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Dealing with Alzheimer's Disease

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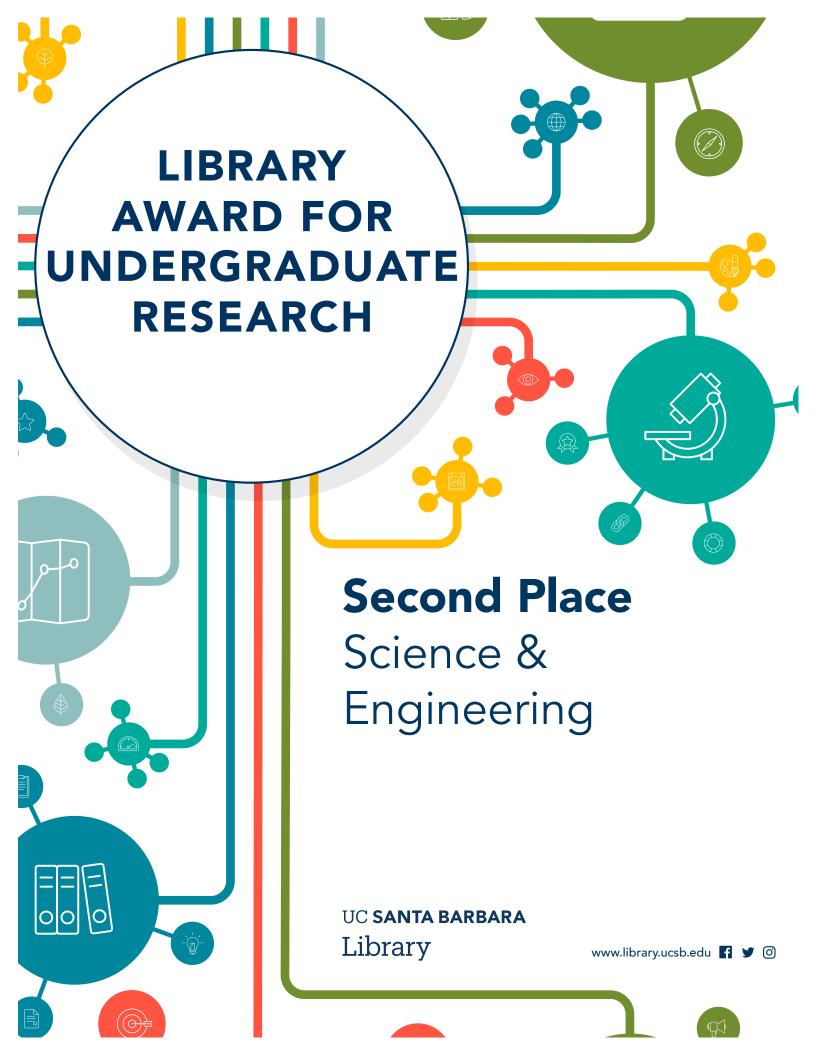
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#### Reflective Essay

I came up with my research topic while taking Writing 50 at UCSB. The topic for our class to write about was memory, so we all had to pick a research topic that had to do with memory in some shape or form. The topic of memory inspired me to look into Alzheimer's Disease as my research topic because I have a strong personal connection to the disease. My family has been dealing with Alzheimer's Disease for the past year because my Grandmother was diagnosed with it in November of 2019. Watching my mom struggle to be a caretaker for my Grandma made me realize how difficult this disease can be not only on the patient, but for their family caretakers as well. I saw this research paper as an opportunity to increase my knowledge towards the disease and also to help my own mother who is currently struggling greatly caretaking for her mother. The aim of my paper is to help caretakers develop a better understanding of Alzheimer's Disease and all of the implications the symptoms may have on functionality in the patient's life both physically and socially. My mother is one of my main sources in my paper (Dr. Karen Schiltz), which makes this paper extremely special and emotional for me. I decided to interview my mother as a source for this paper because one of our assignments for our writing class was to acquire a primary source. There were many ways to complete this assignment, but I was immediately drawn to the thought of interviewing my mother. This was the perfect primary source for my paper because not only is my mother a caretaker of a patient with Alzheimer's Disease, she is also a clinical neuropsychologist who has been studying the disease her whole life. After acquiring my primary source interview, I looked to the UCSB Library for the rest of my sources used throughout my research paper.

I found the UCSB Library website the most useful tool for me to locate articles, books, and journals to use as sources in my paper. The layout of the UCSB Library website was extremely easy to navigate, especially for someone who did not have a lot of prior experience conducting research for papers. I evaluated the sources I used by making sure they were peer reviewed and used the detailed search area on the website to locate appropriate sources for my topic according to specific keywords. I used my subtopics as keywords when searching for sources on the UCSB Library website, and found this to be a very effective method for finding sources.

At the beginning of the quarter, Professor Chenoweth organized for our class to be held inside of the library with a UCSB research librarian. This was an amazing experience because I learned so much from the librarian in regards to using the library to find resources both effectively and appropriately. The librarian taught me a lot of tips and tricks for maneuvering around the UCSB Library website as well, which helped me greatly when I began looking for sources to support my research topic. I also took advantage of the "Ask a Librarian" chat room on the UCSB Library website. If I had any quick questions about a source but was off-campus, I could easily send a chat to a librarian and get a response almost instantly! It was also available 24/7 so even if I was up late with a question, I didn't have to wait to get it answered.

Overall my experience using the UCSB Library for resources was amazing. The librarians who helped me throughout my research process were all so knowledgeable and very supportive of my research. They encouraged me to think outside the box when looking for sources and taught me so many skills especially for using the UCSB Library Website. After finishing the research paper I feel prepared to take on any other research paper college may throw my way!

# Dealing with Alzheimer's Disease

Grace S. Mellor

University of California, Santa Barbara: Writing 50

## Author Note

The Alzheimer's Association 24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Through this free service, specialists and masters-level clinicians offer confidential support and information to people living with the disease, caregivers, families and the public.

#### Introduction

Do you know someone that has been diagnosed with Alzheimer's Disease (AD)? Chances are you do, or have heard about this debilitating disease before. Each year the number of AD patients rises, with more than 5.8 million people in America currently diagnosed with the disease (Alzheimer's Disease "Facts and Figures," 2020). Despite Alzheimer's immense prevalence in our society, sadly, we are not much closer to finding a cure. With no cure yet available, it is essential we do all that we can to understand how this disease affects patients. By increasing our knowledge about how AD affects the brain as well as the symptoms that come with it, we have the ability to improve the quality of life for both the patients and their caregivers.

Alzheimer's Disease impacts the cognitive abilities of a patient, especially the episodic memory system. Episodic memory enables us to learn and retrieve information about unique personal experiences that occur in our daily lives. Examples that use this memory system include visiting the movies with a family member, paying bills, or visiting the dentist. When episodic memory deteriorates due to AD, patients may forget to attend these events, or struggle to recall them at a later date. Episodic memory is supported by the medial temporal lobe (MTL), a region of the brain that includes the hippocampus. The hippocampus allows us to encode, store, and retrieve events that occur throughout our daily lives (Dickerson & Eichenbaum, 2010). Unfortunately, this region of the brain suffers severe damage in patients with AD, caused by a buildup of beta-amyloid plaques and neurofibrillary tangles (Rycroft & Giovannetti, 2017). When it comes to episodic memory, research done by Gold and Budson explores the implications AD has on it and how it contributes to functionality in our daily lives. Gold and

Budson state that in the early stages of AD, impairments in the episodic memory system can lead to missed appointments or lost keys, but these seemingly small issues can quickly progress to dangerous situations, such as leaving the stove on or the house unlocked (Gold & Budson, 2008). Early signs of AD are routinely shrugged off by family members as insignificant instances of forgetfulness. Yet, it is essential to watch out for these signs, because the sooner AD is caught, the sooner the patient is able to receive a plan of treatment.

Unfortunately, there is a shortage of communication about the specific effects episodic memory impairment from AD can have on a patient's functionality in life, both physically and socially. This gap in understanding increases relationship tensions and feelings of burden between patients and their caregivers, especially when that caregiver is a close family member (Garriga et al., 2013). An astonishing 83% of caregivers to AD patients are family members, so it is crucial that we aid caregivers in understanding the effects AD has on the patient, and why it may be affecting their relationship dynamic so drastically (Alzheimer's Disease "Facts and Figures," 2020). To create a bridge between the medical and emotional sides of caregiving, I will be incorporating several anecdotes from Dr. Karen Schiltz throughout my paper. Dr. Schiltz is a neuropsychologist with expansive knowledge about AD, and she is currently a caretaker to her 92-year-old mother who has been suffering from the disease for a few years. Dr. Schiltz's anecdotes will provide an invaluable personal perspective towards AD that medical accounts commonly leave out of their reports.

There is a multitude of ways that episodic memory impairment can impact the functional and social abilities of patients, but there are four that I would like to focus on in this paper. These topics are anosognosia, delusions, safety issues, and loss of independence. I chose these four

topics because not only are they some of the most common symptoms observed, but are also the ones that can present the greatest difficulty for caregivers to deal with and understand. By increasing understanding of these symptoms associated with AD, I aim to demystify this complex disease for caregivers and enable them to deal with it using newfound confidence and understanding. This understanding will not only allow professional caregivers to provide better treatment plans for those diagnosed with the disease but also prepare family caregivers to aid patients in an effective and positive way.

#### Anosognosia

According to Dr. Karen Schiltz, anosognosia is a severe symptom of mental illness that prevents one from understanding they have an impairment or disability. Between 20% and 43% of patients with mild or moderate AD develop anosognosia as one of their illness symptoms (Aalten, 2006, as cited in Garriga et al., 2013). Anosognosia creates a lack of understanding or refusal to believe in a diagnosis, which can not only cause immense frustration for the caregiver but also place the patient in danger. Our lives revolve around self-awareness, and our self-awareness relies on memory functioning, sensory functioning, and emotional functioning. Alzheimer's Disease patients, such as Dr. Schiltz's mother, show moderate diffuse cerebral and cerebellar volume loss, enlargement of the lateral ventricles, and chronic microvascular ischemia in CT scans. This plethora of neurological damage to the brain severely impacts one's ability to integrate new information into memory. The inability to encode new information to the brain affects all areas of functionality previously mentioned, leading to an intellectual lack of awareness (does not have a basic knowledge of deficits and the implications), a lack of anticipatory awareness (does not recognize the impact of deficits while performing a task), and

awareness based on prediction (does not predict how they will perform on a particular task and/or whether a problem will occur given the deficits) (K. Schiltz, personal communication, February 10, 2020).

It is not uncommon for patients diagnosed with AD to refuse help, whether that be in the form of medication or treatment from doctors. This refusal stems from the patient's inability to understand and remember that they are sick, so they truly do not think that they require aid. This can be a difficult hurdle to overcome, especially for the caregiver who is trying to get their family member the help that they desperately need. A study analyzing caregiver burden associated with the presence of anosognosia in a patient was performed by Garriga et al. in 2013. The study assessed 124 patients diagnosed with AD along with their respective 124 caregivers. Anosognosia was assessed using a clinical judgment scale which evaluated the patient's awareness of deficits. Caregiver burden was determined from a Burden Interview, which reflected the caregiver's common perceptions and feelings (Garriga et al., 2013). The results of this study show that the presence of anosognosia in a patient substantially increases caregiver burden, a statistic that rises even higher when the patient lives at home with the caregiver. Since anosognosia increases risky behavior, disinhibition and/or denial of the need for help, it is understandable why caregivers would feel immense stress and burden when dealing with these symptoms, especially if they are not knowledgeable about them in the first place (Garriga et al., 2013).

When someone with AD exhibits anosognosia, it is important to remember that it is the result of neurological dysfunction. This can be hard to do when the patient lashes out unprovoked or seems insensitive to their family who is only trying to help. For example, Dr.

Schiltz experienced great difficulty trying to take her mother to the neurologist for necessary treatment. Her mother refused to see any doctor because she was scared and angry. Many take this personally, and feel that they are doing something wrong when the patient reacts, exhibits refusal, or reacts harshly to the situation, but this is simply not true in most cases. In becoming educated about the multiple facets of anosognosia, caregivers will have an idea of what to expect if this symptom arises, and be better prepared to support their loved ones in a safe and positive way.

#### **Delusions**

Delusions and paranoia are among the most upsetting symptoms of AD to family and friends of the patient (Orr, 1985). Studies done by Aalten et al. (2006) suggest that psychosis is associated with a lack of awareness in AD patients, and as the disease progresses, lack of awareness increases along with psychosis and apathy. According to Orr, hallucinations commonly present themselves as hearing or seeing things that are not present, which can result in the patient talking to themselves or relaying conversations that never occurred. While this may sound only slightly bothersome to the caregiver, delusions can become extremely burdening for the caregiver if they begin to involve them. Severe psychotic symptoms typically manifest as delusions of stealing or infidelity towards close friends and family members of the patient.

According to Dr. Schiltz, delusions of infidelity were the primary complaint of Dr. Alzheimer's very first AD patient, named Auguste Deter. Dr. Alzheimers was the first person to discover AD and associate delusions with the disorder. Delusions of infidelity are to this day some of the most common paranoias reported in patients with the disease, but it is unknown why infidelity

specifically is so prominent in patients' delusions. During her interview, Dr. Schiltz discussed a delusion her mother experienced regarding infidelity:

My mother believes that my deceased father had an affair with our young neighbor in Marshfield, Wisconsin for many years. This is not possible, as my father would have been 90 years old and our neighbor was 35 years old, engaged with one child, and served as a nurse in the NICU unit in town. (K. Schiltz, personal communication, February 10, 2020)

Another common delusion that manifests in the patient is that they are being stolen from. Dr. Schiltz recalled a time her mother suffered from delusions of this nature as well. She explained that her mother has been convinced on multiple occasions that family members were stealing money and credit cards from her when she had simply forgotten where she last placed them. These delusions can result in the patient exhibiting behaviors such as hoarding and agitation towards their caregiver. When Dr. Schiltz explained to her mother that no one had stolen money from her, she did not believe her, instead driving to the bank to withdraw thousands of dollars in cash to hide inside of her purse.

Delusions can be extremely disabling to deal with, both for the patient and their caregiver. When delusions fester towards family members, this can create an uncomfortable environment inside of the home, one where those close to the patient feel they are always walking on eggshells. When working with a physician, it is important for caretakers to take note of the delusions they witness, as keeping a running catalog of these experiences may help the physicians in tracking the progressiveness of the illness (K. Schiltz, personal communication, February 10, 2020).

Currently, antipsychotic drugs are the most common form of therapy and treatment for AD patients with delusional symptoms (Helms, 1985). Antipsychotic drugs have the ability to reduce certain symptoms associated with AD but can have very serious side effects. According to the Alzheimer's Society, antipsychotic drugs are only to be prescribed for patients exhibiting severe delusional symptoms. These drugs should not be used to treat other behavioral or psychological symptoms in AD patients such as anxiety and distress (Alzheimer's Society "Antipsychotic drugs," 2020). No AD case is exactly the same, and while some patients may experience similar symptoms, the nature of these symptoms can greatly vary from individual to individual. It is also important to consider that in some cases, a patient may refuse medical treatment due to anosognosia, or the medicine may simply be ineffective. Because of this, it is essential that caretakers keep in close contact with their patient's physicians in order to develop a personalized care plan to best aid their loved one during this difficult time.

#### **Safety Issues**

Deterioration of memory due to AD can not only be burdensome for a caregiver but also extremely frightening when it puts a patient's safety at risk. Some patient's dementia can be so severe that they should not be left alone at any point in the day for fears of falling down, leaving the oven on, or forgetting to take important medications. Symptoms such as anosognosia can certainly spur a multitude of safety issues for an AD patient, because when one believes they are not ill, they may proceed to participate in activities they should no longer be doing such as traveling alone or driving. Looking back at the incident where Dr. Schiltz's mother withdrew copious amounts of cash for fear her family was stealing from her, this in of itself can present a serious safety issue. If the wrong person found out that an elderly woman was carrying around

thousands of dollars of cash in her purse, she may become the subject of an aggressive robbery. When situations such as these come to the caretaker's attention, it can be hard to know whether it is appropriate to talk to the patient or go straight to a physician. Unfortunately, these matters can be hard to discuss with a loved one, as they commonly refuse to believe that their safety is being compromised in any way. This is especially true when the patient is suffering from anosognosia, so it is usually best to seek professional help regarding the next steps to be taken.

As discussed earlier, caretaking for a patient with AD can create heightened feelings of burden and stress due to the immense time and effort requirements placed upon the caregiver. Unsurprisingly, there is a high incidence of depression and anxiety disorders in caregivers, particularly among those who are women (Garcia-Willix & Sferrazza, 2010). When patient safety becomes a main concern, these feelings of stress and burden will substantially increase, especially when a caregiver is unable to be by their loved one's side at all hours of the day.

Dr. Schiltz recalled an incident during her interview regarding safety concerns she experienced while caretaking: "We are not home during the day. I'm sure my mother has fallen. In fact, I did notice she had fallen about eight months ago when she was living with us." As the vast majority of patient caretakers are middle-aged adults, like Dr. Schiltz, they must work during the day and leave the patient alone. When dealing with a patient of high safety risk, it is important to take into consideration professional care options such as care homes or an in-home nurse. If possible, these options should be discussed in congruence with the patient's physician, as they will have many sources available and also help to develop an appropriate plan of action according to the patient's needs.

Facilities such as care homes or hiring a trained professional can significantly relieve feelings of burden from family members, by providing peace of mind for knowing your loved one is safe. Understandably, these options can cost a lot of money over time, and may even be outright refused by the patient themselves. A study done by Durand et al. showed that 30 patients out of a 50 patient sample were persistent refusers of care services. Patients were found to refuse care services due to a fear of losing independence, meeting new people, and being institutionalized. This study shows that it is not uncommon for caregivers to encounter the obstacle of patient refusal. If this situation occurs, it is important for the caregiver to remember that they are not alone and there are resources available to help such as calling the patient's physician or calling a hotline like the Alzheimer's Association 24/7 Helpline to receive guidance.

# **Loss of Independence**

Due to the progressive nature of Alzheimer's Disease, there usually comes a time when a patient must lose some level of their independence. Loss of independence may result from a conglomerate of the symptoms previously mentioned throughout this paper, as they continue to develop and worsen over time. As a patient's symptoms intensify, their abilities to properly judge whether or not they should perform certain tasks, such as driving, become impaired. If a patient is unable to demonstrate sound decision making, they may make choices that put themselves or others in imminent danger. If this situation arises, a caregiver may feel compelled to intervene in order to keep the patient out of harm's way. When a caregiver steps in, this usually requires them to make an authoritative decision regarding changes in the patient's lifestyle and levels of allocated independence. These changes commonly consist of acquiring outside help such as a care facility or day nurse if the patient can no longer be trusted on their

own. If a caregiver feels this is the best path to pursue for their loved one, it is important that they are aware of the difficulties which may accompany this scenario. As discussed in the study conducted by Durand et al., loss of independence is one of the main reasons AD patients refuse to receive any form of outside assistance. This may be because losing independence can feel like your lifeline to the world has been cut loose. It is very scary to place your life in the hands of a stranger and trust them to take care of your needs when you no longer can. Obviously, losing independence is no easy topic and can be difficult to process, so it is not surprising that it is commonly met with ample pushback from the patient.

This dilemma poses an interesting question: If a patient is recalcitrant towards day services, is it wrong to continue pursuing assistive help? This question can be difficult to answer, as there is a delicate balance between respecting your loved one's wishes and keeping them safe. At the end of the day, if your loved one is placing themselves or others at risk, seek help. A powerful anecdote provided by Dr. Schiltz highlights this type of situation:

I recently reported my mother to the DMV due to her increasing agitation, confusion, problems with gait and balance, poor judgment, and limitations with memory. My mother who is 92 years old will not "give up" her car keys and believes she is absolutely safe when driving. (K. Schiltz, personal communication, February 10, 2020)

Dr. Schiltz's mother refuses to give up her car keys because they serve as a direct link to her sense of independence. Dr. Schiltz went on to explain how personally attached her mother is to her car: sitting in it during the day, constantly washing it, and keeping the gas tank full at all times. She also recounted her mother making weekly day trips to and from a casino up north, approximately 110 miles away from home. Along with the sheer distance of this drive, add in

unpredictable variables, such as intense traffic or poor weather conditions, and this drive would be taxing for even the sharpest of drivers. Obviously, drives like these are much too intense for any elderly woman in her 90s suffering from severe dementia to complete on a weekly basis, multiple times a day. Despite this, it can be exceptionally difficult to help a patient reach the same conclusion as their caregiver if they are cognitively ill. In this scenario, Dr. Schiltz made the right decision by going to the DMV and requesting help for this situation, not only looking out for the safety of her mother but other people as well.

Loss of independence in AD patients is certainly a touchy topic but stems from doctors or family members wanting to keep the patient safe. It can be difficult to have these conversations with a loved one, for fear of driving the relationship apart. When disagreements occur between the caregiver and patient, it is crucial to stay calm and keep a positive attitude towards the situation. Because these situations may cause tensions to run high, this can lead to psychological issues such as extreme stress and physical distress for the caregiver (Garcia-Willix & Sferrazza, 2010). Getting angry or frustrated at the patient will only increase their resistance towards the matter, increasing the amount of burden and stress the caregiver experiences as well. With this in mind, it is essential that caregivers take personal time for themselves to relieve this stress and maintain a positive outlook on the situation. Maintaining optimism towards the situation will make a world of a difference when communicating with the patient by helping to keep the doors of communication open and feelings of love present.

#### Conclusion

More research should be done in the field of cognitive science by geriatric psychiatrists to figure out the best plan of care for those exhibiting symptoms of dementia. By compiling some

of the most common symptoms of AD into a relatable text, I hope to have bridged a gap between the medical and emotional sides of caretaking for these patients. These symptoms all have a hand in creating social and functional impairment throughout the lives of patients that goes far beyond simple "memory loss". As seen in this paper, there are many other factors impacted by symptoms of dementia, such as a patient's emotional stability and changes to their overall personalities. When professional caretakers take the time to develop a detailed understanding of the implications symptoms of AD may have, they will be better able to prepare those who are family caregivers. Most caregivers likely do not know all the ways AD can present itself, failing to realize how big a role memory plays in our everyday lives. By understanding the primary and secondary effects of episodic memory loss, effective personalized care plans can be determined for caregivers to use to improve the quality of life for both the patient and their caregiver. Expanding the caretaker's knowledge of this complex disease will make caretaking a more positive experience by giving them increased confidence in their caretaking abilities. It is important to note that this paper aims to make caregivers more sympathetic towards the patients and better prepared to handle the various symptoms associated with AD. It is still going to be difficult to care for a patient with AD, but hopefully, with more understanding of the situation, it will be easier for the caregiver to handle and preserve the valuable relationship they have with their loved one.

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