

THE ROLE OF COMMUNICATION IN INFORMAL CAREGIVING FOR FAMILY  
MEMBERS WITH ALZHEIMER'S DISEASE

by

Henri Kali Huber  
A Dissertation  
Submitted to the  
Graduate Faculty  
of  
George Mason University  
in Partial Fulfillment of  
The Requirements for the Degree  
of  
Doctor of Philosophy  
Communication

Committee:

\_\_\_\_\_ Chair

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Program Director

Date: \_\_\_\_\_ Spring Semester 2022  
George Mason University  
Fairfax, VA

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by

Henri Kali Huber  
Master of Arts  
George Mason University, 2018  
Bachelor of Arts  
University, 2017

Director: Gary Kreps, Professor  
College of Humanities and Social Sciences

Spring Semester 2022  
George Mason University  
Fairfax, VA



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## **Dedication**

For my grandmother Betty Lou Lusky and to all families impacted by Alzheimer's disease.

## **Acknowledgements**

First, I would like to extend my sincere thanks to my loving husband, David, for his unrelenting and unparalleled support. As well as my sister, Johanna Huber, and my parents, Kimberly and Peter Huber. Without you, none of this would have been possible. I would like to express my deepest appreciation to Dr. Gary Kreps, my advisor, for his overwhelming belief in my work and in my abilities. I would like to thank my dissertation committee for their unwavering guidance throughout this process. I also would like to take a moment to acknowledge all individuals that are currently battling with addiction. May the stigmatization surrounding this disease decrease and the availability and accessibility of help only increase. Lastly, thank you to everyone who believed in me and supported me throughout the years, including all of the teachers, mentors, friends, and professors who pushed me to keep going.

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## **ABSTRACT**

### **THE ROLE OF COMMUNICATION IN INFORMAL CAREGIVING FOR FAMILY MEMBERS WITH ALZHEIMER'S DISEASE**

Henri Kali Huber, Ph.D.

George Mason University, 2022

Dissertation Director: Dr. Gary Kreps

The purpose of this qualitative exploratory study is to examine the role of communication in family caregiving for family members with Alzheimer's disease (AD) and dementia as well as to examine how family caregivers use communication to maintain their well-being. Using the critical incident technique, in-depth interviews were conducted to generate rich narratives about the best and worst communication experiences caregivers had while providing care. This study builds on literature regarding caregiver burdens and stress, Accommodation Theory, and in-depth studies of caregiver experiences. This study provides a framework to prepare future informal caregivers for communicating effectively when delivering care to family members with AD by providing them with useful insights from present-day informal caregivers.

## **CHAPTER ONE**

### **Introduction**

More than 6.2 million Americans are living with Alzheimer's disease (AD) (Alzheimer's Association, 2021). Alzheimer's disease is an incurable form of dementia or a decline in intellectual functioning, often accompanied by physical declines as well. It causes an irredeemable progressive degeneration in a person's brain tissue characterized by tangles and plaques within the brain (National Institute on Aging, 2019). AD patients typically deteriorate both mentally and physically to a stage where they become completely dependent on others. The disease is irreversible and progressively destroys memory, thinking skills, and eventually, the ability to carry out the simplest tasks (National Institute on Aging, 2019). AD is the most common form of dementia disease and accounts for 60% to 80% of dementia cases (Centers for Disease Control and Prevention, 2019). AD kills more people than breast cancer and prostate cancer combined and 1 in 3 seniors dies with the disease or another form of dementia (Alzheimer's Association, 2021).

### **Purpose of the Study**

The purpose of this qualitative exploratory ethnographic study is to examine the role of communication in informal caregiving for family members with AD and dementia as well as to examine how informal AD caregivers past and present have used

communication to provide care and maintain their own wellbeing. The life-changing and consuming lifestyle of caregiving creates demands for caregiver voices to be heard (Sawatzky & Fowler-Kerry, 2003). According to the AARP and National Alliance for Caregiving (2020), in the United States one in three caregivers of an individual 65 or older report the presence of AD or dementia in their patients. This statistic demonstrates just how prevalent the disease is becoming. More than 11 million Americans provide unpaid care for an individual with AD or another form of dementia (Alzheimer's Association, 2021). About half of all caregivers (48%) care for someone with AD or another form of dementia (Alzheimer's Association, 2021). According to the Centers for Disease Control and Prevention (2019), the majority (80%) of people with AD and related dementias are receiving care in their homes. Typically, this care is provided by family members or friends. This particular form of care is often relegated to families as a result of policy decisions and the high costs of professional care. It is also important to note that most elderly individuals do not qualify for subsidized services and cannot afford to pay for care themselves (Bookman & Kimbrel, 2011).

The demands that accompany caring for individuals suffering from AD are high and can often limit caregivers' abilities to care adequately for themselves (CDC, 2019). According to the Alzheimer Association (2021), nearly 60% of Alzheimer's and dementia family caregivers rate the emotional stress of caregiving as high or very high and about 40% suffer from depression. The burden that caregivers experience is mainly caused by the high demands for providing constant supervision and helping services related to the behavioral and psychological symptoms of dementia (BPSD) (Huang, et al.,

2012). These can include things such as the care recipient wandering and getting lost, jumbling words within a conversation, having trouble getting dressed or attending to their own hygienic demands, getting frustrated or agitated, or acting in unexpected ways, like refusing to bathe (Alzheimer's Association, 2021). As the disease progresses things such as sleep changes, physical and verbal outbursts, and wandering often occur.

Hallucinations can also be a symptom of AD. This is when an individual with dementia sees, hears, smells, tastes, or feels something that is not there. As one can imagine, this can cause the individual to react in unexpected ways. Aggression and agitation are also prevalent in AD patients and can be caused by numerous factors including frustration, stress, physical discomfort, environmental factors, and poor communication (Alzheimer's Association, 2021). An important factor that feeds into caregiver distress is the lack of understanding about the progression of the disease and the increasing number of new and unexpected behaviors from those living with the disease. Problem behaviors of care recipients, such as agitation, restlessness, and wandering, are often very distressing for caregivers (Bédard et al., 2000; Pinquart & Sörensen, 2003).

### **Definiton of Terms**

**Dementia:** A degeneration in a person's brain tissue characterized by tangles and plaques within the brain.

**Alzheimer's disease:** A type of dementia that impacts memory, behaviors, and thinking.

**Patient:** A person diagnosed with Alzheimer's disease or dementia.

**Caregiver:** Someone who is providing care for a patient.

**Care Partner:** Someone who is providing support for a patient through their medical journey.

**Care Recipient:** Someone who is receiving care.

**Familial Caregiver:** A family member who is providing care.

**Informal Caregiver:** A familial caregiver or friend providing unpaid care.

**Social Support:** Emotional, informational, or tangible aid provided to help another.

**Accommodation:** The process by which participants in a conversation adjust their communication in order for the recipient to better understand the message.

**Caregiver burden:** The stress or strain a person who is providing care experiences.

**Objective caregiver burden:** tangible caregiver-related disruptions in a person who is providing care for a patient's life.

**Subjective caregiver burden:** The feelings that an individual can have while giving care to another, their perception regarding completing caregiving tasks.

**Schema:** Pattern of thought or behavior.

## **Theoretical Framework**

### ***Accommodation Theory***

Developed by Howard Giles in 1971, the Accommodation Theory refers to the ways that interactants adjust their communication behaviors to either diminish or enhance social and communicative differences between another individual (Giles & Baker, 2008, p.1). It is important to communicate with those who are cognitively impaired in individualized ways that accommodate their disease and therefore support interactions with them. This accommodation is of course one sided, however, since individuals with AD often fail to recognize and adapt to the needs of their caregivers. This can also be frustrating for caregivers. However, even one-side adaptations from the caregiver can help reduce emotional and behavioral issues among individuals with AD (including aggression, agitation, depression, and anxiety) and give back a sense of autonomy.

Effective communication accommodation demands that family caregivers be aware of the evolving communication needs of their loved ones who are living with AD.

Accommodation theory reinforces the importance of conveying your message in a manner that is most digestible, easy to understand, and easy to implement, which is especially important when interacting with people living with AD due to the limited capacity to effectively understand messages (Giles & Baker, 2008). Accommodation Theory suggests that there is a need to examine how caregivers accommodate to care recipients, as well as how people may accommodate to the needs of informal caregivers to help relieve their stress. This study will elicit information about these accommodation issues from the caregiver's perspective.

### ***Developmental–contextual model of dyadic coping***

According to Revenson et al. (2016), Berg and Upchurch's developmental–context model of dyadic coping (2007) has numerous research implications that it can be applied to this context and be applied to caregiving. This model helps extend the notions presented in Accommodation Theory by explaining how appraisals of an illness situation and the coping behavior of just one person involved can affect not only his or her adjustment but also the adjustment of the individual with AD. This model reinforces the proposition that “members of couples confronted with illness (cf. caregivers and care-recipients) mutually influence each other throughout the process of the illness” (p 10). Therefore, if caregivers accommodate their care recipients' communicative needs, it is likely to influence how their loved ones with AD will respond.

### ***Gender schema theory***

The Gender Schema Theory was first developed by Sandra Bem in 1981. The concept of gender schema is defined as a set of gender-related beliefs that influence particular “gender appropriate” behaviors (Cherry, 2020). Caregiving is expected by women in society, whereas when a man takes on the role it is seen as a “heroic act” (Begley & Cahill, 2003). Gender schemas are formed as a result of the children's observation of how society defines what it means to be male and female in his or her culture, and are placed upon individuals by society’s beliefs about the traits of females and males (Williams, 2015). These schemas help children gain knowledge about what being male or female means, and what are considered appropriate gender role behaviors for males or females within society (Williams, 2015). When women choose to deviate from normative gender roles in society, they are often looked down upon or might be considered selfish, which places pressure on them to alter their behavior (Cherry, 2020). In this paper, gender schemas that influence caregiving communication are mentioned by caregivers as they relate to the genderized task that family caregiving has become.

### ***Social Support***

A study by Schulz and Williamson (1991) revealed that a decline in social support for Alzheimer’s caregivers resulted in increased depression among caregivers. According to Lin et al., (1979), social support can be defined as, support accessible to an individual through social ties to other groups, individuals, and the larger community.” A person’s support network for social support is important for maintaining good physical and mental health (Ozbay et al., 2013). According to Kourakos, Kafkia, and Minasidou (2016), social

support can be further explained as “any type of communication that enables individuals to feel that they have control over a situation, or to any type of social resources” (p 1187). The most prevailing theoretical perspective about social support states that support acts as a buffer through stressful life events and health outcomes (Lakey & Cohen, 2000). The Stress and Coping theoretical approach to Social Support proposes that increased support enhances coping performance and leads to appraising situations as less stressful. This is important to mention because typically Alzheimer’s caregivers have high levels of stress and because of this high level of stress often experience increased numbers of personal health problems. The Stress and Coping theoretical approach to Social Support research examines how access to social support can promote adaptive coping and appraisal practices to help deal with stressors. Coping is an individual’s efforts in thoughts and actions to manage demands, while appraisal practices are when an individual evaluates the significance of what is happening to them. This theory proposes that increased support enhances coping performance and leads to appraising situations as less stressful. This can benefit the individual’s overall health and well-being. When caregivers feel alone, 72 percent report feeling high emotional stress, versus just 24 percent when loneliness is not a factor (AARP, 2020). These feelings of loneliness are associated with fairly strong feelings of stress and strain as well as decreased health for caregivers (AARP, 2020). Following this review of previous research and related theory, this study will explore caregivers’ perceptions of social support versus being in isolation and/or without a support network. This can then help inform other informal caregivers who may be unaware of the need for social support and how they might obtain social support.



## CHAPTER TWO

### Literature Review

Alzheimer's disease (AD) is named after Dr. Alois Alzheimer who discovered the disease within one of his patients, a German woman named Auguste Deter. While Auguste was alive, she was suffering from some sort of memory loss as well as psychological complications. Dr. Alzheimer officially discovered the disease in 1906 after examining her brain cells during an autopsy after her death and discovered brain shrinkage and abnormal spots around nerve cells (Alzheimer's Association, 2021). Dr. Alois also found abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles) (National Institute of Aging, 2019). These two findings by Dr. Alzheimer are still considered some of the main features of Alzheimer's disease today.

As noted above, AD is an incurable form of dementia or a decline in intellectual functioning. There are typically three progressive stages individuals experience while battling AD (Mild, Moderate, and Severe) (Alzheimer's Association, 2021). The first being the mild/early stage. Typically, in this stage, an individual is still able to participate in meaningful conversation and engage in some social activities; however, he or she may repeat stories, feel overwhelmed by excessive stimulation, or have difficulty finding the right words to utilize within a conversation. The middle stage is the longest stage of the

disease and can last for several years, during this stage communication skills tend to decrease as the disease progresses. Ultimately, the disease reaches the severe/advanced stages, when typically, the individual with AD relies on nonverbal communication, facial expressions, and vocal sounds to communicate (Alzheimer's Association, 2021). The duration of the stages and progression of the disease differ from person to person; however, because AD currently does not have a cure many individuals will suffer through all the stages and ultimately die with the disease and complications associated with it. One of the most prominent characteristics of AD is the impact that it has on memory. According to the National Institute of Aging, (2019), individuals can seem to be symptom-free, but toxic changes are taking place in the brain possibly a decade before memory loss begins. Memory loss can disrupt everyday life and is one of the most common signs of early-stage AD. Typically, as the disease progresses so does the memory loss which can greatly impact an individual's ability to communicate. Importantly, the different stages of the disease require both individuals with AD and caregivers to utilize different communication strategies.

Now, more Americans than ever are suffering from this disease. Currently, around 6.1 million individuals suffer from Alzheimer's Dementia, with the number anticipated to more than double to 13.8 million individuals by the year 2060 (Alzheimer's Association, 2021). In 2020, 26 percent of caregivers reported that their care recipients suffer from AD or Dementia which has increased from the 22 percent that was reported in 2015 (AARP and National Alliance for Caregiving, 2020). This not only means that the prevalence of the disease is increasing, but also that the number of individuals

becoming caregivers continues to increase as well. When looking at data regarding individuals who care for adults in the United States, the prevalence of caregiving has risen from 16.6 percent of American adults in 2015 to 19.2 percent in 2020, —which is an increase of 8 million adults providing care to a family member or friend (AARP and National Alliance for Caregiving, 2020). Out of these caregivers, one in three caring for someone age 65 or older reports the presence of AD or dementia (AARP and National Alliance for Caregiving, 2020). This data suggests that understanding the caregiving experience is as crucial as understanding the nature of the disease itself.

### ***Challenges of Caregiving***

Johns Hopkins Medicine (2020) describes a caregiver as an individual who assists with the daily needs of another individual. Evidence has shown that caregiving for individuals with AD can be very stressful (Aguglia et al., 2004; Alzheimer’s Association, 2021). As Schulz and Sherwood (2008) explain, “Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods, is accompanied by high levels of unpredictability and uncontrollability, can create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance” (p.1). The causes of caregiver burnout can include role confusion, unrealistic expectations, lack of control (regarding money, resources, skills), and unreasonable demands that caregivers occasionally place upon themselves (American Medical Association, 2018). According to Schulz & Sherwood (2008), “Caregivers first experience distress and depression, which is followed by physiological changes and impaired health habits” (p 105).

Taken together, this information suggests that caregiving is an emotionally taxing task. In fact, nearly 75% of AD and dementia caregivers told researchers that they were somewhat or very concerned about maintaining their health since becoming a caregiver (Alzheimer's Association, 2020). These caregivers need help. To this end, this study will explore the unmet physical and mental health needs of caregivers and attempt to advance family support research. As Revenson et al. (2016) argue, it is important to examine and understand factors that affect caregivers' well-being and challenges that they face in order to create evidence-based interventions to assist them. According to the American Psychological Association website, last updated in 2020, one of the main topics that need to be addressed within the caregiver literature is researchers examining the diverse heterogeneity of attitudes, values, and preferences that individuals have toward caregiving.

One way to do this is to conduct in-depth, qualitative research with diverse members of family caregiver communities, with the goal of eliciting a wide range of subjective caregiving experiences from a wide range of relationship roles, including spouses, adult children, and family friends (Vellone, 2008; American Psychological Association, 2020).

### ***Communication Issues and Caregiving for those with AD***

Among the many challenges that AD can introduce in a family, the most significant is its impact on communication (Small & Perry, 2012). According to Woodward (2013), communication issues impact the lives of individuals with AD, their families, and caregivers. AD impairs verbal expression and can cause misinterpretation of

nonverbal signs; this can be extremely frustrating for AD caregivers increasing the burden and stress that they feel (Woodward, 2013; Savundranayagam et al. 2005). As one can imagine, impaired communication can lead to conflict, isolation, misunderstandings, and a loss of intimacy within a relationship (Wadham et al., 2016; Woodward, 2013). Small and Perry (2012) explain that AD can present changing cognitive and social behaviors of a loved one. According to a study by Murray et al. (1999), spousal caregivers were more distressed by the loss of understanding and conversation with their partner than having to take on responsibility for their basic daily activities. This one-sided communication adjustment can cause distress at times, and frustration because the relationship is not bidirectional. However, this adjustment in communication by caregivers is a good example of the Communication Accomodation Theory. It helps to showcase and represent how caregivers alter their communication behaviors in an attempt to adapt their communication effectively to accommodate their loved ones. According to Lanzi et al. (2017), “Successful communication support involves appropriate, personalized visual and written cues, and appropriate training for individuals and their communication partners” (p 372). This includes teaching caregivers communication strategies that they can implement that may be more effective for their loved one at the time. For example, at-home family members can be taught to provide extra time to let the care recipient express their thoughts (Lanzi et al., 2017), or to use different modes of communication such as gesturing, or drawing, which can help to diminish the frustration felt by care recipients when they are unable to communicate verbally (Hinshelwood & Henry, 2016). Family members also can lead the conversation which can help ease the

burden from the AD care recipient (Lanzi et al., 2017). These are all examples present in the literature regarding how caregivers can accommodate or adjust their communication with their loved one.

Adjusting communication is one method to help provide person-centered or patient-centered care which focuses on the whole person, not only the disease (Lanzi et al., 2017). Patient-centered care, when combined with compensatory communication techniques, helps to take advantage of an individual's remaining functional, emotional, and cognitive abilities (Lanzi et al., 2017). This reflects how caregivers that accommodate how they communicate with their loved ones are taking advantage of their remaining communication abilities. Another way to do this is to utilize “external strategies” which essentially are alternative access routes that help to trigger stored information, as well as reduce the burden caused by impaired cognitive processing (Lanzi et al., 2017). External strategies “capitalize on the remaining strengths of individuals, such as reading and visual processing abilities, and reduce cognitive demands on memory (Lanzi et al., 2017, p 64). Finally, Lanzi et al. (2017), suggest that caregiver communication training should be initiated by establishing rapport with the caregivers by asking questions about the challenges that they face while taking care of their family members, which is what this study did. The interviews also asked caregivers to discuss their communication challenges and their ideas for what topics could be addressed in order to improve their communication with ailing loved ones. Hopefully, this will provide useful information for guiding the development of future communication interventions to ease the burden caregivers and individuals with AD experience. As the literature reveals,

it is often necessary to adapt the way of communication to avoid stress and negative feelings in a person with dementia (Banovic, Zunic, & Sinanovic, 2018). According to Sue et al. (2005), more research is necessary to examine the communication challenges involved with the progression of the disease. Specifically, researchers need to examine what occurs between family members and relational partners with AD.

### ***Caregiver Burdens***

According to Hunt (2003), caregiver burden is referred to as, “the oppressive or worrisome load borne by people providing direct care for the chronically ill” (p 28). There are two different categories of burdens that caregivers can experience, objective and subjective burdens (Hunt, 2003). The objective caregiver burdens are tangible, observable costs that the caregiver experiences as a result of caring for another (Hunt, 2003; Nijober et al., 1999b; Maurin & Boyd, 1990). An example of an objective caregiver burden is the amount of money spent giving care (Caregiver burden, 2016). The subjective caregiver burdens are defined as being positive or negative feelings that an individual can have while giving care to another (Hunt, 2003; Nijober et al., 1999b; Maurin & Boyd, 1990). An example of a subjective caregiver burden is the caregiver experiencing feelings of guilt for not meeting the care recipient’s needs (Caregiver burden, 2016). According to Van der Lee et al. (2014), patient behavioral problems, caregiver competence, personality, and coping traits are the most consistent determinants of caregiver burden, depression, and mental health. Van der Lee et al. (2014) also mention that behavioral and psychological symptoms of dementia (BPSD) are more significant in influencing burden than cognitive disorders or lack of self-care.

Caregiver burden causes poor outcomes for caregivers including depression, illness, and poor life quality (Schulz et al., 2006). The progression of the disease and chronic illness usually unfolds in a cascading fashion and is stressful for both the caregiver and individual with AD. Typically, the time needed to dedicate to caregiving increases as the severity of dementia increases (Langa et al., 2001). The American Psychological Association, (2006) states that the influences that stressors have on caregivers go beyond just mental and physical health effects, and also include... disruptions to education, careers, and other aspects of the caregiver's personal life. The lack of effective and appropriate communication can lead to social isolation, depression in both parties, increased caregiver burden and stress, and ultimately early institutionalization of the loved one with AD (Williamson & Schulz, 1993; Small et al., 1996; Steeman et al., 1997; Orange & Colton-Hudson, 1998). According to Chiao, et al. (2015), BPSD are the primary factors of the person with dementia that cause caregiver burden. Some of the most difficult or challenging stressors encountered by caregivers include the care receiver's problem behaviors, such as agitation, hyperactivity, and aggression (Son et al., 2007). According to a study by Vellone et al. (2008), the factors caregivers reported that improved their quality of life were whether their patient was in good health, having independence from the patient, and increased help with caregiving. Some of the factors in the study that worsened the quality of life of caregivers included worries about the future and the progression of the patient's illness (Vellone et al., 2008). Another study revealed that behavioral problems, instrumental activities of daily living (IADL), dependency of the patient, spousal relationship, hours of caregiving, and the



number of diseases were found to also all impact caregiver burden (Park et al., 2015). A study by Hilgeman et al. (2009), revealed that caregiver interventions must target different aspects of the stress process to provide the optimal benefits for individuals of different cultures or ethnicities.

Another term associated with caregiver burden is caregiver stress and has been used to describe both a “cause and result of a phenomenon – such as caregiving – that alters equilibrium” (Hunt, 2003). The term caregiver stress can often be used interchangeably with the term caregiver burden (Llanque et al., 2016). According to the Alzheimer's Association (2021), symptoms of caregiver stress include denial, anger, social withdrawal, anxiety, depression, exhaustion, sleeplessness, irritability, lack of concentration, and ultimately health problems for the caregiver. This study plans to examine caregiver perceptions on a deep level about the burdens that caregivers have faced and how they are related to communication. Other studies have also made this connection. For example in an interview study conducted by Stiadle et al. (2014), they found that “positive communication was associated with decreased feelings of caregiver burden” (p 370). Therefore, they came to the conclusion that to decrease the overall caregiver burden, aggressive and depressive communication needs to decrease, and positive communication needs to increase. This study will examine conclusions made in prior research by exploring the influences of positive and negative communicative experiences that informal AD caregivers have had with their care recipients. This information can be beneficial in developing a communication intervention to assist caregivers in the future. According to Mason et al. (2020), AD caregiver information-

seeking reveal that caregivers' largest motivation for seeking information is to learn how to better care for their loved ones.

### *Coping Strategies of family caregivers*

There are two prominent coping strategies identified in the literature that specifically focus on reducing subjective caregiver burden, or the amount of caregiver burden that the caregiver perceives that they have. The first being problem-focused coping and the second being emotion-focused coping. Problem-focused coping includes producing and weighing out various options to solve a problem and implementing steps to solve said problem (Lazarus & Folkman, 1984). In emotion-focused coping, the purpose is to manage the emotional distress through methods such as “venting emotions, the positive reinterpretation of events, and seeking out social support” (Baker & Berenbaum, 2007, p 96).

Over time there has been a debate throughout research in family caregiving about what is the most beneficial coping style for caregivers (Sun et al., 2010). For example, in a study by Pruchno and Resch (1989) on spousal dementia caregiving, they said the best coping was emotion-focused strategies due to the long-term nature of the issue. Interestingly enough, in a study by Kramer (1993), it was found that emotional-focused coping was related to depression and positive relationship-focused coping was the best coping mechanism (Sun et al., 2010). As research suggests, a reason for the debate about which coping mechanism is the best choice for family caregivers is due to the vast variance among caregivers. For example, studies have shown that caregivers from different cultural backgrounds utilize different coping mechanisms (Janevic, & Connell,

2001; Burgio, et al., 2003). The literature also suggests a difference in rural versus urban caregivers. For example, caregivers in rural areas had less transportation options for them to access formal services and were less likely to engage in information seeking as a means to cope (Wood & Parham, 1990).

This study will build on the literature regarding coping strategies and family caregivers. This is an important topic to examine, especially with informal caregiving being such a central component within the health care industry and the projected increase of informal caregivers over the next few years (National Research Council, 2010). With the increased use of healthy coping strategies, caregiving skills, and confidence, caregiver burden and depression can be reduced (Gallagher-Thompson et al., 2003; Gitlin et al., 2008; Hepburn et al., 2005). This study will examine whether the coping strategies caregivers employ are more problem-focused or emotion-focused coping, as well as explore in more detail what has worked for the caregivers and why.

### ***Gender and Caregiving***

According to AARP and National Alliance for Caregiving (2020), three in five caregivers are women (61%) and two in five are men (39%). In fact, these groups reported that women are more often caring for two or more adults (i.e., 27% vs. 20% for male caregivers) (AARP and National Alliance for Caregiving, 2020). This brings to light a very important question about whether it is right to expect individual family members – mostly women – to be informal caretakers? Research suggests that daughters provide more care than do sons of elderly parents (Grigoryeva, 2017).

Research has shown that caregiving experiences and the negative effects that can occur from caregiving differ according to gender (Sharma et al., 2016). Many studies have shown that female dementia caregivers reported a significantly higher level of overall burden and depression (Ashley & Kleinpeter, 2002; Pöysti et al., 2012; Pillemer et al., 2018). According to Sharma et al. (2016), women caregivers use more ineffective coping styles (e.g., fantasy, denial, escape, and avoidance) more frequently than men, who tend to use effective coping strategies such as problem-solving, acceptance, and distancing. Cultural factors also have a great impact on caregiving, from men earning more than women, making men less inclined to give up a paid position to work full-time (unpaid) as a caregiver, to “men being less involved in the emotional needs of others and being able to distance themselves from the care recipient” (Begley & Cahill, 2003, p 163). This information supports the Gender Schema theoretical argument previously mentioned. This study will address gender issues by asking caregivers to share their experiences while being caregivers, which some caregivers inevitably will identify as female and share their genderized first-hand experiences.

Exploring issues that AD informal caregivers have concerning gender equity is crucial, because, as previously mentioned, most caregivers are women who seemed to have been forced into the caregiver role by default due to societal and family pressures. Therefore, giving female informal caregivers the platform to share communication experiences that they have encountered caring for individuals with AD, how these experiences have impacted them, their thoughts and feelings regarding their role, and

how they manage their stress, will help to tailor future caregiver interventions more specifically to the needs of the female informal caregiver population.

### ***Political and economic context***

There has been some growth in policies and programs supporting family caregivers; however, they have not kept up with the realities of caregiving for many Americans. Informal caregivers continue to remain “invisible in the health-care system that relies on them to provide this care” (Reyes et al., 2021, p 19). The need for more systematic evaluations of policies and programs regarding informal caregiving is lacking, leaving gaps in our understanding of what works, for whom, and under what circumstances (Reyes et al., 2021). This is a way that governments and health care firms have succeeded in pushing health risks and burdens of dementia care onto individual families.

There have been a few policies that have made some progress in regard to providing recommendations about the best practices for supporting family caregivers. For example, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Care Act of 2018 which included Medicare and Medicaid reimbursement to physicians for the health assessment of caregivers, or Caregiver Advise, Record, Enable (CARE) acts enacted by 40 states that provided caregivers with the date of discharge and instructions for care after discharge if the patient was hospitalized (Reyes et al., 2021). However, the gaps in policies are very prevalent as well, such as informal caregivers providing the majority of long-term services and supports because long-term services are expensive and are typically not covered by Medicare (Doty & Spillman, 2015). These services are

covered by Medicaid, but only for those who are income eligible. Therefore, with many individuals not eligible, or who cannot afford the services, the burden then falls on the unpaid family members (Reyes et al., 2021). The National Family Caregiver Support Program (NFCSP) is the only federally-sponsored program created specifically to address the needs of family caregivers; however, it only provides limited assistance to a small number of caregivers (Doty & Spillman, 2015).

According to Wong (2020), the total cost of care for the treatment of AD in 2020 is estimated to be \$305 billion, with Medicare and Medicaid covering the largest proportion of these costs, estimated to be approximately \$206 billion. Although the patient out-of-pocket (OOP) costs are still to be estimated to be roughly \$66 billion. The financial impact does not stop here but continues to burden the informal caregiver. In 2019, 16.3 million informal caregivers provided an estimated 18.6 billion hours of unpaid care. When evaluating the cost using replacement costs of care valued at \$13.11 per hour, the estimated value of informal care provided in 2019 was \$244 billion (Alzheimer's Association, 2020).

The lack of urgency by the government or health care firms to take action to create and promote supportive policies to address the prevalent and relevant issue of family caregiving is alarming. It will be interesting to discover if informal caregivers share concerns over public policies that are related to caregiver burden and if they share that they experience it firsthand.

Based upon the review of relevant research and theory, the following research questions are proposed for this study:

## **Research Questions**

RQ1a: What positive dyadic communication experiences do informal AD caregivers recall in their experiences caring for individuals with AD?

RQ1b: What negative dyadic communication experiences do informal AD caregivers recall in their experiences caring for individuals with AD?

RQ2: Do informal AD caregivers accommodate their communication to their care recipients? (If not, why? If yes, how so?)

RQ3: What are some of the challenges and stressors that informal AD caregivers face daily?

RQ4: What do informal AD caregivers believe will assist them in mitigating the stressors that they face?

RQ5: What are the major coping strategies that informal caregivers of individuals with AD practice to maintain their own well-being?

RQ5a: Are informal caregivers primarily using problem focused coping strategies or emotion-focused coping strategies?

RQ6: What types of support do informal caregivers of individuals with AD receive?

RQ6a: What types of support do informal caregivers find most helpful?

RQ7: What issues concerning gender equity are related to caregiver burden for informal caregivers of individuals with AD?

RQ8: What issues concerning public policy are related to caregiver burden for informal caregivers of individuals with AD?

## CHAPTER THREE

### **Methods & Data Analysis**

#### ***Study Description***

The purpose of this qualitative exploratory ethnographic study is to examine the role of communication in informal caregiving for family members past and present with Alzheimer's Disease (AD) and dementia as well as to examine how informal AD caregivers (past and present) have used communication to provide care and maintain their own well-being. The study uses the critical incident technique by utilizing in-depth interviews that generated rich narratives about the best and worst communication experiences informal caregivers have had while providing care to their loved ones with AD and also to identify the strategies they employ to maintain their own well-being (Flanagan, 1954; Kreps, 2017).

This study includes 21 semi-structured critical incident interviews which were conducted with AD family caregivers as well as one expert interview with an AD caregiver support group facilitator. The critical incident interviews were conducted until the data collected reached a saturation point (Fusch & Ness, 2015; Saunders et al., 2018). Saturation in this study refers to the point after which additional interviews yielded little new information regarding the study's research questions. According to scholars, the use of semi-structured interviews is an effective method for data collection when the



researcher wants to elicit personal and sensitive in-depth narrative information from respondents (DeJonckheere & Vaughn, 2019).

The interviews were conducted online using a Zoom link that was emailed to participants once they signed up to participate. Participants communicated with the researcher to determine a time that worked for them to be interviewed. The interviews ranged from the shortest being 32 minutes long, to the longest interview being 1 hour and 26 minutes. If participants were unable to Zoom due to technical issues or lack of access, Facetime video calls were used. All of the interviews were recorded through Zoom and field notes were transcribed using the Otter.ai software. Once the interviews were transcribed using the software, they were analyzed again by the researcher and checked for accuracy. The data in this study were kept confidential and pseudonyms were chosen for participants and used to identify them in audio tapings, field notes, transcriptions, and published data. Once data saturation was achieved, the interview recordings were transcribed and thematically analyzed to answer the research questions in this study (Joffe & Yardley, 2004).

### ***Sampling & Subject Recruitment***

This study applied a purposive network (snowball) sampling strategy. According to Cresswell and Clark (2011), purposive sampling is choosing individuals or a group of individuals that have knowledge about or experience with the phenomenon. According to Atkinson and Flint (2001), snowball sampling consists of identifying respondents who are then used to refer researchers on to other respondents. One of the benefits of this sampling method includes providing a way for researchers to gain access to vulnerable

and difficult-to-access groups. The Alzheimer's Association has local chapters listed online that have caregiver support group information that is accessible to the public. Therefore, support group facilitators were contacted if they included their email address online. This way, a contacted facilitator could reach out to informal caregivers attending the support group to see if they were interested in participating in the research study. Many family caregivers recommended participation in the study to one another. Participants also passed along contact information concerning other outlets to contact for additional participants, such as the Institute on Aging, which was also then contacted for the project.

Once the caregivers expressed that they were interested in participating and their contact information was passed along, they received additional information about the study, asked what dates and times they were available to conduct the interview, received the informed consent form, and were sent the link and password for the Zoom room. Because the interviews for this study were conducted virtually due to the COVID-19 pandemic, the caregivers could be located anywhere in the United States. This recruitment technique, as well as previous interviewees telling others about the study and how to participate, is how the sample was created. The sample entry characteristics requirements included: 1) participants should either be at least 18 years of age to participate, and 2) participants should be a family member or friend of a loved one diagnosed with AD or dementia disease who they care for, or (3) participants have previously been a caregiver to a loved one with AD or dementia. The study also recruited individuals who fit the criteria through social media utilizing Facebook.

### ***Data Collection: Critical Incident Technique***

The Critical Incident Technique (CIT) is a qualitative research method that is used to produce meaningful narrative data about user experiences. Since 1954, this technique has been used to study people's activities in a variety of professions and can be modified for specific settings and research questions (Schluter et al., 2008). Therefore, this technique was utilized to provide insights into caregiver experiences and coping mechanisms. The CIT, "is essentially a procedure for gathering certain important facts concerning behavior in defined situations" (Flanagan, 1954, p 335). The CIT is a qualitative, open-ended technique that allows research participants to be able to share their experiences as a story to the researcher, often producing descriptive data about these experiences (Sharoff, 2008). As the name suggests, the technique studies the occurrence of critical incidents and the analysis of these incidents allows researchers to identify similarities, and differences regarding specific activities (Hughes, 2007).

Many incidents of a particular activity are "purposively collected in the course of a CIT research project" (Hughes, 2007, p 51). The technique is implemented through a five-step process including establishing the general aims, establishing the plans and specifications for the project, collecting the data, analyzing the data, and ultimately interpreting and reporting the findings (Kreps, 2017; Hughes, 2007).

### ***Member Validation***

A way to boost the validity of the results and reduce the researcher bias in this study was to include member validation checks. This was done by asking participants to judge the adequacy of the final report (Seale, 1999). A copy of the final transcript of each

individual interview and a draft of the final transcript was sent to participants to ensure that their experience was understood and interpreted correctly. This was implemented to help ensure the participant's perspective and accounts were recorded accurately. It also aided in eliminating any preconceived notions or researcher bias. The feedback from participants through these member checks was used to add clarification where needed in the transcripts as well as eliminate any misinterpretations or misunderstandings in the final report. This application of member validation coincides with the qualitative researcher's commitment to moral and democratic research practices (Seale, 1999).

### **Coding Process**

After reading through all of the interviews, I was overwhelmed with the amount of data that needed to be analyzed. The first step that aided in making the text more manageable was re-reading the research questions before looking at the interview data. This assisted me in being able to focus on the relevant text that was related to my research concerns. I printed all of the interview transcripts so that I would have a hard paper copy to work with. After doing this, I developed a color-coding system to determine what repeating ideas were present within the raw transcript data across interviews. Eventually, these repeating ideas became the themes of the study, once I was able to attach a coherent label to them. Once I obtained these overarching themes, I categorized them further and labeled the section of texts into codes. These codes were used to summarize the overarching meaning of a particular segment of text. To keep track of the codes and themes found, I used research memos, particularly the codebook (seen in appx. D). Therefore, certain interview questions were asked to answer particular research

questions (as seen in appx. B); however, all codes created arose directly from the interview responses.

## CHAPTER FOUR

### Results

From July to September 2021, I conducted 21 in-depth interviews to collect narratives and stories from family caregivers of individuals with Alzheimer's disease (AD) and dementia. In addition, one expert interview was conducted with a support group facilitator to get insights about how the typical support group meetings were carried out. The following demographics were collected from the sample: gender, race, the stage of the disease the care recipient is in, the type of family caregiver, the location of the caregiver, and whether the caregiver is currently a caregiver or was previously a family caregiver. Of the respondents, fourteen are currently caregivers and seven were caregivers until their loved one passed. Five participants expressed that their loved one was in the early stage of the disease, while eight stated that they were in the moderate stage of the disease, and another eight identified with being in the severe stage of the illness or had passed away from the disease. The ages of the participants ranged from 26 to 83. (See the summary description of the sample in Table 1). The sample is reflective of the statistics regarding female AD caregivers with two-thirds of dementia caregivers being women, and over one-third of them being daughters. However, this sample is not reflective of the statistics regarding AD and race, with Black Americans being about twice as likely and Hispanic Americans being about one and one-half times as likely to

have AD than White Americans (Alzheimer's Association, 2021). This will be addressed within the limitations section of the study.

**Table 1. Demographic Summary**

<b>Demographic Summary</b>		
	Characteristic	N (%)
Gender	Female	16 (77)
	Male	5 (23)
Race	White	21 (100)
	Black	0 (0)
	Hispanic	0 (0)
	Asian	0 (0)
Stage of AD/ dementia	Early Stages	5 (23.8)
	Moderate	8 (38.1)
	Severe or Deceased	8 (38.1)
Type of Caregiver	Spouse	14 (66.7)
	Child (caring for parent)	5 (23.8)
	Other	2 (9.5)
Location of Caregiver	Virginia	2 (9.5)
	South Carolina	5 (23.8)
	Maryland	2 (9.5)
	District of Columbia	1 (4.8)
	California	5 (23.8)
	Michigan	1 (4.8)
	Iowa	2 (9.5)

	Pennsylvania	3 (14.3)
Current or Former Caregiver	Currently a caregiver	14 (67)
	Former caregiver (loved one has passed)	7 (33)

### Short Story Narratives

To showcase findings, the following information is organized according to the research question it is answering. The information showcased is a compilation of short stories shared by AD informal caregivers excerpted from the data gathered that exemplify the particular thematic codes mentioned previously. According to Banovic et al. (2018), it is often necessary to adapt communication practices to avoid stress and negative feelings related to caring for a person with dementia. The answers to these research questions will provide context as to why this adaptive communication is needed and how it is provided. All of the participants and their loved ones have been given pseudonym names to help maintain their anonymity. The interviews revealed many descriptive narratives regarding the positive communication interactions between family caregivers and their loved ones. In this section, these components are categorized into three different themes. First starting with words of appreciation from their loved one, followed by moments that delivered a sense of normalcy during the interaction, and lastly the lighthearted moments that occurred between the dyads.

**RQ1a: What positive communication experiences do informal AD caregivers recall in their experiences caring for individuals with AD?**



## Words of Appreciation

To start, examples of positive communication experiences will be showcased.

One in particular comes from Alexander and his wife Natalie, who recently passed away in 2021. Here Alexander expresses that he felt appreciated and recounted this as a positive communication interaction he had with his wife while she had the disease.

*After we moved here, you know, after the diagnosis, and she knew that I was working very hard. You know, I'd keep making things happen for her... she would come up to me two or three times a day and give me a hug and say, "Thank you for taking care of me." That's one of the things I miss. Um in the in the previous 48 years, she never, you know, 45 years, she never said that.*

This example of a positive communication experience harnessed through a sense of appreciation by the care recipient is also showcased by Tiffany and her husband. He knew that she was working hard taking care of him and agreed that she needed a break from her caregiving tasks.

*Yeah, our... caregiver, two weeks ago, she stayed with him overnight for 48 hours, and my girlfriend and I went to Chicago for a pretty whirlwind trip. And there was no point in me. I mean, I had this trip planned for a good few weeks. Um, there was no point in me. You know, "Remember on Friday Jennifer's coming over da, da, da", there was no point in that. So I did, tell him on Friday, maybe around lunchtime. Um, you know, that Jennifer, our caregiver was coming over and she was going to stay for the weekend and that I, you know, was going to go to Chicago, I was going to go on a trip, but I'm coming back. And then he was just kind of like, "okay, okay." Um, and I had my car packed and everything, and she pulled in that evening. And I said... "Okay." I said, "Jennifer's here. And I'm going to..., I'm gonna leave. Um, you know, when she... gets here, I'm going to say hi, and then I'm going to... I'm going to leave, and I'll be back. I'll be back in two days." And then he said, "Really?" And I said, "Yes." And I said, "I will be back. I'm going to Chicago with Joanna." And he just looked at me with perfect clarity and he said, "You deserve to have some fun." (gets emotional) Yeah, so I was like you really, he really, you know, got it. Um, and then he did really well. You know, those 48 hours and when I got back... he had a huge smile. And... he gave me a big hug and was kissing my shoulders... which is something he does... and he said, "My family's back together." So....*

## **Sense of Normalcy**

Another indicator that exposed a positive communication interaction was this overarching **sense of normalcy** that occasionally occurred while caring for their loved one with AD. These moments would spontaneously occur and were described as being a pleasant surprise by caregivers. An example of this was showcased through a granddaughter, Hannah, who when visiting her grandfather after he was placed into a facility had a particularly great conversation with him.

*Growing up, he was always in his recliner, reading his newspaper. And when my grandma and I were in the kitchen, often cooking, then he would be sitting there waiting for supper to be ready or lunch or whatever, and would often fall asleep with this newspaper on his face. And it was so funny, because he'd look over and he had this newspaper like almost as a blanket over him while he's sleeping. So I went over to the memory care unit, and he was sitting where he is every single night reading the newspaper. And I think that that memory triggered just a normal response because I came in and it was a locked unit. So there's this little window, you know, very small, thin window in the door. And he was sitting there where I knew he was going to be reading the newspaper and he saw me and he said, he got the staff members attention and was like, "That's my granddaughter, can you let her in?" And I was like, wow, because he always kind of remembered me. I was there a lot. Um but sometimes he would call me my mom's name, or he knew I was family every time. Okay, so he always knew I was a family member. He just didn't, couldn't always associate who I was. But so for him to say so clearly. That is my granddaughter. And then I came in and he's like, "Hi, Hannah, how are you?" And I was like, "Grandpa, how are you!" You know, It was so exciting. And so that visit, we went back to his room. We talked, I did the normal routine of clipping his nails, making sure he was all trimmed up. And then we just sat and visited and we just talked like it was normal times. And he remembered that I had a boyfriend who's now my husband, he remembered... my sister has two kids and was asking me about them. I mean, it was just crazy how normalized I guess that visit was.*

## **Lighthearted**

Lastly, a commonly expressed characteristic of a positive communication interaction with loved ones with AD included **lighthearted**, fun, moments full of laughter. An example of this comes from Ellen who would do caregiving tasks for her Aunt-in-law, Aunt Martha. One thing that she would often do is take Aunt Martha to get her hair done and out for “girl time”.

*Aunt Martha always was um... was really a dresser, you know. And of course she had her hair all fixed and all this so, and she had an eye for men up until she died. And we were sitting there I was facing this way, she was facing the door and she touched my arm. And she went like, like, look right there. So I look back and there were construction men coming in, you know. And she says they're really cute. And I say well yes they are and then she's looking at them. And they're, you know, going to different tables. And she takes a French fry and she says, "Give this to that man over there". I said, "The French fry?" And she said, "Oh, yeah, he's really cute." And I said, "well, Aunt Martha I think they have their own, you shouldn't do this." And then I started another conversation. But um, you know, the things she did, we just had, we had fun together.*

## **RQ1b: What negative dyadic communication experiences do informal AD caregivers recall in their experiences caring for individuals with AD?**

The interviews with family AD caregivers revealed descriptive narratives regarding the negative communication interactions. In this section, the negative communication components are categorized into three different themes. First, the undesirable interactions were described as transactional, followed by a presence of unresponsiveness within the conversations, and lastly these interactions were accompanied with demanding behavior.

## **Transactional/ No substance**

The negative communication experiences were described as being unsubstantial, and transactional, with conversations typically being simplistic and lacking details. Caregivers further described unsubstantial as conversations that felt one-dimensional, sparse, limited, and depthless which made the conversations feel inadequate. In short, participants often described negative interactions as being oriented toward task completion. The absence and yearning for deep conversation can make the AD caregiver feel lonely as well as craving conversations that they previously could have with their loved ones, thereby causing them to view the interactions they have with their loved ones as unfulfilling. The characteristics of these experiences will also be showcased below. For example, Erick discussed the communication interactions that he had when he was caring for his wife Selena, who was in more of the moderate to severe stage of the disease. He described the communication as mostly suffering on a linguistic level.

*I haven't had a, you know, a meaningful, serious, substantial conversation with my wife in years. She has aphasia, she speaks in a kind of gibberish, I try my very best to understand what she's saying. And I don't know, whether she's saying anything at all or not. Sometimes she expresses a kind of gibberish with such a sense of intention, including, you know, facial movements and, and eye movements and things and, you know, curling or something of the mouth. You'd think that surely, she's telling me something. But there's no real way of confirming it. My wife was brilliant, and articulate. She was a professor. And and now she, I mean, she's still those things, of course. But, but it doesn't, there's, it's there's no outward manifestation of it that's functional, and it causes her a great deal of, of, of angst and sadness. I mean, my communications to her are directive or inquiries regarding her intention, do you need the bathroom? Are you hungry? And I actually never really get a straight answer (chuckles slightly), even on those basic things, either. But sometimes, I guess I think that I recognize some, some little tiny thing that maybe is an answer to my question, maybe like a, like a slight step towards the bathroom (chuckles), or something like that.*

The communication suffering on a linguistic level is exemplified again in detail from Tiffany who explained how it could be occasionally when trying to communicate with her husband Jack.

*His speech is very bad. Um, I mean, sometimes he'll be able to, I mean, he talks all day, and he thinks that he knows what he's saying. But, you know, but I don't or, and he does a lot of counting: 222-555-55 (emphasizes) 1 million. Um, and sometimes at the end of the sentence will be kind of like, what he means like, he'll just, you know, say a string of, a string of words. And then he'll say, "I'm hungry." Um... and I've just kind of had, you know, to just really kind of take into context what we're doing, and try to tease out, you know, tease out a few words. I can definitely tell if he's excited. If he's, you know, trying to be silly or sarcastic, or if he's suspicious, or if he is angry. I can definitely tell that, but it's very difficult kind of speech wise. That's, yeah, that's difficult....*

### **Unresponsive and Demanding Communication**

Another negative communication interaction created by unresponsiveness or the lack of bidirectional communication from their loved one with AD as expressed by Marie referencing her interaction with her husband Chuck who is currently in the moderate stage of the disease.

*And he is very dependent on me. But not at all loving or responsive to my care... demanding, but not responding. So you don't get any strokes for making a great dinner or, or helping him select the clothes that are appropriate, or... you don't get any positive feedback. So you're operating on a duty basis, rather than a love basis, which is a shift. And there's no sharing going on... no sharing, no response to anything like if I sneeze, he won't remember to say, "God bless you," which is not how he was, of course. But it's that change that's happening. And it's taking its toll on me.*

Lastly, the commonly expressed negative communication characteristic was a sense of urgent and demanding behavior as well as repetitive question asking that can wear on caregiver patience. This story comes from Monica who referred back to an interaction that she had with her father who recently moved in with her after his diagnosis.

*Yesterday, we went to the dentist, and he... hadn't been to the dentist, apparently, in many years. And I probably should have been on top of this beforehand, but, I mean, we've been looking at other issues and dealing with those things. So he's gonna need some dental work. And he has dentures on or partial dentures on top, but he has a full set of dentures on the bottom. And when we went in to get these things assessed one of the partials on the top had broken. And so he was having trouble with that. And he wanted to know when it would be done, you know, so they took the measurements, they're going to have to actually go in and extract the teeth and give him full dentures and all that but.. these wonderful people at Amazing Smiles they were great. Um, it's gonna be a four-step process. And it's going to have to take place over several weeks, but they can't, you know, we can't address it immediately because it takes time to make these things. So, he wants his dentures right now. He wants to be able to eat the salad food right now. And I keep telling him well you don't have, you know, we don't have those yet. "Well, when am I going to get, them?" I want them, you know, I need them now. And how long is that going to take? And why is it going to take so long? And what do we have to do to take care of it? He's one of these people who in the past, you know, if you had a problem, you just went and took care of it yourself. And you didn't really wait around for other people. And of course, I don't... we don't have a choice in this case because I can't make dentures myself, but it would be handy if I could (laughs). But he got really irritated with me knowing that that wasn't going to happen right away. And when he gets irritated, he, you can tell... he kind of clenches up and sounds really angry.*

The positive and negative communication experiences both have very different defining characteristics. Positive communication with loved ones is more lighthearted, fun, grateful, appreciative, and often encompasses a glimmer of the past, before the onset of serious dementia symptoms. The negative characteristics of certain communication interactions were described in the interviews as lacking intrinsic value for the caregiver. As Gamble and Gamble (2013) state, individuals develop personal relationships because of the intrinsic rewards they develop from them and whether they are emotionally, intellectually, or spiritually fulfilling. This directly corresponds to the Social Exchange Theory that proposes that in dyadic relationships, the behaviors of each participant influences the psychological costs and rewards of the other (Raschick & Ingersoll-

Dayton, 2004). In these social exchange processes, the goal is to maximize benefits and minimize costs, which will ultimately determine the outcome of the overall relationship (Cherry, 2022). Typically, the research regarding caregiving focuses on the costs of caregiving, which is why including positive communication experiences to showcase the rewards is important.

**RQ2: Do informal AD caregivers accommodate their communication to their care recipients? (If not, why? If yes, how so?)**

While interviewing the caregivers, knowingly, or unknowingly, they each told stories about how they altered the ways they communicated with their loved one with AD after they were diagnosed with the disease. As mentioned previously, Accommodation Theory refers to the ways that interactants adjust their communication behaviors to either diminish or enhance social and communicative differences between another individual (Giles & Baker, 2008, p.1). The adjustments that AD caregivers expressed that they typically enacted were categorized into three different themes. First, the caregivers stated they adjusted their communication by entering their loved ones reality. Secondly, they expressed that they engaged in compensation for their loved ones, and lastly, they redirected their loved ones.

**Communicating in their reality**

One predominant theme of this was showcased by caregivers expressing that they had **to learn how to not argue with their loved one and enter their reality**. The following example is shared by Noah who discussed caring for his wife Alison.

*Me learning to redirect. I'm an engineer by training. "Noah I want to go home." Alison, this is our house. "No, I want to go home." Alison, there's the sewing*

*machine your mother gave you. There's the ice box you got from your grandmother. "No, I want to go home." It took me a long time to understand where she was, and me trying to bring her back to, I'll call it my reality because her reality was different. And it took me a long time to understand and adapt to that, that instead of arguing with her, or trying to convince her of the logic of it...she did not have that facility anymore. And getting me to accept that was an issue. She was always my priority. And uh, you know, like, "I want to go home." So at times, when I just was not adept at redirecting or anything else. We would hop in the car, drive around the block, and "Oh, there's our house." And "Oh, okay." You know, you find all these little tricks, whatever you want to call them, that work that help calm them down.*

This accommodation characteristic is explained more in detail by Holly who was a caregiver to her husband Steve while he battled the disease.

*Some of the conversations were...very poignant. I mean, we weren't talking about anything. He could say, you know, I'm gonna go to the moon today. And I would say well, you know, like, what do you want to pack? I mean, it was just kind of nonsensical. And that's another thing um...the number one rule never argue with your person ever, as you've probably found out because their reality is...their reality.*

## **Redirection**

Other characteristics of caregivers being accommodating to their loved ones needs as revealed through the interviews include things such as **compensating** and **redirection** as seen by Tiffany, who shared in detail about what this looks like with her husband Jack.

*I did a lot of compensating for him. Um, you know, some of it was intentional. Some of it I just, I think I got, I think I got used to doing. Um, because he would have a hard time. Like, a hard time with choices like picking, like picking like, like, you know what he wants to eat, you know, like a menu. You know, a menu like at Applebee's is very overwhelming. Um, and you know, so I do something like, "Oh, they've got a" you know, "they've got a mushroom Swiss burger. You haven't had a burger in a while. Doesn't that sound good? You were talking about one yesterday" or "Well, you had a Reuben last time we came here, let's try something else" and kind of things like, kind of things like that. Or, um, I would kind of stick like close by him at, you know, family gatherings and things if he were floundering, um, you know, floundering a little bit with, with a conversation or remembering something that the larger, the larger the conversation circle, the more difficult it was for him.*



This redirection also occasionally gets physical and includes touching the individual with AD and guiding them to where they need to go.

*If I'm saying, you know...let's go outside, let's go get in the car and go to wherever. Um he'll sometimes, you know, turn around and try to go upstairs. And so there's a lot of physical kind of, you know, touching, guiding, turning um that I have to do. I mean, I guess that would...I'm figuring that that falls under the communication thing, because he's not able to follow my instructions. So it literally then kind of becomes physical.*

As stated by Haak (2003), improving the communication between the AD caregivers and the persons with AD improves the quality of life for everyone involved. The Accommodation Theory helps to provide a framework describing and explaining how caregivers and their partners with AD, modify their communication during interactions in response to different situational, personal, or relational needs (Sue et al., 2005).

**RQ3: What are some of the challenges/ stressors that informal AD caregivers face daily?**

The interviews also revealed a lot of detailed information regarding the challenges and stressors of caregivers. In this section, these components are categorized into three different themes. The first theme is **everyday living tasks**, such as hygiene, eating, driving, and **protecting their loved one with AD from potential dangers** . The next theme is **inappropriate, or problematic behaviors** (BPSD) from the individual with Alzheimer's disease that can trigger stressful situations including racism, offensive comments, aggression, and wandering. And lastly, the **personal demands that continue for the caregiver externally and internally**. Some external factors such as finances, daily schedules, and previous personal obligations can cause a lot of stress on the

caregiver. In addition, internal conflict such as feelings of sadness and grief can cause additional challenges to being a care partner.

### **Everyday living tasks- Hygiene**

The first living task that causes caregivers a tremendous amount of stress is **maintaining hygiene**. The following excerpt is from Erick who explained how completing these tasks with his wife can be complicated.

*I mean, the most stressful things are, you know, toileting, showering, the things that are very personal. Um even though she has Alzheimer's, she has a very deep seeded sort of radar if you will, regarding her own body and her the protection of her own body. She's not too thrilled about being manhandled, if you will. You know, like you sort of... I say, manhandle that's probably an overstatement, but, you know. As much as I possibly can coaxing her to like actually get into the shower stall, sit on the toilet, things like that are very, are difficult and she resists.*

Here is another account from caregiver Sophia who recounted a time in which she cared for her husband Harold and how hygiene was a stressful task for her.

*He did not want me to change his depends. He, you know, he didn't- that's a privacy, you know, they still have their dignity and their privacy. And a couple of times, I mean, he's, he grabbed my wrist and go, "No", you know, he get or he'd fold his arms and go, No. I said, you have to, I said, I have a clean one right here. Let's take that one off and I'll give you a clean one. And that was the most challenging, and that was the most frustrating to me. That gave me my panic attacks was trying to keep him you know, clean. I you know, his lower half clean and that...but we did it. And the other thing you know, he let me cut his hair. He always went to a barber and then I started cutting his hair at home. Because it.. you know, he'd just get up out of a barber chair and then so.. and I'd cut his fingernails.*

### **Everyday living tasks- Driving**

Another challenging or stressful everyday living task caregivers face while caring for their loved ones is **driving and mobility**. This includes both getting into the car but also having the discussion about not being able to drive anymore with a loved one.

Tammy is caring for her wife Rebecca who is currently in the moderate stages of the disease. In this excerpt, she recounted how the driving conversation was difficult to have with her wife.

*Well, yeah...she isn't driving anymore. And that was really quite traumatic. Um it was funny, we talked about it a lot and agreed on talking to doctors that she shouldn't be driving. And then we got a thing from DMV, where they were going to test her again. And so she really wanted to go to the doctor. Because that's what you have to do to get them to sign off on it. Anyway, we went to a doctor, our GP and she asked her questions. And Rebecca didn't know what month it was, or what year it was that particular day. And she said, "Look, I just don't think you should be driving. So I think this is kind of a moot point. And I don't think you should even send this in." Well, on the way home, she was very irate. She was, she felt like she'd been ganged up on. And that it was really unfair. And that the first time she had been tested, that person had passed her... well that was five years ago (chuckles). Um and she just was really, really pissed off about it. And it just struck me as funny because she'd already, we already had the conversation and she was already seemingly aware and okay with it, but then suddenly, not.*

Erick also discussed in detail the complications of actually getting an individual with AD into a vehicle and what this stressful challenge looked like between him and his wife Selena.

*Well what would start to happen, what has happened, is that instead of trying unsuccessfully, to get into the car, she would just stand and lean on the, on the car door, and I couldn't get her to, like, you know, apply herself to the task at hand one more time. And that is my agenda, not hers. And you know, if I again, somewhere in my brain, I really know that she's not. She's not trying to thwart me, she's not being stubborn. She's not refusing to focus on something that I want her to focus on. I know all those things are true. But nevertheless, when I'm standing there (chuckles), and I cannot get her to to interact with me really is what it amounts to. I do get, I got very frustrated. And just recently, I just reached the point where I, I let myself know, first I let myself know that I'm not doing this anymore. I will no longer try and coax her into doing something that she cannot do, that's futile and stupid. But it has consequences. In other words, if I can't get her someplace, well...she's in a dementia daycare center, and I can't get her there now. That's huge, huge. In other words, this little hiccup, has ramifications that are way beyond like, just my personal inconvenience.*

## Everyday living tasks- Protecting their loved one

Another living complication that many caregivers who are assisting someone with AD face is keeping their loved ones with AD safe. One common representation of this was described through the inability to predict dangers during traveling. The following story represents this through an example of how a trip turned quickly into a bad situation. Tammy shares what this looked like while caring for her wife Rebecca while they were traveling to Maine, where they first met, to visit some family.

*We had a terrible experience. We were on vacation in Maine, that's where we met and we love Maine, we go back. Rebecca has some family there. And it's been three years since we've seen them because of my work, and then the pandemic hits. And so we went back, but um she around 12:30 in the morning, I guess got up to go to the bathroom. All of a sudden, I heard a thud, thud, thud, thud thud. And I jumped out of bed, and she had gone out and fell down the stairs. Instead of going to the bathroom, she went the opposite. There's.. she has a lot of problem with direction. You know, it seems like she's always going the wrong direction. And so she fell down the stairs. And it was terrible. But I ran down the stairs. And there was, she had hit her head and there was so much blood, it was like, oh my god, I thought she was gonna die right there. Um anyway, we talked to the other people in the house. We called an ambulance, and she got to the hospital and it turned out. Luckily, no broken bones. She didn't even need any stitches, she has tons of bruises and scrapes. And it was all the scraping of her head that was bleeding. So... (pauses) I mean, that was really, really hard. And then of course you feel guilty. It's like, why didn't I see that coming? You know, but you don't... you can't guess everything. You just can't. I mean, I thought leaving the little hallway toward the bathroom, adjoining where we were staying the bedroom. That was familiar enough. She knew where it was, and I put a sign on the door, it said "bathroom". And I put another sign on this other door across from it that said "Andy's room", because I did notice she tried to go through there a couple of times.*

## **Everyday living tasks- Eating**

Lastly, a living task many caregivers struggle with is regarding their loved one **eating and feeding their loved one**. Gwendolyn talked about this in detail regarding her experiences with her husband William who is in the moderate stages of AD currently.

*He went through a phase where he ...I think he would forget, he ate. And he would go eat again. And he would get in the refrigerator. And I'm like, you already had two bowls of cereal and two yogurts. And I'm in the bathroom getting ready. And I hear things in the kitchen, and I go back in, and he's eating again. And...he increased his weight by about 10 pounds. And so then I kind of started remembering people on my support group page, they talked about how they would have to lock their cabinets. And because it can be a safety issue, you know, if they're going to open up the cabinet and start drinking vegetable oil or something like that, you know. So there's probably going to be a time I have to lock something, but I hide things. And when I did question him about eating, like too many cookies or too many, whatever he got, it was um, he denied it and said I did not and I'm not you know, so he got real defensive on that. And I don't know maybe I didn't approach it right. But I pretty much said who ate all these cookies because I didn't, you know. I probably didn't approach it right but still, and he probably didn't remember doing it.*

As you can imagine all of these everyday tasks that we take for granted can be difficult for individuals with Alzheimer's disease and as a result can cause a lot of stress for their caregivers.

In addition, as expressed previously, behavioral and psychological symptoms of dementia (BPSD) trigger stressful experiences and interactions for caregivers of individuals with AD. These inappropriate behaviors such as racism, inappropriate comments, aggression, and wandering are highlighted in the stories shared below.

## **Inappropriate Behaviors- Racism**

In an interview with Holly, she explains how her husband Steve who was previously a sociologist displayed racist behavior as the disease progressed for him. She

explained that she was quite taken aback by this and was not sure what to do in this situation.

*He became, he became racist. I mean a sociologist becoming racist? That's not usually the thing that's gonna (happen)- if your going to be a racist person, don't go into sociology. He would be mean, we had a fight because I needed to get out. But there was nobody. So I hired a lady three for three hours a day, three times a week. So I had nine hours that...were usually spent at the gym, just to work out all this stuff. And I had a really good friend who, as Steve, -she and Steve got along very well until he got sick. And then it was just too hard for him to see, which I totally understood. But I that's when I needed the support. Which is why these support groups are so- the communication, as you point out is so, so important. I mean, it's the thing that really gets you going or keeps you sane, well, relatively calm. But it was his change in personality, when he would say things when he would judge people right to their face. The ladies that I would get (to help) a lot of the ones that come into the home are black, and Steve, Steve, you know, he wasn't like that. But he would get...he would call them the N word. He would call them. I mean, when they were trying to do something with him, he want[ed] them to clean because that's what black ladies do, they "clean". You know, it just became very embarrassing.*

It is crucial to include this narrative and example of Inappropriate Behavior, due to the lack of research regarding the treatment of inappropriate racist behavior in dementia. This is an example of the type of situation that caregivers express that they need additional communicative guidance with navigating properly. There is little to no research specifically focusing on why this behavior can occur in certain AD/dementia patients, or where these comments are stemming from, but it may be related to loss of normal impulse-control that most people use to monitor the acceptability of comments they make. However, there is no acceptable amount of racism and for individuals who lack impulse-control capacity due to AD or dementia, certain actions should be taken to reduce the occurrence of this behavior (James and Jackman, 2017, p 229). There is some information in the literature regarding what caregivers could possibly say or do to react to

these inappropriate comments, but there is little empirical evidence provided to back up these suggestions (James and Jackman, 2017). This suggests that effective strategies for responding to inappropriate comments from AD patients is a topic that needs additional research.

### **Inappropriate Behaviors - Comments**

Another commonly shared inappropriate behavior expressed by caregivers was that their loved ones said offensive comments to them and others. These offensive behaviors included inappropriate sexual behavior (ISB) by AD patients. Tsai et al. (1999) state that (ISB), has been consistently described in most dementia syndromes. As further explained by De Giorgi and Series (2016), "In elderly patients with dementia, a combination of cognitive deterioration, worsening judgment, and personality changes probably contributes to changes in sexual attitude and behavior" (p 1). Hannah discussed a time in which her grandfather made unwanted advances toward her while he had the disease, which of course triggered stress and additional challenges for her.

*The other struggle was if I was in close contact with him, um, he had reached for my breast multiple times. He knew that I was (pauses) someone that he loved. And yeah, he never had done that before when I was a kid at all. I mean, he was the sweetest, gentle, gentleman, I mean, just the best friend to a grandkid. But as the disease progressed, he definitely got a lot more sexually interactive with me at Thanksgiving, I was sitting next to him, and he actually just reached over and grabbed it in front of our whole family. Um, we were alone, and I was bringing him down to his room. And he had asked me, uh like, yeah, just inappropriate things- And then towards the very end, he was starting to do that to the staff. But he hadn't been at the point that he started with me.*

While caregiving daughter, Stacy also recalled encounters with her mother in which her mother stated offensive comments to her while she was caregiving for her.

*The abuse. It's quite, you know, and it's silly. It's not necessarily stuff that you internalize. But again, I consider myself to be very richly resourced. But like I'll get told, I'm stupid. And I'm mean, and how bad I am and all these kinds of things, which, you know, I have great distance from. If this was coming from a spouse. You know? So um yeah, showing some, I mean, I'm a very, very fit person. But she'll call me fat. She'll, tell me I'm stupid. She'll, she tells me I'm mean a lot. Nobody likes me. You know, like, these kinds of things. You know, I don't dignify them with a reply at all. And the woman that she was would be (emphasizes) mortified. Mortified. Um and you know, it's like when a kid calls you stupid.*

### **Inappropriate Behaviors - Aggression**

Another behavioral and psychological symptom of dementia (BPSD) is aggressive or violent behaviors. This Inappropriate Behavior was discussed by Annabelle when she recounted a recent event with her husband Charles. The example helps to provide context as to what can happen to an individual with AD if they are violent within a facility.

*They found out he had NPH and diagnosed him with that. And then it was recommended they put in a shot. So we put in a shot. And it was just downhill from then on. Um he eventually, one day became combative and hit someone hit a staff member. They called the sheriff (pauses, sighs, and takes a big breath) um you know, I thought that kind of behavior was kind of common to Alzheimer's. Apparently they didn't. So they called the sheriff and the EMS. Now I understand that when that happens, they're usually taken to an emergency room and assessed and if necessary they go to Geri psych, I understand. But when the sheriff gets involved, he said to me, the sheriff said to me, "What do they want me to do? Cuff him and put him in jail?" Yeah, it was just awful. It was just awful. And because the sheriff was involved in this little county in South Carolina, he had to go to the little county hospital in South Carolina, where he laid in the emergency room for five days with a security guard at his door. No psych, no psychiatrist on duty. So they had to do a teleconference with a psychiatrist, who recommended geri psych. Okay. He ended up going to Charleston, South Carolina to the MUSC psychiatric hospital, and was there for a month. Meanwhile, the facility where he had been said, and I got this secondhand, that he was not welcome back. So, here I am, you know, I've got to find someplace else. So fortunately, because I have a support group, because I have contact with people in the industry and so forth. And around Charlotte, I was able to find this new place, and they did their teleconference assessment and accepted him and, he's been there for like, six weeks, I guess.*



## **Inappropriate Behaviors - Wandering**

Lastly, another inappropriate behavior discussed by caregivers that causes them a lot of stress while caring for their loved one is wandering or getting lost. Tiffany gave an example of this happening with her husband Jack.

*He took my parents dog for a walk, and didn't tell anybody. And he just decided to go into a woods behind a house across the street. And he didn't have his phone. He didn't have anything. And I mean, I couldn't find him. And my dad was driving around, I was driving around, I was looking. Neighbors...some neighbors were... looking. Um, and yeah, I mean, I ended up calling 911. And they were sending an officer and canine unit over. And then my mom called me because she stayed at the house. And, um, and he came out from out from the woods, and he was happy as could be, dog was happy, um didn't understand at all what, you know, what the fuss was all about and why I was crying. And why I was talking to an officer saying that they didn't need to come out.*

The life of a caregiver does not stop because they are also performing caregiving tasks. Therefore, another stressor and challenge caregivers referenced were the personal demands (internal and external) that they experience while caregiving. These demands include external factors such as financial struggles or daily scheduling and internal personal factors such as the overwhelming feelings of sadness and guilt that accompany caregiving

## **Personal Demands - Financial**

Marie discussed some of the financial struggles that she and her husband Chuck have experienced while she has been caring for him. He is currently in the moderate stage of AD.

*He's in this program. And he goes three days a week, which is all I can afford (pauses). I got a grant. That help has helped for the first six months, they spread it out. And it's about as much as I can get out of our budget, because I haven't even talked to you about the fact that money is a huge issue. So that's where I am now.*

*And in our case, we had saved but Chuck burned it up before we.. before we were diagnosed... one of the problems is that we lost our savings. So that's what happens sometimes.*

### **Personal Demands – Schedule/ Obligations**

Another stressor or challenge of coordinating schedules and prior obligations was expressed by Amanda who is a working mother and currently also a caregiver for her mother.

*I was trying to schedule a playdate for my daughter recently. And they said like, we can get together like three o'clock on Sunday. And I was like, well, I just said like, the caregiver for my mom leaves at three. So I can't like, take her I can't like leave that that's not a good time for me to leave the house like can we do earlier in the day? And my friend was like, sure, like no problem, whatever works for you. But it was something that it wasn't about coordinating around nap schedules, or like meals, it was around coordinating around like a totally new thing. So it felt like a ..I don't know if it felt like a risk... But it felt like a vulnerability to say like, I want to get together for a playdate. I want to make this happen. But like, here's another parameter that I have to like be thinking of so scheduling things and like my husband and I are trying to figure out how we might be able to take the kids to New York to see my family to see like, my dad's side of the family and it's... to figure out who can stay overnight with my mom. So it's like it's just, it comes up kind of everywhere..we have an established routine that's working well. But like any deviation from the routine is like a whole thing.*

### **Personal Demands- Internal Sadness /Guilt**

In addition to external personal struggles, caregivers also expressed internal personal struggles that they face. Doris talked about this in more detail and how there are feelings of sadness while caring for her wife Cindy who is currently in the earlier stages of AD.

*You know, I think the first, literally, almost every night, the first month after she was diagnosed, I cried. As I would start to go to sleep, because I knew what was going to come. And so it was like the introduction to the grief that we as care partners carry with us for the entire course of the disease, because it is a, you know, a constant... (not constant hyperbole, Doris) it's not constant. But there is some daily sadness to this (pauses) because there are subtle and not so subtle*

*reminders every day of brain change that is constantly occurring. And, I'm not aware of it, until it shows itself like a brain change, a new brain change. But now I can see...that there are chunks of her brain that cannot communicate with other parts. And so, you know, some of them are, are exquisitely painful. Because it's also hard to figure out like, okay, so is there a time span involved? Sort of, but not really. Just little, little chunks of her life and memory have fallen away, like, you know, important things, important people. You know, a whole afternoon spent with somebody who was always very, very important to Cindy, in ways that she has no recollection of at all. And so, there's just like, these chunks of time. And over time, and on a continual basis. You know, there will probably be three or four things today that I noticed that are different. And maybe they were different for her a week ago. But I now have an awareness of it. And so, there's a sadness that is carried somewhere in the back of my mind, all the time.*

**RQ4: What do informal AD caregivers believe will assist them in mitigating the stressors that they face?**

In this section, the needs of AD family caregivers are categorized into two different themes. First, the caregivers stated they need useful and tactful information. Secondly, they expressed there is a significant need to reduce ostracization of AD caregivers and increase the social support that they are offered.

**Need for Useful Information**

Family caregivers have expressed that they believe there is a **lack of tactful and useful information** being disseminated about the disease. In fact, many caregivers in need of information have difficulty in knowing which sources are accurate and good quality, as well as have little knowledge regarding how to access these resources (National Academies of Sciences, Engineering, and Medicine, 2016; Whitlatch and Orsulic-Jeras, 2018). Therefore, caregivers believe **more useful, meaningful information and support** would help them with some of the stressors that they face. They also mentioned their **need for information about financial help and guidance**.

Stacy who is currently a caregiver for her mother expressed her distaste for the current state of the information being disseminated and provided about Alzheimer's disease.

*It's like, "faux help," so I think the experience is you are, you're starved for information. When this first happens, you're on the internet, you're here, there, all sorts of sources. You know, sources tell you things like, "move more, eat less." You know, like, just trivial garbage. You get really turned off about it, and then hunker down and survive. So it's not that there needs to be this. It cannot be meaningless messages and meaningful messages simultaneously.*

This excerpt showcases how caregivers feel as though they are on their own with little expert guidance. And the “typical” individualistic advice or tip of ("self-care") is inadequate to aiding the scale and scope of AD family caregiver needs.

### **Need to Reduce Ostracization**

In addition, caregivers can feel ostracized at times and have expressed situations when they have **experienced stigma**. Tiffany recalled an experience that she had recently while caring for her husband Jack.

*I was helping him sit down at some outdoor seating, and there were really low patio chairs with very long arms. And he kept trying to sit on the arm, and I needed to move the table away, so he could get around the arm, and then I could put his butt down on the chair. Fortunately, he's like, 5'5", and 140 pounds, thank goodness, I don't know what I would do if he was like a former, you know, linebacker or something like that. But...there was a, group of idiots sitting by us um that made some sort of comment, like a few little, a few little comments about, um, you know, needing your mommy to, you know, help you or something like that. And, um, and it was just really grating on me and he needs help eating. Um, you know, some things he can do. You know, if I cut up like a chicken breast or whatever, you know, he'll eat it with his fingers but, I mean, he's not gonna eat baked beans with his fingers. Um, you know, so I do help him eat and I'm at the point where I really don't care feeding him in public because, again, I think that I would be doing him a disservice by not having him out in public and enjoying things. And maybe it, you know, helps to, you know, normalize things for people, um, because again, you know, he has four fully functioning limbs, but he just sometimes can't get the fork to the mouth. But anyway, we were getting ready to*

*leave and that group of guys was still sitting there. And I'd have to say they were probably ranged from maybe, like, early 30s to like, mid 40s, maybe? And anyway, you know, and then I needed to, you know, help Jack up and had to reverse the steps, you know, that we'd already done. And then I said to them as I was, you know, kind of guiding him off of the patio. I said, I said, "This is what early onset dementia looks like. And, and I hope that nobody that you love and care about ever gets the disease." And then walked away.*

Helpful information, resources, support from family, friends, and understanding from society in general, are needs that were expressed by AD caregivers. Stacy expressed her surprise at the amount of support received by family friends while caring for her mother.

*Um yeah, I would say precious, little. Precious little support. I will say, I strive not to harbor negative feelings. But my mother's circle of friends partially, because we did relocate.. but, you know, there weren't a ton of phone calls. You know, um much like divorce there's like a real shrinkage from it. It's been super lonely... um I will say that... But in terms of real social support, I think it's a combination of people don't know what would be supportive. And then, you know, I will say truthfully, in my life, I really felt like people didn't want to do, what would be required.*

While many of the caregivers did not go into depth regarding the types of support they needed, this could further exemplify the normalization regarding the broken system and lack of support during the caregiving process. Samson, who was a support group facilitator for the Alzheimer's Association, explains what he believes based on his years with caregivers individuals can do to offer support, and what they need.

*It's a horrible disease, you don't see it, but if you...when you find out that a friend, or somebody you go to church with or a neighbor, if they're going through it. Just be as supportive as you can, as helpful as you can. Don't, you know...don't walk away from it, kind of. It's...offer to help and actually genuinely help. And the thing that somebody who's caring for the person would know that they need more than anything is just general support. Which means, you know, like bringing some food over there, the way you would treat with somebody who you know, who just*

*got out of the hospital or something, you know, support them, and be there for them.*

Now that we discussed these components we will examine the coping mechanisms caregivers described using to help them mitigate caregiver stress.

**RQ5: What are the major coping strategies that informal caregivers of individuals with Alzheimer’s disease practice to maintain their own wellbeing?**

**RQ5a: Are they primarily using problem focused coping strategies or emotion-focused coping strategies?**

Throughout the interviews, caregivers disclosed which major coping strategies they practice to maintain their wellbeing. The most widely shared coping strategies were categorized into the following: **therapy, exercise, getting out of the house (escapism), seeking additional information about the disease and music.** Marie discussed returning to therapy after caring for her husband Chuck.

*I had worked with a therapist, couple three years ago, and very much liked her and was able to sort of get rid of some of the anger. Because your brain tends to say, "Why am I in this situation?" You know, there are so many places where I should have jumped ship, what the heck. Here I am locked in. I had some of that happen. And I got through that. No more anger, except at the disease, which is where I think the anger was really like, this is really mean. But then I just contacted her and I'm going, I actually spoke with her this morning.*

### **Coping- Exercise**

Another coping mechanism that a lot of caregivers expressed helped them was exercise, as an outlet to allow them to work out their frustrations. According to Kim and McKenzie (2014), “physical exercise contributes to effective problem-focused coping through elicitation of positive emotion” (p. 2578). Caregivers also expressed how it gives

them control over something occurring within their lives. Monica discussed this and how she tried to keep this habit up while caring for her father.

*I do keep up with exercise and that I'm pretty religious about that. Just to make sure that I, you know, I take a yoga class, once a week. I mean, it should be 50, it should be five times a week, but I get to one at least once a week, I walk every day or almost every day. If I could keep those things up, then I feel like I've least got my own health under control. We eat pretty healthfully, and I do make all of the meals.*

### **Coping- Escapism**

The most frequently specified coping mechanism shared was the caregiver reserving time for themselves, and maintaining a sense of autonomy through escapism.

Erick shared his experiences utilizing this coping mechanism.

*Sometimes I just go for a cup of coffee and try to read the paper and gather my thoughts and just be by myself. Just have the the autonomy, if you will, the, you know, my own personhood respecting my own autonomy as a human being. Because when you're a caregiver, you're it's like, you, your personhood is like sacrificed to another.*

Marie also shared how she kept her autonomy while being a fulltime caregiver to her husband, as well.

*I've kept on painting. I'm in a painting group that meets once a month. And I have been able to do that. I now do it on the days that Chuck goes to his daycare, which is something I should tell you about. But he goes to a daycare program and so I do my painting group and I have a poetry group. And in the past couple of years, this started just before COVID I got invited to play bridge with a group of women that are really nice people and I haven't played bridge since college, but I loved bridge then and Chuck never liked games or cards. So I really haven't done that. And it's been very.. it was, it was so good for me to do something that didn't involve anything. No product like writing, or no, just playing.*

### **Coping- Information seeking**

Another common coping mechanism shared was the caregivers educating themselves and seeking information to learn more about the disease. This was reinforced

through an interview with Doris who expressed how she copes while caregiving for her wife Cindy.

*How do I cope.. um, one of my coping mechanisms is to know as much as I can, to me, knowledge is power. And so if I tell you that I've probably attended over 200 hours' worth of training, um that's on the low side. Like if I ever sat down and tried to figure it out, because I thought that was really important.*

Therefore, it is difficult to place caregiver coping strategies into specific camps of either problem-focused or emotion-focused because they are usually intertwined. Problem-focused strategies aim to remove or reduce the cause of the stressor, which can be seen through escapism and removing oneself from the situation. However, through coping strategies such as therapy (including talk therapy with friends), and exercise being used as a tool to help regulate emotions caregivers also utilize emotion-focused coping strategies to help them manage the stressors they are experiencing. Therefore, just like AD is very individualized so are caregiver coping strategies. They are individualized per caregiver and per experience.

### **Coping- Music**

Lastly, another insight caregivers shared with me during the interviews was the power the music had and the therapeutic abilities it provided for their loved ones. Music helped their loved ones cope with what was going on with the disease. Holly shared her experiences with music and how music helped her husband cope during the last stages of his life.

*They had this lady who was going around with a.. lute type of thing with some sort of a one of the medieval types that they kind of like the music that they play in a spa and stuff. It's very gentle, very pleasing. So she came and said, would you like to hear and I said sure. He was he was out, you know, he was he'd been in a coma. So day three of his his outness. And so he she played this lovely little tune,*



*you know, very, just very nice. And he was lying there. I mean, he was like I said he hadn't moved in three days. And when she was finished, he raised his hand and and he went like this (motion with hand to continue playing), he could hear- he had enjoyed it.*

Music can be therapeutic for both the individual with AD and the caregiver. Sophia talks about a time while caring for her husband Harold in which singing helped them complete an otherwise complicated task.

*And I used humor with him. And then, because he just loved to laugh. And then when it was starting to get difficult to get him to bathe himself, you know, they say music is so important. Well, you know, I don't know if you know it, but you know, my generation, "This is the way we wash your clothes, wash your clothes", you know, "All on a Monday morning". So I would sing to Harold "this is a way we take a shower, take a shower" (chuckles). Yeah, because he, I could get him in the shower, but he'd get in there and he wouldn't know what to do with himself, you know. So I would...I wouldn't go in the shower with him because it was small, but I mean, I, I would just take a washcloth then I would say, okay, put soap on and then I would sing to him. Um, and he would kind of- it was like monkey see monkey do. And so he would, you know, kinda follow my lead.*

**RQ6: What types of support do informal caregivers of individuals with Alzheimer's disease receive and what types would they find most helpful?**

The interviews exposed detailed information regarding the types of social support that family AD caregivers receive. The purpose of RQ4 was to establish if social support was something that AD caregivers suggested was needed. The purpose of RQ6 is to establish the types of support they receive and what types they suggest would be most beneficial to them. The findings were categorized into the following sources that provide social support to AD caregivers including support groups, neighbors, family/friends, and extra caregiving help.

## Support Groups

As mentioned previously, social support enhances coping performance and can lead to appraising situations as less stressful. Through talking with the caregivers most of them expressed that they are involved in some type of support group. While most of the support groups have moved online to be conducted virtually, the caregivers view them as being a valuable source of support where they have formed very personal connections. They said that it is a good feeling **being supported by individuals who have either been through or are currently going through what they are**. Annabelle expressed how and why support groups are a good form of support for her to utilize while she is caring for her husband Charles.

*We do have a support group here in Sun City that I found early on. And for a while, we were meeting virtually. And there was a support group through the Ivy, that I joined. And we met virtually, both of those were so helpful. And, you know, I feel badly for anyone who lives in the rural area where they don't have that. Because that's where I got all of my ideas and leads, and contacts to, you know, get him to the right doctor, to get him to the daycare, you know, is through those support groups and hearing other people's experiences. Now, a lot of the members of our Sun City group are survivors, their loved one has passed on, but they still come back and give support and, you know, kind of help the rest of us. Medical people, doctors will just tell you to read the 36-hour day and moments of joy. Yeah, yeah, yeah, I got both of those. That didn't work for me, I need to talk to real people who will nod and say, "Yep, been there, done that." And this is what I tried. And, you know, this is where I put my loved one, and so forth. So I think support groups were the biggest thing. And even during COVID, when we did it all, virtually, it was certainly worth it.*

## Social Support- Neighbors

Another source of social support that many of the caregivers expressed was their neighbors. Many neighbors of Alzheimer's family caregivers knew about their neighbor's loved one having the disease, often just in case the loved one happened to wander.

Alexander discussed the kindness he felt, even when he first moved into his adult community.

*When we moved, the day we moved in, this was a brand-new house and a brand new community or section of the community. And we were the fifth house to close in our, in this whole particular section of about 1,000 homes. The people across the street, their moving- our moving vans, were here at the same time. And about an hour into, you know, going back and forth out into the street and saying hi and back and forth. Marcia walks up to me, pats me on the back and she says, "I got your back (pauses)." She'd been through it with her mother, and her husband's mother. And she took one look at Natalie after having a few minutes of conversation with her, and she looked at me and she's like, "I got your back."*

Other forms of social support include friends, hiring extra help or other caregivers, and family. However, as Erick stressed he wishes that there was more sources of social support.

*I wish there was more support. I mean...as I try and answer your question, mostly, I'm struck by how little support there really is. In the past, when I tried to join caregiver groups, it seemed like they were scheduled for like retired folks. In other words, they took place in the middle of the afternoon or something. And in the past, at least, I was at school, I was teaching at a job, I couldn't participate in those. I might be able to do so now or in the near future, but they were not accessible to me.*

**RQ7: What issues concerning gender equity are related to caregiver burden for informal caregivers of individuals with Alzheimer's disease?**

In addition, the interviews revealed information regarding how caregiving is viewed as being a gender specific task. Thus, the following two categories of information were found regarding the expectations placed specifically on women in society due to gender. One being the expectations themselves, and secondly an explanation as to why this may occur through mention of the systemic ideology of women saintliness and pure nature feeding into this false narrative.

## Gender Expectations

The next topic of discussion is that of gender equity, which as previously mentioned is a serious problem within the caregiving world. One issue of being an unmarried woman in a family dynamic can include women being **expected to perform the caregiving tasks and duties**. Stacy elaborated on her experiences with this.

*Because I was not married. You know, or I didn't have children. The notion that like, you know, people say things. People will say, "Oh, gosh, you've got so much good karma, you're the best." Like, I don't need any leaping compliments (chuckles). You know what I mean like, saying, superlative, you know, or hyperbolic things about my saintliness doesn't actually absolve you of any kind of responsibility. Um, you know, so the, you know, yeah. And I would say that caregivers need to be a squeaker wheel.*

## “Saintly and Pure” Ideology

This impression of **women’s saintliness and pure nature** is systemic and feeds into why women are typically expected to pick up the caregiving roles within the family dynamic. In this quote by Stacy she shares that

*Because of the gender lens the caregivers will be women. You know, people long trained to um, you know, like, "Oh, well your feelings don't matter, just care for other things, just care" you know?*

Caregivers know that this form of gender inequity occurs regularly and oftent adds to the demands of balancing a job, kids, etc., in addition to the challenging demands of providing caregiving. A statement that summarizes this issue best is expressed again from Stacy’s interview:

*If you think about the gender lens on this, it just gets really, really depressing. Because the people that get sandwiched you know, it's the girls.*

**RQ8: What issues concerning public policy are related to caregiver burden for informal caregivers of individuals with Alzheimer’s disease?**

Public policy is another component impacting caregiver concerns. The section the information was coded into two different focuses. One being the **financial implications of caregiving** and secondly a common mentioned policy failure is the **lack of coverage by insurance**. And while there was some discussion about current caregiver relief bills and information concerning public policy, the family caregivers in this study are urging faster action be taken. Samson, who was a support group facilitator for the Alzheimer's Association, as well as owns an at-home care company, explained.

*Well, in my kind of the professional side of it, at the provider side, people reach out to us all the time. You know, they need help, they need care at home. And then so that's a whole.. either they've come to that on their own or somebody else in their family, or somebody else has told them, you know, it's time for you to get some help. You can't do this on your own anymore. That's one thing on the professional side, the other side is just almost everybody that's going through this early on, you know, they've never gone through it before. Why would..they don't know anything about care. And I've heard it once and I've heard it a million times, it's like, "Well, I didn't know there were organizations like this that can help, you know, come into the house and help Mom." There's less of that now, but you know, a dozen years ago, people would go, "I didn't even know agencies like this existed." But just all the other stuff, you know, the question that you hear over and over and over again, it's like, "Well, does Medicare cover this? Does my insurance paid for this?" And it doesn't, generally speaking, insurance doesn't pay for long term care whether it's at home or in a facility. Except at the very end, when you know, if you're in a nursing home and you're indigent, you've run out of all your money. So people don't know the financial stuff, they don't know about the legal stuff, they don't know about the medical part of it, and how to get care.*

**COVID-19 Policy Issues**

Lastly, a prominent topic mentioned throughout all of the interviews concerning public policy was **COVID-19** due to its relevance in society today and the impact that it has had on caregivers. The following issues were addressed within the interviews: how

the **pandemic caused a lack of socialization** for individuals with AD that went unaddressed, the **impact of lockdown on** individuals with AD and the **lack of access to get in and out of facilities, AD individuals remembering safety precautions** (such as masks), and lastly how the **jump to online support groups was beneficial for AD family caregivers**. COVID-19 had a tremendous impact on family caregivers, in fact some of them have also shared that they lost their loved one to the disease. Many caregivers were upset with the way COVID policies were handled and believed that individuals with AD were an afterthought. The preparation to protect them in case anything like this should happen should have already been thought out.

### **Issues with Accessibility and Socialization**

Below Alexander recounts what occurred when his wife Natalie got sick with the virus and how getting access to visit his wife became impossible.

*When I saw her on Christmas day, it was like she had no idea..really who I was. And we were facetimeing with the children and the grandchildren. It was like totally gone. And a couple of days later, they had pretty much a major run of positive tests in the whole nursing home. And while I could have gone in my children told me I wasn't allowed to, because I wasn't vaccinated. And it just didn't make sense to walk into a place like that. Um so we were back to window visits, and she got her first COVID shot on a Monday. And on Tuesday, her test came back positive. And they moved her into an isolation facility, which they had created. And she was there for about 10 days. And the first five days were.. she was, you know, tearing her way around, pacing up and down the halls. But she, you know, she got her 10,000 steps in every day. And then she quit eating, had trouble breathing... I mean, it was just, you know, right down. And it was...then she went straight to morphine, and atropine. And three days of that, and that was it. Again, I could have gone to visit her... I was going nowhere near that place. I just... my job was to continue to live, I couldn't give her anything.*

Similarly, Sophia talks about the difficulty she had accessing her husband Harold during this time.

*So when we moved back last year, he was coming out of stage five and going into stage six. It was getting to the point where I needed to consider placing him in a care facility and I had him on a waitlist. Unfortunately, COVID hit the same time. And the care facility that I had chosen had an opening, but they should not have taken him because they had already locked down. Not letting visitors in.. And they took him in, he lasted there 24 days. They locked him in a room when they started locking. Yeah, this is a sad...He was only there 24 days. I was allowed to FaceTime... you know, they kept telling me he was fine, blah, blah. So on May 2, they call me to tell me that he had fallen and he had gone in April 8. What did I want to do with him? Excuse me? You know, I thought Harold was going to be there for at least a couple of years, and that I'd be able to go... they should have told me. We've got good news. Bad news. We have an opening. Bad news is we can't take him right now, because we locked down. So I said send him to the hospital. The hospital called me back. I couldn't go because of COVID. They said he has severe dehydration, severe UTI. And by the way, we tested him and he tested positive for COVID. So anyway, so five days after I told the hospital, the hospital wanted to put a feeding tube in him, and I said no. And I didn't even go to see him in the hospital because they said I had to be far away from him. I could just see him from a distance. I wanted to remember him the way it was when I dropped him off, not the way he was... (starts tearing up). So anyway, he died five days after he went into the hospital.*

### **Issues with safety precautions**

As if it was not hard enough for caregivers, having their loved ones not remember to take safety precautions was also something discussed related to the pandemic, as expressed by multiple caregivers including Tammy.

*Rebecca would go to the store with me a lot. Even during the pandemic when we'd go and make that every other week trip to the grocery store. It wasn't good. She can't remember to keep her mask on. Next thing you know, she's got it off. Can't remember why she has it on, you know. So that made that even more difficult. So then I just started going on my own. We've kind of gotten back, now that it's not as bad now, of going shopping sometimes together. Which is good.*

The pandemic hit Alzheimer's caregivers and their loved ones hard, with most caregivers suggesting that the lack of socialization and stimulation increased the progression of their loved one's disease. A theme that stemmed through an abundant amount of the COVID-19 responses was one including guilt and self-blame.

## Advice from AD family caregivers to future caregivers

In addition to the research questions, information was also collected in regard to advice present or past caregivers would want current caregivers to know. First, many caregivers expressed the **importance of telling others about the diagnosis of the disease**. Caregivers stressed that this is important in order to obtain the support that they need from others. Samson, the group facilitator advised caregivers to-

*Tell everybody you know...tell your children or tell your siblings, tell your friends, tell your neighbors, everybody what, you know. Be open about it the way you would if your loved one had a cancer diagnosis.*

Doris also shared similar advice,

*And so I honored Cindy's request, not to tell anyone other than my immediate family. And when she made a face, I was like, where do you think I'm going to get support for what I'm going to need? From my family. So I'm not... you know, they all need to know. And I said, and from my friends, these are the people that I am going to tell because I need support.*

Caregivers also stressed the **importance of planning**, making sure a structure is in place for caregiving and things are in order. Tiffany shared some insight into how she communicated with others about her husband Jack, without mentioning the disease constantly in front of him.

*I did print out little, little cards. Um, and I have a stack and our caregiver has a stack and it says something to the effect of, and I would kind of hand it to, like, you know, a waitress or something. I've used it twice. Um, you know, or maybe somebody that he's trying to have a conversation with unsuccessfully...you know, that maybe is standing near us at the bar, or outside, or at some event or something. That says, um, it says my husband, um, you know... I can actually get it and I can tell you exactly what it says hold on. Just a second (goes to find card). Okay, so the card says, "My husband, Jack, has dementia and difficulty with speech. He enjoys getting out, meeting new people, and laughing. We thank you for your patience." We went out to dinner with Jack's family, and the waitress made some sort of comment on how she wasn't sure if she should serve Jack because he appeared to be drunk. And, um, (chuckles) No, he's not. And so I*



*finished the card out and my brother-in-law handed it to her and she was like (makes face that demonstrates realization, mouths "Oh").*

Therefore, communicating about the disease and not being ashamed was a constant advice that caregivers provided for future caregivers. In addition, caregiver advised caregivers to **keep living their lives** and not to waste it. Alexander elaborated on this:

*When I first got there (to the support group), it was like the number we were using was 40% of caregivers die first. Well, that had been refined over the last couple of years. At our age range 70% of caregivers die first (pauses). Think about that, that's...you know, your job is.. your primary task is to outlive the patient. And if you don't take care of yourself, then, you know.. we already, you know, to be horribly blunt, the patient is going to die. So are you, but you have a quality of life remaining. That can continue to stay active and get better. Make a big sign and put it on the refrigerator. 70% of caregivers die first. Your goal is to not die. Your goal is to live. You have to keep reminding yourself, that you count.*

## CHAPTER FIVE

### Discussion

The findings of this research reveal intimate details regarding the complex experiences and demands of caring for someone with AD. In this study, one of the major findings revealed by AD family caregivers was that they regularly accommodate the AD patient (consciously and unconsciously) to communicate with their loved ones with AD through adjusting, redirecting, and compensation. In addition, other significant findings from this study include evidence surrounding the ostracization AD family caregivers feel, as well as the need for specific tailored informational resources regarding how to communicate to loved ones with AD when they are engaging in inappropriate behaviors (BPSD). Lastly, this study revealed that most AD family caregivers believe that their loved ones with the disease were challenged by many of the social-distancing COVID-19 policies and practices. The inability to socialize, the inability to check on loved ones in facilities, and the lack of materials for caregivers to utilize to help explain COVID precautions to AD care recipients were some of the most valuable points mentioned about challenges faced during the pandemic. Although, one positive note regarding the pandemic was that AD family caregivers shared that the introduction of virtual support

group meetings had been very beneficial to them and that they were easier for them to attend than the in-person meetings.

This study reinforced the findings from previous research regarding how behavioral and psychological symptoms of dementia (BPSD) can act as stressors for caregivers and can increase the overall burden that they experience. It also revealed how caregivers need more informational resources focusing on how to communicate with their loved ones effectively when they engage in inappropriate behaviors. During the study when asked to elaborate on specific negative communication experiences with the AD care recipient, caregivers did not typically focus on these behavioral abnormalities and focused mainly on the lack of substance within the conversations themselves. The caregivers interviewed expressed a deep ache and yearning to regain the person that they lost. Hence, when positive communication experiences were shared they typically were indicated by a sense of temporarily regained normalcy between the care partner and care recipient.

All caregivers expressed or exemplified throughout the stories they shared some degree of accommodating to their care recipients' communication needs, however, they expressed this as being both conscious adjustments and inevitable unconscious adjustments. This reinforces the Communication Accommodation Theory in part, showcasing that caregivers understand that the interactions that they have with the care recipient mutually influences both of them. It also illustrates how their communication response can trigger either a positive or negative interaction with their loved one, causing them to alter how they communicate to them. However, AD family caregivers revealed

that the amount of proper information regarding how to accommodate to AD care recipients effectively in certain situations is lacking. Alzheimer's family caregivers expressed that they would like to obtain practical information regarding how to address and communicate with their loved ones when their behavior is inappropriate. They also would like additional information on how to communicate through difficult everyday tasks effectively, and information regarding financial assistance they can receive. This is important because it suggests that this is the kind of content that AD caregivers state will help alleviate some of the burdens and stressors they experience. This kind of pertinent family caregiver information should be made widely available to caregivers to aid with their communication adjustment when faced with difficult situations and to make their communication with their loved one more effective (Lanzi et al., 2017). However, this information truly represents a much deeper issue involving a how a broken health care system is placing essentially all of the burden of care on caregivers who are often least able to cope with these burdens. These caregivers have to obtain information and support, typically on their own, and many of the additional materials/services are inaccessible due to a lack of insurance coverage and care. These overarching limitations within the healthcare system that neglect the needs of family caregivers often leads to caregivers blaming themselves for not being able to do enough for their loved ones. When in reality, there are many systemic health care system policies and programs that need to be adjusted to help alleviate some of the stressors caregivers experience.

After reflecting on the objective versus subjective burdens and the stressors that caregivers experience daily it is undeniably clear that the objective burdens such as time

or financial strain often trigger the caregiver to experience a degree of subjective burden. The fewer resources available to caregivers, whether it be lack of additional support, time, or money can cause the caregiver to experience high burdens of care. This is important to understand because failure to provide caregivers with practical tools to reduce the objective burden that they are experiencing can trigger them to experience a higher degree of caregiver burden overall. It is also important to mention that while caregivers are coping with these objective or subjective burdens it is difficult to place caregiver coping strategies into specific camps of either solely problem or emotionally-focused because the coping mechanisms are so intertwined. Caregivers expressed therapy, exercise, escapism, and knowledge as being the prominent ways in which they deal with all of the stressors occurring around them. As mentioned previously, problem-focused coping strategies aim to remove or reduce the cause of the stressor, which can be seen through escapism and removing oneself from the situation or problems. However, strategies such as therapy (including talk therapy with friends), and exercise could be considered coping mechanisms used to help regulate all of the emotions that the caregiver is experiencing throughout this process. Although coping mechanisms such as obtaining additional knowledge could be implemented by caregivers in an attempt to reduce the objective burden they are facing, most of the coping mechanisms utilized are to address the subjective burden or the caregiver's current perception and feelings towards providing care.

Lastly, the importance of social support was also reinforced within this study, specifically through the use of Alzheimer's family caregiver support groups. This aligns

with previous research regarding social support mentioned and the benefits that it can provide to caregivers (Schulz and Williamson, 1991; Lakey & Cohen, 2000; AARP, 2020). These support groups (mostly now virtual) and neighbors were the most commonly referenced forms of support by AD caregivers in this study. Accounts of family strain were shared during these virtual support groups, reinforcing the notion that the nature of the prolonged illness, the financial implications of the disease, and daily decision-making regarding the care recipient can cause familial strain. When approached with the question regarding social support many caregivers did mention that they do experience a feeling of being ostracized by peers and certain family members after their loved one received the AD diagnosis. In this study AD caregivers talked about wishing there was more social support offered to them. This is important to recognize, and hopefully, in the future, there will be additional training and materials provided to families to help them navigate through this process together.

This feeling of ostracization that caregivers express that they feel extends even further than just within the familial unit. The stigmatization of individuals with Alzheimer's or dementia within society is still prevalent. And while it may be slowly decreasing, caregivers shared that they believed that AD is still stigmatized and is not treated like other diseases. Almost every caregiver interviewed shared that when their loved one was diagnosed with AD they requested to them to not tell anyone else about the diagnosis.

## What caregivers want the public to know about AD

### AD is a disease

At the end of the interview Alzheimer family caregivers were asked the broad question, “What would you like the public to know about Alzheimer's disease?” and two prominent categories of answers were formed. The first being that they would like the **public to understand that AD is a disease** and should be treated as such. Family caregivers stated that due to the long-term nature of AD and the absence of overt pain for others to see it is often disregarded as being a disease, as illustrated by the following excerpt from an interview with caregiver Erick.

*I think that people are most responsive to notions of pain, like, you know, you have cancer and you're in pain, and, you know chemotherapy. All of that stuff is horrific and a painful death. And, you know, and God knows, I mean, I understand that, but this is, I have a feeling that it's the long term quality and the absence of overt pain, that allows society to sort of bracket this, to sort of put it aside as you know, eh it's too bad, but not to really grapple with it's impact on the person, and the person's family, and the caregivers around them.*

Another excerpt from the interview with caregiver Noah is illustrative, in which he expressed what he would like the public to know about Alzheimer's disease.

*It is a disease. And as I said earlier, you wouldn't be embarrassed to say, My wife has cancer, or I have cancer. But people are embarrassed to say- it's not that you're going crazy. It's that a disease has happened in your brain. And you don't have the capabilities that you once had. And often so many of these people in our group, keep commenting about. He or she was so smart. So involved in so many things such, so capable and today... Well yeah, this is the disease. And it seems that there are a number of people who are very, very smart, and they have the disease, and...it's not that they're going crazy. It's that they have a disease.*

The stigmatization of AD is prevalent in the literature (Rosin et al. 2020).

However, courtesy stigma is something I did not anticipate being mentioned within the family caregiver interviews. The literature refers to the term courtesy stigma that is often

applied to family members and/or caregivers of individuals with Alzheimer’s disease as public disapproval for associating with a perceived stigmatized group (Park and Park, 2014; Parks and Smallwood, 2021). Hence, this form of stigma helps to explain the ostracization and isolation AD family caregivers expressed that they feel while caring for their loved one. However, this also raises the question, why is AD stigmatized?

This stigmatization of the disease could stem from multiple different societal aspects, but it appears that the fear and uncertainty that surrounds the disease could certainly trigger feelings of stigma. The conceptualization in society regarding “normal” versus “non-normal” aging certainly could be an underlying reason for this fear that leads to individuals with Alzheimer’s disease and their caregivers being stigmatized (Behuniak, 2011; Rosin et al. 2020). The detrimental ideology that AD is a factor of “non-normal” aging can, unfortunately, result in individuals with AD being viewed as “non-persons” (Behuniak, 2011).

### **AD is more than Memory Loss**

Secondly, caregivers stated that they would like the **public to realize that the disease is not just about memory loss**. The following quote is a continuation of the excerpt from Erick. He expresses how AD “**robs” a person of the identity** of their past self. This was another common theme found when AD family caregivers described the disease.

*I would want them to know that it, entails a long term, complete cognitive breakdown. And that it impacts memory, sure. But firstly, when you think about memory, it's important to know that memory is...more impactful than just remembering what you had for breakfast yesterday. It's like remembering where you live or, when you're home, or what a staircase is, and how you approach it or, you know, or what a toilet is for. Why is this man asking you to sit on this*



*white seat all the time? And that it goes way beyond memory, it robs you of language. It robs you of your, your self control and you know, in terms of personal hygiene, and it it threatens your own sort of personal sort of dignity, if you will. You're always subject to being you know, pushed around and manipulated and coaxed, people are always around. You feel trapped inside a mind that won't let you communicate. You are sad, you're deeply, deeply sad by the knowledge that something is wrong, but you can't even say what it is. I mean, it's really a hell. Um that you're going to disappear as an identity as a personality and identity...you are going to slowly become invisible to yourself and to those around you, and you're trapped inside as it's happening.*

In addition Hannah, a granddaughter caring for her grandfather with AD

worked in a nursing for dementia patients. However, the other participants had to find

this out on their own, by being thrust into the position of caregiver by an uncaring

system. Hannah shared the insight and training that she currently uses to make her staff

understand that AD is more than memory loss.

*I love the dementia live training at my current job, because my boss was supposed to do it and she didn't want to and knew that I had the background, so she just put that on me. And so what that is, is you wear the pokey things in your shoes to represent neuropathy. You have the headphones on to represent hearing loss, you have the goggles on to show tunnel vision. And then you have these big like, contractor gloves on to try to touch stuff and to realize your, like fine motor skills might be gone or whatever, then you have to do different tasks and experience what it's like. And for staff that would come in that maybe didn't have any experience or you know, entry level positions. It would be kind of shocking to them...This is like a lot of people I think, in the general public just think, oh, it's when they lose their memories. But it's actually physical too. So that training, it was always interesting to see how staff react because they learn more. It's not just, like mental, it's also physical. So I think that would be the main thing I'd want to tell them (the public) is like, it's not just they lose their memories. It's actually their whole body is deteriorating because their brain is deteriorating. Like, the whole thing changes. And...I think just talking about those kind of four points that you you know, you lose your vision, you lose your hearing, you lose your ability to use your hands, you have pain, you know, like it's not just grandpa's sitting in a chair, and he forgets yesterday. You know, it's more than that. And that kind of also shows like, yeah, if you had that every day, and you went through life, trying to get ready, trying to eat, trying to do whatever, like, there's a reason you might be a little angry and that you might swear or you might say something inappropriate.*

These are misconceptions and myths that AD family caregivers would like to debunk.

This is important information because this is what should be highlighted and focused on in Alzheimer's awareness campaigns. It is time that we as a society change the way we think about and approach the disease.

### **Contributions to Theory**

For centuries stress and coping studies have focused on mostly just individual processes and not how it can be reciprocal. It is important with a disease like AD to recognize that the ways caregivers adjust their communication with their loved ones can either trigger a “positive” or “negative” interaction. This interaction, depending on the outcome, can contribute to the stress and subjective burden that the caregiver is feeling while caring for their loved one with AD, which in return, can influence the quality of care that the care recipient receives in return. This information showcases the importance of accommodation, change, and fluidity from caregivers as well as reinforces the importance of the Accommodation Theory.

This study also confirms, through the use of short story narratives, the idea that caregivers and care recipients mutually influence each other throughout the process of the illness, as stated in the Developmental–Contextual Model of Dyadic Coping. However, as mentioned previously, due to the nature of the disease AD care recipients cannot adjust their communication. Therefore, the caregiver needs to react and respond to stress appraisals appropriately because it will ultimately impact both parties involved.

Additionally, as stated in the Stress and Coping theoretical approach to Social Support, increased social support enhances coping performance and leads to appraising

situations as less stressful. Therefore, caregivers who are feeling ostracized by peers and loved ones post AD diagnosis feel more stress. The ability to accommodate, the amount of social support, and coping techniques all influence the amount of burden that a caregiver experiences. However, in addition, societal and external factors such as public policy, gender, family, and financial dynamics all place additional strain on the caregiver. This study also reinforced the Gender Schema Theory in revealing how caregivers know that certain responsibilities were only given to them, versus other family members because of societal expectations in regards to gender. Societal expectations should be the same regardless of gender. However, from a young age, women are expected to be compassionate and caring. These ideals young girls are taught and pressured into by society. They are expected to be caretakers, to be nurturing. And if they deviate from this societal expectation it would be seen as inappropriate, or backward (Cherry, 2020). It is important as a society that we become more comfortable discussing the division and expectations of caregiving within families and fairly distribute caregiving responsibilities among all family members, not just women.

### **Limitations and Directions for Future Research**

This study had several limitations especially regarding the recruitment of participants. One of the major challenges for the study was gaining access to the support group facilitator contact emails through the Alzheimer Association website. They do a respectable job of making sure caregiver and facilitator information is kept confidential. However, this made it impossible to obtain emails from certain zip codes. Additionally, only the locations of support groups that had email addresses of the facilitator listed were

considered for the research study, which limited the respondent pool. The recruitment strategy worked, however, with more facilitators responding to the recruitment emails once the study was listed through the Alzheimer Association research website, TrialMatch. Once a location was selected and an individual showed interest in participating most of the sample that followed then came from participants talking to one another and convincing each other to participate. Therefore, the majority of the participants came from the same areas, which could have contributed to the lack of diversity and an overarching racial homogeneity within the sample. Future research should explore the impact of the family caregiving experience specifically for minority caregivers and care recipients. As mentioned previously, Black Americans are about two times more likely than White Americans to have Alzheimer's and other dementias, and Hispanic Americans are about one and one-half times more likely (Alzheimer's Association, 2021). In fact, in the 2021 Alzheimer's Association Facts and Figures report it reveals that more than one-third of Black Americans (36%), one-fifth of Hispanic Americans (18%) and Asian Americans (19%), believe that discrimination is a barrier to receiving Alzheimer's care. In addition, more than half of the non-White survey caregiver respondents say that they have experienced discrimination when navigating health care settings for their care recipients (Alzheimer's Association, 2021). According to the Alzheimer's Association (2021) report minority populations expect and experience more barriers when accessing dementia care, have less trust in medical research and are less confident that they will have access to medical professionals who understand their ethnic and racial background and experiences. While there is research now being done regarding

racism and discrimination regarding AD care, certainly more needs to be conducted. Therefore, exploring the experiences of minority caregivers and individuals with AD is extremely important in helping end AD for all. In fact, without diversifying representation in AD research, minority individuals are likely to lack access to treatment, prevention, and care innovations (Alzheimer's Association, 2021). To accomplish this diversification of AD studies, researchers should consider contacting support group facilitators by phone in addition to via email, since phone numbers can be tied to geographic areas that represent different racial populations. Finding support groups outside of mainly the Alzheimer's Association might also help to diversify the sample. This could be accomplished by establishing relationships with existing organizations and resources in Black communities, indigenous communities and communities of color and looking at the opportunities for research-based partnerships.

In addition, while this study attempted to represent multiple different caregiver relationships, to examine caregiver perspectives from different relational lenses, the most commonly represented caregiver relationship perspectives in this study were from spouses. With the number of "sandwich generation" caregivers growing, another future participant pool to consider interviewing further would be adult children caring for their parents. There are specific support groups specifically tailored for adult children caring for their parents, therefore reaching out to these groups specifically would be a great start. Unsurprisingly, all of the adult child caregivers who participated in this study were daughters. This supports the notion proposed by the Gender Schema Theory, however, I believe it would be insightful to interview sons who take on caregiver roles for their

parents in the family dynamic about their experiences as well. It would be interesting to compare the experiences to one another, as well as obtain the caregiving experience from such a niche population. A way to accomplish this may be future researchers could tailor a study and recruit participants on a wide scale through a social media campaign and explain how obtaining information from sons who are also caregivers is crucial for researchers to further understand this gendered phenomenon. Overall, more research needs to be conducted with a variety of different Alzheimer's family caregivers because they are important sources for learning more about the communication demands of caring for loved ones who are confronting AD.

### **Practical Implications**

The emotional toll that accompanies a disease such as Alzheimer's disease is tremendous. Throughout the interviews, caregivers expressed that they know AD takes a devastating toll on both care recipients and caregivers. According to the Alzheimer's Association (2021), caregivers who perceive higher strain due to care responsibilities were at higher risk for death than caregivers who perceive little or no strain. And previously mentioned Alzheimer's and dementia caregivers experience higher levels of stress. The stressors that caregivers mentioned included managing daily living tasks, navigating through inappropriate and problematic behaviors with their loved ones, and personal demands that the caregiver experiences both internally and externally. These stressors feed into the objective and subjective burden that caregivers experience.

The need to provide the information that family AD caregivers need is crucial. Information that discusses how to negotiate around inappropriate or difficult behaviors

that occur due to behavioral and psychological symptoms of dementia (BPSD). How to communicate during situations of violence, wandering, aggression, and racism. How to be aware of stimuli that may impact your loved one. The practicality of the information disseminated by organizations needs to be revisited in order to aid the communication between the AD family caregiver and the care recipient. This communication adjustment can extend further than family Alzheimer's and dementia caregivers as well.

As shared in various interviews AD family caregivers believe that nursing care staff also need additional training in adjusting their communication with AD care recipients, and this could start with nursing assistants. Nursing assistants are the primary caregivers to AD patients living in nursing homes and assist individuals with bathing, dressing, housekeeping, food preparation, and other activities (Alzheimer's Association, 2021). Many direct-care workers do not receive proper or enough training to properly carry out their jobs (Alzheimer's Association, 2021). Therefore, adjusting the training to be more tactful and requiring nursing assistants to participate in more training, that is paid, would aid in reducing this information gap. Furthermore, as the Alzheimer's Association (2021) states, one in 5 caregivers of people with Alzheimer's or other dementias (22%) report problems dealing with a bank or credit union when helping to manage the finances of people living with dementia. This is unacceptable and additional tools need to be provided for caregivers to help them financially in areas of policy development, insurance, adult care, etc. This aid may come in the form of updating public policies to assist family Alzheimer and dementia caregivers more by providing additional

monetary assistance or employing credible individuals with monetary expertise to help family caregivers develop a financial plan.

Additionally, when the individual is initially diagnosed with AD facilities should employ an individual to aid families in deciding the division of caregiver duties across the family. This would ensure primary family caregivers would get a certain amount of personal time as well as be a way to decrease the unfair genderization of caregiver duties.

### **Conclusion**

A study based on two years of fieldwork, between March 2003 – March 2005, in the northeastern United States disclosed how family caregivers are essentially a “shadow workforce,” and discussed how they have to manage a plethora of tasks include being medical record keepers, paramedics, and advocates to fill the gaps that occur in our current healthcare system that is uncoordinated, fragmented, and often depersonalized (Bookman & Harrington, 2007). This is why it is so important to offer this space to give this shadow workforce a voice. Alzheimer's disease is increasingly becoming more widespread and many of us may find ourselves placed in caregiving roles. It is time we as a society stop overlooking the voiceless and provide them with aid and outlets to share their experiences to further understand what is needed to combat this daunting disease.



## **APPENDIX A: INFORMED CONSENT**

**TITLE:** The Role of Communication in Informal Caregiving for Family Members with Alzheimer's Disease

### **RESEARCHER'S NOTE**

The researcher has also had a loved one diagnosed with Alzheimer's Disease for 15+ years and is dedicated to providing more understanding to the general public about the disease. It is for this reason that extra care and caution will be given in conducting this study.

### **RESEARCH PROCEDURES**

This research is being conducted to understand the role of communication in the family caregiving relationship between Alzheimer patients and caregivers as well as to examine how they use communication to maintain their own wellbeing. The objective of this study is to understand the Alzheimer caregiver experience, how communication plays a role in this experience, the coping mechanisms utilized by family caregivers, as well as the social support that caregivers need and receive. This study provides a framework to prepare future informal caregivers with useful insights from present-day informal caregivers. If you agree, you will be asked to participate a one-on-one in-depth interview with the researcher that will take approximately around 30 minutes to 1 hour. The interview will be conducted virtually, and the information shared will be kept confidential. The researcher will conduct all interviews. The interviews will be recorded, and notes will be taken during the interview. Please inform the researcher of any accommodations to ensure a comfortable experience in the study.

### **RISKS**

There are minimal risks for participating in this research. The risks include psychological discomfort and when discussing topics pertaining to relational conflicts, caregiver experiences, and mental health. To ensure your rights as a participant are respected, you may skip over questions you do not feel like answering or to leave the interview at any time. There are no physical risks or exposure to physical injury or harm in this study. Please inform the researcher if you require any kind of accommodation to minimize physical or psychological strain.

### **BENEFITS**

There are no direct benefits to you for participating in this study. This study's goal is to improve the knowledge and understanding regarding the Alzheimer family caregiver experience, which is often an overlooked workforce.

### **CONFIDENTIALITY**

- The data in this study is confidential. Confidentiality will be achieved this way:

- Aliases will be used to identify you in recordings, field notes, transcriptions and published data.
- All interviews will be conducted and recorded by the researcher.
- Transcription will either be conducted by the researcher, research assistant/s or professional transcription services.
- Only the researcher and research advisor/s will have access to the data gathered such as field notes, transcriptions, audio tapings and artifacts.
- Data collected will be stored in a secure location and destroyed 5 years after the completion of the study.
- Due to mandatory reporting requirements, the only conditions in which confidentiality cannot be ensured is if you indicate intend to cause serious bodily harm to yourself or another person.
- While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of technological transmission.
- Participants may review Zoom's website for information about their privacy statement. <https://zoom.us/en-us/trust/privacy.html>
- The de-identified data could be used for future research without additional consent from participants.
- The Institutional Review Board (IRB) committee that monitors research on human subjects may inspect study records during internal auditing procedures and are required to keep all information confidential.

### **PARTICIPATION**

As requirement, you should either be you must be 18 years of age or older in order to participate, as well as a past or present family caregiver to someone diagnosed with Alzheimer's disease and/or dementia. Your participation is voluntary, and you may withdraw from the study at any time and for any reason.

### **AUDIO TAPING**

By signing this informed consent form, you are also consenting to being recorded during the interview. The record file will be stored securely. The recording will also be identified by aliases. The recordings will be destroyed after being fully transcribed.

### **CONTACT**

This research is being conducted by Henri Huber at the Department of Communication at George Mason University. She may be reached at 540-272-3284 or [hhuber4@masonlive.gmu.edu](mailto:hhuber4@masonlive.gmu.edu) for questions or to report a research related problem. The principal investigator for the study is Dr. Gary Kreps who can be contacted for further inquiry at 703 993-1094 or also via email at [gkreps@gmu.edu](mailto:gkreps@gmu.edu). You may contact the George Mason University Institutional Review Board office at 703-993-4121 or also at [irb@gmu.edu](mailto:irb@gmu.edu) if you have questions or comments regarding your rights as a participant in the research. This research has been reviewed according to George Mason University procedures governing your participation in this research. You have the right to obtain a written copy of this consent form if wanted as well. The researcher will make a copy available to you for your personal records.

### **VALIDATION**

The researcher would like your assistance to verify the accuracy of the study's findings and interpretations. If you would like a copy of the study's preliminary findings, please indicate below.

**CONSENT** I agree with all that has been said, all of my questions have been answered by the researcher and, I agree to participate in this study.

\_\_\_\_\_ Signature

I would like a copy of the findings: Yes • No •

I consent to being recorded for research purposes: Yes • No •

\_\_\_\_\_ Date of Signature

## APPENDIX B: INTERVIEW GUIDE

### Tell me about yourself

- How would you identify (gender, age group, nationality/race)?
- How long have you been a caregiver? Was it something you expected to be doing?
- Tell me about your loved one you care for. What type of relationship (child, sibling or spouse) do you have to the care recipient?
- How long has your loved one been diagnosed with Alzheimer’s disease?

Area of Interest	Question	Probe
<b>RQ1: Communication</b>	Please describe an incident in which you believe you had a positive/ negative communication experience with your loved one since becoming their caregiver.	<p><i>What made this particular communicative interaction different than others?</i></p> <p><i>In your opinion what makes it easier/more difficult to communicate with your loved one?</i></p>
<b>RQ2: Accommodation</b>	Do you believe that you need to adjust your communication with your loved ones to communicate effectively with them because of the nature of AD?	<p><i>If so, can you give some examples as to how you have done this? If not, please explain why you believe communication adjustment is not needed when caring for the patient.</i></p>

<b>RQ3-4: Needs, Challenges, &amp; Stress</b>	What are some of the challenges/ stressors that you face daily while caring for yourself and your loved one while being a caregiver?	<i>What do you believe will assist in mitigating some of these stressors that you face?</i>
<b>RQ5: Coping strategies</b>	Could you explain a few examples of coping techniques that you utilize to maintain your wellbeing? (examples: talk to others, listen to music, get out of the house/escape for a certain period, try to come up with solutions to the problem at hand).	<i>Why do you believe that this coping strategy works for you?  Do you think exposure to different methods of coping would be beneficial for you? Why/Why not?</i>
<b>RQ6a-c: Social Support</b>	Can you describe a memorable example in which you felt supported while being a caregiver?  (Either by other family members, friends, coworkers, doctor, or even strangers).	<i>Which types of support have you received that you believe have been the most beneficial for you?  Who and where did you obtain this support from?  Do you believe that you are receiving the types of support that you need? If so why, if not what type of additional support do you believe would benefit you?</i>

*Closing questions*

1. If you had to describe your caregiving experience in 3 words what would they be?
2. What is something that you would want the public (who generally does not have a lot of insight into Alzheimer's disease) to know about the disease, or individuals who have the disease?
3. Are there any additional comments you would like to share?

## APPENDIX C: SAMPLE INTERVIEW

Thu, 9/2 6:13PM • 1:03:15

**Researcher** 00:15

Hello, Erick, how are you?

**Erick** 00:20

I'm good. How are you?

**Researcher** 00:21

Good, good. Thank you for taking the time today to meet with, with me also beautiful paintings in the background. I can't help but notice those.

**Erick** 00:32

I wish they were mine, but they're not.

**Researcher** 00:35

Well, they're beautiful.

**Erick** 00:36

Yeah, they're lovely. The painter is very talented. I rent this place, it's COVID related, and it's also Alzheimer's related.

**Researcher** 00:46

Oh, Okay.

**Erick** 00:46

To, during, during the pandemic, when I had to teach, I needed a place from which to teach. That was outside of the house because I had a caregiver, caring for my wife, and things are too hectic in my small apartment to teach from home. So I rent this place, and I work here.

**Researcher** 01:07

Yeah, well, that's, that's a pretty cool space you got there.

**Erick** 01:11

It's very nice.

**Researcher** 01:12

Thank you for meeting with me today. So I am going to kind of go over a little bit about that form I sent you, I did receive it the informed consent form. I just want to touch on a few things regarding that. And then I'll just tell you a little bit about myself, just so you kind of know who you're talking with. And then we'll jump into kind of talking about you and your experiences, because that's really what I want to get at. So and make sure we have plenty of time for. So, um, the study is for my dissertation. So I am a student at George Mason University in Northern Virginia. And I'm working on my dissertation research. And the purpose of this study is to interview Alzheimer's caregivers, specifically family caregivers, and kind of get their insight in regards to their experiences. So for instance, you know, positive communication experiences and negative, that they've had with their loved one throughout being a caregiver, as well as coping mechanisms that they, you know, that you might be using, or social support that you have received while being a caregiver and, and could use. And the whole point or premise of getting this information is to be able to have, one stories that other individuals who are just being placed in this role can relate to, but also, you know, give them some advice and guidance as to what to expect, because the disease is more prevalent now than ever, and there are going to be more people that are going to be stepping into this caregiver role. And some, you know, most of them are not, if not, probably all of them unexpectedly. And so, um, you know, giving them some sort of one, you know, something they can relate to, and then also some insight as to what's worked for others and that sort of thing. I do want to let you know that your rights as a participant are important to me. And I just want to make sure that you know, that, you know, if at any time you want to skip over any questions, or you know, leave the interview, you're more than welcome to. I just want to make sure you know that. And then the study is confidential. So, um, you know, your name and your wife's name, and any, you know, anything that you want to keep anything else confidential, I will keep confidential and private. So, just want to make sure that's known before we start, I am recording the interview, just for my own purposes. You know, no one else will have access to this. It's going to be on my computer password protected. And I will be taking notes as well. But the recording is just in case I miss anything while I'm taking notes down. And, yeah, with all that, I do want to ask you, if you would verbally consent to being in the study?

**Erick** 04:18

Yeah, I have some questions, based on what you just said. Is this a good time to ask them?

**Researcher** 04:24

Yes.

**Erick** 04:25

Okay. Well, firstly, thank you for conducting this interview and the study behind it. What is what program are you in, are you like a gerontology student? What is, where is this going?

**Researcher 04:43**

Yeah, so I am I study health communication at George Mason. And that's kind of a you know, some people don't know what that means, or you know what that is and basically, one field that I'm interested in going into is health campaigns. And, you know, campaigns meaning, bringing more awareness to Alzheimer's disease, that sort of thing. That's just a future career goal. But I study health communication. And so that's why some of the questions and information I'm gathering is regarding communication, how you're communicating with your loved one, what, you know, what may cause them to react in certain ways, that sort of thing. And so that's kind of the information that I that I'm gathering from loved ones who are, you know, you know, I do realize this is someone that you love, and this is a family member, but also you are also in that caregiver role as well. And kind of getting some more insight into both of those things, I think is very important. Because most of the time with Alzheimer's disease, a lot of times family, family members take on those caregiver roles, so yeah.

**Erick 05:55**

You just said that information is confidential. Does that mean that if, let's say something I say is of use to you, and you want to quote it, in your thesis? Will my name be withheld? Or will my name be withheld at my request? Or how do you handle? How do you protect my anonymity or my identity? In in, in your citations?

**Researcher 06:18**

Yeah, so basically, essentially, what you just said, so I will, this is kind of, usually I say, this part at the end, but I'll just tell you now. So I will give you a copy of the interview that we have, so the transcript, the analysis, so kind of what I'm finding from all of the interviews. And then also, ultimately, you'll get a copy of the final report before it goes out anywhere or is published or anything. And that's just to ensure that I am relaying your experience properly, because that's really what I'm doing. I'm giving people an insight into your daily experience with this. And so I want to make sure I'm doing it justice, and I'm doing it properly. In regards to quotations, that will probably come a little bit later. But you know, if you're fine with using your name, I can give you credit and use your name. If you would prefer not, then I can, you know, give you a fake name essentially and that sort of thing, so.

**Erick 07:20**

Okay. But we can you'll touch base with me at some later point about that?

**Researcher 07:26**

Yes, yeah, I will. For sure, let you know, you know, what's being used from you. In this study.



**Erick** 07:34

Lastly, in some email, maybe the first one that you wrote to, Alison, I think there was mention of the fact that you or maybe your advisor, or I don't know, who has experienced personally, as a caregiver for someone with Alzheimer's. Did I misread that? Is that true?

**Researcher** 07:51

Yeah, so I my grandmother had the disease. And I was rather young at the time. So I did try to help out with some caregiver tasks, but I was pretty young. But I did get first-hand experience. She had it for a very long time. You know, she was uh official diagnosis was, you know, later in, but she technically had it for 10ish years, which is on the long side. The official diagnosis was probably, you know, 2-3 years into which when we started anticipating things were going on. Which, from the interviews that I'm gathering, it's kind of hard to get a diagnosis right off the bat is, is what people are saying, at least to me. So that that's just something but yeah, my my grandmother had it, and it is something that's very important to me as well. She, you know, sometimes with families, there was a huge, you know, kind of rift, my mother wanted to keep her and take care of her outside of a facility versus her siblings who wanted to put her into a facility. So she ended up eventually going into one but you know, I I've had all the insight I know, all of the personal aspect of thing. I approached the topic from a personal aspect as well. And so that's actually what sparked my interest in researching Alzheimer's disease is her kind of going through that and witnessing it from a such a young age. I didn't really know, you know, what was going on. I just knew my grandma didn't remember me all of a sudden, and then, you know, as I got older, I kind of, and of course now I'm like. Oh, wow. Well, that's what was happening. So that's kind of how I started researching this topic. I have been doing it throughout my undergrad, master's, and now PhD. So I've been really excited to talk with caregivers finally, because I've been practicing and getting kind of guided up to this moment, so.

**Erick** 10:14

Okay, that's great. You know, my decision to answer your, your call had a lot to do with that sentence, actually. I feel much more comfortable talking to somebody who has a context, who understands what this is all about.

**Researcher** 10:30

Right. And, and that's also you know, why I like to, before every interview, I kind of disclose that information just because, you know, it is nice to have someone that has has been been through it and knows what's going on and kind of has that context. So, yeah. But yeah, without further ado, I'd like to know a little bit more about you. Um I did in your email, get that you are caring for your wife, Selena. And how long have you been caring for her? If you don't mind me asking.

**Erick** 11:05

About, um about 10 years. Um nine years since the formal diagnosis, probably about 11 years since a psychologist first documented, I think they call it standard deviation and cognition without without accompanied by a diagnosis of Alzheimer's.

**Researcher** 11:30

Okay. And while while caring for your wife, well actually, give me a little bit more background about you guys, how did you meet? And where are you currently, where do you currently reside?

**Erick** 11:43

We live in San Francisco. It's so dark in here, I'm going to turn on light, excuse me.

**Researcher** 11:49

Okay.

**Erick** 11:50

Um, we are um, we're married for 33 years. We know each other, we met 40 years ago at Harvard.

**Researcher** 12:01

Oh, wow.

**Erick** 12:03

I was a grad student. I just graduated from the Graduate School of Design, the architecture school. And she was doing her Ph.D. at the ED school, actually her EDD at the ED school I should say. And I was teaching at some summer program and she was one of the principals of the program. She was teaching the teachers she was she was teaching this new crop of grads um how to teach the summer school program. That's how we met.

**Researcher** 12:39

Oh, wow. Okay. Yeah, I've I actually am in a program kind of similar to that. So outside of research, I also teach kind of like a intro to communications course at the university, so she would have been my boss (chuckles). But yeah, awesome. Um, okay. So, with your wife, what do you find can be a little bit challenging? Or, you know, what tasks can you find a little bit stressful when care caring for her?

**Erick** 13:15

Well um (pauses) every, just about everything is, is hands on and, and stressful. I mean, the most stressful things are, you know, toileting, showering, the things that are very personal. Um even though she has Alzheimer's, she has a very deep seeded sort of radar if you will, regarding her own body and her the protection of her own body. She's not too thrilled about being manhandled, if you will. You know, like you sort of I say, manhandle that's probably an overstatement, but, you know, as as much as I possibly can coaxing her

to like actually get into the shower stall, sit on the toilet, things like that are very, are difficult and she resists.

**Researcher** 14:14

Right.

**Erick** 14:14

Um, other things that are that, are slightly lower rung would be dressing. Feeding is, is somewhat problematic and very, very time consuming. Um (pauses) mobility in general, is, is stressful because her balance has become very bad. She moves very slowly, which is not stressful, but the frequency with which she thinks she's falling, or she trips or she focuses she stares at the floor because she's not convinced it's flat. Um negotiating any curb on the street could take the longest amount of time. And that's that's not really stressful in a direct interactive sense. It just requires patience.

**Researcher** 15:11

Right, Right. And, you know, that's one thing that I give kudos and kudos and kudos to, you know, family caregivers is that you definitely have to have patience. I remember with my grandmother, I mean, I, I wasn't around her all the time, but I would find myself running out of patience very fast. It could have been because I was a kid, but also, you know, I give caregivers, they, they have to have a lot of patience, and they do deal with a lot. So I can completely understand where you're coming from, and the hygienic and kind of personal care, things I've been finding are kind of a pattern that I'm seeing in everyone's interviews. And I mean, it makes sense. You know, if I just think about if that was me, you know, obviously, you wouldn't want all these people touching you, you know, and that sort of thing. So um kind of going off of that. Do you believe that you have adjusted your communication with your wife since she has gotten the disease? And if so, how? How have you adjusted how you communicate with her if you have?

**Erick** 16:34

Oh, absolutely. And I would imagine everybody you speak with, does as well, you know, my, I haven't had a, you know, a meaningful, serious, substantial conversation with my wife in years.

**Researcher** 16:50

Right.

**Erick** 16:54

She has aphasia, she speaks in a kind of gibberish, I try my, my very, very best to understand what she's saying. And I don't know, whether she's saying anything at all or not. Sometimes she expresses a kind of gibberish with such a sense of intention, including, you know, facial movements and, and eye movements and things and, you

know, curling or something of the mouth. You'd think that surely, she's telling me something.

**Researcher** 17:29

Right.

**Erick** 17:30

But there's no real way of confirming it. My wife was brilliant, and articulate. She was a professor. And and now she, I mean, she's still those things, of course. But, but it doesn't, there's, it's there's no outward manifestation of it that's functional, and it causes her a great deal of, of, of angst and sadness.

**Researcher** 18:04

Right.

**Erick** 18:04

Um, so of course, I've changed my communication with her. I try my best to respect her and to regard her as if she is actually saying something meaningful. But inside I just always experience a kind of disappointment um and a failed communication. More and more, I mean, my communications to her are directive or or, or inquiries regarding her intention, do you need the bathroom? Are you hungry? Do and I actually never really get a straight answer (chuckles slightly), even on those basic things, either. But sometimes, I guess I think that I recognize some, some little tiny thing that maybe is an answer to my question, maybe like a, like a slight step towards the bathroom (chuckles), or something like that. But I'll tell you, and this is probably more important than anything I just said. Even though the communication is dysfunctional, on a kind of um, you know, we'll call on a language level, let's put it that way, a linguistic level. My wife is actually very, very emotional and affectionate and capable of communicating love and receiving love. And that's, that's an amazing thing that I'm very often amazed at and grateful for both.

**Researcher** 19:47

Yeah.

**Erick** 19:48

I think, you know, if I didn't have other obligations, and I had the patience of a saint. I could make her most happy by just hugging her for 24 hours straight, she's happiest when I'm hugging her.

**Researcher** 20:06

Well, that is beautiful, beautifully shared. Thank you. And, you know, that is rather different than, than some of the other reports I've been getting. So that's interesting, just because one thing that the disease comes with, sometimes... It's different, it's, you know, it's a very individualized thing. It's not obviously the same for everyone. So it looks very different. And it comes in all different forms. And that's why I think um interviewing,

you know, so many different family caregivers and getting this insight as to the disease as well, is important because it does come in so many shapes and different forms. And sometimes, you know, there's those behavioral changes. And with my grandmother, she she had some of those.

**Erick** 21:05

(phone rings) No, no, no. Stupid phone, I'm sorry.

**Researcher** 21:13

Oh, no, it's okay. And she was still those things when she had the disease, of course, you know, somewhere inside, but she, you know, just was a lot different, more agitated, that sort of thing. And it makes sense, you know, but that's, that's great. Um, so kind of going off with that, what would you say, are some of the most positive interactions that you've had with your wife? Can you think of certain, you know, incident or circumstance where you had just a really good interaction with each other, and it can be, you know, an every daily thing or weekly thing, but maybe one that stood out?

**Erick** 21:58

Well, well, I'll use last night um, and this is I'm describing a scenario that I've, I've experienced any, any number of times. Um she had kind of like a, a bathroom problem in the middle of the night. And, you know, she needed a lot of cleanup and attention, and you know, it was the middle of the night and I had to go get up and attend to her and clean up floors and everything. Um change her, make sure the bedding was clean. And, you know, finally, when I was ready to bring her back to bed, you know, I held her hand and, and we slowly tottled over to the bed again, and you have to wait for her, she doesn't just lie down. You have to say, "Okay, now lie down." And she, you know, sort of like assesses the bed (chuckles), and plans how she's actually going to get, you know, her rear end onto the mattress. And, and all of that. And the thing is, she was just so sweet and grateful and, and, and happy. And I think, to her these are these are precious moments. And they're precious, not because I mopped up the floor, you know they're precious to her, because I was holding her hand, I was taking my time, I was with her and nobody else and nothing else. There were no other distractions. And it was meaningful to her, and therefore very meaningful to me. And, you know, sometimes I'm human, I do get frustrated, you know, getting up in the middle of the night to mop the floor and all that kind of stuff. And, you know, when she is responsive in that way. I am reminded of her humanity. I'm reminded of my laps, if you will, of patience and how ill-advised and futile and and in no way good is it to become impatient or to feel resentful. Um but it's it's an ongoing task. It's an ongoing challenge. And she's in the midst of all of her incapacity and cognitive problems. She's able to sort of reach out and grab me emotionally, connect to me in this meaningful way. And it just amazes me.

**Researcher** 24:48

Yeah. Well, I do want to let you know, just from the basis of this, I mean, it's only been like 10 minutes but you the way that you put things is very, very good. And I think this will be very beneficial. So I'm just warning you now, I probably will have a lot of quotes from you. But I do want to kind of touch on a few things you talked about. And one of the things, I think that would be really, really helpful for people to see is how you handled that situation, because like you said, you, you could have been resentful, you could have been angry, but you handled it with such poise and patience.

**Erick** 25:31

Oh well you're extending to me a little bit more um saintliness than I deserve.

**Researcher** 25:38

Oh no! Well, it sounds like that story, it sounds like, played out very well. And your wife kind of reminded you and helped, kind of, like you said, reached out emotionally and then kind of helped remind you why you're doing what you're doing. And that's just a beautifully shared experience.

**Erick** 25:59

Well the reason I said, what I said just then is I don't want to create a romanticized narrative. I do not want you or your readers or I, for myself, my own integrity and sense of self to in any way claim that I am in, in total control.

**Researcher** 26:16

Right, very true.

**Erick** 26:16

And that I always catch myself in time, and that, you know, I am not, it's a chall, like I said earlier, it is an ongoing challenge.

**Researcher** 26:25

Right.

**Erick** 26:26

And I try my best.

**Researcher** 26:29

Yeah.

**Erick** 26:29

I try my best, I can't emphasize how, what an ongoing campaign I wage to be the best person I can be for her.

**Researcher** 26:42

So kind of going off of that, um, what would you describe as some of maybe the more negative experiences that you have had with your wife, and where things didn't maybe go so smoothly for you?

**Erick 26:58**

Well, like a recent, a recent challenge that I gave up on was trying to get her into the car. The car is obviously crucial for mobility.

**Researcher 27:14**

Right.

**Erick 27:15**

Um, and, for us, there's been a long transition period, where she had difficulty getting in, but eventually, you know, can be coaxed into doing so.

**Researcher 27:30**

Yeah.

**Erick 27:31**

You know, getting into a car is actually very tricky. You know, we don't think about it, we take it for granted, but it's not as simple as sitting in a chair that's behind you, you actually have to sort of twist, you know, laterally into the, into the seat. The seats facing the windshield, but you don't, but you actually sort of slip into it sideways. And for someone who has these spatial difficulties, it becomes increasingly impossible and you never exactly know when that shoe is going to drop. In other words, when the cognitive ability to negotiate space and she can control her own movements, muscle movements, will decline to that point where she can no longer get into the car. And you want to stretch that transition, you know, full well that it's going to end. Your doctors told you so, you know it yourself, you know, it's going to end, but you don't want it to end because there's so much at stake. And so, you I'm motivated to protract it as long as possible. But in order to do so, my coaxing has to become increasingly aggressive for want of a better word. And it's been frustrating. And finally, I caught myself after, you know, losing myself after I mean, I came to regard her... Um well what would start to happen, what has happened, is that instead of trying unsuccessfully, to get into the car, she would just stand and lean on the, on the car door, and I couldn't get her to, like, you know, apply herself to the task at hand one more time. And that is my agenda, not hers. And you know, if I again, somewhere in my brain, I really know that she's not. She's not trying to thwart me, she's not being stubborn. She's not refusing to focus on something that I want her to focus on. I know all those things are true. But nevertheless, when I'm standing there (chuckles), and I cannot get her to to interact with me really is what it amounts to. I do get, I got very frustrated. And just recently, I just, I just reached the point where I, I let myself know, first I let myself know that I'm not doing this anymore. I will no longer try and coax her into doing something that she can cannot do, that's futile and stupid. But it had consequences. In other words, if I can't get her someplace, well, she's in a dementia

daycare center, and I can't get her there now. That's huge, huge. In other words, this, this little hiccup, has ramifications that are way beyond like, just my personal inconvenience.

**Researcher** 27:40

Right.

**Erick** 28:02

And, you know, suddenly, we can't go pick up our son, and we can't, you know, family gatherings, everybody wants to help her, but transportation is, is a factor in helping her. You know, and I mean, this just happened. But and and we will negotiate other things. I mean, there are these, we've applied for, you know, these senior bus things and but that's not the point you asked me to describe difficulty. And that is difficulty. And I have to emphasize to that, it's my difficulty. In other words, she, she, she's blameless, she's, she's trying her best, she's frustrated as hell, with her own inability to communicate. She cries all the time. And so, this is on me, you know, this is my failure, not hers by any means. And, you know, I'm always, in a sense, fighting with myself and fighting the urge to hold her responsible for what I refuse to acknowledge.

**Researcher** 31:51

Yeah, yeah, I think you made a lot of great points. One, um, I think a lot of times, and not so much, caregivers, obviously, but public, so general public, that doesn't really have a lot of ties to the disease, or really a lot of insight into the disease. They quite often blame the person with the disease, for a lot of things that obviously are not in their control. I think it's, it's crazy to me, that people, they almost dehumanize the person with the disease. And so recognizing that it's your difficulty, and not the person and placing blame on them, I think is just a very important thing to do. I, obviously, you know, that is very difficult sometimes, because we're all human. But I do think it's important to just kind of have that in mind for sure. But yeah, that's greatly said, um, I do want to ask you, what are some coping mechanisms that you use to maintain your own wellbeing while this is all going on? So, you know, this could be hobbies, that you have, outlets that you have, some people, you know, even just leaving their house for an hour or two? What are what are some things that you do to kind of maintain your own sanity, and also make sure that you are being the best caregiver that you can be to your wife?

**Erick** 33:29

Um I have, um I've had to negotiate with other family members to secure a break of two hours for myself on those days when I'm the sole, primary caregiver.

**Researcher** 33:47

Right.

**Erick** 33:49

When I have that personal time, I very often go to the gym. I find that to be very helpful, or go out for a run. Sometimes I just go for a cup of coffee and try to read the paper and



gather my thoughts and just be by myself. Just have the the autonomy, if you will, the, you know, my own personhood respecting my own autonomy as a human being. Because when you're a caregiver, you're it's like, you, your personhood is like sacrificed to another. So much of what you do, even when things are sort of passively, okay. You know, your radar is always up. You're always like, you know, watching, thinking, worrying, planning ahead. Where's the medicine? What is she going to wear? When am I going to change the adult diaper? You know, what are we having for dinner? How am I going to feed it to her? Is the is the night gown clean? Because she's going to get that wet and so what am I going to do then? And and you like lose yourself. The other thing that's, you know, causing me great difficulty is that I've right now, I've kept my job. And I've reached retirement age, I'm going to turn 66. And I'm going to retire. But I have to say I'm not retiring because I want to, I'm retiring because of the the total impact of being a caregiver. What it's had on my career, my ability to do my work. And the ever-increasing aspect of what caregiving requires. Five years ago, I thought, Oh, my God, I can't possibly give more than I do now. Little did I know (chuckles). And for all I know, in five more years, I'll be again, amazed at what, what one person can be called upon, to do to help another. So I love teaching. I love meeting my students and working with them and helping them and interacting with them. It keeps me sane and keeps me young. I have um, young at heart anyway, I um you know, like, like, everyone probably like you and your professors. I've had to go for a year teaching on Zoom. And, you know, I did it. And I and I, of course did the best I could, but it's not the same really, as seeing the young, my young students in person. And I'm going to give that up. And I have to give it up. There's no, you know, there's no, no two ways about it. But I have regrets.

**Researcher 36:53**

Yeah, yeah, I feel like people don't take into consideration that the caregiver still has to do everything that they're expected to do in society, such as keep a job, all of this, and then also take care of a whole other being and do everything for that person. People don't really understand how much work that is. That is, it's crazy that you kept your job throughout all of it, it's great, because it, you know, has been an outlet for you. But it's it, that's a lot. That is a lot.

**Erick 37:34**

It's a lot. It requires. I mean, it's not only well, aside from the substance of job responsibilities, it requires the setting up of an infrastructure to take care of her so that I can do my work.

**Researcher 37:51**

Right.

**Erick 37:53**

And that infrastructure is rather fragile. I'm scared to death, not to death, but um, well, I'm scared to death of COVID not because... I mean, I'm vaccinated. And if I get it, it probably will be mild. But what does it do, if I get COVID and I have to like not, and

have to tell the caregivers don't come, don't come to the house, don't take care of her. I mean, the whole infrastructure collapses, and it was so hard to find these caregivers, and they rely on the money. And I mean, you know, it's like a deck of cards, one thing falls and the whole thing collapses. My university will require me to teach, they're opening up the campus. And it was very funny, they they actually had an email out to all the faculty and it said, you know, you can apply, to like, teach on Zoom again. But you know, and it listed all these all these reasons that you cannot, you cannot and you are not qualified to apply for this exemption. And one of them was "caregiving responsibilities at home". And they actually said, we know that these daycare centers and caregiving and nursing homes, all these, like institutions that were down in the height of the pandemic last year are now open. So you don't qualify to ask for an exemption on that basis. But I mean, it's, it's so short sighted to interpret my circumstances in such a black and white way. I frankly, don't see how I could avoid getting COVID, uh you stick 65 students with me in a room? I mean, oh, but.

**Researcher** 39:47

Yeah, that that's news to me, actually, that that just showcases that people don't understand. The extent to which this could impact caregivers or caregivers, caregivers of Alzheimer's patients, I mean, I've talked to individuals who have been telling me how COVID has been impacting them and their loved one, you know, obviously not as much socialization, especially during the pandemic. Not being able to go to programs and such, but um forcing people to go back in person. Um, yeah, that's, that's crazy. And that's also something I didn't take into consideration, actually, because my university we opened up in person and I. You know, I didn't read all the fine print, because, you know, I just could go back, but that's just something that, once again, it's kind of overlooked how caregivers have to deal with with that and balancing that. Yeah.

**Erick** 40:58

I can promise you amongst the students, staff, and faculty, there are vulnerable individuals who are praying that they get through this without an interruption in their, in their caregiving.

**Researcher** 41:11

Yeah. How often do the caregivers come and take care of your wife Selena?

**Erick** 41:21

Two days a week. And those, those will become my, when school opens in a few weeks. Those are the days that I teach. And then, I also just very recently enrolled her in this wonderful, I think they call it the Enrichment Center. Well, you reached out to Alison, right?

**Researcher** 41:43

Yes.

**Erick** 41:43

She's the director of that program. And it's a great program. And I was I had arranged for her to go there another two days a week. But right now, we're on hiatus until we work out the transportation.

**Researcher** 42:00

Oh, right, right. Yeah, see, it's it's one thing you know, you sharing all this with me. It's so important, because there's things that I would never even have thought of, you know, and my experience with my grandmother, yes, it was tough, but it was a lot different than 24/7 being with someone all the time, because that's not how it was. And I don't want to say that's how it was. So all of these little things such as transportation, they are so vital and crucial and things that I would not even think about, that would never come to the forefront of my mind as that being a challenge or an obstacle to have to deal with. So it is important to share that and I think also it will help other caregivers who are struggling with that know that they're not alone in that challenge, which is important. Um, and kind of going off of that. What are some outlets of social support that you have received while being a caregiver? This can be you know, if you are part of a support group, if you have family members that have really been helpful. What outlets have you received?

**Erick** 43:21

Okay. Um family has been helpful. My son has been great. He pretty much devotes his weekends to helping care for his mother. He moved really he had a job in New York, he moved back to San Francisco when he you know, learned that she was declining. We moved in with Selena's sister. We live in a, what we call it San Francisco an in-law flat. It's a studio apartment behind the garage. Her sister and her sister's family live upstairs in the main flat. We live downstairs and her sister, and my sister-in-law, her partner, they give me, they're the ones who give me the breaks. And they, they help. Well when the caregiver comes they they actually help the caregiver, give showers, things like that. Showers are hard. As I said showers very hard. She does not like, she does not like being, having other people asking her to take her clothes off. And so I think her sister and I are probably the most successful at doing that. So anyway, there's the family. Um, Friends of mine, they help me personally, they, they advise me, they worry about me, they make sure to stay in touch with me. Um friends of hers are there in a very difficult and funny situation because they mean well and they want to stay in touch. But they don't know how exactly because she's, I mean, a telephone call is ridiculous at this point, it just really can't happen at all. So she has, you know, she has a friend in Colorado, she has another one in New York, a few in New York. And they they love her dearly. But, but talking to me and asking me how she is, is not the same thing.

**Researcher** 45:49

Right.

**Erick** 45:50

So there's that. I wish there was more support. I mean, I'm, you know, as I try and answer your question, mostly, I'm struck by how little support there really is. In the past, when I, when I tried to join caregiver groups, they it seemed like they were scheduled for like retired folks. In other words, they took place in the middle of the afternoon or something. And in the past, at least, I was at school, I was teaching at a job, I couldn't participate in those. I could I might be able to do so now or in the near future, but they were not accessible to me.

**Researcher 46:35**

Yeah, that's helpful insight to get, to gain. Because I, I know about the support groups, I don't know about the times that they take place. But yeah, that's interesting that they, but that makes, kind of sense. But yeah, they, they should have some more options out there for sure. Um, but yeah, I do want to ask you two kind of broader questions. So it does sound like you have an abundance, an abundant amount of family support, which is great. That's good. And that's amazing that your son devotes his weekends to taking care of his mom, that's, that's awesome to see. Especially sons, I've been finding that most people I talked to, you know, their son is away somewhere and doesn't really want to be bothered. It seems like so that's, that's good to see that. I do want to ask, if you were to give advice to someone who just got put into a caregiver role that their loved one just got the disease, and they just got placed into this role? What advice would you give them?

**Erick 48:10**

Well, let's go further and say, caregiver role for someone with Alzheimer's. I'm not, I don't, I've never cared for someone say with cancer or something like that. So I don't know what to compare it to. But the thing about Alzheimer's is and you touched on this earlier, is that it is a long haul. And it's very hard going into it to know that. It's very hard to get doctors to give you predictions about the future, especially for someone who has it at a younger age. Selena got it when she was, she was diagnosed at 64. And that was officially considered early onset, um anything before 65. But they don't know or if they do know they're sort of reluctant to, you know, make sort of baseless predictions. In the absence of, you know, what we've learned from the pandemic, the term comorbidities, and the absence of comorbidities is very hard. I mean, it could go on forever. And I would tell someone who's entering this situation to firstly brace themselves and plan ahead for a very long call. And to, early on, try and develop routines that that are set up in advance for taking care of oneself, getting breaks, um finding supportive doctors, medical team. Um you know, maybe things like meditation, yoga things whwere almost like personal practice is to increase your own tolerance and patience.

**Researcher 50:17**

Yeah.

**Erick 50:18**

I don't know what else I can tell you.

**Researcher 50:21**

Those are all great points. And they kind of they all are things that you showcased that you practiced. So they're not just, you know, advice that you didn't actually do yourself. One being, you know, the meditation, yoga, moving your body going to the gym, running that sort of thing, to kind of de stress also, you know, you said, having that time to take care of oneself, you have those two hours that you have that you kind of planned out. That's brilliant, that's smart. Because you can't be you know, that's the thing. Caregivers give and give and give, and they forget to give to themselves a little bit.

**Erick 51:02**

Yeah, and, um, it took me years to set that up for all sorts of reasons, internal and external. The internal reasons were that I didn't realize that I was that, that that was that I deserved that if you will. For a long time I, I prided myself, took pride in, in going the long haul, it was like, almost like a heroic quality to it. And that was nonsense. And then externally, outsiders just don't understand, and they can't understand. A lot of people think that oh, Alzheimer's, it means you lose your memory. And that that doesn't. That doesn't that's so reductive, that it doesn't. It allows people to really deeply minimize how dysfunctioning or, you know, what, it's like a dystopian world that that that occurs for an Alzheimer's patient. And, I mean, if it was just the sort of banal loss of memory? I don't know, I mean (chuckles) that doesn't sound that bad. But it's so much more pervasive than that. There's so much misery attached to it.

**Researcher 52:29**

Yeah, and that actually leads into the last question I was gonna ask you actually, um, so, like you just stated, the general public, or those who haven't really been impacted with the disease, doesn't, they don't really have a good concept about it, like you said, you know, most individuals think it's, oh, you just lose your memory. There's still a lot of stigma in some places about you know, regarding the disease, and you know, that it is a disease that impacts the brain and that sort of thing. Um, what is something that you would want the public to know about Alzheimer's disease? So the public as a whole, that, you know, they have very little knowledge about the disease, what would you want them to know? And it can be anything.

**Erick 53:19**

I would want them to know that it, it entails a long term, complete cognitive breakdown. And that it impacts memory, sure. But firstly, when you think about memory, it's important to know that memory is, is is more impactful than just remembering what you had for breakfast yesterday. It's like remembering where you live or, or when you're home, or what a staircase is, and how you approach it or, you know, or what a toilet is for. Why is this man asking you to sit on this white seat all the time? And that it goes way beyond memory, it robs you of language. It robs you of your, your self control and you know, in terms of personal hygiene, and it it threatens your own sort of personal sort of

dignity, if you will. You're always, you're always subject to being you know, pushed around and manipulated and coaxed, people are always around. You feel trapped inside a mind that won't let you communicate. You are sad, you're deeply, deeply sad by the knowledge that something is wrong, but you can't even say what it is. I mean, it's it's it's really a hell. Um that you're going to disappear as an identity as a personality and identity as a, as an identity, you are going to slowly become invisible to yourself and to those around you, and you're trapped inside as it's happening. You know, I think that people are most responsive to notions of pain, like, you know, you have cancer and you're in pain, and, you know, chemotherapy, and all of that stuff is horrific and a painful death. And, you know, and God knows, I mean, I, you know, I understand that, but this is, I have a feeling that it's the long term quality and the absence of overt pain, that allows society to sort of bracket this, to sort of put it aside as you know, eh it's too bad, but not to really grapple with it's impact on the person, and the person's family, and the caregivers around them. I don't know what the Alzheimer's Association does. Um I was very disappointed that they supported this new drug. What's it called, it starts with an A, it's, you know, they all have these funny names.

**Researcher 56:22**

Yeah. I saw that, that drug on their website. I, my study is they also shared it, but I'm not part of the association. So there's been individuals in interviews that have also expressed their unhappiness with certain things that they have done. So, but yeah, I know the drug that you're talking about. I don't know the exact name. But I know, I saw it on their website, I think the other day or so, yeah.

**Erick 56:57**

I don't really know what they stand for. I mean, I've been able to find resources that are much more responsive to me in my situation. I find their website. Firstly, they rely on this, it seems that they rely on their website primarily. I don't know if it's fundraising, or it's their connections to the companies that make these drugs. I don't exactly know why or what it is. But I find that group to be not especially helpful, it seems to be mostly self-perpetuating rather than helpful. I don't know.

**Researcher 57:33**

Yeah, and that's actually several caregivers have expressed that to me. Now, which is, that's an interesting news to me. Because, you know, I was under the assumption, "Oh, wow", you know, this is super helpful for caregivers, that sort of thing. But a lot of individuals have expressed, you know, they just see it as them getting a bunch of money, and they're not really sure what it's going for. And so, there's been numerous individuals that have suggested that at this point, but which is so interesting, because to the outside world, or general public, you know, they have the perception that that's the organization that really helps everyone that's going through this. So that's interesting. Um but yes, and another thing that you stated that I just want to point out real quick. The (pauses) the lack, or basically the general public ignoring the disease as a whole, sometimes in comparison to, you know, other diseases such as cancer, and you know, where you can overtly see

pain. And I think that's very, very interesting, because I've never thought of it that way before. But there have been other individuals that I've interviewed that also have, you know, suggested you see, all these people, how the general public reacts to individuals with cancer or other diseases. Well, Alzheimer's is a disease too, and it's almost like people don't understand that. And, and I think you just explained two reasons why that might be. And so that's, that's very interesting to think about. And I do, I do agree, it's so long term that people you know, I don't know what it is, but it is a very long road, a long haul, like you suggested earlier. And so and, you know, occasionally there is, you know, expression of pain, but it's not like other diseases like you stated. So, that is very interesting. Um, well, it's been about an hour, we've had great discussion, and I do want to thank you for your time and for everything you've given great insight, great information. And the way that you explain things you can tell one that you're a teacher, but two, the way that you go about explaining things, is, I think it's this is going to be very helpful for individuals that are going through this and reading about it. A lot of individuals I've interviewed so far have been kind of more in the earlier stages. So I think it is good to have, you know, someone that's kind of more experienced, and in those moderate stages, kind of expressing their thoughts. So I'm very grateful for this interview. So thank you so much for your time. Because I know it is precious, you know, so I think you and all the caregivers that have taken the time to talk with me, because you know, I do know how busy you guys are just from interviewing you for, you know, an hour. It's, that's, that's valuable. So thank you. And I will email you the transcript, the analysis, and ultimately, the final report. We'll be in touch, I'll email you, I am going to be wrapping up interviews in the next few weeks or so. So once I wrap those up, I'm going to be working on typing them all up. So it might take a maybe sometime mid next month, I will email you the transcript to this interview. So you can kind of see everything.

**Erick** 1:01:19

Thank you. Thank you for reaching out. Thank you for taking on this important topic.

**Researcher** 1:01:25

Thank you.

**Erick** 1:01:27

It's obviously we agree that this is important work. And that the, and that the world outside hasn't been paying attention. So I'm very grateful that you're doing it. I'm very happy to support you through this participation. I also want to invite you to contact me again, for any reason you need to. I'm happy to help you in any way that I can. By the way, I am sure you know this, but when I, when I was doing interviews, I would. I had research funds, but I would pay someone to transcribe, transcribe the interviews. It's very time consuming. I've done you know, I've done them myself, and I've hired others to do it. And those who are set up to do it, do it a lot faster than you do. They have like they have to they know everything about the start and stop mechanisms on their tape recorders and all that stuff. But I'll leave it at that, by you should know that there are people out there who do this for a living, and they're more efficient. But yes, you have to pay.

**Researcher** 1:02:33

Yeah, well, yeah, that's a great tip because it is very, very time consuming. So, but it's worth it and I am so excited to be working on this this topic. It's so important and I am thankful for your input and insight. And you sharing your experience because it is something very personal, obviously, but it will help someone and so I just want to thank you.

**Erick** 1:03:03

Okay, thank you.

**Researcher** 1:03:05

Alright, have a great day Erick, and thank you again for your time. I will be in touch okay.

**Erick** 1:03:10

Okay, take care.

**Researcher** 1:03:11

Alright, bye.



## APPENDIX D: CODEBOOK & MAJOR THEMES

**Table 2. Codebook and Major Themes**

Communication interactions	Positive	Appreciation
		Feeling of “Normalcy”
		Lighthearted
	Negative	Transactional/ No substance (linguistic suffering)
		Unresponsiveness
		Demanding Communication
Accommodation		Adjust- enter their reality
		Redirect
		Compensation
Daily Challenges & Stressors	Daily living Tasks	Hygiene
		Eating
		Driving
		Protecting loved one
	Inappropriate Behaviors	Racism
		Offensive/ Inappropriate Comments
		Aggression
		Wandering/ getting lost
	Personal Demands	Money/ Financial Impact
		Obligations/ Schedule
		Internal: Sadness /Guilt

Needs	Useful Information	(Finances and Communication)How to communicate through difficult behaviors, money, resources , etc.
	Reduce ostracization and stigmatization	Additional social support
Coping Strategies	Therapy	Journaling, writing, talking with friends
	Exercise	
	Getting Out (Escapism)	
	Information seeking	
	Music	
Social Support	Support Groups	(Virtual and in-person)
	Neighbors	
	Family/ friends	
	Hiring extra help	
COVID (Public Policy)	Lack of Socialization & stimulation	
	Issues with safety precautions	
	Issues with Accesssibility	
	Virtual shift	
Gender	Gender Expectations	
	“Sainly and Pure” ideology	
Advice	Tell Others	
	Importance of Planning	
	Try to keep living	Remember to take care of you
What Caregivers want the Public to know about AD	AD is a disease	
	AD is more than just memory loss	Other medical issues occur too
		Robs the person of their identity

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## **BIOGRAPHY**

Henri Kali Huber received her Bachelor of Arts from Christopher Newport University in 2017, and a Master of Arts in 2018 from George Mason University. She was employed as an instructor with George Mason University and her research focus is to advocate and raise awareness to the prevalence of Alzheimer's disease.