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# Assessing the Effects of Family Caregivers of Alzheimer's Disease

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**ABSTRACT**

This study focuses on the unique challenges faced by family caregivers of Alzheimer's patients in the densely populated city of Karachi, Pakistan. Employing a two-pronged methodology, we aimed to understand the impact of the demographic context on these caregivers. The first phase involved a qualitative survey utilizing a semantic scale with options ranging from "Strongly Disagree" to "Strongly Agree" to gauge emotional conditions. The second phase comprised qualitative interviews to delve deeper into participants' survey responses. Thematic analysis revealed five recurrent themes among caregivers, shedding light on the challenges they face in this specific demographic: guilt, compassion fatigue, religious and cultural stigmatization, lack of official support in Karachi, and enduring long-term effects on caregivers.

This study concludes that family caregivers in Karachi encounter a range of challenges, including guilt, compassion fatigue, religious and cultural stigmatization inhibiting them from seeking professional help, and enduring long-term physical and mental effects. The findings underscore the need for further research to explore strategies to provide support for caregivers in developing nations like Karachi. Such efforts can empower caregivers to navigate their roles effectively while mitigating the adverse effects they experience.

## Introduction

Alzheimer's Disease stands as the prevailing form of dementia, impacting approximately 55 million individuals worldwide [1]. This debilitating disorder disrupts daily functioning as the brain undergoes deterioration, affecting memory and cognitive abilities. The primary caregivers for those grappling with these challenges are often immediate family members, shouldering the responsibility of round-the-clock care and supervision [2]. Despite extensive research on the disease itself, The University of San Francisco Weill Institute for Neurosciences notes a notable oversight regarding the health and well-being of family caregivers [3]. Immersed in the care of the afflicted patient, these caregivers invest all their time, often neglecting their own

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physical and mental health.

This study underscores the imperative to delve into the mental health of caregivers, particularly those situated in diverse demographic locations, potentially impeding their access to essential resources and exacerbating their burdens. As highlighted by K.S Shaji et al., developing nations, while benefiting from extended family and home care, grapple with the dual challenges of economic strain and caregiver burden [4]. In light of this, our focus extends beyond the disease itself to unravel the intricate dynamics of caregiver well-being, shedding light on the impact of different demographic contexts on their ability to access support and navigate the associated challenges.

## Literature Review

### Search Strategies

To understand the effects of caregiving for Alzheimer's Disease (AD) in Karachi, Pakistan, it is important to take a look at the prior research conducted on AD in regard to caregivers as a whole in different settings and circumstances. Sources were obtained by scrutinizing databases that ensured credibility through peer review including Google Scholar, Galileo, and EBSCO. Keywords included "compassion fatigue," "family caregivers," "Alzheimer's disease stress," "developing nations," and "minority groups".

### Specific Outcomes of Caregiving

Limited research exists on AD family caregivers and their experiences with the associated negative effects and contributing factors. Existing studies tend to narrow their focus, examining specific aspects of caregiving and extrapolating them to a broader context. A notable study by the University of Madrid delved into the profound impact of guilt on AD family caregivers [5]. This investigation identified various guilt types, encompassing feelings related to negative emotions arising from changes in the caregiver-patient relationship, guilt induced by the person being cared for, and guilt influenced by external sources. The study also recognized feelings closely associated with guilt or anticipated guilt [5].

However, the conclusions drawn from this research primarily centered on the caregiver's sense of inadequacy in meeting the needs of their patient, categorizing guilt into seven distinct types. While this analysis provided valuable insights into the nuances of guilt experienced by caregivers, it fell short in offering a comprehensive exploration of the broader effects on caregivers' mental health. To address this gap, future research should extend beyond a singular focus on guilt, considering additional factors and wider implications that contribute to the overall negative mental health of caregivers in the context of AD.

Building on this approach of examining specific effects, Dr. Donna Cohen and Carl Eisdorfer conducted a study that explored depression among family members providing care for a relative with Alzheimer's Disease, shifting the focus from guilt to the realm of depressive experiences.

The caregivers, who participated in a study, underwent evaluation using the Beck Depression scale—an instrument designed to gauge the severity of depression through specific questions [6]. The results revealed that over half of the caregivers received a diagnosis of depression. Notably, the study identified external factors as significant contributors to the caregivers' depressive symptoms. An intriguing finding was that the duration of cohabitation with the patient correlated with an increased likelihood of developing depression or experiencing other negative effects. Parallel to the University of Madrid study, Cohen and Eisdorfer's research focused on a single effect of caregiving—guilt and depression, respectively.

However, a study by Gallagher-Thompson et al. challenges the correlation observed in Cohen and Eisdorfer's research [7]. In contrast to the conclusion drawn by Cohen and Eisdorfer that prolonged cohabitation with the patient exacerbates symptoms for the caregiver, Gallagher-Thompson et al. asserted that closer caregivers experience an improvement in their mental health as the patient's cognitive health declines. The pivotal factor, as defined by Gallagher-Thompson et al., was the occurrence of "sundowning symptoms," characterized by a differential nocturnal exacerbation of seven disruptive behaviors, including hallucinations and confusion. The study found that caregivers reported reduced stress levels when sundowning characteristics were evident in the Alzheimer's patient.

Despite its focus on sundowning characteristics, the study falls short of clearly establishing a correlation between these symptoms and the caregiver's well-being, as it does not provide specific examples of the caregiver's health effects.

Other studies focus on compassion fatigue inflicted upon caregivers. Compassion fatigue (CF), as defined by Day & Anderson, is when a caregiver deals with feelings "of anger, inefficacy, apathy, and depression, resulting from a caregiver's inability to cope with devastating stress" [7, 8].

This study specifically focused on female daughters. While it concluded that daughters experienced the highest levels of Compassion Fatigue (CF), the findings may appear generalized due to the potential variation in outcomes across different demographics. A previous study by Day & Anderson examined CF in the context of informal caregiving [9]. This study posited that CF involves a "combination of hopelessness, helplessness, apathy, and emotional disengagement that occurs after prolonged exposure to suffering." Informal caregivers, particularly family members, are noted to be more emotionally attached to their patients due to pre-existing relationships, aligning with Day & Anderson's earlier findings.

Despite successfully defining CF, both studies fall short in accounting for diverse demographics and situational factors, resulting in a broad conclusion regarding the prevalence of CF on a case-by-case basis. These findings raise questions about the potential influence of specific factors such as demographics and the caregiver's relationship to the patient. Further exploration of these variables is essential to understanding the nuanced impact of CF in different caregiving scenarios.

Figure 1: Compassion Fatigue: A model *Adapted from Middleton*

### Caregivers in Developing Nations and Rural Areas

Several studies have explored the impact of rural settings on family caregivers. Wood and Parham conducted a study specifically examining minority groups in rural areas, drawing a comparison between urban and rural contexts [10]. This comparison involved assessing Caucasian caregivers from an urban setting and African-American caregivers from rural areas.

Parham assembled primary caregivers for AD patients, selecting participants based on race and area of residence to draw a distinct comparison between metropolitan and rural environments [10]. The study's findings and scale indicated that urban areas perceive themselves as more capable of accessing assistance compared to rural counterparts, with a notable inclination in urban areas towards resource mobilization. African-American caregivers exhibited stronger family ties, fostering a family-oriented approach rather than an action-centric one. Additionally, the study highlighted that minorities, particularly African Americans, tend to form kinships rooted in religion, leveraging spirituality as a coping mechanism—an observation supported by researchers Hodge and Fei Sun in their study on Latino families [11].

Hodge and Sun's research underscored the positive impact of spirituality in sparking a favorable change in attitude among Latino families, serving as a coping mechanism for excessive stress. However, it is important to note that while this study identifies spirituality as a positive influence, the intertwining factors of religion and culture may yield negative outcomes for caregivers, potentially subjecting them to social pressure and escalating stress levels. This study falls short in providing a conclusive understanding that is universally applicable across different countries and demographics.

In addition, studies have begun to shift their focus to developing nations such as Pakistan, the focus of my research. Farah Qadir et al., researchers affiliated with Fatima Jinnah University, conducted a study in Rawalpindi and Islamabad, Pakistan. Their focus was on informal caregivers, examining their lack of awareness about Alzheimer's Disease (AD) and how this contributed to heightened stress and physical burdens associated with caregiving [12]. Qadir and her colleagues explored AD in the context of Pakistan, shedding light on the prevalent lack of awareness among families regarding the causes and effective management of the disease without sufficient assistance. The study's findings revealed that a significant number of caregivers were unfamiliar with dementia or AD, often attributing the symptoms to the natural aging process. Moreover, religious affiliations influenced caregivers' perceptions and attitudes towards patients, as their adherence to Islam dictated the manner in which they treated their parents with utmost respect.

While the researchers delved into caregiving dynamics in a developing nation, their analysis predominantly focused on the collective attitudes of caregivers rather than delving into individual caregiver effects. Following a similar line of investigation, Amna Aurooj and Zahid Muhammad conducted research on Alzheimer's Disease (AD) caregivers specifically in rural areas of Pakistan [13]. Aligning with the conclusions drawn by Qadir et al., Aurooj and Muhammad identified a significant impact of caregivers' lack of awareness about AD, emphasizing the role this played in hindering optimal performance. The caregivers' limited access to information on AD and lack of comprehensive education were identified as contributing factors to their challenges in caregiving.

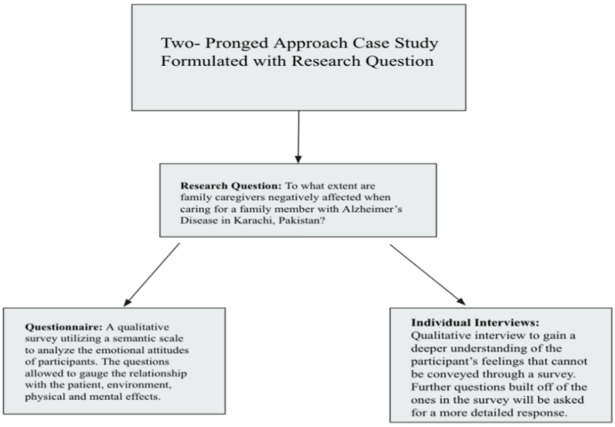
### Gap in Research and Hypothesis

Most studies focus on caregivers or family caregivers as a whole and effects based on generalized approaches rather than looking at specific issues arising in certain family caregivers with an in-depth analysis of each person based on their environment, cultural and religious experiences affecting them in a developing nation [13]. Existing research tends to discuss minority groups or focus on areas in a developing nation that differ from my research. This study aims to focus on the factors as well as the long and short-term effects that caregivers gain due to living in a developing nation, and a particularly overpopulated and religiously affiliated one. Current discussion today focuses on broader aspects of the effects of caregivers and gives similar reasons as to why they occur, rather than going into an in-depth discussion on the types of depression or anxiety arising. These problems and gaps pose the question: How are family caregivers negatively affected when caring for a family member with Alzheimer's Disease in Karachi, Pakistan? The primary objective of this study is to comprehensively comprehend the short-term and long-term impacts on each family caregiver, enabling a thorough analysis of the underlying causes and consequences associated with their caregiving roles. The hypothesis posits that family caregivers in Pakistan experience significant Compassion Fatigue (CF) influenced by religious and cultural affiliations. The anticipated effects encompass mental stress, demographic factors, depression, physical impacts, and a distinct psychological framework following the caregiving period. Additionally, the results may reveal a connection between guilt and strained relationships with the patients.

### Research Design and Methods

### Study Design

This study aims to understand the long-term and short-term effects of family caregivers in Karachi, Pakistan which is a developing nation with strong cultural and religious ties and struggles with overpopulation. A two-pronged qualitative method case study 'The 2-Pronged Approach Case Study' was conducted in the form of a case study. A case study is useful when working with research for in-depth issues in a natural-life context [14]. For this particular study, a case study was chosen since this method of design allowed for a more in-depth analysis of not just a single individual but a larger group. Furthermore, with a case study, especially with people, general trends and patterns are most feasible to identify as opposed to a cross-sectional study. Through interviews, a thorough understanding of the participant's relationship with the patient, CF, as well as long-term and short-term effects. Employing a qualitative method is crucial for this study as it provides a reliable means to acquire information regarding participants' emotional attitudes. With this qualitative analysis, two methods were utilized to gather data which included a questionnaire in the form of a survey and qualitative interviews with each family caregiver. As seen in the literature review, past researchers have neglected to conduct an analysis on participants in Karachi, Pakistan. Moreover, researchers investigating Pakistan through case studies have often relied on the stereotype of rural areas to inform their findings. Utilizing a qualitative method in the urban setting of Karachi, Pakistan, introduces a fresh perspective that brings specificity to densely populated regions, shedding light on the unique effects experienced by family caregivers in these particular circumstances.



Two- Pronged Approach Case Study Formulated with Research Question

**Research Question:** To what extent are family caregivers negatively affected when caring for a family member with Alzheimer's Disease in Karachi, Pakistan?

**Questionnaire:** A qualitative survey utilizing a semantic scale to analyze the emotional attitudes of participants. The questions allowed to gauge the relationship with the patient, environment, physical and mental effects.

**Individual Interviews:** Qualitative interview to gain a deeper understanding of the participant's feelings that cannot be conveyed through a survey. Further questions built off of the ones in the survey will be asked for a more detailed response.

Figure 2: The 2-Pronged Approach Case Study

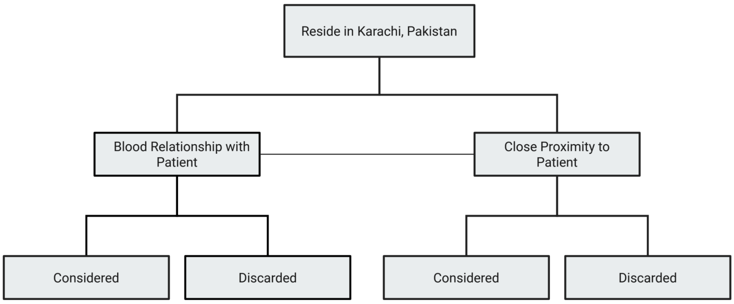


Figure 3: Choosing Potential Participant Criteria

The participants in this study comprised various family members of the patient, each demonstrating distinct caregiving approaches. Specific instances within this demographic included individuals living with or in close proximity to the patient, those visiting the patient weekly or bi-weekly, and individuals staying with the patient for extended periods throughout the year. (Figure 3). The participants must be from Karachi, Pakistan to stay in line with the cultural and religious standards as well as the effects of the environment on their duties as a family caregiver. Subjects were recruited by finding family members in Karachi, Pakistan with a family member diagnosed with AD.

## Research Instruments

After gathering specific subjects, each was emailed a request to participate in the study by explaining the two-pronged approach case study (Appendix A).The email also included a cautionary note that the forthcoming questions were not designed to inflict emotional harm, and participants were assured that they could opt out if necessary. Each subject was instructed to respond by email if they agreed to participate in the study. Upon confirmation from participants, a questionnaire in the form of a survey was subsequently emailed to them via Google Forms. This study involved three distinct families, each associated with an AD patient. In the first family, there were three daughters of the patient, the patient's wife, and two grandchildren. Specifically, one daughter, two grandchildren, and the wife co-resided with the patient. The second family included one son of the patient, the patient's wife, and two grandchildren. The third family comprised one daughter of the patient, one son of the patient, and one grandchild. To be eligible for inclusion in this study, all participants were required to reside in close proximity to or with the patient. Questions revolved around CF to understand the extent to which the caregiver was affected by caring for the patient. The questions utilized a semantic scale for the participant to choose from options “Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree” (Appendix C).

The interviews of each participant took place via Zoom to assess physical body language and create a personal discussion to create an understanding towards the research question (Appendix D). All interviews were standardized with a set of four questions focusing on the participant’s physical and mental well-being during caregiving, the observed effects, the dynamics of relationships, and specific emotions within subsections such as guilt, along with decisions influenced by religious and cultural considerations.

Participants were categorized according to their relationship with the patient, specifically as daughter, son, wife, or grandchild. This categorization facilitated a more efficient identification of commonalities, enhancing the study’s ability to draw concise conclusions. The study encompassed three families: the first family comprised one wife, three daughters, and two grandchildren; the second family included one wife, one son, and two grandchildren; and the third family consisted of one daughter, one son, and one grandchild.

### Thematic Analysis

Once interviews were conducted, the study proceeded to the next step: a case study involving a qualitative thematic analysis. A thematic analysis is a method utilized qualitatively to understand underlying patterns and themes in different participants of a study [12]. This method was employed to scrutinize the interviews and participant responses, with common themes identified through the application of qualitative analysis. A thematic analysis was implemented with both the questionnaire and the interviews conducted. Initially, responses from the semantic scale were analyzed to formulate questions for subsequent interviews with each participant. Subsequently, recordings of interviews involving all thirteen participants were scrutinized to identify recurring themes and underlying patterns

### Findings

Once data was collected from the thirteen participants, the caregivers were grouped into their respective families creating three case studies. For the purpose of this study, the participants will be distinguished based on their affiliation to the respective family (1, 2, or 3) and their relationship to the patient (ex. Family 1, Wife).

| **Interviewee** | **Content** | **Main Points in Caregivers** |
|---:|---|---|
| Wife | Consistently helped the patient with daily tasks such as medication, food, and changing clothes. | CF, guilt, depression, high blood pressure, heart disease. |
| Daughter #1 | In charge of buying medication, organizing toiletries. | CF, guilt, dissociation, frequent panic attacks. |
| Daughter #2 | Took patient to the doctor, entertained patient, helped stimulate brain. | CF, guilt, Post traumatic stress disorder |
| Daughter #2 | Took patient to the doctor, entertained patient, helped stimulate brain. | CF, guilt, Post traumatic stress disorder |
| Daughter #3 | Helped feed medication, organizing everyday items | CF, guilt, frequent panic attacks |
| Grandchild #1 | Sat for an hour a day with patient, helped serve food | Guilt, anxiety |

Table 1: Family 1

| **Interviewee** | **Content** | **Main Points in Caregivers** |
|---|---|---|
| Wife | Manual labor, medicine, helped with motor skills such as feeding food or giving water, stimulated memory | CF, Depression, Essential Tremor, Abdominal Cyst Formation, Guilt |
| Son | Paperwork, finances, medicine bills, doctoral visits | CF, Guilt, Anxiety, insomnia |
| Grandchild #1 | Organizational necessity, spending time with patient | Guilt |
| Grandchild #2 | Spent time with patient | Guilt, Anxiety |

Table 2: Family 2

| **Interviewee** | **Content** | **Main Points in Caregivers** |
|---|---|---|
| Daughter #1 | Emotional connection with patient, utmost respect, conservative viewpoints on mental health | Guilt, Insomnia, Excessive back pain, Anxiety |
| Son #1 | Paperwork, finances, medicine bills, doctoral visits, conservative viewpoints on mental health | CF, Guilt, Anxiety |
| Grandchild #1 | Helping with motor skills with patient, spent 2+ hours with patient per day | CF, Guilt |

Table 3: Family 3

The charts addressed each of the three families. In the first column, the participant's relationship with the patient as a family member was documented, with consent for this information confirmed through a consent form (Appendix B). The second column provided a detailed account of the content covered in each interview, expanding on responses from the survey and engaging in an open-ended discussion on the participant's experiences as a family caregiver. The third column delved into overarching main ideas extracted from the interviews, which were then categorized into themes observed in each participant. By utilizing these three tables, overarching themes within the participants' experiences were identified and subjected to thematic analysis. This approach aimed to enhance the understanding of the challenges and experiences encountered by caregivers within this particular demographic.

### Results

The interviews conducted with each of the participants depicted their experiences being family caregivers and outlined the process they went through throughout their daily lives. The experiences documented in Tables 1, 2, and 3 for each participant were subsequently compiled and analyzed to identify correlating themes, as outlined below. This section serves to discuss the results of the thematic analysis utilized by understanding the recurring themes and patterns in the participants. In doing so, an accurate understanding of the effects of family caregivers in the urban aspect of Pakistan, a developing nation, can be understood and utilized for future steps. The five themes listed below were seen in the majority of the participants, and thus discussed in depth to gain an understanding.

### Theme 1: Guilt

Guilt emerged as the predominant and widespread theme, with all thirteen participants highlighting it as a prominent effect in their caregiving experiences. In the context of this study, guilt refers to the sentiments of family caregivers who believe they are not adequately meeting their patient's needs and experience a sense of hopelessness in improving the patient's diagnosis. These emotions often led caregivers to feel trapped in their thoughts and experience a profound sense of being unloved. Family 1, Daughter 2 articulated: "I often felt guilty because... no matter what I did Abu [Dad] would progressively get worse. I regret not spending more time with him before because now it feels like talking to a wall."

To add on, Family 3, Son explained that he felt guilty that he did not have a close relationship with the patient prior to the AD diagnosis and now was unable to connect to his father. Each daughter, son, and grandchild from family 1, 2, and 3 communicated similar feelings and explained how these emotions affected their performances in being a caregiver. Family 1, Wife explained that "I wish that this never happened, it's just so hard to even have a conversation with him…" The wives in each family, in particular, shared an exceptionally close connection with the patient before the diagnosis.

### Theme 2: Compassion Fatigue

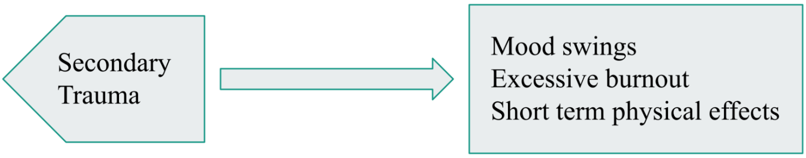


Figure 4: Effects of Secondary Trauma

The next theme seen in eight of the thirteen participants was Compassion Fatigue (CF). As observed in Day's study in the literature review, CF occurs when a caregiver undergoes a range of intense emotions, including extreme anger, sadness, and stress, stemming from witnessing the patient's experiences. As depicted in Figure 1, burnout and secondary trauma contribute to CF. However, this study revealed that secondary trauma also resulted in effects such as short-term physical impacts and mood swings, as illustrated in Figure 4. Multiple participants shared experiences of lashing out not only at other family members but also at the patient throughout the day.

In terms of secondary trauma itself, Family 2, Wife explained that "He [the patient] wouldn't even be able to walk or pick up a spoon. I never thought a day like this would come." This secondary trauma, as depicted in Figure 4, created tremendous effects for the family caregivers. Family 1, Daughter 3 discussed in her interview that, "he [the patient] would just never listen to me and although I knew he couldn't understand what I was saying, it would make me so mad and I just couldn't be patient." This was also seen in three other patients throughout the families. Short-term effects were seen in six out of thirteen participants such as headaches, migraines, and spurts of back pain, making them unable to perform everyday tasks and alter their appetites.

### Theme 3: Religion and Cultural Stigma

The third theme indicated by seven out of thirteen participants was the religious and cultural stigma affecting their caregiving abilities. In Karachi, 91% of the population practices the religion of Islam [15]. As seen in survey question #1, all the family caregivers in this study practiced Islam.

#### Filial Piety

A pivotal concept integral to the roles within family units is filial piety, a term deeply rooted in Karachi's religion and culture. It emphasizes the belief that "family must respect and obey the elders." In the context of Islam, not fulfilling these responsibilities to the best of one's ability is condemned as a sin (Abdullah et al.).Therefore, filial piety imposes a burden on family caregivers, leading to overexertion in their efforts to provide for their patients. Family 3, Son 1 expresses that "I would go out of my way to help my mother [the patient] and would skip work or neglect my own children's needs since I wanted to do my very best for her and would pray for her forgiveness."

The continuous act of praying for the patient and the deeply ingrained concept of filial piety among all participants posed obstacles, hindering caregivers from prioritizing their own self-care, as exemplified in the case of Family 3, Son.

#### Prayer and Supplication to God

The religious and cultural perspectives in Karachi hindered participants from seeking medical treatment. Five out of thirteen participants believed praying and making dua (religious supplication to God) would suffice in their contributions to official treatment as seen in Family 1, Daughter 1 communicating that "I would often go to the mosque and sit on my prayer rug, asking God for forgiveness for Abu [the patient]". This action was seen in eight of the thirteen participants, utilizing religion as the source of answers rather than finding the necessary time to seek external sources for guidance.

### Cultural Stigmatization: Punishment from God

In Karachi, the cultural attitudes towards mental diseases involving memory loss are seen as a punishment from God, thus creating shame for the caregivers as articulated by Family 1 Daughter 1,2, and 3, Family 2, Wife, Son, and Family 3 Daughter 1. "I was often scared to talk to my friends or the public about it because word spreads in Karachi and rumors would just add to my stress," said Family 1, Daughter 2. Moreover, owing to the shame deeply ingrained in the minds of caregivers in Karachi, many sought guidance from religious leaders or healers to interpret the meaning of the initial memory loss. They were often unable to pinpoint that it was Alzheimer's Disease causing the patient's cognitive decline. Family 2, Wife, stated that "I did not even realize that my husband's [the patient] memory loss was connected to a life-altering disease and instead treated the memory loss as an evil sign from God. Because of this, I did not even think to show him to a doctor in the beginning stages. Maybe if I had done so, things wouldn't have gotten as bad as they are now." The prevalence of shame of mental disorders such as forgetfulness (symptoms of AD) causes most caregivers to refuse professional treatment as seen in the three families of this study.

## Theme 4: Lack of Official Support in Karachi, Pakistan

### Healthcare System

The fourth theme seen in this study is the lack of official support in Karachi, Pakistan. According to six out of thirteen participants, there is a lack of support in the healthcare system in Karachi. Family 3, Son explains that "I just did not know where to turn to for advice. No one even knew what AD was and there were only 5 doctors for it in Karachi, all needing money we didn't have." Four additional participants expressed similar perspectives, underscoring the notion that professional help is limited in the city of Karachi. As elucidated through the responses of the participants in this study, the reason for this scarcity is that mental disorders are often overlooked, given that their effects are not as immediately noticeable as those of physical diseases. Due to this, critical diseases such as AD and the necessary training and help needed to support a patient are often not given to families. Expressed by Family 2, Son "Because of the amount of people lined up in different hospitals around the city, it's hard to dedicate ones to just mental diseases since the amount of people with physical ones surpass them" [11].

### Government System

In Pakistan, the inflation rate has risen to 19.4% in the past two decades creating a currency devaluation and a rise in prices of simple everyday items [16]. Consequently, families in densely populated areas of Pakistan, exemplified by the demographic under scrutiny in this study, namely Karachi, encounter heightened challenges due to inflation. The increased competition among a larger population in the area for similar everyday necessities exacerbates these issues. Family 3, Daughter 1 explains that her family could not afford simple everyday grocery items, let alone the expenses of doctor visits and medical bills for the patient. The inability of caregivers to seek formal help or afford the needs to support their patient adds to the overbearing burden they carry when caring for a patient. Furthermore, all three families indicated the Jinnah Postgraduate Medical Center of Karachi as one step and resource that they often resorted to yet the center was understaffed and did not have enough resources to bring about adequate advice to the family members. The government of Karachi in particular, lacks the funding for not just the Jinnah Postgraduate Medical Center, but almost every healthcare facility lacks the funding necessary for research on AD and steps to care for families [11].

### Theme 5: Long-Term Effects on Well-Being

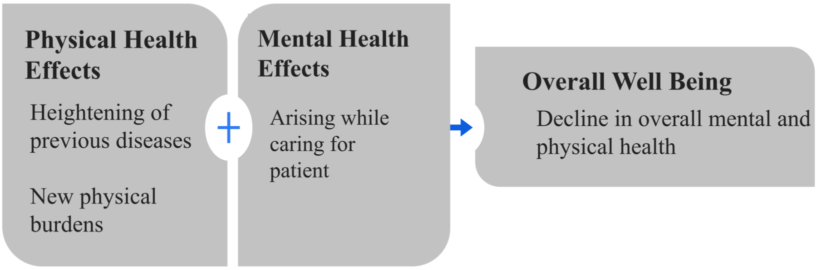


Figure 5: Assessing the Long-Term Physical and Mental Effects on Caregivers

The long-term effects were analyzed and seen as a theme in eight out of the thirteen participants all affecting the overall well-being of each of the caregivers in a decline in their physical and mental health. Firstly, when talking to Family 1, Wife and Family 2, Wife, including Family 1, Daughters 1 and 2 and Family 2, Son faced physical diseases such as abdominal cyst, heart disease, lung cancer, and arthritis. Although five participants in particular faced physical diseases as they cared for their patients simultaneously, they were so immersed in their patients' diseases that oftentimes their own diseases were neglected, and did not spend money on their medicines or doctoral visits. Furthermore, while caring for a patient, mental disorders/diseases arose in eight of the thirteen caregivers including anxiety, depression, Post Traumatic Stress Disorder, and insomnia. The culmination of both physical and mental disorders/effects created an overall decline in well-being for a caregiver 'Assessing the Long-Term Physical and Mental Effects on Caregivers'.

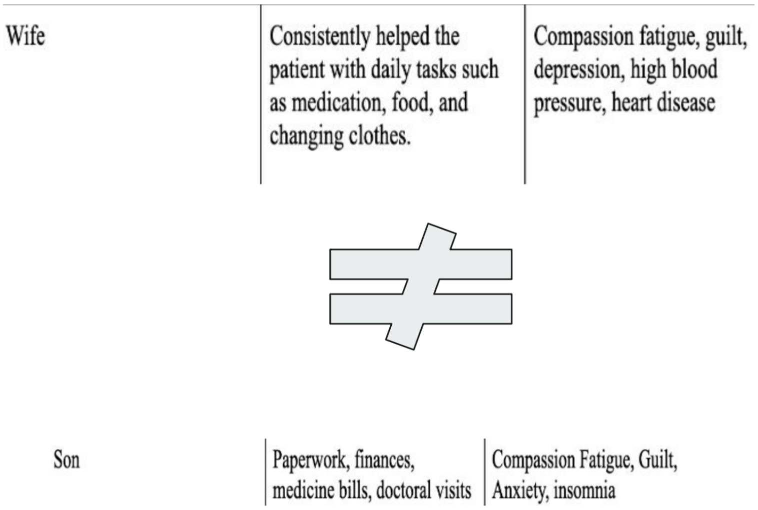
## Limitations

Before gaining a broader understanding of the implications of this study, it is important to note the limitations. Firstly, each of the thirteen interviews were conducted over a virtual platform, Zoom, and the initial survey was conducted via Google Forms. This was due to the geographical distance of Karachi, Pakistan from the area I reside in. If interviews were conducted in person, a better understanding of feelings towards caregiving and experiences could be conveyed with a full scope of emotions through body language and comfort. Next, this study was conducted with participants who did not speak English as their first language, rather speaking Urdu from time to time throughout interviews. Thus, when quotations were translated from Urdu to English, the full extent of the emotions and meanings may not accurately be relayed. Finally, the unfamiliarity of technology with multiple participants (five out of thirteen) created the necessity for a third person to intervene to help with inserting data into the Google Forms and downloading the Zoom application.

## Discussions of Results

Thus, the results of this study prove that the initial hypothesis was inaccurate.Rather than harnessing the positive aspects of religion and culture through spirituality and support groups, which could aid caregivers in similar situations, religion and culture, in this context, served to stigmatize mental diseases like Alzheimer's and impede the search for effective treatment. Furthermore, cultural groups were not implemented to gain an understanding of accurate caregiving since the topic was immensely stigmatized and shunned in society. Lastly, the idea of the dense population serving as an indication of prestigious hospitals with medical treatment was inaccurate since the Karachi government lacked the ability to provide the necessary funds to modernize healthcare centers. Due to the lack of support, many caregivers gained long-term and short-term physical and mental effects, extreme guilt, and Compassion Fatigue with sub effects of secondary trauma and burnout.

**Implications**



| | | |
|---|---|---|
| Wife | Consistently helped the patient with daily tasks such as medication, food, and changing clothes. | Compassion fatigue, guilt, depression, high blood pressure, heart disease |

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| | | |
|---|---|---|
| Son | Paperwork, finances, medicine bills, doctoral visits | Compassion Fatigue, Guilt, Anxiety, insomnia |

Figure 6: Demonstration in Relationships Inequality of Effects

The conclusions drawn from this study regarding the effects on family caregivers in Karachi carry significant implications for the future of caregiving and understanding how to provide effective care. Notably, in Karachi, there exists a 1:3 ratio of patients to family caregivers. This means that the effects identified in the analysis impact over 30% of the population of Karachi, given that 20% of the population is affected by Alzheimer's Disease [17]. The failure to recognize and address the challenges and hardships faced by caregivers is disconcerting. This study aims to shed light on the effects experienced by caregivers in Karachi, elucidating the struggles arising from inadequate support and the impact of the geographical location in an overpopulated area that neglects the prioritization of mental health and mental diseases. An important revelation from this study is the nuanced influence of the caregiver's relationship to the patient on the tasks performed, consequently affecting the degree of negative effects, as depicted in 'Demonstration in Relationships Inequality of Effects' dimension that has not been explored previously. This newfound understanding opens avenues for the development of tailored programs in developing nations like Karachi, addressing the specific needs of caregivers. By allocating funds into such programs, the government can enhance the overall quality of caregiving in these circumstances.

Therefore, it is imperative to take future steps at both the community level and on a global scale to alleviate the challenges caregivers face in developing nations. At a community level (Karachi), religiously and culturally oriented groups can play a crucial role in bringing like-minded caregivers together through forums such as Mosque circles, leveraging shared beliefs and practices as a means to uplift morale throughout the caregiving process. Additionally,the government can enhance its commitment by increasing investments in research and healthcare services specifically tailored for Alzheimer's Disease ensuring that technology and advice remain current and effective. On a global scale, tailored awareness programs can be developed to accommodate each nation and cater to individual caregivers based on their relationship with the patient. Collaborating with organizations like the Alzheimer's Association would be highly beneficial, providing caregivers with awareness and understanding of the challenges associated with Alzheimer's Disease, all presented in their native language according to their respective nations.

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## Appendix

### Appendix A: Initial Correspondence with Potential Participants via Gmail

Note: For the safety of the participants, the names to whom this email was sent to has been replaced with a “___”. This is a draft of the emails sent out to different participants:

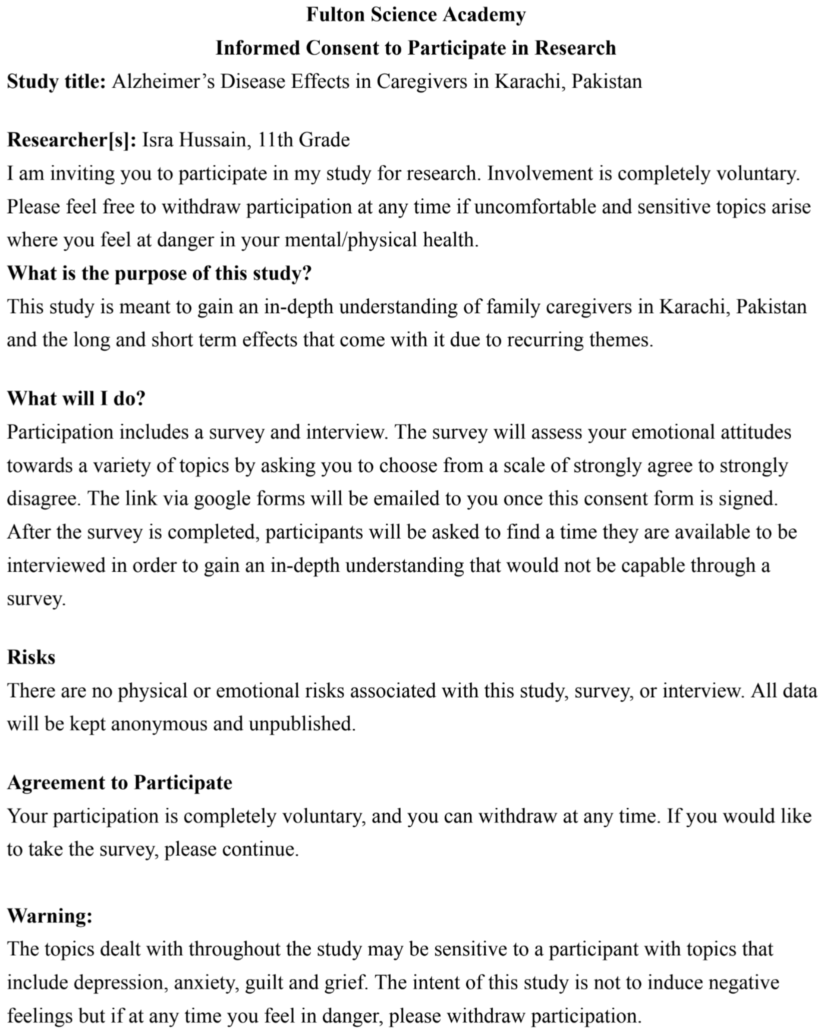
Hello ___,

I hope you are doing well. My name is ___ and I am conducting a research project on Alzheimer’s Disease family caregivers’ effects in caregiving for a patient in Karachi, Pakistan for my AP Research class where we create a year-long project and conduct a study on an evident gap present in a certain topic. The necessary criteria to be considered for this study are to live with or in close proximity to your patient, and be a blood relative of your patient. I am emailing you to inform you that in order to express interest in my study, you must email back expressing your interest in being a participant of the study. The study consists of a survey and an interview to discuss your caregiving experiences in Karachi. Please note that if at any time you feel uncomfortable with the information and questions asked, then you can opt out at any time.

Please let me know the status of your interest

## Appendix B: Consent Form Sent to Participants

Note: The consent form encompasses consent for the surveys and interviews, indicating that emotional topics will be mentioned regarding anxiety, depression, and suicide. Furthermore, the boxes indicate the confidentiality of sensitive information such as personal names and school names.



**Fulton Science Academy**
**Informed Consent to Participate in Research**

**Study title:** Alzheimer's Disease Effects in Caregivers in Karachi, Pakistan

**Researcher[s]:** Isra Hussain, 11th Grade

I am inviting you to participate in my study for research. Involvement is completely voluntary. Please feel free to withdraw participation at any time if uncomfortable and sensitive topics arise where you feel at danger in your mental/physical health.

**What is the purpose of this study?**

This study is meant to gain an in-depth understanding of family caregivers in Karachi, Pakistan and the long and short term effects that come with it due to recurring themes.

**What will I do?**

Participation includes a survey and interview. The survey will assess your emotional attitudes towards a variety of topics by asking you to choose from a scale of strongly agree to strongly disagree. The link via google forms will be emailed to you once this consent form is signed. After the survey is completed, participants will be asked to find a time they are available to be interviewed in order to gain an in-depth understanding that would not be capable through a survey.

**Risks**

There are no physical or emotional risks associated with this study, survey, or interview. All data will be kept anonymous and unpublished.

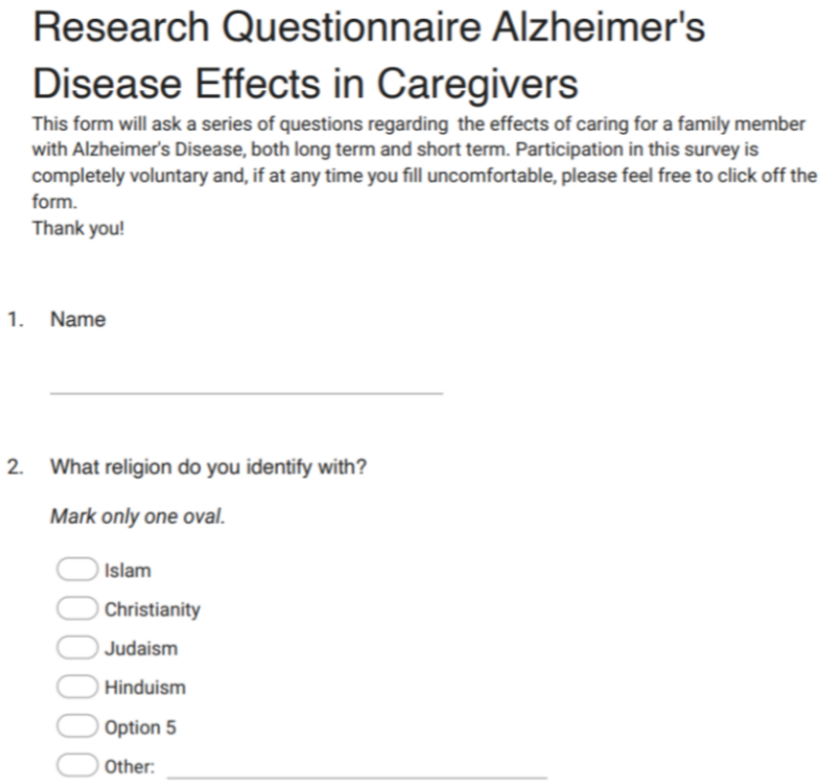
**Agreement to Participate**

Your participation is completely voluntary, and you can withdraw at any time. If you would like to take the survey, please continue.

**Warning:**

The topics dealt with throughout the study may be sensitive to a participant with topics that include depression, anxiety, guilt and grief. The intent of this study is not to induce negative feelings but if at any time you feel in danger, please withdraw participation.

## Appendix C: Questions from the Google Forms



### Research Questionnaire Alzheimer's Disease Effects in Caregivers

This form will ask a series of questions regarding the effects of caring for a family member with Alzheimer's Disease, both long term and short term. Participation in this survey is completely voluntary and, if at any time you fill uncomfortable, please feel free to click off the form.
Thank you!

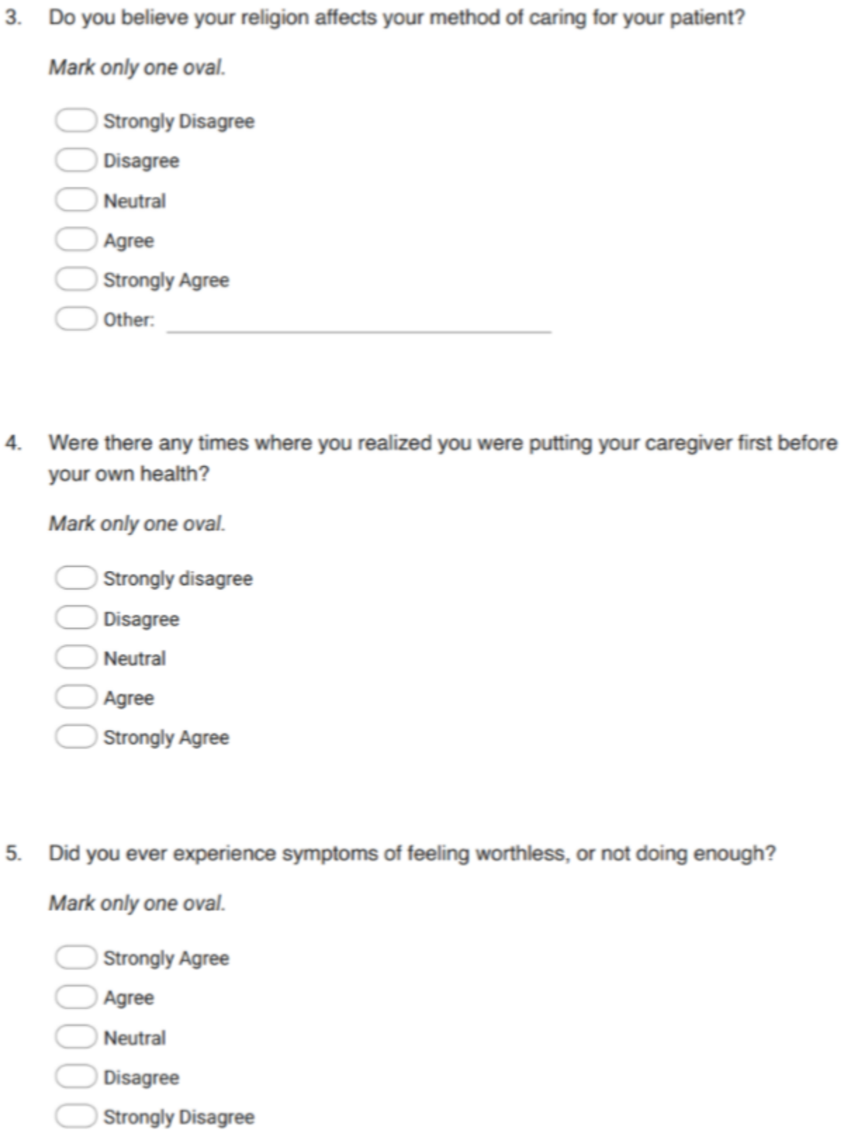
1. Name

   ______________________________

2. What religion do you identify with?

   *Mark only one oval.*

   ○ Islam
   ○ Christianity
   ○ Judaism
   ○ Hinduism
   ○ Option 5
   ○ Other: ______________________________



3. Do you believe your religion affects your method of caring for your patient?

*Mark only one oval.*

○ Strongly Disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree
○ Other: ______________________

4. Were there any times where you realized you were putting your caregiver first before your own health?

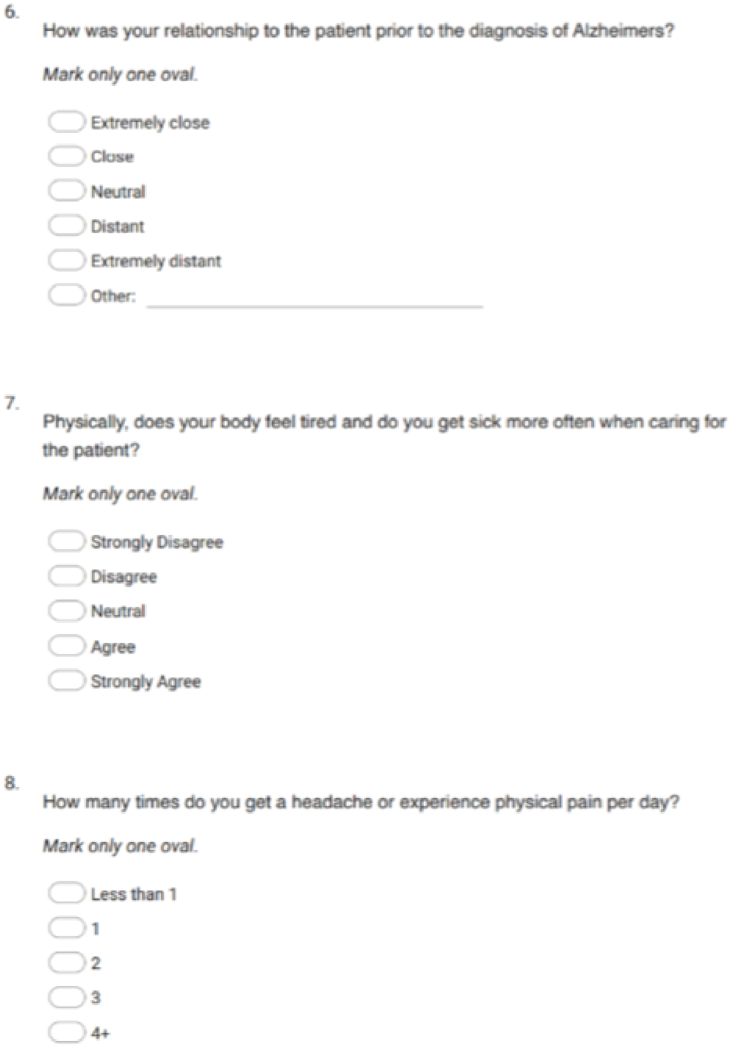
*Mark only one oval.*

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree

5. Did you ever experience symptoms of feeling worthless, or not doing enough?

*Mark only one oval.*

○ Strongly Agree
○ Agree
○ Neutral
○ Disagree
○ Strongly Disagree



6.
How was your relationship to the patient prior to the diagnosis of Alzheimers?

*Mark only one oval.*

○ Extremely close
○ Close
○ Neutral
○ Distant
○ Extremely distant
○ Other: ____________________

7.
Physically, does your body feel tired and do you get sick more often when caring for the patient?

*Mark only one oval.*

○ Strongly Disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree

8.
How many times do you get a headache or experience physical pain per day?

*Mark only one oval.*

○ Less than 1
○ 1
○ 2
○ 3
○ 4+

9. Have you been diagnosed with any physical/ psychological issues after caring for your patient?

*Mark only one oval.*

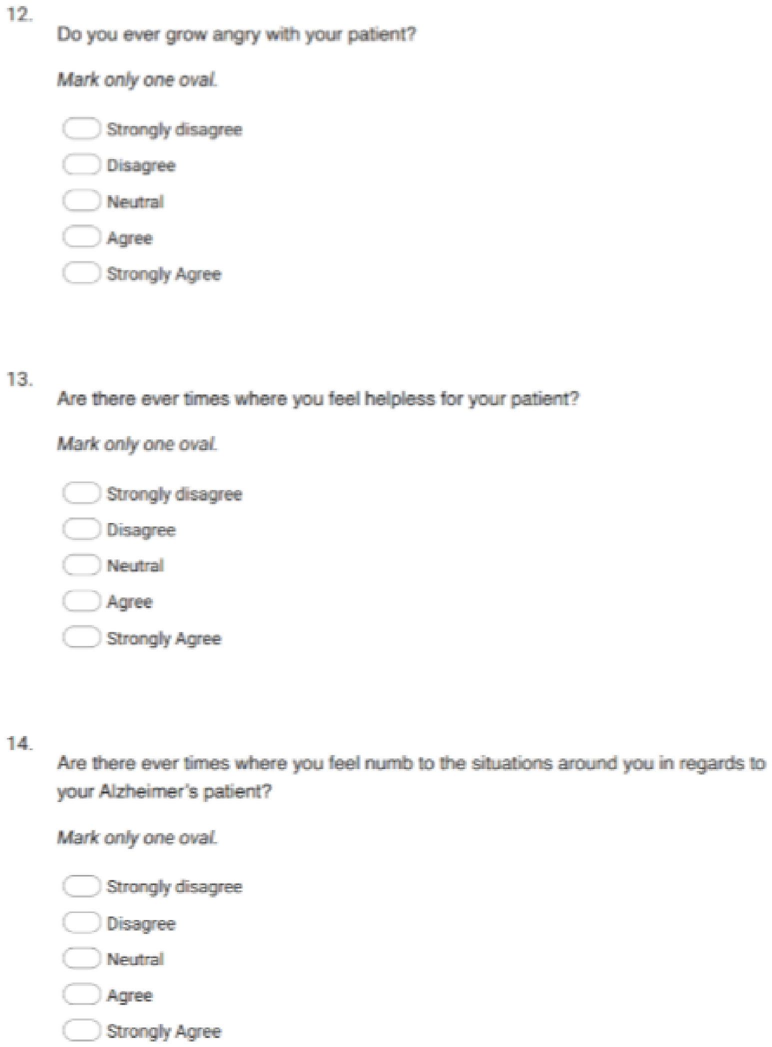
○ Yes
○ Maybe
○ No

10. If YES for the previous question, please list below:

11. Do you tend to neglect your own eating habits when caring for your patient?

*Mark only one oval.*

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree



12\.
Do you ever grow angry with your patient?

*Mark only one oval.*

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree

13\.
Are there ever times where you feel helpless for your patient?

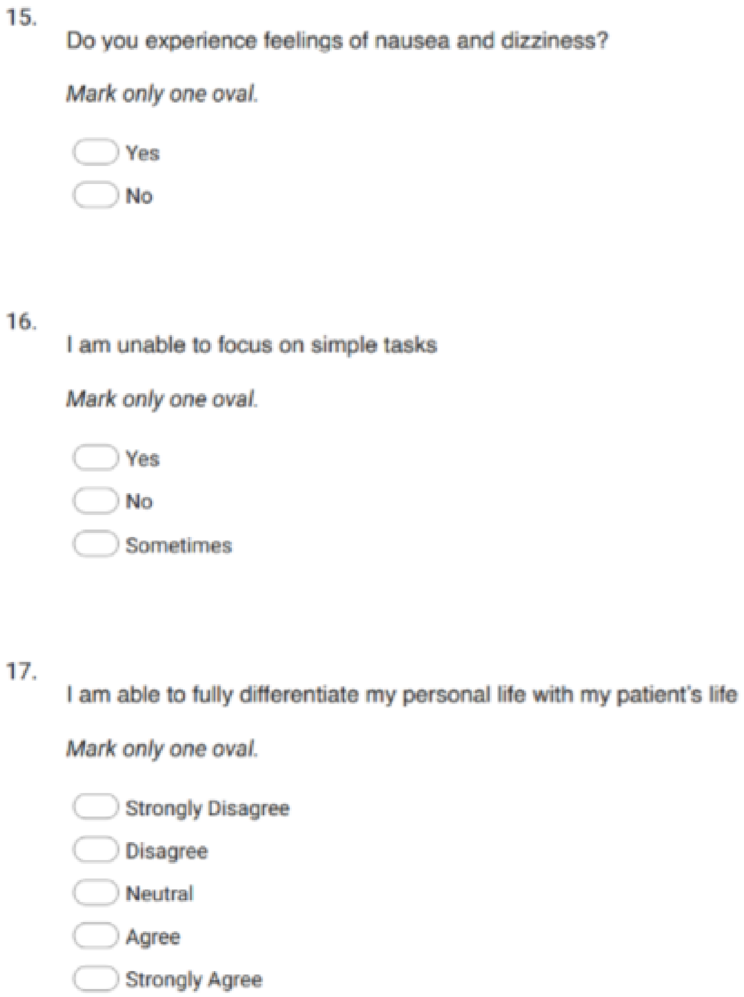
*Mark only one oval.*

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree

14\.
Are there ever times where you feel numb to the situations around you in regards to your Alzheimer's patient?

*Mark only one oval.*

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree



15\.
Do you experience feelings of nausea and dizziness?

*Mark only one oval.*

○ Yes
○ No

16\.
I am unable to focus on simple tasks

*Mark only one oval.*

○ Yes
○ No
○ Sometimes

17\.
I am able to fully differentiate my personal life with my patient's life

*Mark only one oval.*

○ Strongly Disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly Agree

## Appendix D: List of Questions Utilized in the Survey and Interviews

| | |
|---|---|
| Question 1 | What religion do you identify with? |
| Question 2 | Do you believe your religion affects your method of caring for your patient? |
| Question 3 | Were there any times where you realized you were putting your caregiver first before your own health? |
| Question 4 | Did you ever experience symptoms of feeling worthless, or not doing enough? |
| Question 5 | How was your relationship to the patient prior to the diagnosis of Alzheimers? |
| Question 6 | Physically, does your body feel tired and do you get sick more often when caring for the patient? |
| Question 7 | How many times do you get a headache or experience physical pain per day? |
| Question 8 | Have you been diagnosed with any physical/ psychological issues after caring for your patient? |
| Question 9 | Do you tend to neglect your own eating habits when caring for your patient? |
| Question 10 | Do you ever grow angry with your patient? |
| Question 11 | Are there ever times where you feel helpless for your patient? |
| Question 12 | Are there ever times where you feel numb to the situations around you in regards to your Alzheimer's patient? |
| Question 13 | Do you experience feelings of nausea and dizziness? |
| Question 14 | I am unable to focus on simple tasks |
| Question 15 | I am able to fully differentiate my personal life with my patient's life |