

**THE EFFECT OF ALZHEIMER'S DISEASE
PROGRESSION ON CAREGIVERS'
MENTAL HEALTH**

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Abstract

According to the 2021 Alzheimer's Association report, there are more than 6.2 million Americans, 65 years of age or older, who are currently living with Alzheimer's Disease (AD). The neuropathological progression of AD, unlike other neurodegenerative diseases, is characterized by its abundance of extracellular amyloid plaques and intracellular neurofibrillary tangles, both of which increase with time and are thought to be responsible for a reduction in brain function, especially in the hippocampus and the frontal cortex, which are essential for memory and personality changes, respectively. Due to these changes, patients are not the only individuals affected by the disease; caregivers of Alzheimer's patients are often called the "invisible second patient" because they are greatly affected by the progression.

The current study looks at the caregiver's experience and perception of the progression of AD in patients, and compares these experiences to those of non-AD caregivers. Participants that identified either as a caregiver for an Alzheimer's patient or a caregiver for a patient with another disease completed an online survey and were given the option to participate in an interview. Caregivers of Alzheimer's patients reported less social support than non-Alzheimer's caregivers, which was correlated with higher levels of stress. For AD caregivers, data showed that those who felt that they were aging fast also experienced declines in their own physical health. Caregivers of Alzheimer's patients require access to more resources that can help them cope with the burden of being a full time caregiver for a person with a neurodegenerative disease.

INTRODUCTION

PROJECT OVERVIEW

Alzheimer's Disease is a devastating illness for both the patient, caregivers, and the family. Not only is there stigma associated with the disease, but there is also a lack of knowledge of what can be done to care for patients in the advanced stages. This project aims to combine the neurological and anthropological perspectives of Alzheimer's Disease (AD) to determine the causes and contributing factors that make up the disease, as well as the way that the disease is viewed and treated among various cultures. A thorough literature review was conducted regarding the scientific basis of AD, as well as how the disease, and aging in general, was viewed. A survey was created based on this literature review as well as a review of typical measures of stress and strain in caregivers. Interviews were conducted based on the themes of the literature review, with the goal of elaborating on the brief survey responses.

Chapter One will focus on the specific neurological changes that have been observed and recorded in patients with Alzheimer's Disease. It will touch on the progression of the disease, as that is one of the main focus points of the project, as well as what it takes for someone to actually be diagnosed with AD. Lastly, the chapter will touch on the differences in presentation of the disease in different cultures, which will lead to the anthropological discussion in chapter two.

Chapter Two opens with a discussion of the impact of language on the perception of the disease, as well as the importance of familial roles in the patient-caregiver relationship. This chapter highlights role reversals and ambiguous symptoms and diagnoses, and how this compounds the challenges that the caregiver will face. Experiences of groups in Japan and Mexico will be discussed, among many other specific cases reported by the caregivers

themselves. The chapter will touch upon the progression and symptoms of the disease while comparing it to other non-neurodegenerative disorders.

Chapter Three focuses on the anthropological interviews that were conducted, which highlighted themes of isolation and lack of social support. This chapter is very closely related to Chapter Four, which depicts the survey methods and results. These two chapters revealed that social support is instrumental in assisting the caregivers of Alzheimer's Disease, as the nature of the disease is very isolating for both patients and caregivers.

Lastly, Chapter Five discusses the analysis of interviews and survey results, combining and assessing the relationship between the findings. This chapter looks at what is produced when using the neuroscientific perspective to influence the anthropological perspective, and vice versa.

HISTORY OF ALZHEIMER'S DISEASE

Before investigating the effects of a disease, it is important to look at its history. Approaching an issue from multiple perspectives is necessary to construct a comprehensive understanding. In 1901, Alois Alzheimer studied Auguste, a patient with early-onset dementia. During her life, Auguste displayed symptoms such as delusion, decline in general abilities, worsening sense of direction, restlessness, and memory impairment, among others. At 51 years old, she was admitted to a psychiatric facility where Alzheimer cared for her and diagnosed her with presenile dementia (Yang et al. 2016). After her death, the patient was found to have cerebral atrophy, neurofibrillary tangles, and extracellular deposits in the cerebral cortex (Allen 2007: 1). The combination of neuropathy and behavioral outcomes associated with the presence

of these neurological symptoms was given the name “Alzheimer’s Disease” in 1910, and is now known to be the most common form of dementia in the older population.

Chapter One

Literature Review- Neurological Changes in Alzheimer's Patients

According to the 2022 Alzheimer's Disease Facts and Figures, one in nine people over the age of 65 are diagnosed with Alzheimer's Disease, and this percentage continues to increase with age. Despite this high rate of incidence, there are still uncertainties regarding the actual neurological changes that are occurring, and whether these changes are responsible for the challenging symptoms associated with Alzheimer's Disease (AD). Many people assume these symptoms are just those that involve being forgetful, or being unable to remember the names of loved ones. However, the reality of the disease is much more brutal. Alzheimer's Disease is a progressive disease that destroys memory and other cognitive functions in those that have it (Querfurth and LaFerla 2010). Patients become completely unable to take care of themselves, and become fully dependent on a caregiver for the basic tasks associated with daily life that they were once able to complete without a second thought. There is a difference in both symptoms and neurological changes between people who are categorized as having Alzheimer's versus those who are considered to experience normal aging, especially in terms of synaptic connections and neuronal density (James and Bennett 2018).

The current research is interested in understanding the neurological basis of Alzheimer's Disease, and the ways in which these neurological deficits or changes manifest in measurable symptoms. A further question is referencing the symptoms associated with Alzheimer's Disease and how they create challenges for caregivers that are specific to the disease. An important characteristic of Alzheimer's is the extremely slow progression of symptoms from the onset of the disease to the eventual death of the patient (Querfurth and LaFerla 2010). We predict that the

slow nature of Alzheimer's progression will lead to increased challenges and decreased well-being in caregivers, as compared to caregivers of other illnesses such as cancer.

NEUROLOGICAL BASIS OF ALZHEIMER'S DISEASE

Alzheimer's research is continuously developing as new techniques allow scientists to look more closely at the changes that are occurring in the Alzheimer's brain, as compared to a brain going through the normal aging process (James and Bennett 2018). Dementia, a condition whereby patients experience loss of cognitive function, is common in aging populations. Although Alzheimer's Disease and dementia are commonly assumed to be the same thing (Bhattacharyya et al. 2007), this is not the case. Dementia is the umbrella diagnosis of many neurodegenerative diseases, with various etiologies including Alzheimer's disease, vascular dementia, Lewy body dementia, and frontal lobe dementia (Bhattacharyya et al. 2007; Moloney et al. 2021). A 1988 report stated that 15% of adults over the age of 65 in the United States have a diagnosis of senile dementia, and in patients 80 years or older, 20% of dementia cases are categorized as Alzheimer's (Davies 1988). A more recent study from 2007 characterized it as having the highest incidence when compared with other brain conditions, such as Parkinson's or Stroke, with the peak age of incidence being 80 years old or older (Hirtz et al. 2007).

NEUROPATHOLOGY OF ALZHEIMER'S DISEASE

The three defining characteristics of Alzheimer's Disease are symptoms of dementia, an abundance of extracellular amyloid plaques, and intracellular neurofibrillary tangles, or NFTs (Allen 2007). Amyloid plaques and tangles are made up of amyloid A β and tau. A β is made from a larger protein called an amyloid precursor protein, or APP, that may result in early-onset Alzheimer's Disease when mutated (Allen 2007). In general APP is typically responsible for moderating cell survival, growth, and motility, and when diseased, generates amyloidogenic fragments that create toxic A β fragments (Tiwari 2019). The A β fragments are formed by the cutting of APP by enzymes called β -secretase and γ -secretase (Allen 2007). Two specific amino acid proteolytic products, A β 40 and A β 42 are important factors in the pathology of Alzheimer's Disease, as aggregation of each causes blocked ion channels, alters calcium levels, increases mitochondrial oxidative stress, and diminished energy metabolism and glucose regulation (Tiwari 2019). Mutations in the tau gene are not responsible for Alzheimer's, but are more involved in other types of dementia, which means that tau genes are not as influential in the development of Alzheimer's, but still contribute to symptoms and neurodegeneration.

In the 1980s, A β was first extracted and purified from the human brain, and the amino acid sequence of cerebrovascular amyloid was identified. It was found that A β consisted of multimeric aggregates of a 4 kDa polypeptide of about 40 residues and is actually derived from a larger protein called APP, or an amyloid precursor protein (Allen 2007). In 1995, mutations in the gene *PSEN1* on chromosome 14 and *PSEN2* on chromosome 1 were found in many patients with early onset Alzheimer's Disease (Allen 2007). Another protein, apoE, was identified as

present in both plaques and tangles (Allen 2007). The protein Apolipoprotein E is also shown to be associated with amyloid plaques and tangles (Allen 2007).

Alzheimer's Disease has been known to cause a reduction in brain size, especially in the medial temporal lobes and the hippocampus, which is seen through decreases in the size of the cortical gyri, widening of the sulci, and increase in size of the lateral and third cerebral ventricles (Allen 2007). The presence of neurons in the neocortex and hippocampus tends to decrease over time as well, and the most prevalent changes in neurofibrillary tangles are usually located in areas associated with memory and personality, such as the hippocampus, entorhinal cortex, amygdala, and cortical association areas of the temporal, parietal, and frontal cortex (Allen 2007). In the typical onset of Alzheimer's, age is the biggest risk factor because of the changes that are naturally occurring in the aging brain, such as increased oxidative stress and impaired neuronal energy metabolism (Mattson 2007). The first important identifier in Alzheimer's brains are argyrophilic plaques, which are either diffuse or neuritic depending on their size (Esiri 2007). Diffuse argyrophilic plaques are made of homogeneous groups of fibrillar material without the presence of local reactive glial cells or unusual neuritic processes, while neuritic plaques are more heterogeneous with a dense core (Esiri 2007). In Alzheimer's patients, most areas of the brain are affected by both types of plaques, however, the cerebellum only contains diffuse plaques. Argyrophilic plaques are common in brains displaying normal aging, but are much greater in number in Alzheimer's brains, and also contain more neuritic elements (Esiri 2007). The discussion of neurochemicals is also imperative to understand the causes of Alzheimer's Disease. The most consistent reduction is in the cholinergic activity in the neocortical and hippocampal regions (Carlesimo and Oscar-Berman 1992). A decrease in glutamate was also found in the cortical and hippocampal regions, as well as lower levels of somatostatin in cortical

and subcortical areas (Carlesimo and Oscar-Berman 1992). The reduced levels of cholinergic activity in the cortical and hippocampal regions may also be due partly to neuronal loss. The exact mechanism in which cholinergic levels influence memory impairment is not known, and it is assumed that it is not the only relevant factor.

Neurofibrillary tangles are abnormal structures found in neurons of individuals with Alzheimer's. They look like bunches of unbranched fibers that are wound around each other in a helix shape (Esiri 2007). Cells that contain NFTs appear to be under stress, as they express a protein called ubiquitin that is typically related to various forms of stress (Esiri 2007). When neurons containing NFTs die, they leave behind a "ghost tangle", which exists as the third stage of NFTs, following pretangles and mature tangles (Moloney et al. 2021). Pretangles are found in normal neurons that do not appear to be dysfunctional in any way, since there are not yet fibrillar structures formed (Moloney et al. 2021). On the other hand, mature tangles show evidence of thicker fibers in neurons with smaller neurons or a displaced nucleus that affects the positioning of the cytoplasm of the neuron, as NFTs eventually will take the shape of the cell in which they are taking over (Moloney et al. 2021). Lastly, ghost tangles are a more loose form of mature tangles, because they are the final broken down form of the NFTs (Moloney et al. 2021).

Additionally, astrocytes appear to be enlarged and greater in number in a brain affected by Alzheimer's, along with increased expression of glial fibrillary acidic protein, or GFAP, which are important features of neuritic plaques. Similarly, microglial cells are also enlarged in size and are greater in number in gray matter areas that hold neuritic plaques and NFTs (Esiri 2007). Granulovacuolar degeneration is also associated with Alzheimer's, and is typically found in hippocampal pyramidal neurons, and manifests as the buildup of double membrane bound bodies in certain neurons (Esiri 2007).

Changes in small blood vessels in the brain are also associated with Alzheimer's Disease, specifically the leptomeninges and cerebral and cerebellar cortex, called congophilic angiopathy. There are mild cases in regular aging, but extreme cases are found in patients with vascular dementia. NFT-prone neurons are usually found in the cerebral cortex, hippocampus, and some subcortical nuclei (Esiri 2007). These areas, among the other more common areas where NFTs occur, are responsible for functional impairment associated with the onset and development of Alzheimer's. Specifically, memory deficits are associated with damages in the transentorhinal and entorhinal cortex, as well as the hippocampus (Esiri 2007). Recent research has suggested that an increased density of NFTs in the neocortex might correspond to the severity of the disease, and might be correlated with memory when found in the hippocampus (Tiraboschi et al. 2004). Additionally, a study conducted by Farber et al. (2000) found that there was an increase in the number of incidences of psychosis in Alzheimer's patients when a greater density of NFTs were measured. These findings provide further evidence that NFTs are extremely important in the pathology of Alzheimer's, and are relevant in many all stages of the disease, from early memory issues to symptoms toward the end of the disease. There is also evidence that there might be increased levels of brain aluminum in patients with Alzheimers, which is typically found in NFTs, nuclear heterochromatin, and the amyloid core of neuritic plaques. Increases in aluminum are assumed to create significant changes in physical properties of the membranes, which can also impact memory and general cognitive function (Pettegrew 1989).

Research suggests that there may also be elevated levels of phosphomonoesters (PME) in the early stages of Alzheimer's, which leads to higher levels of phosphodiesterases (PDE). The increased levels of PME are suspected to occur in the neocortex and allocortex, while the changes in PDE are suspected to occur in cortical and subcortical regions (Pettegrew 1989).

Interestingly, there has not been significant evidence that the presence of PME and PDE is related to the presence of NFTs, however there seems to be a significant interaction between PME and the L-glutamate receptor. Low concentrations of PME can block the L-glutamate receptors in the hippocampus, which can contribute to memory impairment (Pettegrew 1989).

Nerve growth factors, or NGFs, are created in the hippocampus and the neocortex with the purpose of binding receptors on the cholinergic axon terminals, which in turn affect the basal forebrain. Because of this, early issues with NGF receptor expression are identified as possible precursors to eventual nucleus basalis cell loss, which is common in the ending stages of Alzheimer's Disease (Mufson et al. 2007). Nerve growth factors and their involvement in the pathology of Alzheimer's has been studied mainly through transgenic mice that are anti-NGF, or AD11. This means that these mice show deficits that are associated with cholinergic atrophy, neuronal loss, tau hyperphosphorylation, and insolubility (Mufson et al. 2007). The major effects and presence of these deficits have been shown to be reversed by the introduction of NGF, suggesting that NGF is imperative in many necessary functions. In terms of the progression of Alzheimer's, reduced brain-derived neurotrophic factor (BDNF) mRNA is shown in decreased cortical proBDNF, which is a precursor for BDNF, and mature BDNF protein (Mufson et al. 2007). This protein is important in brain plasticity, which is required for both learning and memory, a key deficit in Alzheimer's patients. The reduction of proBDNF and mature BDNF are assumed to be early in the stages of Alzheimer's, as it lessens the synaptic connectivity and weakens the strength of memory (Mufson et al. 2007).

De La Torre (2002) has created a theoretical scheme for the basis of Alzheimer's pathogenesis, such that two biological events must occur simultaneously; advanced aging and the presence of a vascular risk factor for Alzheimer's Disease, which create a critically attained

threshold of cerebral hypoperfusion, or CATCH. CATCH is responsible for destabilizing neurons and synapses in general, and weakening specific areas in the brain would allow for NFT and plaque formation to occur more easily (De La Torre 2002).

PROGRESSION OF ALZHEIMER'S DISEASE

The slow progression of Alzheimer's and dementia in general is believed to be caused in part by the cumulative loss of synapses and neurons over time, as the loss of neurons does not occur all at once (Korzyn 2002). Progression of Alzheimer's is heavily dependent on factors such as aging, genetic mutations, metabolic and nutritional disorders, exposure to environmental variables, and social factors (Tiwari et al. 2019). Cerebrospinal fluid biomarkers are able to predict the rate of cognitive decline in Alzheimer's patients, but previous data shows a contradictory relationship between slow and rapid progression. One possible explanation of this might be that a rapid progression diagnosis could be overlapping with other neurodegenerative diseases. A study conducted by Podlesniy et al. (2020) looked at the relationship between cell-free mitochondrial DNA and other biomarkers of Alzheimer's to determine whether a particular biomarker profile underlies the different rates of progression. When looking at the 49 control patients who had no dementia diagnosis, but a diagnosis of another neurological disease, 37% showed at least one of the core biomarkers of Alzheimer's. Of the 46 patients with clinical representations of dementia, 50% did not have either biomarker. The results confirmed previous knowledge of Alzheimer's patients having CSF that contains lower concentrations of cell free mitochondrial DNA compared to non-Alzheimer's patients. The cell free mitochondrial DNA also correlates positively with A β and negatively with p-tau, but not with t-tau. The results of

this study generally provide support for the hypothesis that alterations in the CSF content of the cell free mitochondrial DNA come before neurodegenerative processes, which eventually cause the clinical signs of dementia or Alzheimer's to be noticeable.

Armstrong conducted a study with the purpose of identifying important factors in the variation of progression rates of Alzheimer's Disease. In this study, they looked at 103 cases of Alzheimer's Disease, and used the Kaplan-Meier estimator and Cox regression analysis to find patterns in post-mortem patients. 18% of the participants had early onset familial Alzheimer's Disease, and were diagnosed before the age of 65. 11.6% of the sample had late onset familial AD. 21% of participants were early onset SAD, and 49% were late onset. For all participants, the mean duration of the recorded disease was 7.1 years, with 25% of the patients dying within four years of their diagnosis. According to the Cox regression analysis, patient age did not have a significant effect on the duration of the disease, but duration was significantly associated with disease onset, such that people with early onset had longer durations. Duration of Alzheimer's seemed to decrease in SAD cases (Armstrong 2014).

As the severity of the disease increases and the progression continues, linguistic communication abilities of the patients tend to decrease. To address this, Bayles et al. (1992) investigated the effects of linguistic communication abilities in 152 patients in different stages of Alzheimer's, compared to 60 normal aging adults. The Global Deterioration Scale (GDS) is commonly used in assessing dementia patients to determine the severity and stage of the disease, usually independent of language function. There are seven stages ranging from normal (1) to early clinical deficits (3) to early dementia (5) and finally, to late dementia (7) (Bayles et al. 1992). Participants also completed the Core Linguistic Battery tasks, as well as the sentence formulation, generative naming, generative drawing, picture description, object description, and

the mini-mental state examination. These tests were administered once a year, at the residence of the participant.

Overall, there was a tendency for task performance to decrease as GDS severity increased (Bayles et al. 1992). People who were classified as level 3 of the GDS were able to score at least at 90% or higher of the mean on various tasks, such as oral reading, superordinate identification, auditory comprehension, and writing to dictation. The same level of patients were less successful on tasks such as object description, picture description, and superordinate naming, scoring only 55% of the mean (Bayles et al. 1992). Similarly, level 4 patients only scored 50% of the mean for object description, coordinate naming, superordinate naming, generative naming, and object description tasks (Bayles et al. 1992). GDS stage 5 patients perform less than 50% for every task except the oral reading, auditory comprehension, writing to dictation, reading comprehension, and pantomime expression tasks. Stage 6 patients, due to being unaware of recent events and retaining little information, showed a lower than 50% performance on every task. The highest task was on oral reading, which was only at 37% of the mean (Bayles et al. 1992). Lastly, level 7 patients lost all verbal abilities and psychomotor skills, so they unsurprisingly performed at less than 1% of the mean for all tasks. The greatest changes occurred between stages 4-6, suggesting that the most important decline in cognitive ability is in the middle of the disease's progression, rather than just at the end.

Thalhauser and Komarova (2012) conducted a study in which they asked whether or not a true difference in rate of progression existed, specifically if there were two separate disease courses for rapid and slow progression of Alzheimer's. They used the functional assessment staging (FAST) procedure, considering the diagnosis, date of assessment, and demographics of the participant as well. The FAST assessment divides the progression of Alzheimer's Disease

into seven consecutive stages, with stage one individuals being considered as normal, functioning adults and stage seven individuals considered severely impaired and at the end stages of the disease (Thalhauser and Komarova 2012). The FAST staging data set was sorted using a separation algorithm, which showed that most of the patients were either classified with slow progression or fast progression, with very few patients in the middle. This evidence suggests that there are truly two courses of progression, as individuals with a slow progression in the early FAST stages also had a slower progression in the later stages, and vice versa (Thalhauser and Komarova 2012).

NEUROLOGICAL VECTORS OF ALZHEIMER'S DISEASE

A diagnosis of Alzheimer's based on both a cognitive and neuropathological profile is currently not possible until after death (Allen 2007). The clinical definition of Alzheimer's Disease relies on short term memory loss with relative preservation of distant events, aphasia (language deficits), apraxia (loss of ability to perform tasks) and agnosia (loss of ability to recognize objects) (Allen 2007). Psychiatric symptoms and behavior changes are also commonly present in individuals diagnosed with Alzheimer's.

There are two types of Alzheimer's Disease, familial (FAD) and late-onset (LOAD). Familial Alzheimer's Disease is characterized as an autosomal dominant trait, with an early onset, usually before the age of sixty. There are genetic risk factors associated with FAD, specifically mutations in the *APP*, *PS1*, and *PS2* genes, as these are important in the production

of A β (Kauwe and Goate 2007). FAD mutations have been used to create transgenic mice to model A β changes. *PS* mutations increased A β 42/A β 40 ratios, which also increased the number of neuritic plaques that are characteristic of an Alzheimer's diagnosis (Kauwe and Goate 2007). Late-onset Alzheimers' Disease is much more common, and has an average age onset of much later than sixty years old. *APOE*, or apolipoprotein, is the only known genetic risk factor for LOAD and is located in chromosome 19. Almost all individuals who are homozygous for the *APOE4* allele develop LOAD by the time they are eighty years old (Kauwe and Goate 2007). *APOE* is also involved in the aggregation, or formation, and misfolding of A β (Veitch et al. 2019). The amyloid hypothesis claims that the production of A β is extremely relevant in Alzheimer's due to the effect it has on NFT formation, synaptic dysfunction and loss, and neuronal death, and has been supported by the fact that A β has been shown to be toxic to cultured neuronal cells (Lee and Lee 2007). The A β sequence begins with the extracellular domain of APP, where exons 7, 8, and 15 encode regions in the extracellular domain, and have alternative splicing. APP has three major isoforms, but the central nervous system and peripheral nervous system primarily express the APP695 isoform. This specific isoform is lacking the Kunitz-type serine protease inhibitor (KPI) domain, as well as a domain that is homologous with the MRC OX-2 antigen, corresponding to exons 7 and 8, respectively. However, the neurons that are lacking these two domains are the main source of APP and A β in the central nervous system, which suggests that they do not appear to play an important role in the pathology of Alzheimer's Disease.

There are currently many hypotheses surrounding the functions for APP. Mice have shown that APP is necessary for the development of locomotor defects, poor grip strength, and deficits in long term potentiation, among others, yet they still appear fertile and healthy in all

other aspects (Lee and Lee 2007). Additionally, the deletion of a single homologous amyloid-precursor-like protein is not lethal for mice, whereas the deletion of multiple is lethal.

The exact function of APP is still unclear, but specialized sorting and attention to metabolic pathways can help identify the trafficking and breakdown, or proteolysis, of APP. APP is made in the endoplasmic reticulum and travels through the default secretory pathway, where it will acquire N- and O-linked carbohydrates from the ER and Golgi, in addition to tyrosine sulfates and phosphates (Lee and Lee 2007). In order for cell-surface APP to be degraded, it must be taken into the cell, specifically into endosomes and lysosomes, which regulate the contents of the cell and remove anything not needed.

Synaptic markers are vital in the cognitive processes, such that the loss of these markers is correlated with dysfunction found in Alzheimer's Disease, and more importantly, correlates with the severity of Alzheimer's that is presented (Lee and Lee 2007). A β accumulation only usually occurs as a result of aging, and has effects on cognitive functioning in general. A β also has various conformational states, so it is unknown which version is involved in the synaptic dysfunction and neuronal death that is involved in Alzheimer's. However, one concept repeatedly supported by research with transgenic mice is the idea that fibrillar A β enhances NFT formation (Lee and Lee 2007).

CLINICAL DEFINITIONS OF ALZHEIMER'S DISEASE

Clinical dementia is characterized by neuropsychological symptoms and components, such as amnesia, aphasia, apraxia, and agnosia, as well as the inability to perform activities of daily living (Bhattacharyya et al. 2007). Additionally, behavioral symptoms might include

depression, paranoia, misidentification, hallucinations, aggression, and wandering (Bhattacharyya et al. 2007). The most common symptom of Alzheimer's is obviously memory dysfunction; however, there are other common features such as difficulties with daily activities or new language barriers, as well as personality changes that might bring about increased agitation or aggression.

Compared to vascular dementia, Alzheimer's has a much slower onset and progression, meaning that it usually takes much longer for the patient to seek medical attention for their symptoms. The Diagnostic and Statistical Manual of Mental Disorders (DSM) holds a set criteria that includes a gradual onset and continuing cognitive decline, specifically not associated with other conditions such as Parkinson's or Huntington's Disease, among others. Unlike most disorders, the most widely used diagnostic criteria for Alzheimer's is not the DSM, but rather the National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (NINCDS/ADRDA) (McKhann et al. 1984). Like the DSM, the NINCDS/ADRDA begins with the characterization of Alzheimer's as progressive decline and loss of cognitive functions, including memory impairment and either aphasia, apraxia, agnosia, and the loss of the ability to plan. Importantly, these issues presented must occur in the form of a substantial decline, and must cause significant deficits in everyday functioning. Symptoms cannot be associated with the result of other conditions that cause cognitive decline, and cannot be caused by conditions such as hypothyroidism or HIV infection, among others. Additionally, there are other features that have been associated with an Alzheimer's diagnosis, such as plateaus in the progression of the disease, a normal CT scan, as well as associated symptoms such as depression, insomnia, delusions, and weight loss, and other abnormalities in the brain including increased muscle tone and a shuffling gait (Crystal 1988).

There is some evidence that Alzheimer's patients show a reduced capacity of short term memory store, as well as an impairment in the process of storing items in long term memory (Miller 1973). However, this finding has not been consistently replicated, so it may not be the sole explanation of the neurological changes that are associated with Alzheimer's (Carlesimo and Oscar-Berman 1992). Working memory is a theoretical memory system composed of an amodal central executive system and the peripheral domain-specific buffer stores for short-term maintenance of information (Baddley and Hitch 1974). One buffer store in the working memory model is called the phonological loop, where verbal information is maintained prior to encoding in long-term memory. Colette et al. (1999) found that the phonological loop seems to be disrupted in patients with Alzheimer's. The overall conclusions of the study show that Alzheimer's memory impairments are not the same across the different domains of memory; explicit memory is disrupted, but acquisition of visuomotor skills remains possible (Carlesimo and Oscar-Berman 1992). It also seems as though encoding and consolidation processes are not completely functional (Carlesimo and Oscar-Berman 1992).

TREATMENT FOR ALZHEIMER'S DISEASE

While there is no known cure for Alzheimer's, there are certain treatments that have been found to be helpful. For instance, acetylcholine esterase (AChE) inhibitors have been found to be useful in treating Alzheimer's symptoms, which might encourage patients to seek medical assistance earlier. Zetterberg and Blennow (2007) identify the 42 amino acid fragments of β -amyloid (A β 42) as being very likely to play a pathogenic role in Alzheimer's Disease. It has

been shown that the tangles associated with Alzheimer's are made of hyperphosphorylated tau proteins that have lost the ability to bind to or support microtubules, which is needed for axonal transport and function.

At one point, memory loss was believed to be caused by the hardening of the arteries of the brain, called cerebral atherosclerosis, because of the decrease in blood flow to the brain that is observed; however this does not appear to be attributed to the loss of functionality of the neurons which eventually leads to their death (Thal 1998).

CULTURAL DIFFERENCE IN SYMPTOMS PRESENTATION

Interestingly, Fujishima and Kiyohara (2002) found that the specific type of dementia that is most common varies by region. For example, using the same criteria to diagnose dementia that is used in the United States, they found Japan to have higher rates of vascular dementia than Alzheimer's, unlike the United States. They explain this phenomenon as being partly due to the fact that hypertension is a risk factor for the development of vascular dementia, such that people with a history of hypertension were three times more likely to later receive a diagnosis of vascular dementia (Fujishima and Kiyohara 2002). They identified a possible mechanism of the relationship between hypertension and vascular dementia to be the blood brain barrier, as it allows substances in and out of the brain. Interestingly, this relationship is not replicated in patients with Alzheimer's; in fact, individuals diagnosed with Alzheimer's tend to have lower blood pressure than non-affected individuals of the same age group (Fujishima and Kiyohara 2002). Management of stroke risk has actually reduced the incidence of vascular dementia in the

older population, as hypertension is also the focus when looking at causes of strokes. Given this, it is not surprising that strokes increase the risk for the onset of dementia by a factor of eight, as they increase the amount of white matter lesions present in the brain (Skoog and Gustafson 2002).

Skoog and Gustafson (2002) compared the risk factors for hypertension and Alzheimer's and found that the relationship between the two might be mediated by risk factors such as high salt intake, psychological stress, diabetes mellitus, and oxidative stress, among others. Traumatic life events that cause high levels of stress are also risk factors for both hypertension and Alzheimer's (Skoog and Gustafson 2002).

Chan et al. (2013) examined the incidence of dementia in China, highlighting a hardship with caregivers to be due to the one-child policy that leaves less support for caregivers. Additionally, there are more people with dementia located in rural regions. Of the 340,247 participants in this study, 6357 were diagnosed with Alzheimer's, 254,367 participants were diagnosed with another main form of dementia, including vascular dementia, frontotemporal dementia, or Lewy body dementia (Chan et al. 2013). The numbers of people with dementia or Alzheimer's in China has risen each year, but the proportions generally have not changed, with about one third of patients, aged 55-59, considered to have Alzheimer's (Chan et al. 2013). The goal of this study was to address policy issues regarding education and care for Alzheimer's and dementia patients. Because the prevalence of these diseases is increasing, it is important to know the risk factors and the symptoms, as well as how to treat them.

Jorm (1991) examined the cross-national comparisons of instances of both Alzheimer's and vascular dementia, specifically in Great Britain, North America, Scandinavia, Italy, Switzerland, Austria, Australia, China, and Japan. He found that in North America and Great

Britain, Alzheimer's disease was more common than vascular dementia, as in most of Europe and Australia (Jorm 1991). As mentioned above, Japan and China had consistently higher rates of vascular dementia than Alzheimer's. The evidence of different rates of Alzheimer's and vascular dementia suggests that there would also be a difference in knowledge and care for the patient in a medical sense, which would contribute to the difficulties faced by caregivers, as discussed in later chapters.

CONCLUSION

Alzheimer's disease is characteristic of neurofibrillary tangles and senile plaques, which differs from other forms of dementia due to its direct neuronal impact rather than blood vessels. Severe memory deficits are due to the changes in the hippocampus and surrounding areas, and other common symptoms such as language deficits, personality changes, and confusion are often present. The differences in presentation of Alzheimer's Disease from patient to patient is one of the main reasons why it is so difficult for medical professionals, and therefore caregivers, to provide the best care for the patient. In the next chapter we examine the role of caregivers for those with Alzheimer's Disease.

Chapter Two- Alzheimer's Disease Impact on Caregivers

Despite the commonality of Alzheimer's Disease, there continues to exist a stigma surrounding the onset and progression of the disease, such that patients are often looked at through a lens of pity and discomfort. The stigma associated with Alzheimer's is extremely important because it has a major impact on caregiver experience. However, stigma is not exclusive to Alzheimer's, rather it is present in most accounts of aging. It is the belief of many cultures that aging individuals generally have less to offer to society than younger individuals. Further, it is important to note that many people believe that the way a person ages is a direct reflection of how well they took care of themselves and kept themselves active during adulthood. How gracefully a person ages can also be attributed to the involvement of their family in their lives.

Cultural anthropologists have found that views of 'aging' may vary considerably based on local cultural understandings. People's views are based on shared cultural models of the aging process in societal context. One helpful concept has been called a cultural script; this script is extremely influential in how people think about their lives and transition from adulthood to older adulthood, and it gives them the comfort of knowing what will likely come next. A cultural schema can be seen as a more tightly structured script, one that has a "bounded, distinct, and unitary representation" (D'Andrade 1995:122). Cultural schemas or scripts act as organizing frameworks that are used to process and make sense of new information.

Caregivers play a crucial role in the lives of patients, whether AD or otherwise. Informal caregivers are often untrained family members that are asked to care for someone with no

positive solution. There is only one outcome of Alzheimer's Disease; the only unknown variables are the duration of the disease and rate of progression that the patient will display. Previous anthropological research has focused on identifying these informal caregivers. For instance, high percentages of caregivers are the patient's spouse, with the next common relationship being parent-child. There are certain factors associated with both the caregiver and the patient that can increase the negative emotions such as stress, anxiety, or depression that the caregiver may feel. These factors include duration of illness, support from family and outsiders, health of the caregiver, and perceived burden. Caregivers are often labeled as the "invisible second patients" (Ma et al., 2017) because they are just as involved in the process as the patient, yet they have the extra hardship of remembering what the patient was like before the onset of their symptoms, while watching them slowly decline over time. Ma et al. (2017) conducted a meta-analysis in which they combined data from 18 independent studies containing over 72,000 total participants, including 2351 caregivers of Alzheimer's patients. They reported a general theme that caregivers were categorized as having lower mood scores than non-caregivers, as well as higher anxiety levels as measured by the Beck Anxiety Inventory or the State Trait Anxiety Inventory. It is clear that caregivers are significantly affected by the experiences associated with the role in part because of the nature of their responsibilities and the intensity at which they are faced with challenges.

Alzheimer's is a unique disease in that the majority of caregivers are family members, since most patients do not necessarily need to spend an extended amount of time in a hospital. If the spouse of the patient is able, they are usually the first person called upon to become primary caregiver, or "care partner" as they are referred to in "The Emotional Journey of the Alzheimer's Family" by Santulli and Blandin (2015). This wording emphasizes the idea that the caregiver is

heavily affected by the state of the patient, as well as the idea that the patient is reliant on their partner for help, in the form of both large and small tasks. Santulli and Blandin focus on what they call the Alzheimer's family, which is the "friends, close neighbors, and others whose lives are touched in some way by the person with the disease" (Santulli and Blandin 2015: 2). This is important because when the spouse of a person with AD is unable to care for the patient, the responsibility often falls on the children of the patient. This is true in many cultures, and for many different diseases and illnesses other than Alzheimer's. In some ways, the expectation of being a caregiver becomes somewhat normalized, causing the hardships associated with providing long term care for a parent to be somewhat ignored. A concept that is common in Alzheimer's literature is "role reversal", which is the idea that a child who takes care of their parent with AD will become the parent, and the patient will begin to resemble a child, as they are slowly losing the ability to care for themselves independently. There is no doubt that caregivers have an extremely difficult but important role in the lives of Alzheimer's patients, and this role is likely to affect their mental health in a negative manner.

ANALYSIS OF LANGUAGE AND FAMILIAL ROLES

As mentioned above, it is a common practice for children to be expected to care for their elderly parents. This is the case in America, Mexico, Japan, and China, among others. There have been shifts in cultural scripts that have altered the expectations for children as caregivers, yet it seems that there will always be some sort of responsibility to care for their parents as they once cared for them.

We will start the conversation with Japan, whose aging process has been studied heavily by John Traphagan. He starts with the book entitled *Taming Oblivion*, discussing what the definition of age is in Japan. Since the calendar year is not based on continuous progression, but rather who is in power at the time, age terms split the discussion into either relational or periodic terms, comparing people based on their rank or what stage of life they are in, respectively (Traphagan 2000: 73). Age in Japan is not defined in chronological age, but rather one's "position in the life course relative to others, particularly in reference to birth order and social status" (Traphagan 2000: 73). The stage that people exist in impacts how they interact with others, and how they assume their social status. Each of the stages is associated with certain terms based on the expectations of the individuals within that stage, and how they are viewed in society. The most common words associated with older individuals are *boke*, *rojin* and *otoshiyori*, which tend to have a negative connotation because it carries a sense of "oldness". Aging or senility in Japan in general is viewed as a very negative process. Aging and becoming dependent on others is highly negative, especially in a society where one is expected to be a role model for younger family members. There are various paths to aging, and the Japanese form a cultural script that states that a person's actions in life have an impact on how they age. For example, they believe that there is a way to act in order to "avoid a bleak old age confined to a bed or lost in the oblivion of dementia" (Traphagan 2000:133), which is different from the Western perspective, as it is less likely that the patient will be solely blamed for the onset of their dementia. It seems as if the main goal is to avoid becoming *boke*, or the loss of self characterized by a major decline in memory and health (Traphagan, 2000: 135). Interestingly, there is no direct word "Alzheimer's" in the Japanese model, and it is instead referred to as *chico*, which is defined as "blockage of intellectual abilities" (Traphagan 2000: 136), which again hints at the belief that

there might be something that can be done to “unblock” a person’s mind to make them fully functioning. Traphagan identifies men post-retirement as the most likely group to be susceptible to being *boke*, since they have much more free time and a major decline in activities to keep their minds stimulated.

People who are identified as *boke* are viewed as being somewhat of a burden on their family members, as they begin to lose their independence. The main struggle with the loss of independence is the idea that the elderly individual will not be able to repay their family for the help that they give them, causing them to forever be indebted to them. In terms of family, the terms *kazoku* and *ie* are extremely important. Both refer to the family and responsibilities associated with being a child, but *ie* represents a complex set of ideas ranging from meaning and authority within a household to the familial structure that elder care so heavily relies on. In the past, elder care relied solely on the children, in accordance with Confucian ideas of filial piety, which identified the parent-child relationship as one of the “five primary human relationships” (Jenike and Traphagan 2009: 246). However, due to the increase of life expectancy and the consequential increased need for support of the elderly, there has been a shift in the cultural script of caregiving. Many caregivers have their own age related health concerns, or are not financially able to support their family as they once were. These shifts cause the aging individuals to feel like more of a burden, which has resulted in an increased suicide rate in Japan for people over 60 years of age, as they feel an “obligation to leave this world if he or she has become burdensome” (Jenike and Traphagan 2009: 247). This supports the view that the hardships associated with caregiving for aging individuals, especially those with cognitive declines, is a very difficult task that many people are no longer equipped for. When caregiving relied solely on family members, it led to caregivers being unable to have their own children or

keep their jobs because they had a constant need to be with their parent, and spend all of their time keeping them safe. The necessary shift to social welfare programs such as the Gold Plan was theoretically helpful, but in reality placed even more of a burden on families who, on paper, should be able to care for each other but had extenuating circumstances that prevented them from being able to care fully for the patient in the way that was needed. Other programs have been implemented to lessen the responsibility and burden of family caregiving; the fact that such programs are becoming readily available emphasizes the idea that the burden is too much for an untrained individual to be faced with. It is important to note that family caregiving still exists in Japan, and in some ways is even expected, but there are now additional alternatives.

Japanese views and ways of coping with Alzheimer's are distinct for various reasons, but arguably the most important difference is revealed through the language used to describe the stages of aging. Connotation of certain words has a large impact on the way a patient, as well as their caregivers, views their progression. Whether they are viewed as *boko* or *chico* seems to change where blame is placed for the onset and symptoms of the disease. Family ideals play a major role in caregiving, and the Japanese views of parent-child dynamics also impact the sense of burden that a patient feels that they place on their caregiver. Similar themes are seen across various cultures, yet they are emphasized in Traphagan's work in the Japanese community, as well as Jonathan Yahalom's work in Southern Mexico.

American culture emphasizes that people find life satisfaction through their work, so it is not surprising that the negative consequences associated with caregiving can bring extra stress and negativity to the role. The work-life balance of a caregiver is certainly affected by the progression of the disease. Whether that takes the form of taking time off of work to care for the patient, leaving early to deal with some sort of emergency, or being stressed, tired, or distracted

due to caregiving responsibilities, there is no way to avoid having the role affect work performance, creating “disharmony in the workplace” (Hendershott 2000; 78). Many people refrain from disclosing the fact that they are acting as a primary caregiver because they think it might affect people’s perceptions of them, as well as prevent them from obtaining promotions. This is especially prevalent in academia, in which people are already told that they should wait to start a family until after they are established in the field, because they might be seen as not taking the role seriously. However, some people view work as an escape from the demands of caregiving, as caregiving can often feel “isolating and alienating” (Hendershott 2000; 89).

SYMPTOM DISMISSAL AND ROLE REVERSAL

Yahalom’s work in the Oaxacan community located in Southern Mexico is another example of the differing cultural perspectives of aging. In this community, elders are typically looked to as keepers of tradition, anchors to the historical past, and steadfast pillars of the family that brings people together. However, when faced with the changes brought by Alzheimer’s or Dementia, the elders are unable to continue to fill the roles due to memory loss and cognitive decline. Similar to Traphagan’s observations in Japan, the people of the Oaxacan community do not recognize Alzheimer’s as a real disease, but rather view it as a “modern condition that occurred in response to the stresses associated with nontraditional ways of living” (Yahalom 2019: 26). This phrase creates the belief that the diagnosed individual would be to blame for their condition, seemingly dismissing the biological influences that Western societies tend to focus on. The individuals who are at blame are viewed as not following the proper way of aging,

such as keeping themselves active or “thinking too much”. A woman named Cynthia was introduced as someone who withdrew herself from normal life events due to excessive sadness, which caused her to begin to forget. Unlike the traditional family experience with Alzheimer's in which the causes are not known and there does not appear to be a clear reason for the onset or progression, blaming the person who is diagnosed allows families to come to terms with the situation more easily because there is a clear reason that they can point to as the cause of the forgetting. People in the Oaxacan community tend to dismiss the severity of symptoms associated with Alzheimer's, to the point where most people who are diagnosed do not actually go to a physician, in hopes of receiving an Alzheimer's diagnosis. Instead, they go for an unrelated health concern because becoming forgetful is considered normal.

American families tend to dismiss symptoms at the beginning of their onset as well, but usually in a different way. Often before an official diagnosis, there will be family conflict over whether the signs and symptoms being displayed are due to natural aging or if there is something more serious going on. Many times these arguments originate because family members do not want to admit that there might be an “issue” with their parent or spouse. This display of denial usually conflicts with other family members, perhaps those who spend more time with the individual, who see the changes and acknowledge that it is probably not just normal aging. Anne Hendershott is a Professor of Sociology that dealt with caregiving herself, for her mother-in-law Katharine. She admits to dismissing early symptoms as just normal aspects of aging, Even when there were obvious signs, the family dismissed them as unimportant or rare. When Katharine forgot Christmas and was confused why her family was showing up to her messy house with presents and food, her son kept telling everyone that “it's not as bad as you think” (Hendershott 2000; 6). Denial can lead to continued risky or harmful behaviors from the patient, since they are

not being given the resources or care that they need. A lack of a diagnosis can also lead to the “missed opportunity for the undiagnosed Alzheimer’s patient to participate in the drug therapies which may help to alleviate some of the symptoms” (Hendershott 2000; 10). These therapies would not cure the disease, but could make it less difficult for both the patient and family. Conceptualizing Alzheimer’s as a disease leads to a contrast between normal aging and diseased aging, creating a space for those affected by it to blame the disease, rather than the person displaying the various frustrating symptoms. One of the symptoms that can’t be ignored is wandering, as it can lead to very dangerous outcomes if the person gets lost and can’t find their way back home. Hendershott identifies the wandering behavior as a patient trying to go home, which can be interpreted as a metaphor for the patient’s “desire to return to the past, when things made sense to them” (Hendershott 2000: 11).

Yahalom identifies an important concept in Alzheimer’s research dealing with family caregivers: role reversal. Children are often expected to care for their elderly parents who are no longer able to care for themselves, and especially in the case of Alzheimer’s, the parent often loses the ability to perform simple tasks that they have always been able to do, such as feed themselves or use the bathroom. This not only changes the relationship between the parent and child, but reverses it, making the child assume the parental role and take care of all of the needs of the parent. This is sometimes viewed as the normal progression of life, that children are supposed to take care of their parents when they are older, whether due to illness or just normal aging. However, with Alzheimer’s this role reversal is exaggerated because the patient becomes incapable of simple tasks, and often view it as losing their dignity when someone else has to help them use the bathroom or get into bed. Even with the difficulty of this change in responsibility, some caregivers find that they are more attentive if they see the patient as someone that needs

more help than the average adult, since they know that it is up to them to provide the patient's basic needs for them (Yahalom 2019: 126). This type of role reversal is not present in every culture, as some group beliefs place an emphasis on the wisdom and respect of elders, so treating them as if they were a child would be unacceptable.

In Aaron Seaman's article entitled "'Like He's a Kid': Relationality, Family Caregiving, and Alzheimer's Disease", he continues the conversation of role reversal, and the positive and negative effects that might surface when viewing the relationship this way. The piece opens with a story of a couple whose lives have been affected by Alzheimer's; Jonathan was diagnosed with early-onset Alzheimer's, and after observing behavioral changes, his wife Shawna started comparing him to a child as she felt that she had to reteach him everything. She then alters her opinion on the basis that there exists a fundamental difference between her husband and a child, which is the fact that he cannot learn or retain the information that she was trying to teach him. In contrast to Yahalom's claim, Seaman describes the evidence supporting the idea that treating an Alzheimer's patient as a child can actually "contribute to the erosion of personhood" (Seaman 2019: 4) because it seems to erase the life that they had before their diagnosis, as well as the relationships they had, especially with their familial caregiver. This undermines the person's sense of self, which will likely contribute negatively to their progression.

However, viewing the patient as a child might be considered a coping mechanism for the familial caregiver. If an individual has to take on the role of a 'parent', it gives them a greater sense of responsibility and purpose. The patient is dependent on the caregiver, but it does not necessarily mean that they will lose all of the meaningfulness of the relationship that they previously had with that person. Seaman gives the example of another couple, Alan and Joann. Joann is acting as the caregiver for Alan, reporting that she often feels like his mother, due to the

fact that she has to remind him to eat and get dressed. However, she does not let this new responsibility destroy her relationship with her husband, as she still described moments that felt 'normal', such as meals or conversations that they shared. Despite this, Joanne reported feeling a sense of sadness surrounding the dual nature of their relationship because, unlike Alan, she is not able to forget the nature of the relationship they once had, and she is constantly reminded of everything that she has lost due to her husband's Alzheimer's diagnosis. Importantly, Seaman emphasizes the fact that Alan's dependence on her never seemed to be infantilizing, as Joanne "constantly reaffirmed who Alan was" (Seaman 2019: 8). The degree to which the caregiver and patient lean into or acknowledge the shift in responsibilities in their relationship has an effect on the general perspective they will carry about the loss associated with Alzheimer's.

In addition to the normal role-reversal that is discussed by many, Hendershott also identifies the need to "Alzheimer's proof" her house, similar to how people baby proof (Hendershott 2000; 43). This is especially important because Alzheimer's patients tend to struggle with sleeping through the night, so they often get into 'trouble' such as emptying cabinets, breaking valuable items, etc. while everyone else is sleeping. She had to put iron bars on the patient's windows so that she wouldn't escape, and they set up a security system that was designed to keep her inside. Additionally, as if they were parenting a nervous child, Hendershott and her husband would go along with her delusions, attempting to comfort her rather than upset her by telling her she was wrong. People with Alzheimer's, especially the later stages, tend to react in catastrophic ways to disappointments or when they are asked to do something that they do not want to do, reminiscent of behavior that is somewhat acceptable in children but not adults.

SUPPORT SYSTEMS AND CARE PARTNERS

Coping with the changing of roles in the patient-caregiver relationship is important because the caregiver needs to learn to be less dependent, whether the patient is their spouse or their parent. Many caregivers rely on support from outsiders, whether that be with medical assistance for the patient, or emotional support for the caregiver. Santulli and Bladin acknowledge the hardships associated with being a caregiver, or what they call “care partner” in their book *The Emotional Journey of the Alzheimer's Family*. In their discussion of the difficulties that families, especially spouses, face, they emphasize the existence and importance of the Alzheimer's family, which they define as the “friends, close neighbors, and others whose lives are touched in some way by the person with the disease” (Sanulli and Blandin 2015: 2). These individuals not only sometimes become the care partners themselves, but often act as emotional support for both parties. One main difficulty that caregivers face is discordance, or the lack of agreement that may be caused by memory impairment, denial, agnosia, or even the stigma and general social disapproval that is associated with Alzheimer's. Unlike many other authors, Santulli and Bladin offer a possible explanation for the stigma associated with memory loss; from a young age we are rewarded in school with being able to memorize large quantities of information, and if we are not able to do so, others often view us as stupid or lazy. Another contributing factor to stigma is the decreased ability to control oneself in social situations. Anne Hendershott describes her feelings of embarrassment around her mother-in-law's behavior in public after her diagnosis of Alzheimer's in the book entitled *The Reluctant Caregivers*. She describes how Katharine, her mother-in-law, lost all sense of things that are deemed socially acceptable versus not, so she tended to just do the first thing that popped into her mind, even if it

meant taking off her clothes in the middle of the department store to try on a new shirt. No Alzheimer's patient is intentionally engaging in behaviors that make the people around them uncomfortable, yet that is often the outcome. Being an Alzheimer's caregiver is a 24/7 disease that just continues to progress and require more care and assistance.

In addition to seeking support from others, there are many methods of coping that a family might utilize in their journey with the disease. These strategies are not necessarily unique to Alzheimer's caregivers, but the way in which they were used are important. Repression is often the first strategy implemented, along with denial. Both of these methods are ways for caregivers to attempt to live their life without constantly thinking about the struggles of caregiving. Expression of these methods could range from denying that there is anything significantly wrong with their individual prior to their diagnosis (called minimization), blaming cognitive declines on normal aging, or just avoiding the topic because it is upsetting. Family members might attempt to come up with what they see as a logical explanation for the changes they are observing, in accordance with methods of avoidance or compartmentalization. People may also displace their feelings and take out their sadness or anger in other areas of their life, possibly without even noticing. Lastly, people may turn to a more practical solution and attempt to learn everything that they possibly can about the disease and the ways it might progress, to ideally lessen their anxiety about the unknown. Pratt et al. (1985) identified that spiritual support was also a common indicator of lower burden and stress levels, possibly because it gives people someone to rely on or blame for the situation. Additionally, caregiver confidence also has a large impact on the perceived sense of burden that the caregiver feels, such that lower confidence in their decisions will be related to higher levels of burden since they are constantly questioning their own actions and decisions (Pratt et al. 2985: 31). There are various ways to reduce feelings

of burden and declining mental health, but finding a support system is central to many of the other strategies.

Common experiences shared by virtually all caregivers of Alzheimer's or Dementia patients involve negative emotions such as anxiety, stress, depression, and grief, among others. It should not be surprising that depression is at the center of the grief journey that caregivers are a part of, as depression is often present until the person reaches acceptance. The nature of Alzheimer's, the extended duration, slow progression, and gradual loss of the fulfilling relationship that they once knew, causes grieving throughout the progression of the disease rather than just at the end like many other diseases. In accordance with many other cultures, Santulli and Bladin report Americans dealing with feelings of guilt regarding not being able to provide the care that they believe the patient deserves, or the idea that they are somehow at fault for the onset of Alzheimer's. This guilt might be due to pre-existing issues that might have already been present in the relationship, manifesting itself in something that is not controllable by either party. The authors point out that guilt can act as a double-edged sword, making the family more likely to miss the good moments with their loved one, because they are preoccupied with thoughts about what they should be doing differently or what they failed to do.

The main form of grief associated with caregivers of Alzheimer's Disease is known as ambiguous loss, or when the patient "remains physically present, but is psychologically absent", which has previously been referred to as the "goodbye without leaving" (Santulli and Bladin 2015: 90). This is obviously directly related to the hardships that come with watching someone lose the parts of themselves that have always seemed to make them who they are. They are physically still in the company of the caregiver, but the meaningful conversations and the time spent with them is not the same. The stages of grief commonly associated with this form are

anguish, adaptation, and acceptance. Adaptation is highlighted, as that is the point in which caregivers are willing to take responsibility for their role and respond to the changes that they are seeing in their family member. Adaptation really emerges when the memory and ability loss of the patient becomes so bad that they are unable to perform basic tasks that were once second nature to them. Of course, this leads to acceptance of the fact that “the person who existed before Alzheimer’s disease has been irreversibly transformed (Santulli and Bladin 2015: 115). The stages of grief associated with the Alzheimer’s family will differ based on how the disease is medically categorized in different cultures, as that will alter the family’s sense of guilt, as well as their sense of loss. If the natural process of aging of one group is similar to the Alzheimer’s aging process in another, the two groups will have different reactions based on their perception of what is normal or natural.

AMBIGUOUS DIAGNOSES AND AGING PROCESSES

The word Alzheimer’s does not have any meaning in India. When American anthropologists asked an Indian anthropologist about the prevalence of dementia or Alzheimer’s in India, they were unable to answer the question because the concept was not “central to his frame of reference” (Cohen 1998:15). The concept of senility was not known in his experience because the elders were well taken care of, preventing them from aging poorly. He viewed senility as a western cultural concept used to counter the “joint family”, which is considered to be the “index of Indianness” (Cohen 1998:17). The joint family was supposed to act in a way that prevented the onset of senility in their elders such that if they were taken care of, they would remain healthy. The joint family is the major determining factor in assessing the health of elders,

and the Indian culture viewed discussions of “senile old bodies” as being exclusive to Western families (Cohen 1998:17). This difference in identifying language is key in understanding the differences that are observed regarding treatment of the elderly.

Interestingly, the same neurological changes such as the presence of tangles and plaques are still discussed, but these changes are not framed as if they are directly related to Alzheimer's or dementia. The medical model of neurological variations in general is widely different in India, as it appears that Indian brains “grow senile and degenerate much slower than westerners, and the number of senile persons in India is far less than that abroad” (Cohen 1998: 19). It is unclear what the reason for this is, possibly because fewer people in India are seeking medical treatment for symptoms of Alzheimer's, since they do not necessarily recognize it as a real disease.

In order to be able to discuss the symptoms and effects of dementia, Cohen first refers to the Diagnostic and Statistical Manual of Mental Disorders (DSM) to come up with a definition. It is clinically defined as a “set of multiple and relatively stable cognitive deficits, and in particular a deficit of memory” (Cohen 1998: 26). There does appear to be a cultural difference in diagnosis, as in western Europe and North America, over half of the patients over 65 years old are diagnosed with “probably Alzheimer's disease”, and less than a fifth of people over 65 are diagnosed with vascular dementia (Cohen 1998: 29). However, in Japan, Alzheimer's is diagnosed “only half as often as vascular dementia”, and Russian studies have also produced these results (Cohen 1998: 29). There are arguments that this might be due to differences in physician proficiency rather than actual disease prevalence, as well as a general difference in the definition of both Alzheimer's and Dementia.

Cohen attempted to recruit participants from a dementia clinic of the Banaras Hindu University Hospital, asking people who recently received dementia diagnoses to join the study.

He was able to recruit six participants, and the majority of their diagnoses were not consistent with the dementia symptoms of the DSM-III-R, which was the most current version at the time. This suggests that the differences in prevalence might actually be due to differences in diagnosis rather than the actual presence of the disease. On the other hand, some doctors reported being pressured to push a dementia diagnosis, in order to prescribe certain drugs and continue their relationship with pharmacy companies. This is not something that is uncommon in America, and it is likely the product of westernization of the medical field in India. One key difference in Indian culture, however, is how patients of Alzheimer's or dementia are treated. Despite a medical diagnosis, people are thought to be making up their symptoms, and are told that "no one here cares" about the disease or struggles that come along with it (Cohen 1998: 299). Additionally, the accessibility of services such as facilities for elder care are extremely expensive and inaccessible to most people.

Cohen then switches gears to focus on the types of people that typically are diagnosed with dementia. He states that it usually happens to good people; he deems it unfair or tragic. He compares this to epidemics such as AIDS, which tends to be discussed in terms of morals or values, even when it shouldn't be. Similar to Trapanhagan's findings while studying in Japan, the parent-child dynamic has changed. Previously children resumed the sole responsibility of taking care of their parents when they were unable to care for themselves, but now "families fall apart, children no longer respect and take care of their elderly parents" (Cohen 1998: 87), suggesting that the assumption that parents need not worry about elder care is no longer true. Many elders reported feeling "dependency anxiety" (Cohen 1998: 125) because there was no guarantee that their children would be willing and able to care for them as they needed it. However, the root of most of the fears associated with dependency anxiety is the physical weakening of the body

rather than the weakening of the mind as one might expect. The shift in responsibility between the caregiver and patient, especially in parent-child relationships, is viewed as the parent slowly losing their independence as their “voice” becomes more monotone. A monotonous voice both represents a lack of command over a situation and a shift in dynamics away from the head of the household. The elder is considered the household itself, as “his or her performative control over it signifies the moral integrity of the family” (Cohen 1995: 328).

Prior to the 1980s, there was not a fully understood concept of aging in India, to the point of gerontology's primary task becoming the creation of this concept, rather than just studying it. The concept of a second childhood emerges, in a similar fashion to the previously mentioned role reversal that elderly people often face. The second childhood is viewed negatively, as they are said to act like a helpless child that is unable to do basic tasks that they were once able to do. Often, looking at the aging individual as a child is negative for the relationship between the caregiver and the patient, as it can be frustrating that they are not able to learn like most children are. Their abilities decline instead of progress which causes frustration in all involved parties. The second childhood and memory loss is associated with “softening”, which is analogous to the general decline of a person with cognitive impairment.

THE LANGUAGE OF ALZHEIMER'S

There are many instances in which children become primary caregivers for their parents with Alzheimer's or dementia. As stated previously, many children believe that it is their responsibility to care for their parents since they were cared for their entire life. This sentiment is reflected in Janelle Taylor's work called “On Recognition, Caring, and Dementia” in which she

discusses her experiences as the primary caregiver for her mother who was living with dementia. She reflects on the common questions that she receives about her relationship with her mother, and finds the most frequent to be some variation of “does she recognize you?”. It makes sense that this question would be asked of family members, as it can be quite difficult when a parent gets to the point where they do not know who their child is anymore. Taylor, however, expresses her dislike of this particular question. She says that her mom will sometimes refer to her as “stranger” when she sees her in the facility she is now living in. At first, this might seem upsetting but Taylor views it as her mom just using a new pet name for her; she might not remember her name but she knows her face and the way that it makes her feel when her daughter is around. Making the decision to put her mother in a professional care facility was not one that was easy for Taylor, as she previously felt the responsibility to be her primary caregiver as long as she realistically was able to. She particularly emphasizes that the level of her involvement in her mother's care is due to the fact that her father passed away, leaving her as the primary caregiver.

Most previous research has enforced the idea that once patients are unable to recognize and remember certain people, it's possible that they are unable to care about them. This seems harsh and not necessarily supported by the experiences of Taylor, who argues that even though her mom might not always recognize her, she is still sitting there having a meaningful conversation with her, which shows that she cares. Even if the name of the person is not information that is readily available, the presence of someone that the patient cares for is important and appreciated. Taylor discusses the questions that people most often ask her, which she identifies as the “stills”; can she ‘still’ do this, does she ‘still’ know that, do they ‘still’ recognize someone. People also often ask about firsts- the first time that the patient needs help

with a specific task, or the first time that they ask the same question repeatedly because they do not remember doing so the first time. These words have very negative connotations, so Taylor flipped the words to show a positive aspect of her situation. She talks warmly about the first time that she and her mother sang a childhood song at a high volume, the first time that they held hands and crossed the street since she was a child. This indirectly points back to the shift in responsibilities between parent and child, as the daughter has become the caregiver.

CAREGIVER STRUGGLES

Sue Matthews Petrovski refers to Alzheimer's as the "impatient thief" (Petrovski 2003: 40) as she watched the relationship she once had with her mother become destroyed. In her book *A Return Journey*, Petrovski introduces the book by reflecting on her eight year struggle, during which she didn't have time to do anything except care for her mother and mourn the person she was losing. Being a caregiver had become so much of her life that when discussing the loss of her mother, she states "in addition to the loss of the loved one, the caregiver must also deal with the loss of personal identity and purpose" (Petrovski 2003: 5). Petrovski's purpose in writing this book was to help herself heal and regain control over her mental health, and mourn her mother for the person she used to be.

Petrovski reflects on how it was "close to unbearable" when the day comes where you are no longer recognized by your loved one, because the disease has "chiseled away until there is no relationship" (Petrovski 2003: 45). This perspective of forgetting villainizes the disease rather than blaming the victim. Most people do not intentionally blame the patient, but it can be hard

not to become angry with them when they are displaying behaviors that they once knew were inappropriate. As an Alzheimer's caregiver, one watches the patient lose their etiquette and understanding of social rules. Petrovski describes it as "Alzheimer's teach[ing] us to see life painted in different colors than we ordinarily view it" (Petrovski 2003: 83). Tasks are not easy anymore; one of the main tasks is finding a way to creatively help the patient without angering or frustrating them.

This concept is shown repeatedly in Robert Hershberger's book *Diary of an Alzheimer's Caregiver*, in which he documents his own experiences with acting as a caregiver for his wife, Dee. The book spans over five years, from her initial diagnosis of early-onset Alzheimer's Disease to her eventual death. Hershberger highlights many extremely difficult changes he observed and the new mental and physical challenges he had to overcome to continue to care for his wife. During the third year, Dee had to have her husband nearby at all times, which prompted him to describe his situation as "raising a child in reverse" (Hershberger 2022: 21) because she lost her memories of how to do basic tasks, and was not able to relearn them. Hershberger also struggled with not getting angry at his wife for her actions and her difficult behavior even though he acknowledged that the behaviors were only because of the disease. He describes Alzheimer's as the "long goodbye", and writes "it is so hard to lose the love of my life a little bit more each day with no prospect of improvement or cure" (Hershberger 2022: 32), which supports the idea that caring for someone you have built a life with is very difficult, especially when the person you love and are caring for is unable to cooperate, and most days cannot even remember who you are.

Petrovski also mentions the guilt that caregivers often feel when taking care of an Alzheimer's patient. Because the disease progresses to the point where the patient can no longer

make any decisions for themselves, it all falls on the caregiver. This causes a constant questioning over whether or not the right decisions are being made, and contributes greatly to the feelings of burden and stress. The responsibilities involved in caregiving have a physical effect in addition to mental. It is surprisingly not uncommon for caregivers to actually pass before the patient that they are caring for because it is a “physically demanding, sleep-depriving, and mentally exhausting job, and the decisions we have to make cause unmitigated stress” (Petrovski 2003:114). Petrovski herself identifies her most challenging aspects as guilt and lack of confidence in her decisions, which is likely a commonality between first time caregivers, which most are.

In *The Reluctant Caregivers*, Anne Hendershott discusses how the progression of becoming a caregiver is analogous to the progression of Alzheimer's. As the diagnosed individual becomes less able to do things on their own, the caregiver begins to take over more responsibilities. Just as the disease will take over a person's life, being a caregiver often becomes a person's main responsibility and can seemingly take over their family, job, and just about every aspect of their life. Many people go into the role of caregiver expecting to be able to balance it with their life, but Alzheimer's is a 24/7 disease that continues to progress. Once the need for care starts, it does not stop. A common difficulty in being a primary caregiver is admitting that outside help is sometimes necessary, because the demands of the patient are “far too burdensome for one person to handle” (Hendershott 2000: 65). It is difficult to find the perfect balance, because hiring just one person would likely burn them out, but hiring multiple people in shifts leads to a lack of continuity that might confuse the patient and make them more agitated and upset. Oftentimes, putting the patient in a long term facility is not possible. Most facilities will not accept a patient that has been diagnosed with Alzheimer's because they are less equipped to

deal with the challenges that they will bring. Additionally, they tend to act in a more violent manner because they are unable to control their behavior.

The work-life balance of a caregiver is certainly affected by the progression of the disease. Whether that takes the form of taking time off of work to care for the patient, leaving early to deal with some kind of emergency, or being stressed, tired, or distracted due to caregiving responsibilities, there is no way to avoid having the role affect work performance, creating “disharmony in the workplace” (Hendershott 2000: 78). Many people refrain from disclosing the fact that they are acting as a primary caregiver because they think it might affect people's perceptions of them, as well as prevent them from obtaining promotions.

PROGRESSION OF ALZHEIMER'S DISEASE

Hershberger's diary is a clear example of the different stages of caregiving for a patient as they progress through Alzheimer's. At the onset of symptoms and initial diagnosis, it is common for the family to deny that the symptoms they are observing are of real concern. It is difficult to accept that the person you know and love is sick and will not get better. Often, if they do accept that their loved one is sick, they view it as a disease that can be cured, and will often try to find solutions to stop or slow the inevitable progression. Hershberger reflects on the copious amount of research he did once he accepted the symptoms and his wife received an official diagnosis of Alzheimer's Disease. He joined support groups and worked to get their affairs in order. As the years went on, he discusses how she became more and more childlike and was unable to do simple tasks by herself, such as bathing or using the bathroom. Dee became mean and violent, which he said was uncharacteristic. In the first few years, she was extremely

dependent on her husband, but as time went on she would tell him how much she hated him for forcing her to do things she did not want to do, and wanted to be more independent even when it was not realistic. Hershberger describes the situation as feeling “trapped and angry about what is happening to Dee and me” (Hershberger 2022: 63). This shows the effect that the progression of Alzheimer's has on both the caregiver and the patient, especially when every day is different, and the caregiver never knows what to expect. This uncertainty makes it difficult for the caregiver to have a life and separate themselves from the patient, because they feel responsible for the patient's every need.

This sentiment is echoed in the study by Reed et al. (2019) that looked at the impact on informal caregivers of Alzheimer's progression. This study utilized the Zarit Burden Interview, among other tests, to identify factors associated with subjective and objective caregiver burden. The study was a 36-month observational report conducted in France and Germany, looking specifically at the costs and resources associated with community-living patients with an Alzheimer's diagnosis that were cared for by an informal, or non-professional, caregiver. The greatest increase in caregiver burden was strongly associated with a worsening in patient behavioral problems over a period of 18 months, but this increase was smaller when there were multiple caregivers for the patient (Reed et al., 2019). Not surprisingly, proximity to the patient was also seen to be a significant risk factor for higher caregiver burden, which makes sense because they feel that they have to be able to help the patient at all times since they are close by. They might feel as if they always have to be available and are unable to enjoy their own life because they are responsible for the wellbeing of the patient. Similarly, Soltys and Tyburski (2020) identify informal caregivers as being more likely to experience higher levels of stress and anxiety due to their inexperience in the medical field. Interestingly, they are also more likely to

experience anger, possibly due to feelings of powerlessness, that might affect the type of care they are able to provide (Soltys and Tyburski 2020).

Hershberger struggled at the end of Dee's life, when deciding whether or not she should be placed in a long term care facility. Every time he tried to place her in a facility because he believed that he could not fully care for her anymore, he ended up taking her back home because she was being violent or she refused to eat or cooperate with the nurses. He felt "crummy and guilty" about leaving her (Hershberger 2022: 112), but often felt worse trying to care for her alone at home. There seemed to be no easy solution for him; rather it seemed like every decision he made ended in a traumatic way for his wife. The effects Hershberger felt were intensified on the first New Year's Eve that he spent away from his wife, as he reported feeling lonely in the house that he designed for the two of them, and felt guilty because he knew she would not understand why he was not with her. Upon visiting Dee, he noticed that she seemed to be more calm because they were seemingly sedating her. He compared her state to chemotherapy treatments for cancer patients, where "doctors nearly kill the patient to kill the cancer" (Hershberger 2022: 122). This comparison is eye opening, as many memory care facilities seem to be using this type of treatment seeing it as positive, but it can be devastating for family members to see their loved ones in this state. After her passing, Hershberger looked back on his decision to have Dee "stabilized" as the "worst decision of [his] life" (Hershberger 2022: 169). It seems like there is no "right" thing to do when caring for an Alzheimer's patient; every patient has different needs, but no matter what they involve, they are always hard to satisfy.

COMPARISON TO OTHER DISEASES

It is impossible to talk about the difficulties of becoming an Alzheimer's caregiver without comparing it to other illnesses. Salini and Munisumitha conducted a study that examined stress of caregivers for stroke patients. This is an interesting comparison because recovering from a stroke usually involves short and long-term disability of some sort, but usually not full loss of function. Similar to Alzheimer's patients, stroke survivors tend to be very dependent on the caregiver, which is typically a family member. In this study, almost half of the caregivers developed physical symptoms after becoming a caregiver, and 90% reported emotional issues such as forgetfulness, sadness, confusion, anger, or irritability (Salini and Munisumitha 2017). However, unlike many Alzheimer's caregivers, 81% of stroke caregivers said the role did not affect their personal work and 91% said that their social life was also unaffected (Salini and Munisumitha 2017). This might be because the patients are not typically getting progressively worse every day, to the point where they are unable to care for themselves at all. Alzheimer's caregivers never get a day off, and they are struggling with the added burden of knowing that their patient will never recover from the disease. Another stark contrast to Alzheimer's caregivers was their confidence level in caring for the patient, as 52% of stroke caregivers felt confident in caring for the patient's needs and dealing with emergencies (Salini and Munisumitha 2017). This is likely to be one of the reasons that being an Alzheimer's caregiver is more stressful and burdensome than other illnesses or conditions.

CONCLUSION

There are many factors that affect the experience of being a caregiver for an individual who is diagnosed with Alzheimer's Disease. A cultural framework of the disease exists for any group in which it might be relevant, and this framework is essential for the way that Alzheimer's is viewed. For example, the Japanese referred to in "Taming Oblivion" view aging as a more negative process, as it causes a loss of independence. In Southern Mexican culture, the patient-caregiver relationship is more characterized as being a role reversal, in which the patient becomes more like a child and the caregiver, usually the patient's offspring, becomes more like the parent. The way the patient is described and cared for is extremely dependent on the way that the disease is viewed within the group. A key similarity in many cultures is the importance of family. Many caregivers take on the role of caregiver because they feel that it is their familial responsibility to care for their loved ones. This feeling of obligation might also lead to increased levels of stress or depression, as well as grief due to the gradual loss they are facing. Caregivers face many hardships through the role, and their mental health commonly suffers because of the demands of the role, combined with the fact that they have to watch their loved ones slowly deteriorate over time.

Chapter Three- Caregiver's Reported Experience

The following chapter will focus on the interviews that were conducted with caregivers in order to gain a better understanding of their experience. The goal of the interviews was to compare the caregivers of Alzheimer's and dementia patients to caregivers of other illnesses, in order to identify common and differing themes between the two groups.

There were many commonalities between the two groups, such as a feeling of familial responsibility to take on the role of caregiving for the parent, grandparent, or spouse. The individuals who were caregivers of Alzheimer's Disease focused much of the conversation on the hardships and burdens that they associated with their time as a caregiver, as well as the lack of support they received from many resources. The concept of a role reversal was very prevalent among parent-child caregiving relationships, as the parents with a cognitive disorder were reported to seemingly revert back to a child-like state, leaving their children to take care of them. Lastly, caregivers of all types consistently highlighted societal expectations associated with gender roles having an effect on their experience as a caregiver, especially in terms of their mental health. There are multiple dimensions that contribute to the experience of being a caregiver, and the neurodegenerative nature of Alzheimer's Disease can often intensify the hardships of the role.

METHOD

At the end of the survey distributed through CloudResearch, participants were asked if they were interested in a follow up interview. To ensure that participants' responses to the

original survey were in no way tied to their interview, they were asked to fill out a separate Google Form where they could indicate if they wished to be contacted for an interview, and also were given a space to include more information about their experiences, whether they wanted a follow-up interview or not. Participants who indicated they might be interested in an interview were contacted via email and were scheduled for a thirty-minute interview via Zoom. All participants who indicated their interest in a follow-up interview were contacted, and all that responded were scheduled for an interview. Two individuals did not show up to their interview, so they were not included in the analysis.

Participants were first asked about the diagnosis of the patient, as we were interviewing both Alzheimer's and non-Alzheimer's patients. They were asked to elaborate on issues such as the diagnosis of the patient, the reason they took on the role of primary caregiver, and the struggles they faced while acting as a caregiver. Participants were compensated \$15 for their time. A total of three interviews were conducted via zoom, and four were conducted in person. The in-person interview participants were contacted because we had knowledge of their experiences as a caregiver. The questions allowed us to gain insight into the struggles of being a caregiver, and investigate further the impacts of a person's background and culture on their decision to take on the caregiving role, as well as their general experiences.

INTERVIEW THEMES

Five interviewees identified as caregivers of patients with Alzheimer's or another form of dementia. In order to obtain enhanced statistical power, and due to the similarity in terms of rates of progression and symptoms that are seen, other forms of dementia will be included in this

discussion. For the purpose of simplicity, all forms of dementia will be discussed as “AD” in this and the following chapter. Two individuals who were acting as caregivers for patients without Alzheimer's were also interviewed. One was a caregiver for a patient with cancer, and the other was a caregiver for a patient with encephalitis and a brain injury. All interviewee names have been changed in order to keep their responses confidential.

The first caregiver we will focus on is Christina, who is currently caring for her mother, Joan, who has dementia. Christina started caring for her mother a long time ago, when her symptoms mainly focused on suspicion and paranoia. Like many others, Christina says that her reasons for becoming a caregiver hinged on her feelings of family obligation. Her father passed away many years ago, and she recalls that she told him she would “always take care of her”. This feeling of familial obligation goes hand in hand with the perceived gender roles that Christina has fit into. She discusses the difference between herself and her brothers, who “don't tend to notice if [her mother's] struggling”. Interestingly, this theme of being the sole caregiver is common among all caregivers that were interviewed, but Christina faced more difficulties because her mother would not admit to anyone else that she was struggling, especially the plethora of doctors that Christina brought her to in an attempt to receive a diagnosis. This denial of symptoms and losing the ability to be independent is a common theme in dementia and Alzheimer's, as the individuals who are going through it often are ashamed or embarrassed that they seem to be failing, and might not hold the same role in their familial or personal relationships. This loss of relationships leads into the idea of a role reversal, which refers to the idea of a swap in the typical roles between parent and child. In this case, the child is acting as the caregiver, and as the cognitive abilities of the parent are declining due to the progression of Alzheimer's or dementia, they begin to act more like a child, needing help with even the most

basic tasks that used to be second nature. Christina touches on this by comparing her time caring for her mother with time working at a nursing home when she was in college. She says

It's totally different when you are taking care of someone and you don't know what they were like before and it's not a direct relative. It's definitely a lot easier to do that than it is to do it with someone who you have seen all these mental or physical changes with, someone you're close to.

Becoming a caregiver for a person who was once the one responsible for caring for you can be an extremely difficult change. The schema, or framework, that is relevant in this situation focuses on the expectation of children to care for their sick parents, no matter the cost. This might be specific to Western ideals, as individuals from other cultures were not interviewed in this chapter. The representation of children as their elderly parent's caregivers is a core focus of the Alzheimer's experience.

This schema is also discussed by Amy, who became a caregiver for her father with Alzheimer's. She recalls promising him she would care for him, saying "I told him I would take care of him to the end because that's really what I wanted to do", again referring to the fact that she felt that being family oriented was a "determining factor" in the decisions she made early on. However, even while she wanted to care for her father, to give back to him everything that she gave her, it was not without difficulty. Amy says "kicking and screaming the roles reversed, because who wants to be told by your kid you have to do this or that." Role reversals are very difficult for both people involved, especially in Amy's case. Her father struggles with losing his independence and ability to make his own decisions, yet he seemed to acknowledge that it needed to be done and Amy was helping him do what was best. I also interviewed his wife, Jane, who was involved in his care as well. Jane took on the role of a care partner, as described by Santulli and Blandin (2015). She told me that it was John's idea to stop driving when he knew it

was no longer safe. He repeatedly said that he did not want to hurt anybody, and even though it was not what he wanted, the result of hurting someone while driving would be much worse than being dependent on his wife or daughter for transportation.

When I asked Amy and Jane what the hardest part of being a caregiver for someone they loved and cared for all their lives, Amy immediately said

I feel like I lost two fathers. I lost the person he was, and then the person that he became. We even named him, it was like a split personality. First he was John, my father, and then he was Pops, the man with the disease. That I think had a huge impact on me, it was like I really did lose two people that I loved. It was very difficult.

This statement is powerful, because it not only shows the specific hardships associated with loving someone with Alzheimer's Disease, but it really highlights the further challenges associated with being a caregiver. As a primary caregiver, Amy did not get any days off. Every day she woke up and was reminded of what she was losing; she was reminded of the fact that the father she grew up looking up to, the one she was once fully dependent on, was now fully dependent on her. She elaborated on this feeling of losing two people, saying

I missed who he was, and it was difficult in between to take care of the person that he was then, and in the end, I always wished that I could go back to the original person. And then once he was gone, you feel helpless because you say I was so busy and you lose your identity because you were so busy taking care of him, trying to deal with everything else in life and all of the sudden he's gone, and where's that responsibility what do I do now?

This quote highlights how being a primary caregiver is an all-consuming role. There is no chance to take a break, to step back, until care is no longer needed. Many people report feeling lost after the person that they are caring for passes, because they feel like their main purpose for an extended period of time was to look after someone who is not there anymore. This sentiment was

replicated in another interviewee, Catherine. She helped take care of her grandmother who had Alzheimer's. It has been almost a year since she passed, but Catherine reflects on the fact that she is still recovering, saying that "all aspects of [her] life went by the wayside, it went on the back burner" because providing care was her priority. Catherine's story is somewhat unique, as she had her whole family helping provide care for her grandmother, yet she still felt extremely alone. She recalls that her whole family seemed to hide their feelings, refusing to discuss the difficulties and hardships they were facing with losing someone they loved. For Catherine, who was very close to her grandmother when growing up, this had extremely negative effects. Not only did she have memories of what her grandma was like before she got sick, but she says

Everybody else was trying to act so tough and I'm over here falling apart and I was like am I overreacting? Is this really not as big of a deal as it seems to me? It seemed like everyone was taking it so well, and that affected my mental health because I'm like okay, what's wrong with me... what's happening in my mind that's not happening in theirs. Why is this so much harder for me than it was for them, and why can't I be as strong as they are?

Catherine's story really suggests that one's environment has a major impact on the way they perceive events happening around them. She refers to her family as having the mentality of "you take care of your own, but all the rest of it is hush hush- do what you got to do, but shut up about it". This was harmful for Catherine, to the point where she disclosed that she had to be put on medication for depression and anxiety. It is hard enough to watch someone you grew up with lose everything about themselves, but when your family is acting like they are unaffected by it and you're falling apart, there is no doubt there will be negative effects on your mental health. Catherine also ties this into the typical gender roles that she and her cousins are expected to fit into. For example, when talking about her dad, she says that he was "one of those men that are like 'men don't have feelings', so [he] hid things and acted like nothing was wrong". As harmful as this mentality was for Catherine, it is likely that the actual act of hiding one's feelings was

difficult and led to a lack of coping skills that were necessary to deal with such a difficult time. Unfortunately, Catherine's family is not alone; another interviewee, Steve, expressed similar beliefs. While Steve was not a caregiver of a patient with AD, he describes the difficulties of caregiving as "a gender thing; men are supposed to tough it out and that's what we're expected to do". Harm caused by assumed gender roles aside, only taking on the caregiving role because one feels like they have to is also harmful and can even lead to resentment, which came through in Steve's testimony.

Steve is the caregiver for his mother, who has encephalitis and a brain injury. When discussing his obligation to the role of caregiver, he says "I don't really want to be a full time caregiver either, but there's no one else to do it... There's some resentment there because instead of being appreciative for what I do, there's a lot of resentment for needing the help." The dynamic between Steve and his mom is difficult because she is still aware of the relationship that they are in, and she is aware that she is dependent on him. This is different from Alzheimer's or dementia patients who eventually become less aware of the care that they are receiving. The relationship between an AD caregiver and patient is not easy either, as Catherine discusses. She discusses the personality changes that she observed during her grandmother's journey with Alzheimer's. She mentions that they stayed relatively close, even through the progression of the disease, saying "she got really mean when things started going downhill- it was really hard and the relationship changed a lot". A change of personality is an extremely common factor in Alzheimer's due to the changes in the brain in key areas such as the amygdala and frontal cortex. Catherine describes her grandmother as becoming "hateful", especially toward Catherine's grandfather, which was disheartening to watch since they had been together for over sixty years. As discussed earlier with Amy and her father, she had to mourn the loss of the person that she

once knew, while still being responsible for the care of the person he was becoming. While this type of relationship change is likely present in many caregiving situations, it seems to be more played out for the Alzheimer's caregiver, who has to face the difficulty of losing their loved one twice.

The sentiment of initially taking on the role because of a sense of familial obligation is also a consistent theme in work done by Cox and Monk (1993), which identified providing care as a familial expectation due to the "emotional ties that unite both the older and younger members of the family". They used similar methods of data collection including the CES-D scale and burden interviews with caregivers. Their work focused on the Hispanic population in New York City, but this is a generalizable theme. Another factor that was found to help with mental health of caregivers was having a confidant available (Cox and Monk 1993), which ties into the theme of social support.

LACK OF SUPPORT

Another common theme among interviewees was the lack of resources that they experienced. This outcome was surprising, as organizations such as the Alzheimer's Association exist specifically to support caregivers of AD. However, only one of the individuals I interviewed, Christina, found that the Alzheimer's Association and other resources such as Meals on Wheels were helpful for her and her mom. Before moving her mom to a closer facility, Christina was often traveling about two and a half hours to get to her mom, so she found outside resources to be essential to her care.

On the other hand, Amy vehemently opposed the Alzheimer's association, saying "the Alzheimer's Association is worthless. They had nothing to offer whatsoever. They were the first call that I made and they couldn't give me- wouldn't give me any information." While this seems like an intense hatred of a resource that only exists to help people, it is surprisingly not the only one that I heard. Many people referred to the Alzheimer's Association and other similar organizations as unhelpful, and reported feeling like they were on their own when it came to providing care. This definitely contributes to feelings of burden and stress, especially because many caregivers of AD and dementia are not professionally trained.

It was mentioned various times that doctors seemingly "give up" on Alzheimer's patients, saying that there is nothing left that they can do for them. Another caregiver, Andrea, described the time she brought her mother with Lewy-body dementia to a gerontologist, saying it was one of the worst experiences of her life. She said

I filed a complaint against the doctor, and I said to him, "so basically my mother's not worthy of care, she's not even a human being anymore, so I should just stick her in a closet until she dies... that's what you're telling me?" And I am not a confrontational person on any level but I was so exhausted, I was burnt out, and the way this doctor treated her was as if she was nothing. We never returned.

It is extremely disheartening that the aging population has very little support from society, and those that are trying to help them are almost completely on their own. If caregivers were more supported they would likely feel less burnt out, and therefore would be able to provide care for a longer period of time and a higher quality.

Catherine's statements are in agreement with Andrea's, she says "Towards the end, it felt like the doctors sort of gave up on her, saying "well... just make her comfortable, nothing else we can do", and just kind of sent us on our way. We didn't have many resources except for the

family.” This kind of dismissal by medical professionals can be extremely discouraging, especially if someone was acting alone as a caregiver and did not have family to lean on. This, of course, is not to say that Alzheimer's is treated the same way by all doctors and medical professionals everywhere. The nature of the disease makes care more focused on comfort rather than cures, as a cure simply does not exist. However, it is the language in which people discuss the disease that can make it harmful. The image painted of the Alzheimer's population is one that is helpless and embarrassing because they are unable to control their actions. It is not really addressed that there are different stages of the disease, but rather the stigma is created as soon as someone is diagnosed with Alzheimer's or dementia. They are no longer a person, but rather a risky illness that is unstable and could overreact at any moment. Amy puts this into words, saying “They didn't know what else to do, everyone was just kind of shrugging their shoulders... I think in this country, we do a horrible job of taking care of the elderly.”

Mace and Rabins (2006) wrote a book entitled “The 36 Hour Day”, in which they give advice for caregivers that are struggling with changes in their life due to Alzheimer's. It might be considered a helpful resource by some, as it lays out the various symptoms and challenges that the patient might present the caregiver with, as well as advice on how to cope with their eventual death. A big emphasis is placed on the fact that the behaviors are not the fault of the patient, as even when it may be extremely frustrating it is important to remember that the patient is most likely just as frustrated as the caregiver is. Making the public more aware of Alzheimer's Disease would make it less frustrating or embarrassing for the caregivers who, on top of trying to care for the patient, are concerned about how they might be perceived by the people around them. Zarit et al. (1980) reported that proximity to other family members reduced the feelings of burden that the caregivers felt. Support from any angle, whether it be directly from other family members or

medical professionals or even just from strangers on the street who have a baseline understanding of the disease would be extremely beneficial for caregivers.

CHARACTERISTICS OF PROGRESSION

An important theme that came up multiple times in the interviews was the progression of the disease impacting the caregiver's experience. Catherine's explanation was interesting, saying "one day it seemed like she just sat down and never got back up". When asked to elaborate, she compared her grandmother's progression to a rollercoaster, saying "you know how on a rollercoaster it starts out really slow but once you get to the peak it just drops? That's what it was like. We were slowly working our way to the peak and then she went over the hill and it was just really bad, really fast." This explanation certainly helps one visualize the experience that Catherine went through. She mentions how at first, her grandmother was just a little more forgetful than normal, until the point when she was throwing her phone in the garbage, or driving in a very unsafe manner. This seems to be a pattern in Alzheimer's and dementia patients, as Jane describes her husband's symptoms as starting out with forgetfulness and a loss of interest in his hobbies. She seemed to experience a similar progression, saying "towards the end, one of the reasons we couldn't participate in holidays is because he looked normal and people that didn't know him as well as we did expected him to have a conversation with them and he just couldn't." Because of the nature of Alzheimer's progression, it is very hard to be prepared for what is going to happen next. Often, caregivers have to focus on the day that is in front of them, trying to provide for every need that the patient might need. Paired with the fact that there is no break for a family caregiver, as it is not just a nine-to-five job, it leaves them exhausted and burnt

out. Andrea recalls that she “would be bone tired waiting for it all to stop”. Another important factor is that since this is not a person’s paid position, they likely still have a job, possibly have kids, and certainly have other relationships and responsibilities that they often put on the back burner, because giving care becomes a priority. Catherine discusses that as her grandmother’s condition grew worse, she had issues with her job, saying they “weren’t as understanding as you would hope”. She had to use up the time off that she had built up, but once she ran out of this time, she wasn’t paid when she had to take time off to care for her grandmother. This calls back to a larger systematic issue of being able to care for loved ones without facing consequences at work, but this case just highlights the impact of being a caregiver on all aspects of life.

Aguglia et al. (2004) conducted a study in which they found that in Italy, caregivers, who are typically the wife or daughter of the patient, often end up devoting more of their time to the patient that they are caring for and running out of time for other important sectors of their life, including their job. They identified a striking 75% of a caregiver’s day as being spent caring for the patient, which likely only increases as the disease progresses (Aguglia et al. 2004). It is basically impossible for one to accomplish anything else or tend to any other responsibilities if such a large proportion of the day is taken up by their caregiving duties. Not having any personal time away from the patient will likely also result in increased levels of anxiety and stress.

Amy’s experiences support this point; when I asked what other parts of her life might have been affected by becoming a caregiver she said

Everything was affected. When he was first diagnosed, I remember the social worker saying to me ‘this is a family disease’ because it affects everyone and everything. And it did. It affected our jobs, when we could be there and when we couldn’t. When he was sick my mom would have to come home from work, I’d have to switch my days that I was working depending on who could show up and if they needed extra help. It affected

every relationship. He was my full time job. It affected friends and relationships and family.

The characterization of Alzheimer's as a "family disease" is very revealing. It really emphasizes the fact that having a loved one who is diagnosed with Alzheimer's or dementia is extremely difficult for the whole family, especially when primary care comes from within the family, which it normally does. Long term facilities are less likely to allow Alzheimer's patients into their facilities because of the higher risk of violence that might be dangerous to the staff and other patients. This leaves the family to take on the responsibility of care even if they are completely unprepared to do so.

DIFFERENCES BETWEEN ALZHEIMER'S AND OTHER DISEASES

One of the other main themes that was observed was the mental state of the patient throughout the progression of the disease and before the passed. Chris, who was acting as a caregiver for his father with cancer, explained that he was not needed as much until the last week of his father's life, when he was losing consciousness and was very medicated. Like all of the other interviewees, Chris describes the reasons for stepping into the role to be because he is part of a "family first family." He watched his mother do the same for her parents, and he had a close relationship with his father, so he did not think twice before becoming his caregiver.

When discussing the last week of his life, Chris reflects on his father's attitudes, saying

His attitude toward the whole thing made it easier for everybody. From my conversations with him, he was ready. He wanted it to be over as soon as it could be, of course he didn't

want to suffer. He had his humor all the way until he couldn't speak anymore. Knowing him the way I knew him, knowing his attitude, it really wasn't [unexpected].

Chris continued to reflect on how his father's passing was easier on the family than most people might assume, because everyone "got to say goodbye and I love you and all that stuff". This would not be possible for someone with AD, as they are usually unable to communicate with their loved ones, and if they are, they are not completely themselves, as Amy points out. Also unlike AD caregiver experiences, Chris reports that there were not many aspects of his life that were disrupted due to him caring for his father. This could be due to the fact that it was a much shorter period of time, or because his cognitive abilities were still intact when he passed. This suggests that a severe decline in cognitive function is detrimental to the mental health of the caregiver themselves.

MENTAL HEALTH CONCERNS

Throughout this entire study, it was hypothesized that caregivers of Alzheimer's would report higher levels of stress and depression because of the nature of the disease. Caregivers like Catherine might need to go on medication in order to help push through the challenges brought by the demanding role. During her time as a caregiver, Catherine herself also had a baby, while at the same time dealing with the difficulties of the COVID-19 pandemic. She says

Then with covid, that was depression and anxiety all over the place plus this, plus the baby; it was a lot and I think that even if all that hadn't been going on, I think it still would've been really difficult but I think I would've handled it better. I ended up having to get on meds for depression and anxiety towards the end of her life because it was really difficult to get going. From that grandma I've always known, to a couple years later seeing her just so mean, and then a couple years after that she doesn't even know who I am. Mentally it was very draining and just very difficult to see her like that.

This also highlights that even when a person takes on this important role, there are many other things happening in their lives that they are unable to forget about. Christina talks more about the stress that she felt while caring for her mother, specifically because she felt as though all the work all fell on her due to her mother “burning out” those around her, because she would call them multiple times a day when her symptoms first started. Christina ended our conversation by saying “I will never do this to my children, to the best of my ability”, which summarizes her feelings toward the caregiving role very neatly. It was not ever something she considered not doing, due to the familial obligation that she felt toward her mother, yet she still would not wish it upon her own children after going through it herself. Taking on this role can be very burdensome, especially when one is doing it alone.

This type of “burning out” is typical for someone who is taking on the role of caregiver all on their own. Andrea shares that this was one of the most difficult parts of caregiving;

It was exhausting because I had no relief. I struggled with people coming into the house and losing 100% of our privacy, or doing it all on my own. When I left my mom in my sister's care one time... by the time I got home... it had turned into a nightmare so I felt like I could never leave again. I continued to do everything on my own after that, and if my sister came up to give me a break I would only leave for a couple hours.

Amy reflects on her stress during the time, saying that it manifested most in her sleep, because even that was uninterrupted. Amy's father had overnight caregivers so that they could have some form of a break, but often she would get calls in the middle of the night because they needed help. She mentioned that this dramatic increase in stress contributed to concerns about fluctuations in weight, because when someone's life is literally in your hands, it is hard to look after yourself. Amy and her mother eventually could not provide the care John needed, so they

attempted to put him in a care facility. This was an extremely difficult process and he was let go from multiple facilities due to violent tendencies. However, even when he finally found a place to stay, they never stopped being his caretakers. Amy says

We still went there to feed him two and three times a day, there was always someone checking in and making sure he was okay. And on the rare occasion that one of us couldn't make it, we were on the phone, so I don't think the caretaking ever really stops until they're gone and there's no care that needs to be done.

Caregiving becomes such a part of one's identity that it is no surprise that one might feel lost without it when the person passes. Catherine refers to this, saying "I feel like I'm recovering, but I'm not recovered", because it is not an immediate fix when the person passes, your life cannot just go back to normal. For a long time, being a caregiver was their version of normal. Poveda (2003) emphasizes the difficulty of AD caregiving by referring to Alzheimer's as a "never ending funeral", suggesting that the end starts with the diagnosis, or maybe even with the onset of symptoms, and is not over until the death of the patient, usually many years later.

CONCLUSION

The life of an Alzheimer's Disease or dementia caregiver is a very difficult one. The disease is not only all-consuming for the patient, but for the caregiver as well. Their sole purpose and focus is simply to make the end of their life more peaceful and as comfortable as possible, which is extremely difficult with a neurodegenerative disorder. Providing care tends to be a familial responsibility, and the way that one reacts to the challenges is typically influenced by societal gender roles. Most of the interviewees were women, one even stating that she felt she was born to care for people. The taking on of this role was greatly influenced by the way the

caregivers were raised, and the degree to which they watched their family take care of each other. As described above, each caregiver expressed sentiments of feeling isolated and alone, which likely had a negative impact on their mental health, especially in terms of depression. It would be interesting to interview caregivers across many cultures to determine if this loneliness is a common element of the role, or if it is more of a Western characteristic. A lack of resources and support from the community might also lead to this common feeling of isolation. Social support and caregiver strain will be a main focus in the following chapter, based on the results of the survey that was distributed to caregivers across the United States.

The differences between the Alzheimer's and dementia caregivers and the caregivers of other illnesses show that the specific nature and progression of symptoms have an effect on the mental health of caregivers. According to interviews, Alzheimer's caregivers seem to have an experience in which the difficulties of typical caregiving are compounded, such that they eventually take on the sole responsibility of providing care for the patient, who begins to display the same level of functionality as a young child. The nature of Alzheimer's creates an environment in which caregivers are grieving the person they once knew while simultaneously taking care of the person that the patient is becoming, putting other important aspects of their own life on hold.

Chapter Four- Investigating the Impact of Disease Duration on Caregiver Health

The overall objective of this study was to determine whether or not the length of time in which someone is acting as a caregiver has an effect on their mental health. We hypothesized that Alzheimer's caregivers, due to the slow progression and longer duration of care, would report worse mental health outcomes due to the high amount of stress and feelings of burden they experience. This chapter will provide an overview of the participants, methods, and results of an online study targeting the caregiver population. Here we present the results of a survey study in which we recruited participants that were caregivers for others (AD or not) and asked them about their experiences as caregivers, as well as about their mental and physical health and relationship changes they observed.

PARTICIPANTS

A sample of 95 individuals participated in an online survey, recruited through Cloud Research. Participants were split into the following two groups: those caring for Alzheimer's patients and those caring for patients with other diseases or illnesses. Due to the small number of participants who identified as AD caregivers, and for enhanced statistical power, caregivers of other forms of dementia were included in the AD-caregiver group. The Alzheimer's group consisted of 48 participants, and 47 participants were considered caregivers of non-Alzheimer's patients. Forty-seven males and 48 females participated in the study, and the mean age of participants was 40.34 years old. Table 1 shows participant demographics for the current study.

Participants also disclosed their relationship to the patient that they were caring for. Participants signed an informed consent form at the beginning of the online survey, and were compensated \$1 for their participation under a protocol approved by the Union College Institutional Review Board.

After the first round of data collection, we observed that many of the responses appeared to be the result of bots, despite the captchas put in place at the beginning of the study. All of these responses were removed, and the captchas were updated before publishing the study again for the second round of data collection. Participants that participated in the first round were unable to participate a second time.

MATERIALS AND PROCEDURE

Participants were presented with an online survey through Qualtrics. Participants first were given captchas to ensure that they were a valid participant, as well as demographic questions and a question asking if they were a caregiver or not, which was designed to keep non-caregivers from participating in the study. Any participant who did not pass the captchas or did not identify as a caregiver was prohibited from completing the study. Participants were asked to describe the relationship between themselves and the patient they were caring for, as well as the patient's official diagnosis. In order to obtain the perspective of progression of the disease, participants were asked to report the severity of the disease as they observed it, as well as the patient's conditions when they began and ended caretaking. Participants were asked to reflect on their reasons for becoming a caregiver, as well as whether or not they felt that their cultural background pushed them to take on the role. Participants reported on their perceived level of

support they received from friends, family, doctors, and advocacy groups on a scale from 1 (Never) to 5 (Always). Participants rated the level of change they perceived in their relationship with the patient, as well as the presence of role reversal between themselves and the patient. Participants reflected on their overall mental and physical health, rating whether there was no change, moderate change, or severe change.

There were various modified scales that participants were asked to complete as well. These scales measured mental health related symptoms such as depression, anxiety, and stress, as well as physical health and perceived strain. Participants completed a modified version of the CES-D, where they rated items on a scale of 1 (rarely or none of the time) to 4 (most or all of the time). Questions using this scale were focused on their mental health, and included statements such as “I was bothered by things that usually don’t bother me”, “My sleep was restless”, and “I felt hopeful about the future”, among others. Participants completed a modified version of the TBI-CareQOL Caregiver Strain questionnaire, in which they rated their agreements with various statements on a scale from 1 (Never) to 5 (Always). Statements included topics such as stress (“I feel stressed when it comes to providing care for the person”), responsibility (“I feel like I can never take a break from my caregiver responsibilities”), and pressure (“I feel like I am under too much pressure when it comes to providing care for the person”), among others.

At the end of the survey, participants were asked if they would be interested in participating in a follow-up interview to help further examine the effects of the rate of progression of Alzheimer’s on caregiver mental health and well-being. Regardless of their answer, all participants were debriefed and compensated for their participation.

RESULTS

All hypothesized outcomes and statistical analyses were pre-registered on aspredicted.org (<https://aspredicted.org/4nt3p.pdf>). First, we will present the relationships reported between the patient and caregiver, then we will present the relationships between Alzheimer's and non-Alzheimer's caregivers on various measures such as mental and physical health, stress, support, and strain. As stated in the pre-registration, we predicted a longer duration of care to be positively associated with more negative changes in mental and physical health. We also predicted that AD caregivers would face lower levels of support but higher levels of strain. Levels of cultural expectation were also measured; we predicted that people who indicated feeling a cultural expectation to take on the role would be more likely to report that they felt as if they were the only ones able to provide care for the patient.

Table 2 shows the relationships that the participants reported between themselves and the patient that they were providing care for. 80% of all responses were either parent-child or grandparent-grandchild relationships, which is consistent with previous work (Pratt et al. 1985). This percentage is likely partly attributed to the implied sense of familial responsibility that children and grandchildren feel. Many people believe that they should take care of those who took care of them when they were young.

In Table 3, we present means and standard deviations for Alzheimer's versus non-Alzheimer's on specific measures of mental and physical health, as well as other relevant factors of the disease. Measures of stress were the only variables that produced a statistically significant difference between AD and non-AD caregivers, with non-AD caregivers reporting more stress than their AD counterparts, see Figure 1. Depression levels and physical health

scores were marginally significant, such that non-AD caregivers reported higher rates of depression and more changes in their physical health. Duration of care was also marginally significant, such that AD caregivers provided care for a longer period of time than non-AD caregivers, see Figure 2. Rate of progression was also numerically slower for AD caregivers and the duration of care was longer, as expected.

Table 4 shows Pearson's correlations between measures. Examination of this table reveals that there was a significant correlation between length of care and mental health for the Alzheimer's group only. This suggests that Alzheimer's caregivers who faced longer durations of care had the most severe changes in their mental health. There was also a significant relationship between support and strain, such that as social support increased, the amount of strain a caregiver felt decreased, see Figure 3. This was observed when combining all caregivers together, as well as when looking at only AD caregivers, but not when looking only at non-AD caregivers. There was not a significant relationship between caregivers reporting a cultural expectation to provide care and also reporting feeling as they hold the sole responsibility of care for the individual. Lastly, there was significance found in the relationship between changes in caregiver physical health and the feeling that they were aging faster, such that they were more likely to report more severe changes in their health when they reported feeling as if they were aging faster. This was true overall, as well as for both AD and non-AD caregivers.

DISCUSSION

Prior research suggests that caregivers of Alzheimer's Disease might face increased difficulties in providing care due to the rate of progression of the disease. Compared to other

neurodegenerative diseases and disorders, Alzheimer's Disease is characteristic of a slow progression, beginning with the patient's memory deteriorating, followed by changes in personality, resulting in the eventual complete loss of normal function. We hypothesized that Alzheimer's caregivers would report a longer duration of care overall, due to the slow nature of the disease. However, there was not a significant difference in length of care. This might be because many participants who identified as AD caregivers also indicated that they were still currently acting as a caregiver, so their actual length of care would be longer than what was accounted for. Additionally, many of the other diseases that participants were acting as caregivers for were long term conditions, such as heart failure. While these long term conditions are extremely difficult to care for, it is different from diseases such as Alzheimer's or dementia that are focused on cognitive impairments that cause the patient to gradually decline over time.

Unexpectedly, caregivers of AD did not report higher levels of stress when asked to reflect on their caregiving experience. This could be because their stress is prolonged over a longer period of time instead of concentrated over a few months like many other diseases, so they may be more well-adjusted to the stress that is caused by their role. Alzheimer's is an all consuming disease for the patient and the caregiver; the caregiver often has to give up other aspects of their life in order to care for the patient because they lose all sense of their independence. This relates to the decreases in mental and physical health that were observed, as increases in cortisol associated with stress are said to have negative effects on health, especially when combined with negative behaviors such as poor sleeping or eating habits. In combination, this is referred to as allostatic overload, and can have negative impacts on the hippocampus, prefrontal cortex, and amygdala (McEwen 2008). Schulz and Sherwood (2008) reported that aspects of caregiving have the same features of a chronic stress response, due to the sense of

responsibility and unpredictability of the role. Son et al. (2016) investigated the impact of stress specifically with dementia patients, focusing on two factors: behavior of the care recipient and the caregivers feelings of overload. They found that caring for someone with more behavior problems was associated with poorer caregiver health, as well as greater feelings of overload among caregivers (Son et al. 2016). These results are relevant to the present study because, although we did not directly measure behaviors of the patients, we assumed that patients with AD or dementia would display a higher number of problematic behaviors than people who do not have a cognitive impairment, due to the fact that they become less aware of the 'socially acceptable' behaviors of society. These unusual behaviors are more likely to cause stress for caregivers because they feel responsible for the actions of the patient. This extended sense of responsibility might lead to increased stress when assisting those with cognitive impairments over other conditions that might affect the mobility of the patient, for example.

It is evident that social support, whether that be from the medical community or one's own family, will reduce the stress and levels of strain that caregivers report. Many caregivers feel alone, especially when they are the sole individual responsible for making the medical decisions for the patient, if they are unable to do so anymore. Wilkes and Croom (2008) found perceived stress to be negatively correlated with resilience, whereas overall social support was positively correlated with resilience, which was measured with the S-RS. It makes sense that social support is important for caregiver well-being, which is likely why groups such as the Alzheimer's Association exist. It is known that being a caregiver for certain groups of people is difficult, so the development of support systems and resources is necessary. We wish to further examine the relationship between strain and social support, as this can lead to the development of long term aid for caregivers. It would be interesting to focus on different types of social support that might

be helpful, and ensure that each type of support is available for caregivers, no matter where they are located and what socio-economic group they belong to.

The present data also supports the idea that caregivers who report lower levels of physical health are more likely to perceive themselves as aging faster. Aging faster is also associated with increased levels of stress, so it is not surprising that these two factors are correlated. This relationship was seen for caregivers of all types, suggesting that providing constant care for any patient is both physically and emotionally taxing.

There were various limitations we faced in this study, however. Participant recruitment and verification were difficult due to the online nature of the study. When the survey was first published, many of our participants were clearly bots, as they did not answer the questions and had many automated responses. We successfully overcame this by increasing the number and intensity of the captchas, as our second round of data collection only contained one response that was determined to be submitted by a bot. All responses that were not considered to be from real people were discarded and not used in the analysis of responses. Additionally, it was difficult to recruit caregivers for Alzheimer's specifically, so caregivers of dementia were counted in the AD caregiver group. While dementia and Alzheimer's are not the same disease, the similarities in progression and some symptoms allowed us to combine their responses. We also had a limited sample size, as our target was only caregivers, which is a relatively small demographic on platforms such as Cloud Research.

Future research could focus on the resources caregivers found to be helpful, as increased levels of social support will decrease the stress and strain a caregiver will experience. It should be identified which groups have easier access to these resources, in order to make them more available to everyone else. Additionally, further research might be focused on levels of stress and

burden that a caregiver experiences, and how that relates to the disease they are caring for. An extended sample size, and possibly an extended survey that includes questions on the specific symptoms of the disease that caused the most stress, might be helpful.

Research focusing on caregivers is an increasingly important topic. Most caregivers have little to no formal medical training, yet are expected to take on the medical decisions and care of their loved ones. Due to the neurodegenerative nature of Alzheimer's Disease, the patient-caregiver relationship introduces much strain and stress into the life of the caregiver. Caregivers require additional support from their community to be successful in the role; a burnt out caregiver will not be able to provide the best possible care for their patient, no matter how hard they try.

TABLES AND FIGURES

Table 1: *Participant Demographics*

Frequencies for Gender

Gender	Frequency	Percent	Valid Percent	Cumulative Percent
Female	48	4.620	50.526	50.526
Male	46	4.427	48.421	98.947
Other	1	0.096	1.053	100.000
Total	95	100.000		

Table 2: *Relationship between caregiver and patient*

Relationship Coded	Frequency	Percent	Valid Percent	Cumulative Percent
1- parent	47	4.524	49.474	49.474
2-grandparent	29	2.791	30.526	80.000
3- great-grandparent	2	0.192	2.105	82.105
4- sibling	3	0.289	3.158	85.263
5- spouse/partner	5	0.481	5.263	90.526
6- aunt/uncle	6	0.577	6.316	96.842
7- other	3	0.289	3.158	100.000
Total	95	100.000		

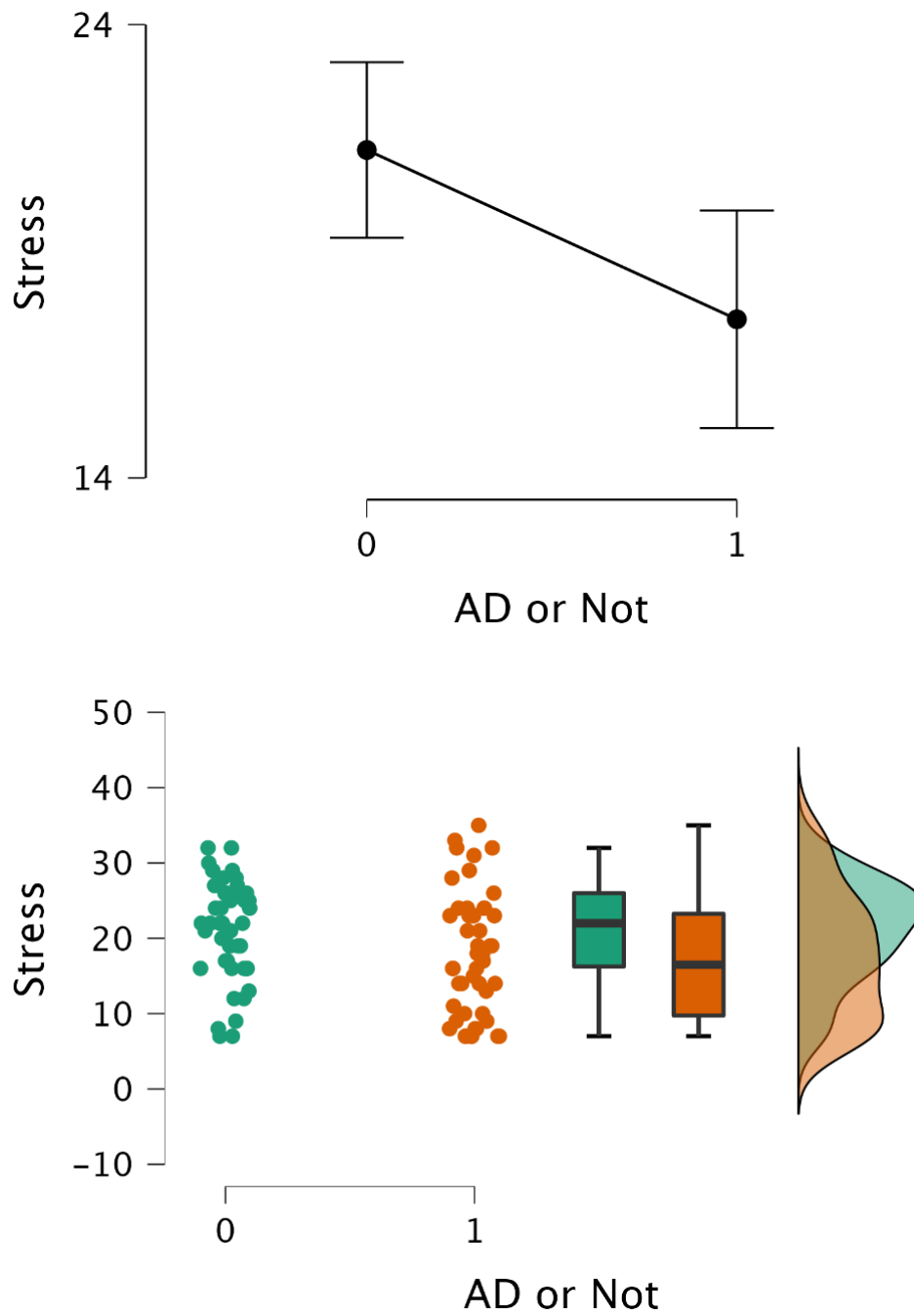
Table 3*Means and T-tests*

Variable	Non-AD (<i>n</i> = 47)	AD (<i>n</i> = 48)	<i>t</i>	<i>p</i>
Stress	<i>M</i> = 21.23 (<i>SD</i> = 6.60)	<i>M</i> = 17.50 (<i>SD</i> = 8.26)	2.431	.02
Depression	<i>M</i> = 42.94 (<i>SD</i> = 11.01)	<i>M</i> = 38.50 (<i>SD</i> = 12.73)	1.82	.07
Social support	<i>M</i> = 3.23 (<i>SD</i> = 0.92)	<i>M</i> = 3.52 (<i>SD</i> = 0.95)	-1.39	.17
Physical health	<i>M</i> = 1.75 (<i>SD</i> = 0.61)	<i>M</i> = 1.52 (<i>SD</i> = 0.55)	1.89	.06
Mental Health	<i>M</i> = 1.96 (<i>SD</i> = 0.56)	<i>M</i> = 1.75 (<i>SD</i> = 0.70)	1.56	.122
Rate of progression	<i>M</i> = 57.06 (<i>SD</i> = 26.82)	<i>M</i> = 49.02 (<i>SD</i> = 23.08)	1.57	.12
Duration of care	<i>M</i> = 25.02 (<i>SD</i> = 27.67)	<i>M</i> = 36.71 (<i>SD</i> = 31.47)	-1.91	.06
Relationship change	<i>M</i> = 3.94 (<i>SD</i> = 1.34)	<i>M</i> = 3.85 (<i>SD</i> = 1.58)	0.27	.79

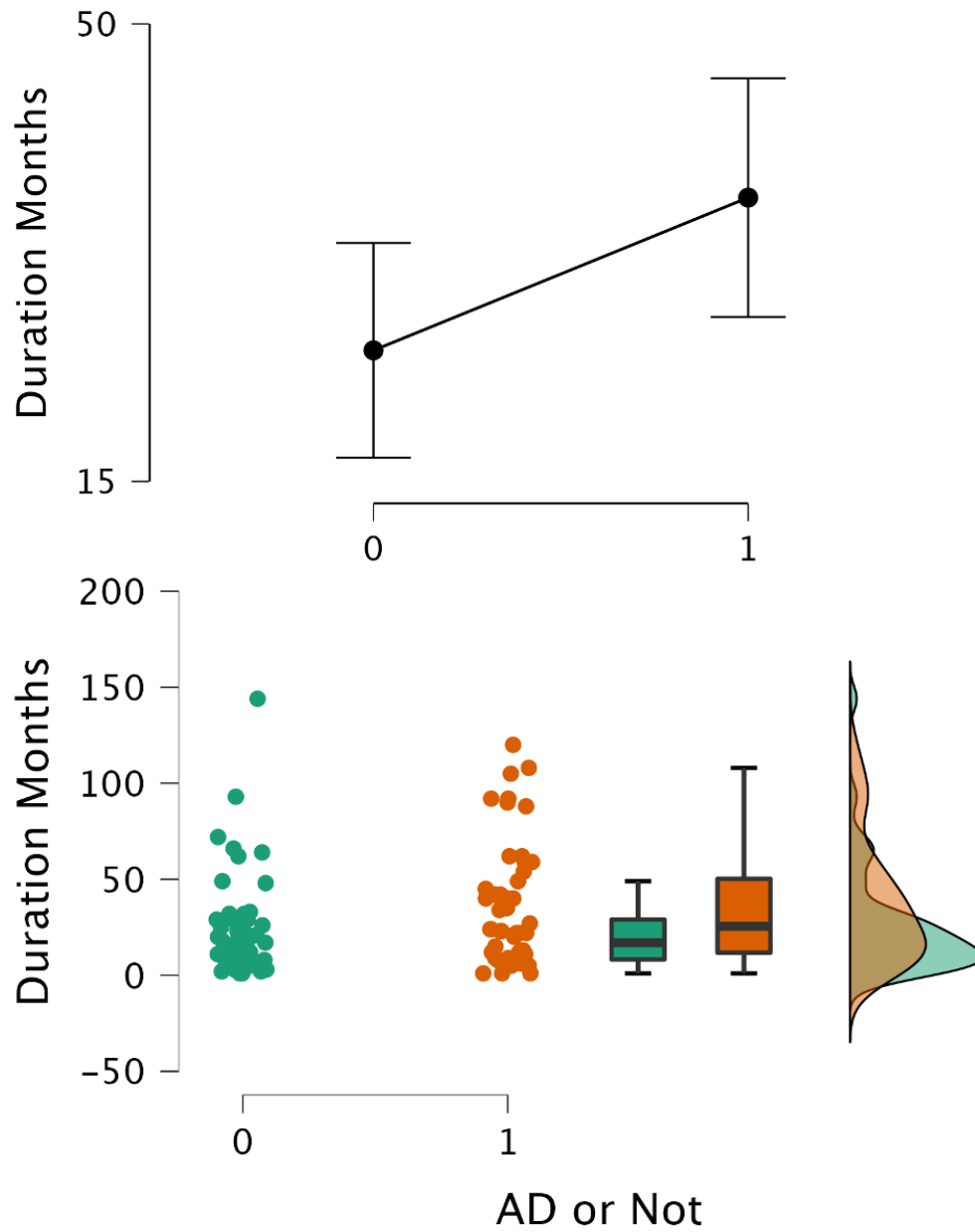
Table 4*Pearson's Correlations Between Measures*

Variable	Overall	Non-AD	AD
Duration and mental health	0.14	-.05	.34*
Duration and physical health	0.03	.10	.04
Support and strain	-0.34***	.01	.56***
Aging faster and physical health	.42***	.31*	.52***
Cultural expectation and responsibility	.18	-.15	-.18

Note. ****p* < .001, ***p* < .01, **p* < .05

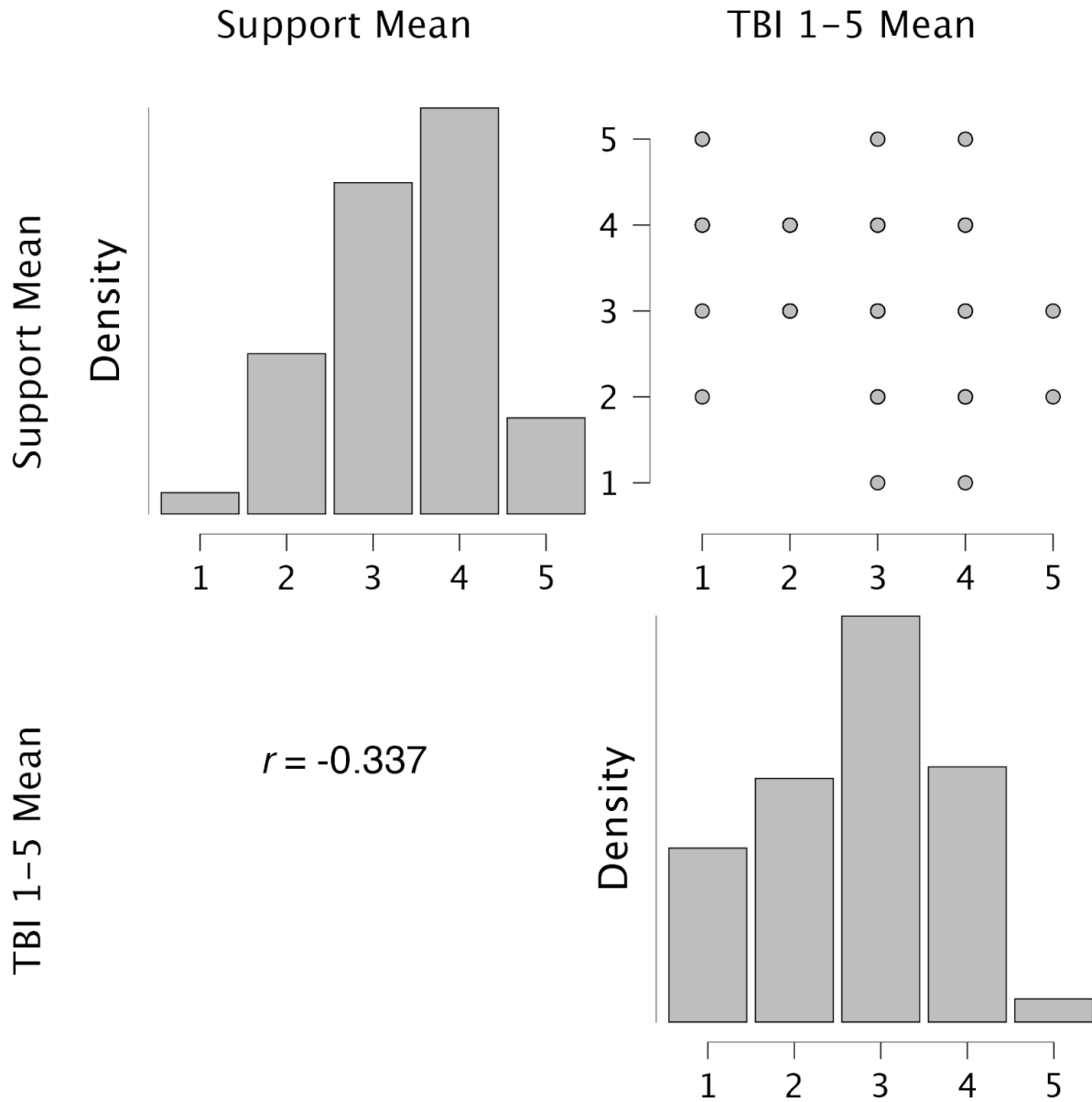
Figure 1: *Measures of stress in AD caregivers vs non-AD caregivers*

Note: The figure above shows that non-AD caregivers reported significantly higher levels of stress than non-AD caregivers.

Figure 2: *Duration of care for AD caregivers versus non-AD caregivers*

Note: The above figure shows the marginally significant ($p < .10$) relationship between duration of care reported by AD and non-AD caregivers.

Figure 3: *The relationship between support and strain in AD and non-AD caregivers*



Note: This figure shows the negative correlation between caregiver strain and feelings of support, such that as support increases, levels of strain decrease significantly.

Chapter Five- Analytic Comparison and Concluding Remarks

This chapter serves to compare the results of the interviews with the quantitative data from the survey. Since only a limited number of interviews were conducted, it is important to determine whether or not they represent the general population, or if the people who are willing to be interviewed are not a fit representation of those affected by AD. We will discuss the extent to which the neurological perspective informs the anthropological perspective, and the extent to which the anthropological perspective informs the neurological perspective. This chapter serves as a synthesis of the project, and therefore will highlight the most important results.

COMPARISON OF INTERVIEWS AND SURVEY

Because the survey was easily distributed to a larger group of people, the results likely have more statistical power than the interviews. The relevant findings that will be discussed further relate to social strain and support that caregivers feel. We found that only caregivers of Alzheimer's Disease showed a significant relationship between the amount of strain they felt due to their role and the level of support they felt that they were receiving from family and the community in general. Alzheimer's can be an isolating disease because as the patient progresses, it is often easier to stay with them at home rather than bring them into the public eye, where their behaviors might not be completely accepted. The survey showed that the majority of people are caring either for their parents or grandparents, which was supported by the individuals that were interviewed; all but one was either a child or grandchild of the patient that they were caring for.

This brings in the concept of familial responsibility and the feeling of cultural obligation to act as a caregiver for loved ones. While there were not significant results in the survey that suggest that this is unique to dementia or AD, many interviewees revealed that the familial obligation they felt towards their loved ones is what influenced their decision to become a caregiver. Numerous times the phrase “it’s what you do for family” was said, yet people did not feel like their culture had an influence on their assumption of the role. I would argue that the way one interacts with family is part of their culture, as anthropologists view kinship roles and personal relationships to be very important in shaping the way individuals view and interpret the world. Not everyone feels a strong sense of connection to their family, or at least not one strong enough to go through all of the hardships associated with caregiving. Being a primary caregiver is a difficult role, and one that most people might not be able to handle without proper training. However, numerous families are internally cared for because it is considered the right thing to do. This concept of repaying the people who have always taken care of you when they are in need is certainly an aspect of one’s culture.

This familial responsibility likely contributes to the stress that they feel while acting as a caregiver, as it often feels like they are the only ones who are qualified to care for the patient. People are often extremely hesitant to put their loved ones in a care facility, because they believe they will be neglected or not cared for properly. From the interviewee’s perspective, it was better to have people come into the home to care for the patient, because they could still be present and ensure the patient was receiving sufficient care. It is often hard for people to accept help in caring for the people that they love most, because they assume that they are the only ones who will, in fact, do everything correctly.

One of the main hypotheses in this study was that the longer the individual was caring for the patient, the more their mental health would decline. This relationship was only significant for caregivers of Alzheimer's Disease, which is an interesting finding. Perhaps it is because at the beginning of the disease, the patient seems to just be forgetful or confused, which might not take such a toll on their caregiver's mental health. However, when the patient is slowly deteriorating over time, and they slowly begin to become someone that their loved ones are unable to recognize, it can lead to higher levels of depression. These slow changes, combined with the fact that the person eventually becomes completely helpless increases the feelings of responsibility and stress that a person would feel, which relates to their levels of strain and likely increases their anxiety. Another common theme in every interview with an Alzheimer's caregiver was their inability to continue with many of their normal activities. This also contributes to the relationship between mental health and duration, as the amount of time spent with the patient is consistently increasing over time, taking away more and more time from the caregiver's other responsibilities.

NEUROSCIENTIFIC PERSPECTIVE INFLUENCING THE ANTHROPOLOGICAL PERSPECTIVE

There are many unique factors of Alzheimer's Disease that make caring for a patient extremely challenging. There is a chance that a diagnosis of Alzheimer's, or even dementia in general, has an impact on the caregiver's experience. It creates an importance surrounding the patient, which might cause medical professionals to take symptoms and treatment more seriously. Additionally, an early diagnosis allows for the patient to make treatment decisions and

arrangements for their future before they are unable to do so. In order to receive a clinical diagnosis, the following steps must be completed by a physician or medical professional: establishment of history of illness that is compatible with the disorder, document mental deficits and cognitive impairments consistent with AD, document a physical exam in order to ensure that symptoms of other disorders, such as Parkinson's, are not present, as well as ensuring that there are no other disorders present that simulate symptoms of Alzheimer's, and finally a psychological assessment (Crystal 1988). Knowing that a patient you are caring for is going to be declining in a certain way can help prepare for the difficult aspects rather than just live day to day, not knowing what is next. On the other hand, the expectation of what is to come could cause increased anxiety in caregivers and family members, so some might wish to stay unaware of the exact challenges that they are soon to face.

For patients of all illnesses and diseases, it might be helpful for them to know the exact changes their body might be going through. For Alzheimer's patients, this is likely not possible, because by the time they are diagnosed with AD they are experiencing severe symptoms that prevent them from learning new information. To combat this, it might be beneficial to make the symptoms and progression of Alzheimer's more well-known, to allow for a degree of preparation of the diagnosed for what is coming.

ANTHROPOLOGICAL PERSPECTIVE INFLUENCING THE NEUROSCIENTIFIC PERSPECTIVE

On the other hand, the reflection on culture and the way in which groups see Alzheimer's Disease might impact the way the disease is scientifically discussed. For example, as previously

discussed, different cultures categorize aging in multiple ways, so the amount of medical resources and information received might differ. The Japanese culture described in *Taming Oblivion* views aging in terms of rankings among society members, impacting their social standing. For this reason, Alzheimer's and dementia, which take away the independence and abilities of those who are affected, are viewed very negatively. If individuals have a disease that is considered to cause them to "age badly", they might just be discarded and forgotten by society, as they could be seen more as a burden than someone that is able to be cured.

The Oaxacan issues of dismissing symptoms and refusing to accept Alzheimer's as a real disease will not lead to any advancements in the neuroscientific field, and could lead to less support from medical professionals, who just assume that the patients are at fault for their symptoms. This compares to patients in America, where it is more commonly recognized that the onset and progression of AD are not under the control of the patient, so they will be cared for as appropriate. This is not to say that there are not extreme amounts of AD patients who are mistreated or dismissed by their doctors because the doctors feel that there is nothing else that they can do, but there are some resources available to the patient and their family that will ideally help them cope with the challenges of the disease.

CONCLUSION

There were many overlapping themes that contributed to the findings of the current study. The themes presented above are also in agreement with the literature on caregivers of long term diseases. The relationship between science and anthropology is an important one that should be taken into consideration, especially when dealing with the medical field. The same care is not provided across cultures, just as the same beliefs and knowledge is not identical across cultures.

The results of the current study give rise to many ideas for future research. There continues to be work that needs to be done to determine the difficulties of being an informal caregiver, especially for diseases like Alzheimer's that are all-consuming. Future research might focus on the different stages of being an Alzheimer's caregiver; for example one might assume that the early stages would be easier because the patient is still functional, but the family is beginning to grieve the person they knew, while taking on many new responsibilities. One might find it easier as the disease progresses, because they have more experience in the role, and maybe know what to expect more than they did in the beginning.

Another extremely important direction for future research is to identify support systems and organizations that are truly helpful for families and caregivers, and make them more accessible. End of life care and discussions on the topic should be commonplace in doctor's offices, because many people look to medical professionals as the guides for how to cope with an extremely difficult situation. When families are repeatedly told that the medical professionals do not know how to help them and cannot do anything to prepare or treat the patient, it is extremely disheartening. According to our results, this would lead to more strain felt by the caregiver, which might lead to decreases in their mental and physical health in general.

Alzheimer's is far from being rare; as a society we need to learn how to assist the aging population. We should focus on the ways in which we can understand the neurological changes and alterations in behavior in a way that will aid in coping with the progression of the disease. It is important to also recognize that a person's cultural background has an impact on the way that they view aging, and the extent to which they feel a responsibility to care for their loved ones. Understanding why someone takes on the role of a caregiver can be extremely helpful in discerning what resources would provide them with the necessary support.

There is a large population of Alzheimer's caregivers who are underserved and overworked, and their presence and needs should not be overlooked. The nature of Alzheimer's Disease itself makes caring for the patients very difficult, especially when the patient is a loved one. Watching someone transition into a person that is no longer recognized by loved ones, and is no longer able to complete basic life functions can have severe effects on the mental and physical health of the caregiver, as well as on the relationships and other responsibilities that they hold. Informal caregivers are not trained medical professionals, therefore they should have more support from society to help them cope with the challenges of the disease.

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