated and alone	2.0	3.3
Unable to give care much longer	4.0	3.7
Lost control of your life	3.5	3.7
Tired	4.5	4.0
Nervous and Depressed	2.5	2.7
'Trapped'	4.0	4.3
Angry at individual	2.0	2.3
Only one they can depend on	3.5	3.3
Not enough money to care	4.0	4.3
Resentful	3.0	3.0

* Moderate range combined GDS Stages 4 & 5; severe range combined Stages 6 & 7.

A mean comparison of the subjective impact of caregiving by severity found that “hard to plan because care needs are so unpredictable” and “patient needs determined how their days were spent” were of greater concern for the severe group (see Table 5). Family members of moderate needs patients reported not having enough time for themselves and concerns about leaving caregiving to someone else.

Table 6

*Mean Comparison of Subjective Impact of Caregiving by Severity of Patient Illness**

	Moderate (n=2)	Severe (n=3)
Leave caregiving to others	4.0	3.3
Social life has suffered	3.5	3.7
Not enough time for yourself	4.5	3.7
Hard to plan because care needs are so unpredictable	3.5	4.0
Patient needs determine how your days are spent	3.5	4.3
Ask for more help than necessary	2.5	2.0

* Moderate range combined GDS Stages 4 & 5; severe range combined Stages 6 & 7.

CHAPTER VI

DISCUSSION

Overall, the findings suggest that providing care to a loved one who is placed in a long-term care facility because of memory deficits present with sometimes confusing physical, mental, and emotional consequences for the caregiver, regardless of the patient's level of cognitive deficit. It was somewhat surprising that the average score of the five individuals surveyed indicated that their health was not suffering as a result of the patient's needs. This may reflect barriers to data collection, such as having a small number of individuals available to survey resulting in a barrier to evaluating these questions during COVID-19 while abiding by the precautions in place to prevent further positive cases. In other words, there may have been more immediate concerns that could not be accounted for.

The data reflects that overall the families surveyed agreed they have some problems, i.e., feeling tired (mean 4.2), trapped, and not having enough money(4.2) to keep their loved one in long-term care placement for the remainder of their lives, or being able to pay for a caretaker within the home (mean 4.2). These findings are consistent with other authors who have found that even with placement, family members continue to experience chronic stress that puts them at greater risk for cognitive decline, unhealthy sleeping patterns and lower levels of selfcare (Chene, 2006). Even though caregiving after placement shows lower levels of mental health issues for the family member, they continue to feel trapped, reflecting that even though their loved one is in long-term care

placement, they still feel trapped or controlled even though they are not the sole caretaker of the patient because the loved one is still a high priority for the caregiver. Many adult children act on a sense of obligation that starts by devoting time periodically to their loved one; however, escalation to needing more care can lead to realization that any spare time they had in the past is now gone and replaced with multiple to-do lists for the loved one (Wilson, 2018).

While long-term care placement is often necessary in the disease progression, the financial strain is one of the highest severity scores in the research conducted in this study. There are two options when caregiving becomes unrealistic; a live-in caretaker within the home, or admission to a memory care facility within a nursing home. Both options are expensive, adding financial strain to the individual or the family.

Published studies consistently show higher levels of stress on the caregivers than non-caregivers and report neglecting their own health due to not having time to get to the hospital or doctor; or having to miss scheduled appointments (Doran, 2015). Data collected in this study did not reflect as great of an impact on health as other studies because of long-term care placement and having a medical team in place to assist with caring for the individual. Current findings suggest, in this small group of participants, one potential benefit of placement is that it protects the caregiver's health and improves quality of life.

When caregiving within the family system for AD patients, it is very rare that the process is organized and distributed evenly among individuals within the family system, which results in demanding and exhausting dynamics. Having a support system in place

in a long-term care setting for the caregiver may help organize care for the AD individual and reduce stress on the caregiver (Silva et al, 2018).

The participants in this study also leaned more towards the disagreement of feeling isolated and alone, reflecting the impact of long-term care placement versus caring for the patient at home. When caring for an AD person in the home the biggest challenges were aggressive outbursts, repetitive behaviors, wandering around and sometimes outside of the home, incontinence, lack of eating or overeating leading to nutrition challenges, sleeplessness, refusal to take medications, unpredictability, etc.(Sauer, 2019). Reporting feelings of isolation and loneliness (mean 2.6) are factors that did not appear to influence the current cohort under study. This suggests that the care nurses, social workers, and medical professionals provided within the long-term care setting have collaborated with the caretaker to maintain a meaningful quality of life for both the patient and the caretaker (Lillekroken et al, 2017).

This specific group under study found caretakers had lower levels of depression and nervousness (mean 2.6) as a result of their family member's placement; however, this does not fully eliminate the impact of caregiving. As found, in this case the family members were not completely absent anger at the diagnosed individual (mean 2.2), even though they are no longer inside their own home.

As suggested in the literature, caregiving is stressful, and placement requires some acknowledgement from the caregiver that they are unable to provide care much longer (mean 3.8). The current findings suggest that there remains some ambivalence among those surveyed because even though they have placed the family member, they are still not certain that they were incapable of continuing to provide care. The mean

reporting feeling like they lost control of their own life (mean 3.6) showing that some of the caregiving burden is relieved when placed in a nursing home; however, the stress and burden of caretaking is still present. With long-term care placement, the caretaker assessment shows a neutral feeling of the loved one seeming to expect the caretaker's caring as the only one they can depend on (mean 3.4). This raises a problem in most family systems, as caretakers in this study reported feeling resentful (3.2) of other relatives who could help but are not involved. When the caretaker within the family reaches out to other members of the family for help, it often causes conflict, controversy, and results in an unresolved conflict within the family system (Falcao et. al, 2016).

The data on the impact of caregiving reflect agreement that even with long-term care placement, they still felt as if they did not have enough time for themselves (mean 4.0) and that the patient's needs were still the priority of their lives (mean 4.0) on the assessment. This result reflects a neutral feeling of having pressure of not being able to plan due to unpredictable patient needs (mean 3.8) and patient needs taking precedence in how days are spent.

There was a neutral attitude reflected scoring higher severity in regards to wishing the caregiving could be left to someone else (mean 3.6), feel as if their social life is suffering (3.6) due to giving care and having time for oneself, unpredictability of patients' needs and inability to make plans (mean 3.8).

Patients and families affected by AD have a critical need for social work intervention due to the significant challenges for both the diagnosed and the caregiver, and the fact that there is currently no medical cure for the disease. With the profession's continued advancements in the primary care setting, medical social workers can

distinguish their role as advocates of integrated care. This is evidenced by the results, as all the family caregiver wellbeing assessments proved that there were significant barriers present when it came to caring for their loved one.

Social workers are a key proponent in advocating for the diagnosed individual and assisting families, medical staff, and other entities in helping them meet them where they are in their diagnosis. It is as if the diagnosed person is begging to come and find them and wants acknowledgment that they are still here even with their diagnosis. Social workers can educate on how to implement new routines, strategies, and interventions that improve quality of life for the individual. Combining clinical practices and using treatments that are in place currently provide a platform for opportunities to collaborate with multidisciplinary teams in primary care using social work practitioners to improve quality of life and integrate interventions that support and advocate for those most at risk for having their mental and medical needs unmet.

CHAPTER VII

CONCLUSION

This study found that even under the best of circumstances, caretakers experience challenging situations that result in a complex problem that are not solved quickly or independently. Instead caregiving is a process that comes with a variety of emotions. Each person in the study had similar challenges; however, some showed greater impact in differing areas than others in the group. The barriers with each participant require an intervention that will help identify needs, frustration, coping with feelings of anger/resentment, guilt, helplessness and guidance in improving interactions with the diagnosed individual that creates meaningful connections as the disease progresses.

This study found that most caregivers are consumed with their responsibilities of caring for their loved one and are not aware of the negative effects, such as employment complications, strain on mental and physical health, or the constant conflict of time for leisure activities and time spent with other family members. The stress of caregiving leads to potent stressors that move rapidly towards burnout, long-term care placement for the patient, and less support for the diagnosed individual.

The presence of grief in both the caretaker and the individual with dementia is a tremendous piece to this diagnosis that is overlooked. The most general assumption of grief is thought to be present at the end of life; however, it was discovered in the study that grief is present, and real, and acceptance of losing a loved one has in fact already begun. The gradual death of a loved one's memory, ability to care for one's own self, loss

of companionship, permanent changes, etc., result in depression, grief and other challenges for both the caretaker and the diagnosed. This is a unique form of grief for both the caretaker and the individual with the diagnosis. Each party faces difficult situations in the grief process. The journey of being the caretaker often results in losing the ability to perform as well as they have in the past, leading to career strain, relationship problems, difficulty making financial and medical decisions, as well as managing their own health problems. They are not able to spend as much time with other family members and have limited time to engage in activities they used to enjoy. The diagnosed party faces a different set of challenges that bring about grief in an alternate form. They are no longer able to function as they did in the years past and begin noticing changes that make them feel as if they are losing all control of mind and body.

Grief is not something commonly associated with this particular diagnosis; however, the impact of grief is to be respected and acknowledged in order to aid in the journey. The disease progression gradually takes away the “normal” person that the caretaker once knew and loved. The phases of grieving are experienced with both parties presented in differing circumstances, however, acknowledging grief.

Limitations of the Study

A limitation of the study is that the protective and causative factors for AD are still not clearly understood. Currently preventive approaches and improvements in living conditions are primarily the only way to slow the disease process, but the fact of the matter is that there is no cure for the disease. There have not been any medications or new drugs released, only existing drugs that support the communication between nerve cells that are still functioning; however, no medications have been released that stop the

damaging of cells, but rather they help lessen or stabilize symptoms. At this time there are only preventive medications, and best suggestions to combat the disease is exercise, healthy diet, healthy sleep patterns, and staying socially involved.

The number of deaths from AD is not reported accurately. Individuals with AD do not die from the disease itself, but rather secondary conditions from the disease.

Difficulty swallowing often develops into aspiration pneumonia, blood clots due to being bed ridden, weight loss due to lack of nutrition, etc., are causes of death; however, this is not reflected on death certificates. This results in incorrect reflection of numbers on death from AD.

Implications for Further Research

The data gathered through this study, as limited as it may be given the small number of surveys collected, supports advancing the need to diligently search for a cure for this disease and implement interventions with caregivers, nursing facilities, and the diagnosed individuals that advocate for one living with this disease and enhancing their quality of life. This researcher recommends further studies focused on the need for both qualitative and quantitative data allowing patients to share data about their mental health status, the disease process, and the effects of the disease on the family system, as well as the healthcare system as a whole.

Early screening reveals earlier detection and diagnosis that leads to a demand for pre-surveying to assess the patient's knowledge of diagnosis, disease progression, understanding of symptoms, options for treatment, financial planning, and preparation for the future. There is little research that follows the patient before diagnosis; however, to

find a cure for this disease, it is important to gather data prior to one presenting with symptoms of this disease.

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APPENDIX A

Institutional Review Board Approval Letter

ABILENE CHRISTIAN UNIVERSITY
Educating Students for Christian Service and Leadership Throughout the World

Office of Research and Sponsored Programs
320 Hardin Administration Building, ACU Box 29103, Abilene, Texas 79699-9103
325-674-2885



February 15, 2020

Laci Bach
Department of Social Work
Box 27866
Abilene Christian University

Dear Laci,

On behalf of the Institutional Review Board, I am pleased to inform you that your project titled "The Face of Alzheimer's",

(IRB# 20-010) is exempt from review under Federal Policy for the Protection of Human Subjects.

If at any time the details of this project change, please resubmit to the IRB so the committee can determine whether or not the exempt status is still applicable.

I wish you well with your work.

Sincerely,

Megan Roth

Megan Roth, Ph.D.
Director of Research and Sponsored Programs

APPENDIX B

Family Caregiver Well-Being Assessment

PART 3 - FAMILY CAREGIVER WELL-BEING

Please indicate your degree of agreement with each statement by circling a number according to this scale:

Strongly Disagree = 1 Disagree = 2 Neither agree nor disagree = 3 Agree = 4 Agree Strongly = 5

Subjective Caregiving Burden:

- | | | | | | |
|---|---|---|---|---|---|
| 1. Your health has suffered because of the care you must give. | 1 | 2 | 3 | 4 | 5 |
| 2. You feel isolated and alone as the result of giving care. | 1 | 2 | 3 | 4 | 5 |
| 3. You feel you will be unable to give care much longer. | 1 | 2 | 3 | 4 | 5 |
| 4. You have lost control of your life since having to give care. | 1 | 2 | 3 | 4 | 5 |
| 5. You are very tired as a result of giving care. | 1 | 2 | 3 | 4 | 5 |
| 6. You feel nervous or depressed when giving care. | 1 | 2 | 3 | 4 | 5 |
| 7. You feel trapped when giving care. | 1 | 2 | 3 | 4 | 5 |
| 8. You feel angry when you are around the relative who needs care. | 1 | 2 | 3 | 4 | 5 |
| 9. Your loved one seems to expect your care as the only one he/she can depend on. | 1 | 2 | 3 | 4 | 5 |
| 10. You don't have enough money to care for your loved one. | 1 | 2 | 3 | 4 | 5 |
| 11. You feel resentful of other relatives who could help, but do not. | 1 | 2 | 3 | 4 | 5 |

Impact of Caregiving:

- | | | | | | |
|---|---|---|---|---|---|
| 12. You wish you could just leave your caregiving to someone else. | 1 | 2 | 3 | 4 | 5 |
| 13. Your social life has suffered because you are giving care. | 1 | 2 | 3 | 4 | 5 |
| 14. Because of time spent giving care, you don't have enough time for yourself. | 1 | 2 | 3 | 4 | 5 |
| 15. It's hard to plan things ahead when the patient's needs are so unpredictable. | 1 | 2 | 3 | 4 | 5 |
| 16. It's mostly the patient's needs that determine how your days are spent. | 1 | 2 | 3 | 4 | 5 |
| 17. Your loved one asks for more help than is necessary. | 1 | 2 | 3 | 4 | 5 |