

**Caring for Caregivers: How Alzheimer's Disease Communication is Associated with
Caregiver Knowledge, Stress, and Coping Strategies**

by

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THESIS ABSTRACT

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Title: Caring for Caregivers: How Alzheimer's Disease Communication is Associated with Caregiver Knowledge, Stress, and Coping Strategies

Alzheimer's disease is a neurodegenerative disease that significantly impacts one's memory, behavior, and motor functions—ultimately, a person with Alzheimer's disease requires constant care. Caregivers are often unpaid relatives, sacrificing their own time, money, and personal lives to care for a loved one with a debilitating disease. Previous research suggests that caregivers experience detrimental effects to their mental health resulting from caring for someone with Alzheimer's disease, including increased stress, depression, and isolation. The study survey draws on questions from the Alzheimer's Disease Knowledge Scale, Perceived Stress Scale, Ways of Coping Questionnaire, and a newly designed Caregiver Communication Scale to understand the relationship between caregiving communication and the caregiver's own mental health. The findings indicate that increased communication is associated with a decrease in perceived stress and an increase in the use of active coping strategies among caregivers. English language preference was also found to be associated with the caregiver's level of Alzheimer's disease knowledge.

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INTRODUCTION

Alzheimer's disease is a neurodegenerative, cognitive disease that results in severe memory loss over time. Although many people are aware of the disease itself, specific knowledge of what Alzheimer's disease entails and its symptoms are less common among the general public (Streckenrider, 1993). Because it tends to be associated with memory loss alone, Alzheimer's is often downplayed as a feature of old age, rather than a serious and tragic disease that causes those inflicted to experience the loss of self and basic human functions and mobility (Lane et al., 2018).

Misrepresentations of Alzheimer's disease prevents the dissemination of accurate Alzheimer's information to those affected and their caregivers, which in turn affects the rate at which patients utilize the resources available to them. There has been a historical gap in awareness and knowledge of Alzheimer's disease between different racial and ethnic groups (Anderson et al., 2009). Factors such as level of education and English language knowledge can prevent those impacted by Alzheimer's from getting the help they need (Ayalon & Areán, 2004), creating a stressful situation for patients and their families (Werner & Heinik, 2008). Although the worst stages of Alzheimer's can take years to develop, the sooner a patient can get help, the sooner they can start preventing significant memory loss (Anderson et al., 2009).

There are several preventative measures to deter the progression of symptoms and genetic tests to determine if one is predisposed to Alzheimer's, but there is no known, permanent cure to the disease (Scheltens et al., 2016). The lack of widespread public knowledge of Alzheimer's across all racial and ethnic groups not only impacts when people living with the disease can get help, but also the type and quantity of research that can be conducted to find a cure (Gallagher-Thompson et al., 1997; Hinton et al., 2000).

Due to the challenging nature of the disease, patients with Alzheimer's disease require caregivers, whose role becomes increasingly involved throughout the 6–12-year lifespan of an Alzheimer's patient following diagnosis. Caregivers are charged with ensuring that Alzheimer's patients are comfortable, watched over, and provided with a decent quality of life in their final years (Sullivan et al., 2007; Scheltens et al., 2016). The role of an Alzheimer's disease caregiver is not simple, however—to care for an Alzheimer's disease patient requires a basic understanding of what the disease is, how patients behave and the best approaches to caring for a patient (Ercoli et al., 2021). A caregiver's position is also often a lonely one—a typical caregiver spends anywhere from 69 to 117 hours a week providing care for their patient, leaving little time to care for their personal health or interests (Pagán-Ortiz et al., 2014).

In an effort to understand the role of resource communication within the process of caring for an Alzheimer's disease patient, this study aims to measure levels of perceived stress associated with caring for a family member, as well as caregiver confidence, knowledge of Alzheimer's disease, and existing resource communication for caregivers. Understanding the challenges faced by Alzheimer's disease caregivers can provide insight on health literacy among caregivers across different sociodemographic groups. Findings from this study may help Alzheimer's and caregiving resource organizations understand the role their communication plays in empowering caregivers and providing them with the mental, emotional, and physical support required to care for a family member with Alzheimer's disease. Additionally, recognizing the stressors and coping strategies that Alzheimer's caregivers face can inform caregiving communication, including outreach and support to caregivers in other areas of health care.

LITERATURE REVIEW

Alzheimer's Disease Overview and Care

Alzheimer's disease (AD) is a type of dementia associated with behavioral changes, loss of ability, and memory loss that becomes more severe over time (Hinton et al., 2000; Weller & Budson, 2018). Alzheimer's disease is not linked to memory alone—those diagnosed with Alzheimer's disease may also experience behavioral changes, hallucinations, seizures, and disability concerns (Hinton et al., 2000; Lane et al., 2018). The disease is classified as a mental disorder, most commonly found in adults aged 65 and older, and is therefore sometimes considered to be a regular symptom of aging (Werner & Heinik, 2008; Lane et al., 2018).

In recent years, Alzheimer's has been named a global priority, rapidly becoming one of the most expensive and lethal diseases of the century. It is the fourth-largest cause of death among U.S. adults and kills over 100,000 people annually (Dungee-Anderson & Beckett, 2009). New data indicates that the number of Alzheimer's patients is expected to double in Europe and triple worldwide by 2050, in turn increasing the cost of care and the need for caregivers (Scheltens et al., 2016; Scheltens et al., 2021). Although the exact cause of Alzheimer's disease has not yet been found, the risk of developing Alzheimer's has been found to depend largely on heritable factors, specifically in the APOE gene, as well as lifestyle or environmental factors (Lane et al., 2018; Scheltens et al., 2021). No cure has yet been found for Alzheimer's, but major studies have been and continue to be conducted to find a solution (Scheltens et al., 2016).

For many Alzheimer's disease patients, caregiving comes in the form of family members or hired caregivers rather than an assisted living facility (Carpenter et al., 2009). A more recent trend of non-institutionalized care for elderly patients has led to an uptick in family-based

caregiving, which creates its own challenges for the caregiver (Navab et al., 2012). Dementia patients have also been found to have a better quality of life in a familiar home environment.

Caregiver education about Alzheimer's and how to care for a patient are imperative to the quality of care that they can provide (Ercoli et al., 2021). The treatment and care of an Alzheimer's patient can rapidly become a full-time task as the motor functions and cognitive abilities of an Alzheimer's patient dissipates over time, emphasizing the importance for a caregiver to understand the needs of the patient and how to respond to them (Sullivan et al., 2007; Scheltens et al., 2016).

Downplaying Alzheimer's Disease

Alzheimer's disease is faced with contradicting narratives of normalization and stigmatization, which work together to hinder early detection and treatment (Ayalon & Areán, 2004). Because Alzheimer's is commonly found in older adults, it is sometimes believed to be a regular symptom of memory loss associated with aging (Hinton et al., 2000; Werner & Heinik, 2008). Overcomplicated terminology used to describe Alzheimer's disease, such as "preclinical" and "prodromal," create confusion among patients and caregivers attempting to diagnose memory loss concerns. The overuse of the term "dementia" has also created an association between dementia and the normal aging process (Rosin et al., 2020).

As with many mental disorders, Alzheimer's disease and people with Alzheimer's have historically been stigmatized by others (Werner & Heinik, 2008). Misconceptions about the disease are common, even among those who care for Alzheimer's patients (Sullivan et al., 2007). Some people consider the disease to be a sign of insanity, or a psychotic disorder akin to schizophrenia (Gallagher-Thompson et al., 1997; Ayalon & Areán, 2004). The association of Alzheimer's disease with psychotic behavior leaves some family members fearful of the

diagnosis itself and the implications it carries. Others avoid an official diagnosis for fear of the stigma associated with Alzheimer's, or associations with insanity or divine retribution (Gallagher-Thompson et al., 1997). The avoidance of a diagnosis, however, makes it more difficult for caregivers to find and provide the proper resources for an Alzheimer's patient in a timely manner (Hong & Lee, 2022).

Stigma isn't maintained by family members and patients alone; studies have found strong public stigmatization of Alzheimer's and patients with Alzheimer's (Stites et al., 2018; Rosin et al., 2020). Alzheimer's disease is seen as a cause for discrimination, as some people believe Alzheimer's to be tied to psychosocial issues, such as stress or unemployment, or religious and moral concerns such as fate or a lack of faith (Blay & Peluson, 2010). Regardless of whether Alzheimer's disease patients are perceived as deserving discrimination, there is an expectation that they will be discriminated against in areas such as employment and healthcare (Stites et al., 2018). One study on Alzheimer's stigma found that people with fewer years of education were 2.32 times as likely to stigmatize Alzheimer's patients (Blay & Peluso, 2010).

Historical Impact on Ethnic Minority Groups

Prior research has found a disparity in Alzheimer's disease knowledge between different ethnic groups (Anderson et al., 2009). Factors such as level of education, internet access, and knowledge of the predominant language can hinder ethnic minority groups from learning of Alzheimer's and getting their loved ones the treatment they need (Hong & Lee, 2022). Online Alzheimer's information has long been one option among several for Alzheimer's disease education and caregiver support, but the COVID-19 pandemic caused many Alzheimer's disease services, information, and resources to switch to online-only platforms. This isolates caregivers and patients without access to technology or the internet, especially during a global pandemic,

forcing them to navigate Alzheimer's disease without a method to connect with others (Ercoli et al., 2021).

Linguistic barriers hold the public back from becoming educated on Alzheimer's or caring for a loved one with the disease (Gallagher-Thompson et al., 1997; Ayalon & Hyuck, 2002). Nguyen et al. (2020) found that when Vietnamese caregivers had access to tools and services in Vietnamese, they were better able to understand their AD patients' needs while simultaneously easing their own burden and stress from caregiving.

Resources in languages other than English are important for caregivers who are more fluent in another language, but it is also crucial to note that Alzheimer's information must be translated into other languages with care and attention. Some languages do not have the terminology for Alzheimer's disease symptoms and effects and cannot be directly translated from English, so it is as equally necessary to take time in correctly translating Alzheimer's educational information as it is to create non-English educational tools (Gallagher-Thompson et al., 1997). A study conducted by Valle et al. (2006), which focused on participants from a local Latino community, used educational tools written in Spanish and structured their study in a way to avoid cultural rudeness. The study found that their method of educating elderly adults about Alzheimer's, which used fotonovelas and group discussions, was successful in increasing Alzheimer's disease knowledge between sessions three weeks apart (Valle et al., 2006). Their findings emphasize the importance of both language and culture in creating a wider understanding and acceptance of Alzheimer's disease.

The impact of linguistic challenges in caregiving are also passed along to the patients. Ethnic minority elders are typically diagnosed with the disease during its later stages as a consequence of stigmatization and general lack of knowledge, decreasing access to early

intervention or availability of treatments (Ayalon & Areán, 2004). A lack of ethnic minority representation also leads to significant underrepresentation in Alzheimer's research and clinical trials for Alzheimer's disease (Ayalon & Hyuck, 2002; Faison et al., 2007). This can be remedied, however, through better educational material and outreach in languages other than English (Ayalon & Huyck, 2002).

Caregiving for Alzheimer's Disease

For many people with Alzheimer's disease, caregiving comes in the form of family members or hired caregivers rather than an assisted living facility (Carpenter et al., 2009). In recent years, family-based caregiving has become especially common due to a trend in non-institutionalized care, although this also increases the burdens placed on the caregiver (Navab et al., 2012). Although dementia patients have been found to have a better quality of life in a familiar home environment, the quality of life of family caregivers can subsequently decrease. Several studies have found that caregivers of a family member with Alzheimer's disease are more likely to experience depression and loneliness, as well as negative impacts on their social and intrafamily relationships (Ocaña et al., 2007; Ercoli et al., 2021; Peavy et al., 2022). In addition, Ocaña et al. (2007) found that only 14.7% of family caregivers are paid for their time, indicating a significant financial sacrifice in addition to the mental sacrifice involved in caring for someone with Alzheimer's disease.

Caregiving Challenges

A number of impediments can affect how and whether a family caregiver is able to find and retain the information required to successfully care for an Alzheimer's disease patient. Although online Alzheimer information has long been one option among several for caregiver education and support, caregivers have a limited capacity to take action with the health

information provided to them (Queiroz et al., 2020). The COVID-19 pandemic has also caused many Alzheimer's disease resources and support groups to switch entirely online, isolating caregivers without ready access to technology (Ercoli et al., 2021). Online support also increases the need for the caregiver to be proficient enough in English to seek out and process Alzheimer's information, as the burden of finding information falls solely onto them.

The restriction of online-only support is only the first hurdle of many for caregivers who do not fluently speak English. Linguistic barriers hold Alzheimer's caregivers back from finding the information required to provide for their patient while limiting caregivers in the ways in which they express their own needs (Gallagher-Thompson et al., 1997; Ayalon & Hyuck, 2002). Resources in languages other than English are important for caregivers who are more fluent in another language, as it is important to create resources that are culturally relevant and meaningful to different communities (Gallagher-Thompson et al., 1997).

Caregiver education about Alzheimer's and how to care for a patient are imperative to the quality of care that they are able to provide (Ercoli et al., 2021). The treatment and care of an Alzheimer's patient can rapidly become a full-time task as the motor functions and cognitive abilities of an AD patient dissipates over time, emphasizing the importance for a caregiver to understand the needs of the patient and how to respond to them (Sullivan et al., 2007; Scheltens et al., 2016). A study by Gaugler et al. (2003) found that out of more than 1,000 caregivers, most had only received a high school level of education. In addition to understanding the existing challenges faced by Alzheimer's disease caregivers, this study will also examine if there is any relationship between the level of caregiver education and their Alzheimer's knowledge and perceived stress.

Caregivers and Stress

Caring for a patient with Alzheimer's disease is also mentally challenging for caregivers. Numerous studies have found that caregivers of Alzheimer's patients experience symptoms of loneliness, depression, anxiety, and high levels of stress (Du et al., 2020; Rose et al., 2021; Peavy et al., 2022). Due to the large time commitment associated with Alzheimer's patient care, caregivers lack the personal time and space needed to attend to their own mental health, which in turn suffers the consequences.

Online support groups have been found to alleviate stress by reducing feelings of depression and isolation, while providing caregivers with a virtual space to share their thoughts and express how they feel (Pagán-Ortiz et al., 2014; Ni et al., 2022). Platforms such as Facebook and Reddit have their own groups and threads dedicated to Alzheimer's caregivers, who often turn to online support groups as an emotional outlet. In an analysis of Reddit threads, Ni et al. (2022) found that the most common topics of discussion relate to negative feelings, home care, and legal/financial issues related to Alzheimer's disease patients. Other popular themes from the threads included negative relationships, eating/sleeping issues, and death.

Stress and Mental Health

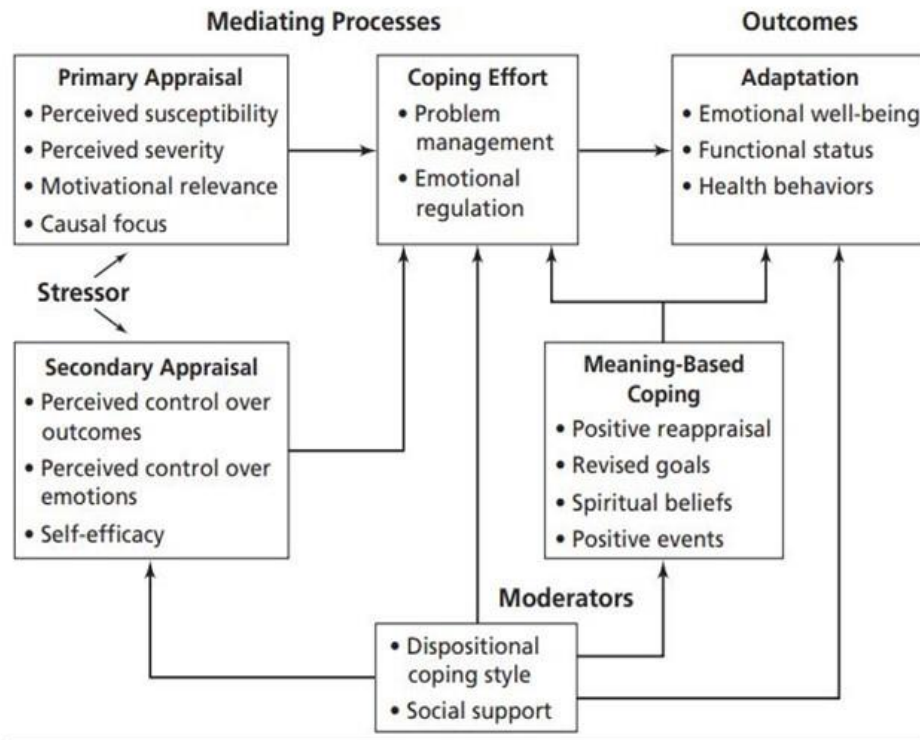
The Transactional Model of Stress and Coping explains how people appraise a given situation and cope with it based on perceived stress (Salva et al., 2021). The model involves a three-step appraisal process: cognitive appraisal, primary appraisal, and secondary appraisal. When appraising a situation, a cognitive appraisal allows a person to decide whether the given situation is relevant to them, and in what ways (Folkman et al., 1986). If relevant, a primary appraisal determines the significance of the threat, followed by a secondary appraisal that analyzes the controllability of the threat (Chow & Ho, 2015). The concept of coping, which

involves the cognitive and behavioral changes required to overcome and perceive stressful situations, begins in the secondary appraisal stage (Folkman et al., 1986).

Stress and appraisal are subject to the perceptions of the appraiser, and coping responses are subsequently influenced by perception. Folkman et al. (1986) defines coping as a process-oriented and contextual response to stressors, focusing on how a person and the variables that arise from a situation work together to contribute to their coping strategy. Coping is also understood as neither good nor bad; how a person copes with a given stressor is dependent on their own background and perceived concerns (Folkman et al., 1986). With this in mind, coping has two purposes according to the Transactional Model of Stress and Coping: to regulate stress-related emotions and to alter a given troubling situation. A model of the Transactional Model of Stress and Coping is found in Figure 1 below (Glanz & Schwartz, 2008):

Figure 1

Transactional Model of Stress and Coping



The Transactional Model of Stress and Coping explains that a person will evaluate an environmental stressor based on their perception of the threats and risks involved with the stressor. As such, the greater the perception of threat, the higher the level of stress will be for the person in question. In a patient-caregiver situation, stressful situations may include the behavior of a person with Alzheimer's disease, the commitments required of caregiving, or the act of caregiving itself. The intense level of care required for a patient with Alzheimer's disease may already be stressful to any caregiver, but the additional challenge of predicting and responding to uncontrollable changes in behavior consistent with Alzheimer's disease can further impact the level of stress put on the caregiver. Increased caregiver stress and strain is linked to a lower quality of life and higher emotional distress (Chow & Ho, 2014). This is especially difficult given that problem-solving coping strategies, such as altering the troubling situation, are not possible for caregivers of Alzheimer's patients unless a new caregiver is found.

The behavior of the caregiver can impact the stress of the patient, so that the two people have a cyclical relationship of stress and responsive behavior (Lecavalier et al., 2006). Coping efforts, such as emotional expression and the use of spirituality, can result in physical and mental health benefits to the stressed individual (Glanz et al., 2022). Active coping strategies in particular can ensure that the patient is receiving the care that they need, and the caregiver is able to reduce their own stress levels and improve their mental health as a result. Active coping, a form of problem-focused coping, is the process of taking active steps to eradicate a stressor or prevent its affects (Carver et al., 1989). These methods take direct action to the situation and suggest the suppression of competing activities so that one's sole focus is on the situation at hand. Active coping is different from other coping methods, such as venting emotions or denial

of the situation. While the former focuses on real-time responses, the latter are coping strategies that do not directly and actively impact the situation (Carver et al., 1989).

Knowledge of Alzheimer's disease and proper care may act as an active coping strategy for caregivers. As Folkman et al. (1986) states, coping is "a person's efforts to manage demands" (p. 993), and finding health information can be a tactic toward managing the demands of caring for a patient with Alzheimer's disease. A caregiver is likely unable to change the situation they are placed in, but they can mediate their emotions by finding health information relevant to their patient and given situation. As such, it is imperative that health communication about Alzheimer's disease is readily available and accessible to caregivers seeking ways to cope with their situation. By analyzing both Alzheimer's disease knowledge and perceived stress levels, this study may be able to establish a relationship between the two variables.

When studying the Transactional Model of Stress and Coping in relationship to caregivers of patients with Alzheimer's disease, it is important to recognize the cultural factors and trends that may factor into caregiver burden. As life expectancy increases and a higher percentage of adults reach old age, so does the number of Alzheimer's patients. However, many developed countries are seeing a decrease in family members in each subsequent generation as adults choose to have fewer children than their predecessors, thus decreasing the number of future caregivers between children and their parents. Additionally, modern employment demands and financial strains can restrict the ability for children of Alzheimer's patients to care for their parents (Chow & Ho, 2014). As such, primary caregivers for patients with Alzheimer's disease are often spouses, who are at a similar age to the patient themselves (Gaugler et al., 2003). To get a better idea of how age impacts caregiving, this study will also ask caregivers to provide their age.

In analyzing how Alzheimer’s disease caregivers appraise their caregiving situation and cope with taking care of a family member, the Transactional Model of Stress and Coping can help explain how different approaches to caregiving impact mental health. This can be coupled with an analysis of caregivers who frequent online support groups, with the assumption that their use of online platforms to cope with caregiving may provide insight to their stress and the methods through which caregivers take care of themselves.

Research Questions

After considering the challenges that caregivers of patients with Alzheimer’s disease face in caring for their patient, this study seeks to answer the following question about the caregiver experience and the ways in which communication can empower caregivers. For the purpose of this study, the term “Alzheimer’s disease communication” refers to any health information that caregivers receive about Alzheimer’s disease, including websites, newsletters, and social media. Any media that caregivers consume relating to Alzheimer’s will be considered “communication” that they are receiving.

RQ1: To what extent does Alzheimer’s disease communication for caregivers impact:

- a) Alzheimer’s disease knowledge*
- b) Caregiver stress*
- c) Caregiver active coping methods*

In an effort to develop a better understanding of the relationship between communication-relevant caregiver demographics, such as level of education and preferred language, and caregivers’ ability to care for their patient given the information available to them, this study will also explore the following questions:

RQ2: How does caregiver education level impact caregiver a) Alzheimer's disease knowledge, b) stress, c) active coping, and d) communication?

RQ3: How does caregiver English language preference impact caregiver a) Alzheimer's disease knowledge, b) stress, c) active coping, and d) communication?

RQ4: Does caregiver education level moderate the relationship between caregiver Alzheimer's disease communication and caregiver a) Alzheimer's disease knowledge, b) stress, and c) active coping?

RQ5: Does caregiver English language preference moderate the relationship between caregiver Alzheimer's disease communication and caregiver a) Alzheimer's disease knowledge, b) stress, and c) active coping?

METHODS

Participants and Procedures

The study used an anonymous Qualtrics survey with questions probing caregiver confidence, Alzheimer's disease knowledge, Alzheimer's disease messaging, caregiver stress levels, and caregiver active coping strategies (Manzini & Vale, 2020). Anonymity of participants in this study was an essential factor in encouraging participation and ensuring that responses are authentic (Rose et al., 2021). Questions were drawn from prior studies, the Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009), Perceived Stress Scale (Peavy et al., 2022), the care stress-management scale (Sharif Nia et al., 2023) and the Ways of Coping Questionnaire (Folkman & Lazarus, 1985). The survey also contained demographic questions including racial and ethnic group, level of education, and prior experience with Alzheimer's to test findings found in past studies pertaining to Alzheimer's disease (Ercoli et al., 2021).

The target population in this study was caregivers who care for a patient with Alzheimer's disease. This study had a participant goal of 200 caregivers, based on the precedent set by Cohen et al. (1983), Ayalon & Areán (2004), and Carpenter et al. (2009). Participants were initially recruited from Reddit threads and Facebook groups created for self-identified caregivers, due to the importance of these spaces in relation to caregiver stress (Pagán-Ortiz et al., 2014; Ni et al., 2022). Participants were also later recruited via Prolific, an online research platform.

A total of 13 Facebook groups and four Reddit threads were used for participant outreach. The groups ranged in topic from Alzheimer's caregiving support to general caregiver groups. Although the groups had a collective total of thousands of members, the survey response was minimal, and therefore Prolific was used to achieve the participant goal. Prolific participants were filtered by those who self-identified as having "informal/unpaid caring responsibilities." An additional question in the beginning of the survey asked participants if they were a caregiver specifically for someone with Alzheimer's disease. Anyone who selected "No" to this question was immediately taken to the end of the survey. All Prolific participants were paid \$1.50 for completing the survey.

Measures

Knowledge

This variable measured the participants' current knowledge of Alzheimer's disease using questions on the Alzheimer's Disease Knowledge Scale. The Alzheimer's Disease Knowledge Scale (ADKS) is a true-false test with 30 statements pertaining to Alzheimer's disease knowledge and is a reliable measurement of internal consistency and test-retest (e.g., "People with Alzheimer's disease are particularly prone to depression").

Cronbach's alphas for internal consistency and test-retest of Carpenter et al.'s (2009) knowledge scale were .71 and .81, respectively. Consistent with Carpenter et al. (2009), Cronbach's alpha for the Alzheimer's Disease Knowledge Scale's internal consistency in this study was .72. Over 400 studies have cited the Alzheimer's Disease Knowledge Scale as a method of measuring Alzheimer's knowledge. Questions on the knowledge scale cover a broad range of Alzheimer's knowledge and include more recent information about the causes, symptoms, and care for people with Alzheimer's disease. The knowledge scale questions are based on information from the Alzheimer's Association, prior Alzheimer's studies, and Dieckmann et al.'s (1988) Alzheimer's Disease Knowledge Test, the latter being outdated (Carpenter et al., 2009). If respondents were unsure of how to respond to some of the survey's true/false questions, they were advised to guess an answer. Despite its breadth, Carpenter et al. (2009) cautioned against breaking apart the Alzheimer's Disease Knowledge Scale into subscales during analysis, as the knowledge scale is a cumulative scale of Alzheimer's knowledge.

Participant responses were scored out of 30 points—one point for each true/false question answered correctly on the Alzheimer's Disease Knowledge Scale. A total of 187 participants answered every question on the knowledge scale, and participants who did not answer all 30 questions were not included in the analysis of the scale scores. Most participants received a score between 19 and 25 ($n = 112$, 59.9%), although participant scores ranged from 10 to 30. The mean score was 21.79 ($SD = 4.12$).

The most missed questions on the knowledge portion of the survey were a) “When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should

take over right away” ($M = .37$) and b) “It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease” ($M = .48$).

The most correctly answered questions on the knowledge portion of the survey were: a) “Alzheimer’s disease is one type of dementia” ($M = .94$) and “Alzheimer’s disease cannot be cured” ($M = .93$).

Stress

This variable tested the perceived levels of stress endured by caregivers. Perceived stress is subjective and will vary depending on the caregiver’s appraisals of each situation. The Perceived Stress Scale (PSS), originally created and tested for reliability at the University of Oregon, is designed to measure individuals' stress levels in a given scenario (Cohen et al., 1983). The Perceived Stress Scale has been used previously to study stress on elderly caregivers of patients with dementia (Peavy et al., 2022). Cohen et al.’s (1983) stress scale continues to be used by studies today to understand the prevalence of stress and the ways in which it presents itself. There are 14 questions on the Perceived Stress Scale, which are answered using a five-point scale ranging from 0=Never to 4=Very Often (e.g., “In the last month, how often have you felt you were unable to control the important things in your life?”). In this study, the stress scale ranged from 1=Never to 5=Very Often ($\alpha = .88$). Individual question scores were reversed for all positively stated items, then summed across all 14 questions for a final score.

A total of 194 participants answered every stress scale question in the survey ($n = 194$), resulting in an average score across participants of 42.43 out of the possible 70 points ($SD = 8.52$). The majority of participants scored 43 or lower on the stress portion of the survey ($n = 101, 52.1\%$).

The questions on the Perceived Stress Scale with the highest response scores were a) “In the last month, how often have you found yourself thinking about things that you have to accomplish?” ($M = 3.97$) and b) “In the last month, how often have you felt nervous and ‘stressed’?” ($M = 3.59$).

Coping Methods

This variable measured the ways in which Alzheimer’s disease caregivers respond to the stressors they experience within their role. The Ways of Coping Questionnaire, designed and revised by Folkman & Lazarus (1985), was created to analyze the frequency of different coping methods. It is one of the most frequently cited coping scales among published studies, and it is the most frequently used coping scale for studies about caregiving (Kato, 2015). The original Ways of Coping Questionnaire has 66 questions and uses a four-point Likert scale ranging from 0=Not Used to 3=Used a Great Deal to allow participants to describe their usage of each of the listed coping strategies (e.g., “Just concentrated on what I had to do next – the next step.”). For the purpose of this study, only items from the Ways of Coping Questionnaire utilizing active coping methods will be used, as determined by the active coping definition in Carver et al. (1989). There are four items validated for the active coping sub-scale, which are answered using a four-point scale ranging from 1=I usually don’t do this at all to 4=I usually do this a lot in response to a prompt that asks them to indicate how they respond when they are under stress as a caregiver (e.g., “I concentrate my efforts on doing something about it,” “I take additional action to try to get rid of the problem,” “I take direct action to get around the problem,” and “I do what has to be done, one step at a time”) ($\alpha = .75$).

A total of 193 survey participants completed the abridged Ways of Coping Questionnaire ($n = 193$). The coping score was calculated for each participant based on the mathematical mean

of their responses to each of the 11 Ways of Coping questions. The overall mean score was 2.66, falling between 2=I have done this a bit and 3=I have done this a fair amount ($SD = .46$). The most used active coping methods among participants were a) “Just focused on what I had to do—the next step” ($M = 3.04$), b) “Came up with a couple of different solutions to the problem” ($M = 3.03$), and c) “I knew what had to be done, so I doubled my efforts to make things work” ($M = 2.98$).

Communication

This variable measured the existing level of Alzheimer’s disease communication that caregivers receive. Participants were informed that “communication” can include any type of media they consume about Alzheimer’s disease. A Caregiver Communication Scale was created for the purpose of this study to measure the accessibility, timeliness, and relevance of AD health information. The Caregiver Communication questions were created based on the care stress-management scale and a variety of studies on the challenges faced by caregivers of patients with Alzheimer’s disease (Manzini & Vale, 2020; Ni et al., 2022; Peavy et al., 2022; Sharif Nia et al., 2023). These questions used a five-point Likert scale for participants to select the point that they feel best represents them (e.g., “I have access to the information I need about the different stages of Alzheimer’s disease,” “I have access to the information I need about how Alzheimer’s disease affects a patient,” “I have access to the information I need about caring for an Alzheimer’s disease patient”) ($\alpha = .90$). One out of the 11 questions in the Caregiver Communication Scale was reverse-coded due to its negative framing.

A total of 195 survey participants completed the Caregiver Communication Scale ($n = 195$). The communication scale score was calculated for each participant based on the mathematical mean of their responses to each of the 11 Caregiver Communication Scale

questions. The overall mean score was 3.90, falling between 3=Sometimes and 4=Fairly often ($SD = .70$). The most agreed-upon statements were a) “I am able to understand the information I receive about Alzheimer’s disease” ($M = 4.23$) and b) “I am able to find information about Alzheimer’s disease when I need it” ($M = 4.11$).

Participant Demographics

Participants were also asked to answer demographic questions, including one about their existing English language knowledge (e.g., “Is English your preferred language?”). Due to the linguistic challenges faced by caregivers who are less experienced with the English language, it was important to recognize that some participant responses may have been influenced by language-based factors that can impact Alzheimer’s disease information access. There was also a question about participant education level to identify if level of education acts as a moderator on Alzheimer’s information access and care (e.g., “What is your highest level of completed education?”). For the purpose of analysis, the categories were combined: no degree, high school graduate, and associate degree and bachelor’s degree, master’s/graduate degree, and doctoral degree. A full list of the questions that were used in this study can be found in the Appendix.

A total of 237 participants responded to the survey for this study ($n = 237$). Out of these participants, 39 of their responses were eliminated for not being a self-identified caregiver for someone with Alzheimer’s disease, dropping the total to 198 ($n = 198$).

Participants in the study were asked if English was their preferred language for information. Out of the total participants, 185 responded to this question, with 82.7% saying yes ($n = 153$) and 17.3% saying no ($n = 32$).

A follow-up question asked participants about their level of English language knowledge. Out of the total participants, 193 responded to this question, reporting that they were completely fluent (n = 155; 80.3%), somewhat fluent (n = 36; 18.7%), or not very fluent (n = 2, 1.0%) in English.

Participants were also asked about their highest level of completed education, to which 184 participants responded. Out of those who did respond, 50.5% had a bachelor's degree (n = 93), 21.2% had a high school degree (n = 39), 19.6% had a master's or graduate degree (n = 36), 5.4% had an associate degree (n = 10), 1.6% had a doctoral degree (n = 3), and 1.6% had no degree (n = 1.6%). The dichotomous education variable was split between degrees leading up to a bachelor's (n = 52; 28.3%); and a bachelor's degree and beyond (n = 132; 71.7%).

Participant ages varied, but the majority were 50 years old or younger (n = 155; 80.3%). The average survey completion time was 11.40 minutes.

RESULTS

Data Collection and Analysis

For each continuous measure from the survey, reliable items were averaged into a composite scale: Alzheimer's Disease Knowledge Scale, Perceived Stress Scale, Ways of Coping Questionnaire, and Caregiver Communication Scale. Both descriptive and inferential statistical tests were run to establish any correlational and regression relationships between caregiver communication and caregiver knowledge, stress, and active coping. Descriptive statistical tests were run for participant education level, English language preference, English language proficiency, and age. Independent samples t-tests were also run to identify if there were any significant relationships between the dichotomous education and language preference variables, and each individual scale.

Simple linear regression tests were used to answer RQ1 in this study. A regression was conducted with the Caregiver Communication Scale and each of the remaining scales, totaling three tests. RQ2 and RQ3 were answered using independent sample t-tests for each scale. For RQ4 and RQ5, multiple regression tests were run in a similar manner to RQ1 but included an interaction variable between the Caregiver Communication Scale and education/language preference in order to account for a potential moderating relationship.

Before running the statistical tests needed to answer the research questions, a correlation test was run on the six variables analyzed in this study. See Table 1 for results.

Table 1

Descriptive Statistics and Correlations for Study Variables

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	1	2	3	4	5	6
1. CCS score	195	3.90	.70	—					
2. Education level	184	.72	.45	.06	—				
3. Language preference	185	1.17	.40	-.219**	.03	—			
4. ADKS score	187	21.79	4.12	-.06	.06	-.02	—		
5. WCQ score	193	2.66	.46	.38**	.12	-.04	-.21**	—	
6. PSS score	194	42.43	8.52	-.25**	-.01	.07	.11	-.19**	—

***p* < .01

1. Caregiver Communication Scale, 4. Alzheimer’s Disease Knowledge Scale, 5. Ways of Coping Questionnaire, 6. Perceived Stress Scale

Connecting Communication on Knowledge, Stress, and Coping

Three separate simple linear regression tests were conducted to evaluate the extent to which participants' level of caregiver communication could predict their Alzheimer's disease knowledge, perceived stress, and active coping methods.

RQ1a examined the relationship between caregiver communication on Alzheimer's disease knowledge. A non-significant relationship was found between caregiver communication and Alzheimer's disease knowledge ($F(1,182) = .66, p = .419, R^2 = .004$).

RQ1b examined the relationship between caregiver-related Alzheimer's disease communication on the caregiver's perceived stress and found a significant relationship. Caregiver Alzheimer's disease information communication significantly predicted caregiver stress scores, $B = -3.04, t(191) = -3.55, p < .001$. Caregiver communication also explained a small but significant proportion of variance in stress scores, $R^2 = .06, F(1,190) = 12.63, p < .001$. This means that a unit increase in an Alzheimer's caregiver communication is associated with a 3.04 reduction in caregiver stress.

RQ1c examined the relationship between caregiver-related Alzheimer's disease communication on caregiver stress and found a significant relationship. Caregiver Alzheimer's disease information communication significantly predicted caregiver active coping scores, $B = .26, t(191) = 5.73, p < .001$. Caregiver communication also explained a significant proportion of variance in coping scores, $R^2 = .15, F(1,190) = 32.88, p < .001$. This means that a unit increase in Alzheimer's caregiver communication is associated with a .26 increase in caregiver active methods.

Connecting Education Level and English Language Preference on Knowledge, Stress, and Coping

RQ2a explored the relationship between the caregiver's education level and their Alzheimer's disease knowledge score. An independent samples t-test, comparing the means of Alzheimer's Disease Knowledge Scale scores of participants with less than a bachelor's degree and those with a bachelor's degree or higher, found that there was no statistically significant difference in knowledge scores ($t(172) = -.79, p = .56$).

RQ3a examined how the caregiver's English language preference is associated with the caregiver's Alzheimer's disease knowledge score. An independent-samples t-test, comparing the mean Alzheimer's Disease Knowledge Scale scores of participants whose preferred language was English to those whose preferred language was not, found a significant difference between the means of the two groups ($t(172) = .25, p = .045$). The mean of participants who preferred English was higher ($M = 21.65, SD = 4.25$) than the mean of participants who did not prefer English ($M = 21.45, SD = 3.33$). The data shows that participants whose preferred language is English do have a higher level of Alzheimer's disease knowledge than participants whose preferred language is not English, according to the Alzheimer's Disease Knowledge Scale.

To further analyze findings according to English language knowledge, another independent samples t-test was run between participants who were completely fluent in English and participants who were either not very or somewhat fluent in English. The independent samples t-test found that there was no statistically significant difference in Alzheimer's Disease Knowledge Scale scores between levels of English language knowledge ($t(180) = -2.55, p = .19$). Table 2 displays the descriptive statistics for Alzheimer's Disease Knowledge Scale scores in relation to English language preference and educational background of the participant.

Table 2*Descriptive Statistics of ADKS Score by Participant Group*

Variable	<i>N</i>	<i>M</i>	<i>SD</i>	Min	Max	Skew	Kurt
English preferred	143	21.65	4.25	10	30	-.14	-.48
English not preferred	31	21.45	3.33	14	28	-.529	.248
Associate degree or below	51	21.24	4.05	13	29	-.24	-.37
Bachelor's degree or higher	123	21.77	4.11	10	30	-.166	-.373

RQ2b and RQ3b examined the relationship between a caregiver's education level and English language preference on the caregiver's perceived stress score, respectively. Two different independent samples t-tests were run, one with education levels and one with English language preference, comparing the mean Perceived Stress Scale scores of survey participants. No statistically significant conclusions were found for education ($t(179) = .14, p = .13$) or English preference ($t(180) = -.94, p = .09$).

RQ2c and RQ3c explored the relationship between a caregiver's education level and English language preference on the caregiver's active coping score, respectively. Two different independent samples t-tests were run, one with education levels and one with English language preference, comparing the mean Ways of Coping Questionnaire scores of survey participants. No statistically significant conclusions were found for education ($t(182) = -1.68, p = .38$) or English preference ($t(183) = .47, p = .18$).

RQ2d and RQ3d explore the relationship between a caregiver's education level and English language preference with the caregiver's Alzheimer's disease communication score, respectively. Two different independent samples t-tests were run, one with education levels and

one with English language preference, comparing the mean Caregiver Communication Scale scores of survey participants. No statistically significant conclusions were found for education ($t(181) = -.77, p = .38$) or English preference ($t(182) = 3.02, p = .31$).

Education Level as a Moderator Between Communication and Knowledge, Stress, and Coping

Three separate multiple regression tests were conducted to evaluate the extent to which caregiver education level moderates the relationship between a caregiver’s received communication and their Alzheimer’s disease knowledge, perceived stress, and active coping methods. Caregiver communication and education level were entered into the first model. The interaction term between communication and education was entered into the second model.

RQ4a examined the interaction between caregiver-related Alzheimer’s disease communication and education level, and its association with the caregiver’s knowledge score. Education level did not moderate the relationship between caregiver communication and Alzheimer’s disease knowledge (Model 2, $F(3,169) = 1.54, p = .13, R^2 = .03$). Table 3 displays the regression output for this interaction:

Table 3

Regression Table for Communication and Knowledge, Moderated by Education Level

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	170	1.12	.33	.01	.62	.68	.07
2	3	169	1.54	.13	.03	-1.54	1.00	-.23

Model 1: Communication, and Education

Model 2: Communication, Education, and interaction term between communication and education

Dependent Variable: Alzheimer’s Disease Knowledge Scale

RQ4b examined the interaction between caregiver-related Alzheimer’s disease communication and education level, and its association with the caregiver’s perceived stress score. Education level did not moderate the relationship between caregiver communication and perceived stress (Model 2, $F(3,176) = 3.61, p = .98, R^2 = .06$). Table 4 displays the regression output for this interaction:

Table 4

Regression Table for Communication and Perceived Stress, Moderated by Education Level

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	177	5.44	.005	.06	.07	1.34	.004
2	3	176	3.61	.98	.06	-.06	1.98	-.004

Model 1: Communication and Education

Model 2: Communication, Education, and interaction term between communication and education

Dependent Variable: Perceived Stress Scale

RQ4c examined the interaction between caregiver-related Alzheimer’s disease communication and education level, and its association with the caregiver’s active coping score. Education level did not moderate the relationship between caregiver communication and active coping methods (Model 2, $F(3,179) = 11.85, p = .15, R^2 = .17$). Table 5 displays the regression output for this interaction:

Table 5*Regression Table for Communication and Coping, Moderated by Education Level*

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	180	16.61	<.001	.16	.10	.07	.10
2	3	179	11.85	.15	.17	.15	.10	.20

Model 1: Communication and Education

Model 2: Communication, Education, and interaction term between communication and education

Dependent Variable: Ways of Coping Questionnaire

English Language Preference as a Moderator Between Communication and Knowledge, Stress, and Coping

Three separate multiple regression tests were conducted to evaluate the extent to which caregiver English language preference moderates the relationship between a caregiver received communication and their Alzheimer’s disease knowledge, perceived stress, and active coping methods. Caregiver communication and language preference were entered into the first model. The interaction term between communication and language preference was entered into the second model.

RQ5a examined the interaction between caregiver-related Alzheimer’s disease communication and English language preference, and its association with the caregiver’s Alzheimer’s disease knowledge score. A significant relationship was not found between caregiver communication, English language preference, and Alzheimer’s disease knowledge (Model 2, $F(3,169) = .64$, $p = .65$, $R^2 = .01$). Table 6 displays the regression output for this interaction:

Table 6*Regression Table for Communication and Knowledge, Moderated by English Preference*

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	170	.86	.43	.01	-.44	.83	-.04
2	3	169	.64	.65	.01	.55	1.21	.12

Model 1: Communication and English Preference

Model 2: Communication, English Preference, and interaction term between communication and English Preference

Dependent Variable: Alzheimer's Disease Knowledge Scale

RQ5b examined the interaction between caregiver-related Alzheimer's disease communication and English language preference, and its association with the caregiver's perceived stress score. English language preference did not moderate the relationship between caregiver communication and perceived stress (Model 2, $F(3,177) = 3.82$, $p = .63$, $R^2 = .06$).

Table 7 displays the regression output for this interaction:

Table 7*Regression Table for Communication and Perceived Stress, Moderated by English Preference*

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	178	5.64	.004	.06	.32	1.62	.02
2	3	177	3.82	.63	.06	1.14	2.38	.12

Model 1: Communication and English Preference

Model 2: Communication, English Preference, and interaction term between communication and English Preference

Dependent Variable: Perceived Stress Scale

RQ5c examined the interaction between caregiver-related Alzheimer’s disease communication and English language preference, and its association with the caregiver’s active coping score. English language preference did not moderate the relationship between caregiver communication and active coping methods (Model 2, $F(3,180) = 11.50, p = .23, R^2 = .16$). Table 8 displays the regression output for this interaction:

Table 8

Regression Table for Communication and Coping, Moderated by English Preference

Model	Regression <i>df</i>	Residual <i>df</i>	<i>F</i>	<i>p</i>	<i>R</i> ²	Coefficients		
						<i>B</i>	<i>SE B</i>	β
1	2	181	16.48	<.001	.15	.07	.09	.05
2	3	180	11.50	.23	.16	-.15	.12	-.28

Model 1: Communication and English Preference

Model 2: Communication, English Preference, and interaction term between communication and English Preference

Dependent Variable: Ways of Coping Questionnaire

DISCUSSION

The findings from this study suggest that there is a statistically significant relationship between caregiver communication, perceived stress, and active coping methods. An increase in caregiver communication was shown to be associated with a statistically significant decrease in perceived stress on the caregiver. Likewise, an increase in caregiver communication was also connected to a statistically significant increase in active coping methods for the caregiver’s stressful situations. Findings from the study show that the level of communication a caregiver receives about their role does not have a significant relationship with their knowledge of Alzheimer’s disease. Altogether, these findings indicate that communication does help caregivers

of Alzheimer's disease, specifically allowing them to care for their own wellbeing while they are caring for others.

The Relationship Between Communication and Caregiving

The Transactional Model of Stress and Coping explains how people evaluate and navigate stressful emotions and situations. When relating this model to caregivers and specifically those who work with patients who have Alzheimer's disease, the Transactional Model of Stress and Coping suggests that increased communication for caregivers could give them the tools they need to mitigate stress-related emotions and aid their coping efforts. The findings in this study corroborate this idea: increased communication with caregivers was associated with statistically significant differences in their perceived stress and active coping methods. In the Transactional Model, a primary appraisal allows someone to determine the significance of a threat. A caregiver who lacks much knowledge of how to care for a patient with Alzheimer's disease may find a given stressor to be a significant threat, but another caregiver who has received better communication may determine that the stressor is a much smaller threat, simply due to the information they've received.

A secondary appraisal puts caregiving communication to even greater use. The Transactional Model explains that secondary appraisal allows a person to examine the controllability of the threat at hand. Guided by their knowledge of caregiving, an informed caregiver could determine that a threat is largely controllable because they know how to handle the situation via the information they've learned. As such, the caregiver can reduce the level of stress that may arise from a situation and respond with the appropriate coping methods that they know will resolve the task at hand. A less-informed caregiver may find the same situation uncontrollable and stressful because they lack the knowledge to prepare themselves. When

dealing with a disease as unpredictable and unexpected as Alzheimer's disease, understanding how to respond to different scenarios may be critical to reducing caregiver stress.

This study has found that knowledge and information communicated to caregivers is related to a decrease in the threat perception of the stressor. This suggests that as caregivers receive more information about caring for a patient with Alzheimer's disease, they may become better equipped to handle their role and approach it from a more knowledgeable standpoint. Caregivers who receive greater communication may find that they are better able to utilize active coping methods to mitigate a stressful caregiving situation. As their coping methods and tools increase, their stress can go down, therefore increasing the mental health of the caregiver. When caregivers have access to information that is understandable and empowering, they might approach a stressor from a better mental mindset. They become better able to take care of themselves, and in doing so, they become better able to take care of their loved ones.

A Connection with English Language Knowledge

The average participant score on the Alzheimer's disease knowledge portion was 21.79—many participants incorrectly answered nearly one third of the questions. Participants whose preferred language was English had an average score higher on the Alzheimer's Disease Knowledge Scale than the scores of participants whose preferred language was not English. This suggests that there may be a disconnect in the flow of information communication between communicators and caregivers. As the literature suggests, caregivers who predominantly consume media in English are more easily able to seek and procure the information they need to learn about Alzheimer's disease. Caregivers who prefer resources in a language other than English appear to have difficulty learning about Alzheimer's disease. Regardless of whether Alzheimer's knowledge is associated with the caregiver's ability to perform in their role, those

who do not prefer English resources are automatically placed at a disadvantage for a reason outside of their control. The statistically significant knowledge scale scores between the two groups indicate that there is a need for communication resources in languages other than English.

Communicating Needs for Caregiver Success

Overall caregiver communication levels were high, indicating that caregivers generally have access to the communication they need to understand their role and the needs of a person with Alzheimer's disease. Participants largely seemed confident in their ability to find and comprehend information about Alzheimer's disease. Although caregivers seemed to have access to the communication they needed, findings related to the Alzheimer's Disease Knowledge Scale suggest that the communication received does not necessarily pertain to knowledge of Alzheimer's disease—with an average knowledge scale score of 21.79, caregivers are lacking in Alzheimer's knowledge. This could either be because the information they find does not educate them about the disease itself, or because they are not actively looking for more knowledge about the disease when searching for information. Regardless of the cause, study data indicate that caregivers do not find a complete understanding of the disease to be necessary to their success as a caregiver. Caregivers are satisfied with their perceived level of knowledge about Alzheimer's disease.

Participants scored an average of 42.43 points on the Perceived Stress Scale and responded with “sometimes” or “fairly often” for most statements. It comes as no surprise that the survey data shows that caregivers deal with a significant amount of stress—with a point range of 14 to 70, the average score is considered moderate to high perceived stress on the Perceived Stress Scale. Even with access to caregiving communication, caregiver stress levels suggest that they regularly interact with unavoidable stressors. This appears to be a universal

experience regardless of education level or English language preference, as neither had a statistically significant association with perceived stress.

This study focused solely on active coping strategies, but among the active coping strategies, the most used methods were those that required taking next steps. Participants seem to prefer taking action and moving forward one step at a time in an effort to make progress, rather than dwelling on the situation or focusing on themselves. With less frequently used Ways of Coping Questionnaire options such as “I got professional help” or “I changed something about myself,” the study findings imply that caregivers spend less time coping by fixing their own attitudes and emotions, instead coping by pushing forward. By moving forward and not taking the time to process their emotions, caregivers are increasing their own stress levels and leaving a negative impact on their mental health. In a situation as mentally taxing as caring for a person with Alzheimer’s disease, neglecting one’s own care in favor of caring for others can prove to be detrimental in the long run.

Study Limitations

The most significant limitation in this study was the number of participants completing the survey. Although the 198 responses provided a preliminary idea of caregiver communication needs and relationships, this is a proportionately small sample compared to the millions of caregivers worldwide. Additionally, the overwhelming majority of participants represented in this data were under 50 years old. Alzheimer’s disease is most commonly found in adults 65 years or older, and their caregivers are often spouses or older children. To have such a large quantity of young participants suggests that the data may not represent caregivers across all ages. The findings from this study therefore should not be generalized over a larger caregiving population.

Although there was a wide range of education levels represented in the overall data, each individual level was not represented equally. For example, only three participants had no degrees at all, while 93 participants had a bachelor's degree. Because of this imbalance, the data could not be analyzed according to education level and was instead configured into a dichotomous variable. The dichotomous education variable could still be used to conduct statistical analyses, but the conclusions were less specified than they could have been with more representative data.

Likewise, statistically significant conclusions relating to English fluency and preference should be analyzed with caution. With a limited quantity of participants who are not fluent in English, it becomes more difficult to generalize conclusions for caregivers without high English language fluency.

This study was largely conducted through Prolific, a research study recruitment website. In understanding the platform used to conduct this study, it is important to recognize that participants would be required to have internet access, familiarity with the English language, and a pre-existing interest in research participation before arriving at the Prolific website. The study findings corroborate this: many participants were under 50 years old, indicating a participant pool on the younger side with generally easier access to technology. The majority of participants were also completely fluent in English, and preferred English as their primary language, suggesting that they are able to find caregiving and Alzheimer's disease information more easily if they were to seek it out. The study itself reached its maximum participant count of 200 within a few hours of survey publication, so that only people on Prolific within that limited window had an opportunity to respond. With these restrictions in mind, it is likely that the participants reached through this study may not be an accurate representation of all caregivers of people with Alzheimer's disease.

Another drawback of Prolific was the anonymity of the platform itself. Although the survey included a question verifying the participant's role as a caregiver for a person with Alzheimer's disease, there was no way to validate that information. Recruitment was initially conducted via Facebook groups and Reddit threads to increase the likelihood that participants were caregivers with a desire to share their experiences. The act of joining a Facebook group or Reddit thread is a voluntary process, and many of the groups used this study were a place for members to discuss shared trauma, challenges, and suggestions. There would be little benefit for someone to join unless they are or have been a caregiver. In contrast, Prolific is a platform open to anyone interested in participating in studies, with the intent of completing studies for money. Although participants were screened for having "informal/unpaid caring responsibilities," this is based on self-reported information, for a website that is less emotionally motivated compared to social media.

Future Research

Although this quantitative study provided significant insight on the caregiver experience and their communication, a future qualitative study could add to these findings. As observed in prior literature as during the recruitment process of this study, Facebook groups and Reddit threads are a space for caregivers to vent about their experiences, receive advice from other caregivers in similar situations, and generally express their emotions to a group of people who likely understand and share similar thoughts. These thoughts and emotions can be generally expressed in a quantitative survey study, but interviews would provide a much deeper picture of the caregiver experience. Future research could expand on this study's findings by collecting personal narratives that support the concept of decreasing stress and increasing active coping through communication.

CONCLUSION

Caregivers of people with Alzheimer's disease are tasked with an incredibly challenging job: to care for someone who is slowly losing their ability to communicate, move, and live. Caregiving is an unforgiving role that often falls on the shoulders of the spouses, siblings, or children of the person with Alzheimer's disease. Among the difficulties that arise with caring—often unpaid—for someone with a neurodegenerative disease, are the mental and emotional sacrifices of the task at hand. There is little time to care for one's own mental and physical wellbeing when so much time is devoted to caring for a loved one, and the effects can be incredibly harmful to the caregiver. Despite the potentially detrimental side effects of caregiving, there is a lack of adequate communication aimed at and for caregivers of people with Alzheimer's disease, particularly for those whose primary language is not English.

This study sought to understand the challenges that caregivers face in terms of stress, active coping, Alzheimer's disease knowledge, and communication. Through the use of an anonymous survey about caregiver experiences, a narrative of the caregiver experience was formed. Data collected and analyzed was used to determine if there are relationships among the four facets of caregiving. Education level and English language preference were also analyzed to determine if they moderated the relationship between caregiver communication and the remaining three components.

Education level and English language preference were not found to moderate the relationship between caregiver communication and their stress, coping, and knowledge in this study. However, they do play a role in how a caregiver seeks, processes, and perceives information. The challenges of caring for a person with Alzheimer's disease are universal—spanning generations, languages, and sociodemographic groups. However, the similarities of

challenges does not mean that everyone has the same access to resources that will help them overcome the challenges they face. Prior studies have found that racial and ethnic minoritized groups have difficulty finding resources that cater to their cultures and languages. This study identified a similar concept, noting a significant difference in the average Alzheimer's disease knowledge score between people who preferred English language resources and those who did not. Language access may not moderate a relationship between communication and knowledge, but it can still hold power over how information is distributed and to whom.

Communication can empower caregivers. The data collected indicate that there is a statistically significant relationship between caregiver communication and the caregiver's own perceived stress and coping methods; receiving better communication helps the caregiver take care of themselves. The right communication, done in a way that is accessible to all, can help caregivers feel better equipped to take care of their loved ones. In a role often underappreciated and overlooked, it can be incredibly challenging for caregivers to receive the same level of attention and care that they devote to their loved ones. Caregiving communication steps in to fill this void, caring for caregivers when they cannot.

APPENDIX

Alzheimer's Disease Knowledge Scale

People with Alzheimer's disease are particularly prone to depression.

It has been scientifically proven that mental exercise can prevent a person from getting
Alzheimer's disease.

After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.

After symptoms of Alzheimer's disease become agitated, a medical examination might reveal
other health problems that caused the agitation.

People with Alzheimer's disease do best with simple instructions given one step at a time.

When people with Alzheimer's disease begin to have difficulty taking care of themselves,
caregivers should take over right away.

If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try
to make sure that the person gets plenty of physical activity during the day.

In rare cases, people recover from Alzheimer's disease.

People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for
depression and anxiety.

If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's
disease.

Most people with Alzheimer's disease live in nursing homes.

Poor nutrition can make the symptoms of Alzheimer's disease worse.

People in their 30s can have Alzheimer's disease.

A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets
worse.

When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.

Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.

Eventually, a person with Alzheimer's disease will need 24-hour supervision.

Having high cholesterol may increase a person's risk of developing Alzheimer's disease.

Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.

Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.

Alzheimer's disease is one type of dementia.

Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.

One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.

When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.

Prescription drugs that prevent Alzheimer's disease are available.

Having high blood pressure may increase a person's risk of developing Alzheimer's disease.

Genes can only partially account for the development of Alzheimer's disease.

It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.

Alzheimer's disease cannot be cured.

Most people with Alzheimer's disease remember recent events better than things that happened in the past.

Perceived Stress Scale

In the last month, how often have you been upset because of something that happened unexpectedly?

In the last month, how often have you felt that you were unable to control the important things in your life?

In the last month, how often have you felt nervous and "stressed"?

In the last month, how often have you dealt successfully with irritating life hassles?

In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?

In the last month, how often have you felt confident about your ability to handle your personal problems?

In the last month, how often have you felt that things were going your way?

In the last month, how often have you found that you could not cope with all the things that you had to do?

In the last month, how often have you been able to control irritations in your life?

In the last month, how often have you felt that you were on top of things?

In the last month, how often have you been angered because of things that happened that were outside of your control?

In the last month, how often have you found yourself thinking about things that you have to accomplish?

In the last month, how often have you been able to control the way you spend your time?

In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Sample Caregiver Communication Scale Questions

I have access to the information I need about Alzheimer's disease symptoms.

I have access to the information I need about the different stages of Alzheimer's disease.

I have access to the information I need about how Alzheimer's disease affects a patient.

I have access to the information I need about caring for an Alzheimer's disease patient.

I have access to Alzheimer's disease information that is meant for caregivers.

I am able to find information about Alzheimer's disease when I need it.

I am able to understand the information I receive about Alzheimer's disease.

I have received good communication about the role and responsibilities of an Alzheimer's disease caregiver.

The information I have received about Alzheimer's disease treatment has been helpful to me as a caregiver.

The information I have received about Alzheimer's disease makes me feel more capable of being a good caretaker.

The information I have received about Alzheimer's disease makes me feel less capable of being a good caretaker.

Ways of Coping Questionnaire

Just concentrated on what I had to do next – the next step.

I did something which I didn't think would work, but at least I was doing something.

Tried to get the person responsible to change his or her mind.

Went on as if nothing had happened.

I got professional help.

I made a plan of action and followed it.

Changed something so things would turn out all right.

Stood my ground and fought for what I wanted.

I knew what had to be done, so I doubled my efforts to make things work.

Came up with a couple of different solutions to the problem.

I changed something about myself.

Sample Caregiver Communication Scale Questions

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a good caretaker.

The information I have received about Alzheimer's disease makes me feel less capable of being
a good caretaker.

Demographic Questions

What is your highest level of completed education?

Is English your preferred language?

How would you rate your level of English language knowledge?

What is your age?

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