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Adult-Child Caregivers' Fear and Coping Regarding the Risk of Inheriting Alzheimer's Disease

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This is to certify that the doctoral dissertation by

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Abstract

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by

Rebecca Ledbetter

MA, Walden University, 2020

BS, Ashford University, 2017

Dissertation Submitted in Fulfillment

of the Requirements for the Degree of

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Abstract

Caring for elderly parents with Alzheimer's disease (AD) poses two major challenges for adult-child caregivers: the tasks involved in taking care of ailing parents and also potentially living in fear of developing the same disease. This research examined how caregivers with such fear regard their vulnerability to AD and how they manage the stress that comes with caregiving for someone with a disease they dread developing themselves. This grounded theory study employed the appraisal theory of emotions and the theory of moods as frameworks and aimed to establish awareness regarding coping strategies that adult-child caregivers have about caretaking, and their likelihood of developing AD. Semi-structured interviews were conducted via videoconference with 12 caregivers recruited through an AD support group as well as online through social media sites. The data was analyzed for emergent themes using coding derived from comparative methods focused on coping strategies. The findings indicated that caregivers experience significant anxiety about their future health, which they manage through various coping mechanisms such as seeking information, emotional support, lifestyle changes, and mindfulness. Despite these challenges, some caregivers reported positive outcomes, including strengthened family bonds and personal growth. The findings of this study may be used to promote social change by indicating the importance of identifying coping-based interventions that may enable caregivers to manage their fear and enhance quality of life for themselves and their parent with AD. The results may also assist healthcare professionals in the delivery of support services to caregivers of parents with AD.

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Dedication

In profound reverence and enduring memory of my beloved parents, Larry and Eleanor, whose unwavering love, wisdom, and sacrifices continue to inspire me in all aspects of my life. As I embark on the presentation of this dissertation, I am acutely aware of the profound influence they both have had on shaping my character, values, and aspirations. Your unwavering support and encouragement, even in the face of life's challenges, have been the guiding light on this path. Though you are no longer with me in the physical realm, your enduring legacy lives on in every word of this dissertation. I dedicate this work to you, as a testament to the values you instilled in me, perseverance, diligence, and a thirst for knowledge. As I reach this academic milestone, I am profoundly grateful for the foundation you provided and the lessons you imparted. I carry your memory with me, knowing that your love and guidance continue to propel me forward. To my esteemed advisors, Dr. Robbins, Dr. Scharff, and my academic advisor, Jackie Cook-Jones, your profound expertise, relentless commitment, and invaluable mentorship have helped shape the foundation of this research. To my family, whose unending encouragement and sacrifices have allowed me to pursue my academic aspirations, I am eternally grateful. To my friends and colleagues, who have been a source of inspiration and motivation throughout this endeavor, your camaraderie has been a pillar of strength. I also want to thank my dear friend Edna for her support and encouragement throughout the challenging journey of working on my dissertation. This dissertation is a tribute to all those who have played a pivotal role in my academic and personal growth. Your unwavering belief in me has made this achievement possible.

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Chapter 1: Introduction to the Study

Adult-child caregivers for people with Alzheimer's disease (AD) may experience weariness and stress, as well as a reduction in mental well-being, as a result of their parent's social and behavioral issues like social withdrawal, suicidal ideation, and mood changes depicted (Robertson, 2023). By 2020, it was estimated that as many as 5.8 million people in the United States had AD (Rajan et al., 2021). While young individuals may develop AD, the vast majority of individuals with this diagnosis are older adults. According to Borenstein et al. (2014), the number of individuals with AD doubles every 5 years among people that have attained the age of 65 years; this number is estimated to reach an all-time high of 14 million by 2060; this would mean more adult-caregivers will be affected by the rising cases in the future. As the number of people with AD continues to climb, adult-child caregivers are confronted with the obstacles of caring for their loved ones.

The purpose of this qualitative research study was to investigate adult-child caregivers' fear and coping regarding the risk of inheriting AD while providing care to their parents with the disease. People caring for AD patients frequently experience social issues like psychological health issues and family conflicts (Talib et al., 2021). In addition to coping with the communicative and behavior problems exhibited by the individual with AD, adult-child caregivers live with fear and stress surrounding the risk of inheriting the disease (Talib et al., 2021). Based on the issues that adult-child caregivers face in caring for their AD parents, an investigation into the mechanisms they use to cope with stress is critical in promoting their well-being.

Background

Over 5 million people in United States have been diagnosed with AD, and one in every three older people will die from this disease (Khanamadi et al., 2015). The burden a caregiver feels determines how the physical, social, economic, and emotional costs of the caregiver-patient relationship are perceived (Reed et al., 2014).Various scholars have suggested that equipping the caregiver with the ability to adaptively cope (i.e., self-compassion, task-focused or problem-focused coping, seeking social support) may help reduce the adverse emotional effects of looking after a family member with AD (Khanamadi et al., 2015). I explored the fear associated with inheriting AD experienced by adult-caregivers and the coping mechanisms for managing those fears.

Arcaya (1979) used a qualitative, descriptive technique to conduct an empirical phenomenological study of fear. The findings, presented in narrative style, are a distillation of the principal lived and existential features of this emotion; fear is caused by a lack of choice, which is one of such features. Esandi et al. (2021) used constructivist grounded theory in their study to explore how family groups responded to the early stages of AD. Their data analysis indicated four family dynamic types: close mechanics at the beginning that remained consistent across the experience, close mechanics at the beginning that would become conflicting, conflicting dynamics at the beginning that remained troublesome, and conflicting dynamics at the beginning that would become closer over time. Fischer (1989) provided a general description of his empirical-phenomenological human emotionality study approach, as well as a brief contrast and comparison with its more common equivalents in natural scientific psychology. He

exemplified his approach by describing schematically how he solicits, analyzes, and reflectively grasps an accurate explanation of the situated anxious experience of an individual. Gendlin (2018) discussed Heidegger's core idea of human feeling capacity and attempted to demonstrate its crucial implications. In his own words, he gave a thorough explanation of Heidegger's concept, as well as some discussion of the relationship between psychology and philosophy. Navab et al. (2012) noted that, following data analysis, three major categories of personal growth, care satisfaction, and caregiving gains, as well as nine subcategories, arose, demonstrating caregivers' favorable assessment of their caregiving.

When caring for a loved one with AD, caregivers face many risks and stress. The effects of AD on caregivers may cause a wide range of feelings, from guilt to fury, affecting their health and economic well-being; this is even more pronounced when the caregiver is a child of the affected person (Erdelez et al., 2019). Conversely, research on the risk perceptions of the offspring of those with AD can provide in-depth information on coping mechanisms since they are the most affected. Previous studies on siblings genetically predisposed to adult-onset diseases have focused on the genetic testing procedure and persons' decision to undergo or respond to testing (Losada et al., 2018). While such studies are important in understanding clinical results, they do not effectively address an individual's personal experiences with a condition and their coping mechanisms. The way people and their families deal with a condition impacts their attitudes about it, the coping mechanisms they use, and perhaps crucial life decisions such as self-care and financial management (Levy et al., 2021). Siblings' perceptions are

relevant and largely unexplored. Most caregivers' perception and risk studies have concentrated on close relatives of afflicted persons or how perception of risks influences caregiving (Gallego-Alberto et al., 2021). Illness experience studies often focus the states of carers, whereas caregiver studies typically focus on spouses, for example, as evident in studies by Shim et al (2022) and Hebert et al. (2007). There are, nonetheless, several reasons to learn about adult-child caregivers' experience with AD. Not only are such adult-child caregivers at a higher risk of developing AD, but their experience may have substantial psychological repercussions.

Neary and Mahoney (2005) looked at the issue of AD caring in a varied sample of Latino carers with the objective of exploring cultural aspects of the caregiving experience. In terms of recognizing dementia, symptoms, and views about the caregiving role impacting continuing care, this multiethnic Latino carers' sample had many similarities in those variables. Smith (2013) adapted his paper from a 2012 Melbourne workshop. The workshop described a process and experience driven approach to treating anxiety, fear, and panic that is based on the clinical observations of the author. The workshop included an outline of how clients appear and how that might guide therapy, as well as a presentation of the "paradigm shift," as he refers to it. The session was then proceeded with an experiential activity meant to increase the awareness of participants of how they connect to their own anxiety, fear, and panic, as well as how this may unintentionally impact the therapeutic approach they follow with clients. Vellone et al. (2012) conducted a study that explored what quality of life meant for Sardinian caregivers of persons affected with AD. Caregivers highlighted factors that harmed or

improved their quality of life. For many caregivers, family was especially crucial. Vellone et al. conducted a phenomenological study of Italian caregivers of people with AD. Relationship changes, lifestyle changes, caring difficulties, hopes and anxieties about the future, family obligation and respectful treatment were highlighted as six themes in the analysis. Caregivers went through significant life changes, such as changes in how they related with patients' lifestyles, and relationships with other family members. Yiu et al. (2021) explored how Confucianism influenced the process and perceptions of family carers in China. Their findings shed light on how Confucianism impacts family caregivers' experiences caring for dementia patients in Chinese communities. These findings can only aid in the development of culturally appropriate treatments to increase support for family carers of dementia patients.

AD affects a significant percentage of the senior population, some of whom require round-the-clock care from adult-child caregivers (Goren et al., 2016). According to revised estimates, 6.2 million Americans aged 65 and higher in 2021 are living with Alzheimer's dementia (Goren et al., 2016). Seventy-two percent are over the age of 75. AD affects upwards of one in nine people aged 65 and older (11.3%) in the United States (Alzheimer's Association, 2021). The proportion of the population with AD rises with age: in the United States, 5.3% of individuals aged 65 to 74 years have the diagnosis, while 13.8% of individuals aged 75 to 84 years and 34.6% of individuals aged 85 years and above are diagnosed with Alzheimer's (Alzheimer's Association, 2021). AD can affect people under the age of 65, although it is far less prevalent, and an individual's risk

of developing the disease is high when a first-degree relative has Alzheimer's (Alzheimer's Association, 2021).

Problem Statement

The problem I addressed in my study was how adult child caregivers of AD patients cope with the related stress of inheriting the disease. Exploring caretakers' fear regarding the possibility of inheriting AD can bring much-needed awareness about caregiver experience while caring for their parents (Yang et al., 2014). Adult-child caregiving often involves challenges in caring for one's deteriorating parent (Yang et al., 2014). Documenting this aspect of the experience of caregivers may add to the understanding of caring for parents suffering from AD.

Adult-child caregivers become susceptible to stress-related conditions while caring for a parent suffering from AD such as depression, anxiety symptoms, and high stress levels (Springate, 2014). Reed et al. (2014) reported that 26.2% of the sample of adult-child caregivers living with their parent had a greater burden compared to those not living with the parents. Clearly, this is a population with a significant risk for psychological distress, and one part of that distress may be the fact that they are at a significantly higher risk than the general public to one day need the same care that they are providing to their parent (Springate, 2014).

There are few studies undertaken to address the experiences of fear of inheriting AD. One such study was conducted in Iran, and the researchers stated that family caregivers suffered from guilt, sorrow and fear regarding their loved one's condition becoming worse as well as their own fate (Navab et al., 2012). Researchers who

conducted similar research in Japan stated that adult-child caregivers had concerns regarding their possible inheritance of AD (Vellone et al., 2002). Additionally, researchers in an Italian study reported that caregivers revealed fears of the future including a lack of personal time as Alzheimer's becomes worse in their loved ones, requiring more care (Piras et al., 2012). Although there have been studies conducted in several countries, few studies have been conducted in the United States focusing on the experiences of caretakers regarding fear of inheriting AD, and the coping mechanisms used in addressing such fears. Fear is particularly important and is the central point of my study because it affects the caregiving experience of adults who care for a parent with AD.

This study may promote positive social change by contributing to the existing literature on adult-child caregivers' fears of inheriting AD. It may provide useful information to adult-child caregivers and professionals who work with caregivers. Furthermore, this study may contribute to the field by providing clinicians with knowledge of the nature of these fears and the participants' perceptions of their most adaptive means of coping, which could be useful in clinical practice.

Purpose of the Study

The purpose of this study was to explore the experience of fear in adult-child caregivers about their potential to inherit AD. Additionally, a second aim of the study is to investigate the coping mechanisms that participants use in handling with their fears of inheriting AD. It has been established that six out of ten American caregivers taking care of a parent with AD report fears of inheriting the disease (Piras et al., 2012). To gain

more insight into the fear of inheriting AD as well as coping mechanisms, semi structured interviews were used to collect data from the impacted population.

The mental and physical burden of managing their parents' activities of daily living may affect not only the lives of caregivers, but their entire families. Studies have established that adult-child caregivers experience high levels of stress that impacts all facets of their lives (Flynn & Mulcahy, 2013). Comprehensive understanding is needed in this area, as the incidence of AD has escalated globally within the last 10 years (Alzheimer's Association, 2020).

Research Questions

My aim of this study was to investigate the fear of inheriting AD experienced by an adult-child caregiver who cares for a parent diagnosed with AD. Findings may improve understanding of the fear of inheriting AD experienced by adult-child caregivers. This topic was explored through the following research questions.

RQ1: How do adult-child caregivers of individuals with AD perceive their risk of inheriting AD?

RQ2: How do adult-child caregivers of individuals with AD manage their worry/fear of inheriting AD?

Theoretical Framework for the Study

Grounded theory, as developed by Glaser and Strauss (2009), was chosen as the best methodology for developing a theory from the current research. Grounded theory is a qualitative approach for studying a specific event or process and developing new ideas based on the gathering and analysis of real-world evidence (McCall & Edwards, 2021).

Unlike typical hypothesis-deductive research methodologies, in which a researcher develops a hypothesis and tries to prove or disprove it, grounded theory is an inductive strategy in which new theories are produced from facts. Data gathering, data analysis, and theory formulation are all iterative processes. Glaser and Strauss proposed that in grounded theory, iterative data collecting, and analysis continue until theoretical convergence is achieved, at which time further data adds no new insight. According to Albert et al. (2019), researchers should consider grounded theory when there are no existing theories explaining phenomena under examination.

In the present study, I generated a theory, processes of intent described, and theoretical sensitivity incorporated given other related studies. A theoretical sensitivity guided data collection, as exploration was focused on deriving meaning from different perspectives to develop a theoretical framework that can explain challenges faced by adult-child caregivers and how they cope with them. I used a qualitative research approach incorporating 15-minute interviews of 12 participants. Other theories taken into consideration include the appraisal theory of emotions (James,1890, as cited by Szigeti, 2022) and the theory of moods (Rossi, 2021).

Anxiety and fear have strong impacts on individual reactions and choices. Theories help researchers understand stressors, moderators, and outcomes in specific settings. For example, Osborne (2020) suggested that caregivers attempt to moderate their stressors through social and family support. When the moderators fail, they experience burden, depression, fear, and anxiety. The theoretical account for the present study included Lazarus' (1966) appraisal theory and Heidegger's (1981) theory of moods.

Appraisal theory plays a vital role in studying human emotions (Metts & Planalp, 2011). The theory suggests that each discrete emotion is a process that involves a particular set of attributes, feelings, physiological responses, and behavioral predispositions. I focused particularly on fear and anxiety caused by situational uncertainty about possibly inheriting AD. Heidegger's theory of moods represents a paradigm change in the way moods are conceptualized and classified. He rejected the traditional view of sentiments as sensual states that merely accompany the perceived higher faculties of reason and will, as well as the common practice of categorizing moods based on their aptitudes of desire, pain, and pleasure.

Researchers have come up with diverse theories on how human emotions develop through the brain's representation. Psychologists agree that anxiety has a central importance in structuring human behavior (Fischer, 1970). Their theories increase the debate on the processes behind our emotions in relation to cognitive processes. The appraisal theory of emotions was primarily developed by Lazarus, (cited by Conte et al., 2022) who proposed that emotions develop from an individual's appraisal, such as evaluations, interpretations, as well as explanations of phenomena. Lazarus' appraisal theory originated from ancient Greek thinkers who explained that people can avoid damaging effects of emotions. The theory presents primary and secondary aspects. Primary appraisal is the first movement of emotions while secondary appraisal involves judgement and critical thinking. Appraisal is the cognitive process of evaluating an event in terms of what is at risk (primary appraisal) and the coping tools available. The primary appraisal process involves goal relevance, congruence, and ego involvement while the

secondary appraisal process involves blame or credit, coping strategies, and future expectancy. Primary appraisal is unconscious and automatic while secondary appraisal is conscious and gives birth to specific emotions, such as fear. Additionally, Smith (2013) explained that fear and anxiety stemming from the worry of the consequences of disease might influence patient recovery. Lived experiences also trigger fear and anxiety when people worry that the experiences may happen to them in the future (Navab et al., 2011). Thus, fear comes from the susceptibility of structural transformation that leads to negative integration that produces and spreads fear (Sik, 2020).

The theory of moods explains moods as a mode of disclosure. According to Smith (1981), moods disclose thrownness, belonging to the world, being, and being of importance. According to Heidegger (1981), thrownness is defined as being thrown into the world and a person's ability to make sense of things; he asserted that the notion of existential identity and the notion of the world are joined. Gendlin (1978) explained that moods denote how people sense themselves in different situations, making it an inward and outward phenomenon. Ranasinghe (2019) recognized that Heidegger's explanation of moods presents it as a state of mind, which can be altered if an individual opts to change it. Thus, people alter fear and anxiety by seeking to understand the aspects that trigger fear (Aspers, 2009). That is why individuals harbor different emotional reactions towards similar events. These differences bring individuals in touch with the realities of life and conceal them from their desires (Miller, 2005). Heidegger presented a phenomenology of fear. His theory is that fear is encountering something threatening, something specific in the world (Smith, 2013). Heidegger claimed that anxiety renders the world meaningless,

appearing as an inauthentic spectacle, a kind of tranquilized and pointless bustle of activity. Anxiety can appear from the most innocuous of situations though always reveals human mortality, or being-towards-death, resulting in the inability to take the world for granted; whereas fear is imminently triggered by stimuli that convey harm to oneself (Smith, 2013). Human life is flooded by an unforeseeable future, considering that living today is a blessing and living to see tomorrow is a gift. According to Smith (2013), fear and anxiety have been used synonymously, although they each reference a separate emotion and situation depending on how they emerge. Grounded theory was chosen as the best methodology for developing a theory from the current research. Grounded theory is a qualitative approach for studying a specific event or process and developing new ideas based on the gathering and analysis of real-world evidence (Bytheway, 2018).

The experiences of fear of inheriting AD of adult-child caregivers were examined using semi structured qualitative interviews developed for this study. The interviews provided an opportunity to use the vocabulary or language that interviewees can understand easily and to understand their perspective on the topic easily (see Bevan, 2014). The approach provided a comprehensive understanding from an empathetic view of caregivers' experiences to examine their fear of inheriting the disease and how they cope with that fear. Additionally, qualitative interviewing guided the conversation to allow for listening to the respondents to *hear the meaning* of their responses and to inform distinct elements of the study through cultural inferences (Warren, 2011). By exploring the individual experiences presented by the participants, I condensed the phenomenon to its central root (see Neubauer et al., 2019); thus, understanding the

meaning of the respondents' experiences and lifeworld's through their responses. I also investigated the phenomenon of fear among adult-child caregivers regarding their potential to inherit AD. The target population in this study consisted of adult-child caregivers of parents suffering from AD who express a fear about inheriting the disease. About 25% of caregivers are adult-children caring for a parent suffering from AD (Day et al., 2014).

Nature of the Study

From the current research, the best process for generating a theory was identified as grounded theory. Grounded theory is a qualitative way to investigating a particular process or situation and producing new concepts based on real-world data. Unlike traditional hypothesis-deductive research approaches, in which a researcher forms a hypothesis and attempts to prove or disprove it, grounded theory is an inductive strategy that generates new theories from data (Yu & Smith, 2021). Iterative procedures are used in data collection, data analysis, and theory formation.

Definitions

The terms presented herein represent a fundamental key concept that exhibits a consistent presence within the literature examined for this study. Definitions have been thoroughly conceptualized to align with the contextual nuances expanded upon within this dissertation:

Adult Child-Caregiver: Adult-child caregiver refers to a child of a person with AD taking active care and assisting in everyday duties of caring. The roles of the informal adult-child caregiver entail more than providing physical assistance, but also

legal, financial, and coordinated aid care (Barnett, 2015). Despite personal issues, children of the elderly have always been a source of aid to their parents; however, seeing their parents' health deteriorating can be a source of fear for their well-being. The understanding of different stress coping mechanisms is critical for developing strategies to help ensure caregivers' wellbeing.

Caregiver Stress: Stress, according to Leigh et al. (2018), is a relationship between an individual and the environment, and is seen by the individual as a load that surpasses their resources to adopt appropriate coping mechanisms that will reduce the probability of jeopardizing their well-being. Caregiver stress is defined as negative effects endured by an individual giving care, and the strain suffered while doing so (Leigh et al., 2018). The definition of stress is drawn from factors that interrupt a person's life balance. Caregiver stress arises following the mental and physical burden of caring for others. Caregivers experience much greater levels of stress than non-caregivers (Leigh et al., 2018). Almost every day, many carers are required to provide assistance or be on call; this often consumes most of their time and they may not find time for themselves or friends. The stress can even be heightened when a caregiver is a child of the patient with AD following the fear that they will to inherit the disease (Leigh et al., 2018).

Coping: As caregivers encounter heightened levels of stress while caring for persons diagnosed with AD, there are a variety of management strategies that can help to mitigate the harmful impacts of stress. Coping in this study was understood as how caretakers respond to a stressful incident. Responding to stressful circumstances necessitates the use of appropriate stress-reduction tactics. Caregivers can handle the

stress that surpasses their resources by employing good coping mechanisms (Koch et al. 2021).

Assumptions

One assumption I had in this study revolved around the mechanisms employed by caregivers in coping with stress; I assumed that the participants understood different coping mechanisms. Understanding coping methods to improve their well-being might be better understood by researching the experiences of carers that have experienced the hardships of caring for an AD individual. I also assumed that the participants would effectively recollect earlier experiences with the coping techniques they had used and express those experiences through interviews. I also be assumed that grounded theory was an effective technique for analyzing caregiver processes and experiences; the notion is that by investigating the concepts reflectively, a fuller theory would emerge rather than a recounting of the sensations of the specific set of respondents. Another assumption was that that caregivers face unique challenges while providing for AD patients and that such challenges are worth exploring. In this study, I relied on the participants to offer context for their experiences within the framework of the global care planning process. Lastly, I assumed that the participants were truthful and transparent about their experiences.

Scope and Delimitations

In this study, I investigated adult-child caregivers' fear of inheriting AD and mechanisms they use in coping with the related stress. Equally, the study was limited to caregivers that have cared for AD parents. Since the research's focus is on adult-child caregivers’ experiences, an endeavor was taken to ensure that the responses provide

reliable indicators. Using open-ended questions, I collected data from only adult-child caregivers of parents with AD (see Grill et al., 2013).

Limitations

The characteristics of the sample were examined to determine if samples include individuals who are representative of the targeted population. A major limitation of the qualitative research is that it uses a small number of participants (Busetto et al., 2020); this study's sample consists of 12 prospective participants caring for a parent suffering from AD. Moreover, while there are different coping strategies, the collection of qualitative data limited certain analyses, compared with quantitative measures; for example, it was not be possible to compare participants' coping strategies to other groups.

Significance

AD is a significant problem in the United States. Adult-child caregivers report significantly more anxiety than nonrelative caregivers (Springate et al., 2014). According to a meta-analysis conducted by Flynn and Mulcahy (2013), adult-child caregivers of parents with AD are significantly more stressed than non- AD caregivers, and they have significantly higher levels of depression symptoms and physical issues, with overall prevalence rates of anxiety and depressive symptoms of 44% and 34% respectively. The impact of caring for a parent suffering from AD affects the whole family unit (Chirico et al., 2021).

AD impacts all cultures around the world (Chin et al., 2011). Although there has been significant progress in the research on AD, there is a gap in knowledge as current

studies focuses on the effect of the disease on the patients leaving out the experiences of adult-child caregivers caring for their parents (Werner et al., 2012). In a recent U.S. study conducted by Awang et al. (2018) on adult-child caregivers, spouses, and domestic partner caregivers, the scholars reported that participants experienced fear of AD more than other chronic diseases. Researchers have not studied adult-child caregivers' experience of fears about AD within the United States (Werner et al., 2012).

This study is significant because it will address the phenomenon of adult-child caregivers becoming afraid of inheriting AD (Yang et al., 2014). Additionally, I addressed how caregivers cope with these fears when caring for a loved one with AD. The findings may provide information regarding the difficulties adult-child caregivers experience coping with their fear and approaches they can employ in coping with the related stress (see Sansoni et al., 2013). Moreover, the findings of the study may inform adult-child caregivers and the medical community of the need for continuing education about the mental consequences of caring for a parent who has AD. The psychological health of an adult-child caregiver can be affected negatively by caregiving experiences (Flynn & Mulcahy, 2013). The suffering imposed by AD poses a challenge to the adult-child caregivers, and it becomes increasingly challenging to care for their own well-being as their parent's disease progresses (Springate & Tremont, 2014). Furthermore, the fear associated with inheriting AD grows as the caregivers continuously interact with parents as they meet their obligation to care for them (Springate & Tremont, 2014). This study may also promote social change by providing information about coping strategies that may aid in supporting and educating adult-child caregivers caring for their parents.

As the prevalence of AD continues to climb, professional and informal adult-child carers of such patients confront diverse problems (Springate & Tremont, 2014). Furthermore, when care is delivered, issues such as stress, weariness, and diminished mental well-being are evident (Waddill-Goad, 2019). Caregivers of people with AD are continually subjected to change and disturbance in their daily life. Caregivers have repeatedly reported a significant degree of caregiver load, including a reduction in mental well-being and inappropriate actions when caring for individuals with AD (Kallander, 2020). Conversely, I addressed a vacuum in knowledge by exploring strategies of coping reported by informal caregivers in Northern California.

The study may aid in building theoretical frameworks of change that address elevated stress levels, and how an absence of support can affect caregivers, by handling stress-related challenges, psychological benefits, and coping styles, where few studies have been centered on caregivers of people with AD. By addressing such issues, a better knowledge of how reduced stress levels, enough support, and proper care might improve adult-child caregiver well-being can be acquired. Furthermore, the study's findings may help in guaranteeing that caregivers receive essential assistance to allow them to offer the best possible care for persons with AD by applying a holistic approach.

Significance to Practice

The study's findings can be used in developing techniques for coping with stress levels that adult-child carers of persons with AD face. Key variables (behavioral or emotional) that can lead to higher stress levels, weariness, and poor well-being can be addressed or alleviated by enlisting stress adaptation approaches (Sin et al., 2021).

Raising awareness of these difficulties will also enable caregivers to get fresh insights into these obstacles when they seek essential assistance. The findings may also provide insight to psychologists on areas to focus on in addressing the needs of adult-child caregivers as well as in designing supervised training, competencies, and advocacy as related to providing services to adult-child carers.

Significance to Theory

My goal was to characterize, comprehend, and explain phenomena related to AD caregiving. The inquiry dealt with experienced fear that adult-child caregivers face while providing care to individuals with AD as well as coping mechanism employed. Conversely, the findings may give adequate insight into what coping strategies caregivers use and find useful to inform caregivers and health professionals about potentially therapeutic strategies. Subsequently, the study could provide a means of understanding adult-child caregivers' experiences from the perspective of Lazarus' appraisal theory of emotions and Heidegger's theory of moods.

Significance to Social Change

The outcomes of this study may have a useful advantage in uncovering a range of fears that caregivers confront when caring for individuals with AD, approaches to reducing the potential consequences of stressors, and generating the possibility of more beneficial coping approaches that will enhance caregiver health. Since AD is so prevalent, and there are so many adult-child caretakers, any research that may benefit them will help society because it touches on many people; this represents a loss of significant productivity and increased cost arising from caretakers' healthcare needs.

Summary

It is undeniable that adult-child caregivers of persons living with AD face different challenges including stress arising from fear of inheriting the disease. Equipping caregivers with the ability to adaptively cope (i.e., self-compassion, task-focused or problem-focused coping, seeking social support) may help reduce the adverse emotional effects of looking after a parent with AD (Leigh et al. (2018); however, the input of caregivers themselves is missing in such studies. While the rising level of stress is linked to the challenges that caregivers of people with AD face, there is still a lack of understanding about caregivers' perception of the related fear and effective coping mechanisms to enhance their well-being.

Chapter 2: Literature Review

The public's general perception of multifactorial adult diseases and conditions such as cancer, heart disease, and AD is modelled by individuals' experiences, disease patterns in the family, and how they compare themselves to affected individuals (Losada et al., 2018). Martin et al. (2020) found that individuals with a familial history of AD have a higher perceived risk of developing the condition than people who have no firsthand experience with the disease or have only had contact with unrelated people. Perceived risks are further influenced by views about illness etiology, fatalism, coping abilities, and personal control requirements. It thus holds that adult-child caregivers of patients with AD perceive themselves to be at a higher risk of developing the disease. Such findings align with existing theories of sickness representation and perception of risk across a range of disease types (Leventhal et al. 2020). Moreover, individuals' risk perceptions are linked to changes in health behaviors. Conversely, this study, an inquiry of adult-child caregivers' fear of inheriting AD, and the mechanism of managing related worry may help fill the knowledge gap on how to manage the fear of inheriting the condition.

Alzheimer's caregivers are accountable for accomplishing everyday activities for their loved ones and themselves when giving care. Adult-child caregivers frequently provide continual monitoring and redirect troublesome behaviors as well as aiding with dressing, washing, and toileting (Marsack-Topolewski & Maragakis, 2021). Literature attests to the notion that care recipient and caregiver outcomes are suboptimal due to caregiver load (Gallego-Alberto et al., 2021). AD caregivers are more prone than

noncaregivers to suffer chronic physical ailments and depression as well as making tough financial decisions (Teixeira et al., 2019). Adult-child caregivers may feel the need to quit their employment or reduce other day-to-day engagements to meet the need of their parents with AD (Teixeira et al., 2019).

Literature Search Strategy

The literature search was conducted in learning databases including SAGE Journals, PsychArticles, PsychINFO, PsycNET, SocIndex, Thoreau multi, and Web of Science databases. The search was conducted using a variety of keywords, including *fear of developing AD (FDAD)*, *adjustment*, *coping*, *Alzheimer's caregiver worry and fear*, *outcomes*, *adult-child caregivers*, and *AD fear* complete with Boolean operators. Some terms differed with databases based on database-specific filters and availability of index terms, for example, PsycNET search: *Coping* AND *AD* OR *outcome* AND *adult-child caregivers*. Web of Science search: *AD* AND *Adjustment* OR *Coping* AND *adult-child caregivers*. The publication data limit was set between 2015 and 2021.

The approach I used in study selection involved removing duplicates and reviewing results based on abstracts and titles. Full texts were retrieved for further review for inclusion or exclusion for eligibility. Data extraction from articles was achieved through piloted extraction focusing on aims, design, measure, samples used, and findings. Inclusion criteria for the current study included reported experiences of adult caregivers, stressors, and coping mechanisms. On the other hand, inclusion criteria for qualitative studies included reported experiences of adult caregivers, investigation on the perception of AD, and discussions on coping strategies.

Theoretical Foundation

Anxiety and dread have a profound influence on people's behaviors and decisions. In the context of the current research, theories aid in comprehending stressors, modifiers, and outcomes in unique circumstances. It is worth noting that caregivers mitigate their stress through social and familial support (Montgomery et al., 2018). When the moderators fail, they feel burdened, depressed, fearful, and anxious. I used Lazarus' appraisal theory of emotions and Heidegger's theory of moods (see Montgomery et al., 2018). Appraisal theory is important in studying human emotions; each distinct emotion is a process that incorporates a specific collection of qualities, sensations, physiological reactions, and behavioral patterns (Reed et al., 2020). I concentrated on the worry and anxiety generated by situational ambiguity when caring for patients with AD. The theory of moods provides a comprehensive view of the definitions and categorization of feelings (Cruz-Oliver et al., 2020). The theory's ideas were used as a framework for understanding how adult-child caregivers feel and manage their worry of acquiring AD. Moreover, I used the theory in developing interview questions and in coding narrative data (see Reed et al., 2020).

Appraisal Theory of Emotions

Researchers have proposed diverse ideas on how human emotions arise through brain representation (Todd, et al., 2020). From a psychology point of view, anxiety has a critical role in shaping human behavior; theories in this area contribute to the discussion of the mechanisms that underpin emotions in connection to cognitive activities. Appraisal theories assert that emotions arise from people's assessments and accounts of their

situations even when sensation is absent. In the appraisal theory of emotions, Lazarus (2020) posited that emotions arise from an individual's appraisals, such as assessments, judgments, and explanations of occurrences. Lazarus' theory is based on the ideas of ancient Greek thinkers who outlined how humans might prevent the negative impacts of emotions. The idea discussed both primary and secondary issues. Primary assessment is the first emotional movement, but secondary appraisal comprises judgment and critical thought. According to Lazarus, the metacognitive awareness involved in perceiving emotional resonance can be unconscious or conscious, and it can take the shape of abstract processing. He emphasized that cognitive processes affect the quality and strength of emotions by mediating the link between individuals and situations through coping methods, which in turn form the basis of an emotional outburst. Lazarus identified two basic evaluation procedures in his research: first, the primary appraisal, which aims to determine the importance or meaning of an event, and second, the secondary appraisal, which analyzes individuals' capacity to cope with the effects of an event.

Theory of Moods

The concept of mood in psychology is understood from the analysis of emotions. A mood is understood as persisting feelings related to cognitive and evaluative states that affect future feelings, evaluations, and actions (Smith, 1981). Heidegger (1981) introduced the theory of moods, which describes moods as a form of revelation. According to Smith (1981), moods reveal the thrownness (humans' individual existences) and the connection to the world, existence, and relevance. Thrownness, as per Heidegger, is characterized as being thrown out into the universe and the ability to make meaning of

things. Heidegger essentially claimed that the idea of existential identity and the notion of the world are one (Khanbazian & Sabouri, 2021). Moods represent how individuals perceive themselves in various settings, making them an inside and outer phenomenon. Heidegger's description of moods showed it as a state of mind that may be altered if an individual chooses to do so. Conversely, people adjust their anxiety and fear by comprehending the factors that cause dread (Aspers, 2009). As a result, people have diverse emotional reactions to comparable circumstances; these distinctions bring people face to face with life's reality while shielding them from their wants (Miller, 2005). According to Heidegger's idea, fear results from experiencing something scary and distinctive in the world (Smith, 2013). According to Heidegger, anxiety makes the world meaningless, making it look like an inauthentic show, a tranquillized and senseless whirl of activity. Anxiety can arise from the most harmless conditions, but it always indicates human mortality resulting in an incapacity to take the world for granted. In contrast, terror is triggered by stimuli that threaten one's safety (Smith, 2013). Human existence is saturated with an uncertain future, even though living today is a blessing and surviving to see tomorrow is a gift, it is worth noting that fear and anxiety have been used interchangeably, even though they each relate to a distinct feeling and scenario depending on how they manifest (Smith, 2013). The theory of moods holds that individuals are motivated to alleviate negative states or feelings to intensify positive effects; therefore, I used it as the foundation for understanding the basis of the coping strategies used by adult-child caregivers in overcoming related stress and maintaining well-being while

caring for AD parents. The following section is a discussion of the expected relationship between the study's variables.

The review of the literature was not employed in the building of a theoretical framework to describe the events under research since the I employed a grounded theory technique. Since the grounded theory is supposed to build a theory or create an explanation directly from data, using an established theory as a prism to guide the research would violate the selected technique (Forde, 2023). Related literature was reviewed during the analysis stage, rather than before the start of data collection. However, an initial literature analysis was completed to offer a broad view on the issue of concern, which assisted in justifying the need for the investigation.

The grounded theory was used as a foundation for this study to investigate and seek knowledge regarding caregivers' fear and coping while caring for persons with AD. The grounded theory concept, created by Glaser and Strauss in 1967, is an intuitive technique that creates an account of processes, activities, or connections produced by the viewpoints of a large population (Mruck & Mey, 2019). When Glaser (1967) originally formulated the grounded theory, he concentrated on organizing qualitative approaches into coherent codes, and developing middle-range ideas towards sustaining an empirical approach. Strauss (1990) expanded the grounded theory by elaborating on discourse and practical elements. The grounded theory, influenced by Strauss, emphasizes humans as active actors in a constantly developing process that influences the environment in which they live. Furthermore, when the emphasis shifts to transformation, dynamics, variation, and the intricacies of life, such emerging processes offer meaning to acts as they unfold.

Grounded theory is a broad approach used by academics to explain phenomena based on evidence collected and examined consistently (Yu & Smith, 2021). The focus on theory creation is the major feature that separates the technique from other qualitative methods of investigation (Singh & Estefan, 2018). Another distinguishing feature of this technique is the attention to ongoing comparison analysis during the data gathering process, which provides for the validation of evolving theory and assumptions. Within the current qualitative inquiry methodology, I was responsible for giving voice to the participants' experiences as well as interpreting such experiences.

The methodology for this research included identifying recurring themes connected to the study's particular phenomenon, uncovering and characterizing respondents' responses into abstractions, making comparisons of fear and coping mechanisms, and exploring the consequences of those constructs to generate an explanation. The next section demonstrates how grounded theory has previously been used to identify stressors, fears, and associated coping methods connected to caregiving.

Literature Review Related to Key Variables and/or Concepts

Many ideas about inheritance, sense of guilt, responsibility, and communication hurdles between family members have been discovered in studies of individuals who have lost relatives to adult illnesses (Crook et al., 2021). Responses may be challenging for a person whose parents have AD due to emotional or physical distance and the other duties related to adulthood, such as employment and family obligations (Sihto, 2018). Factors influencing family functioning may influence how a person views parents' conditions, particularly one with hereditary issues like AD (Sihto, 2018). Social stigma

has been linked to various neurological and psychiatric illnesses, and it can limit an individual's and a family's capacity to discuss illnesses and how they are inherited (Sihto, 2018). Poor communication may result in myths, misunderstandings, or misinformation about a condition's risk (Berzenski et al., 2019); this may interfere with the challenging or unpleasant work of discussing a genetic risk in a family or conveying requirements as a caregiver. Individuals' experience with AD is most likely to be intertwined with the degree of perceived risk of acquiring the disease, the transparency of communication within a family unit, and the influence that the individual feels following the perceived risk.

According to Werner et al. (2021), children of individuals with AD frequently display symptom-seeking behavior. The early development of a condition related to AD in a sibling may cause greater fear and stress than a delayed onset of the disease, affecting their ability to care for their ailing parents. Moreover, young adults may be more concerned about their risk of acquiring AD than elderly adults. The attitude of caregivers tending to Alzheimer's patients may range from positive to negative. Caring for people with AD is frequently stressful; however, some adult-child caregivers may see this experience as an opportunity to give back or get closer to their ailing parents (Galvin et al., 2020). As a result, the viewpoints of each individual adult-child caregiver may be essential in determining how the family system as a whole interprets the experience of caring for a family member with AD and how they cope with related stress. The viewpoint may be established due to caregivers' bonds to their ailing parents and their want to offer proper care. A family structure with secure ties, for example, may have a

positive outlook on caring, resulting in high endurance. The resilience of caregivers may be linked to their ability to offer care. Studies on caregivers' emotional responses while caring for family members with AD have uncovered high levels of worry and anxiety (Pristavec, 2018).

There is much evidence of caregivers' negative perceptions on health, for example, as noted by LaManna et al. (2020), but more data on caregivers' positive attitudes and how they improve patients' quality of life is needed. According to Rigby et al. (2019), adult-child caregivers caring for a patient with AD think the experience has increased their caregiving abilities, patience, purpose in life, positive predictive override, and pleasure; however, it is largely unknown whether strong readiness and attachment correlate to positive perspectives.

With the understanding that caring for patients with AD is stressful, most of the time, the link between predictors and caregiver load is non-linear. A mix of events, experiences, and abilities complicate the connection (Park et al., 2019). Since the negative repercussions of Alzheimer's caregiving are so severe, it is critical to look at factors that help explain the causal link between variables and outcomes. Coping, defined as actions and practices utilized in response to life's issues, was discovered as a mediator in the association between stressors, fear, and caregiver burden in the formulation of the Stress Process model (Falzarano, & Siedlecki, 2020). Using Hierarchical regression analyses to examine which primary and secondary stressors emerge as predictors of cognitive performance Falzarano and Siedlecki (2020), found that coping moderated the relation between caregiver's stressors and caregiving workload. The words "mediator"

and "moderator" have been employed interchangeably in research, despite the terms giving two independent interpretations of empirical correlations. The study concluded that moderator factors influence the link between two variables so that the effect of the predictor variables is influenced by the moderator's degree, but mediator factors explain the impact.

Assessments, adaptability, and social supports were investigated as modifiers of AD in adult-child caregiver burden in an exploratory study by Moss et al. (2020). To qualify for the study, the adult-child caregivers had to provide direct care and be a child of the care receiver. The study included 123 white and 74 black adult-child caregivers; caregivers' demographic data were extracted including age, race, sex, and marital and job status. Information on socioeconomic status was gathered and classified using aggregated income divisions (Moss et al. (2020). The Social Support Questionnaire Short Form was used to compile a list of social supports, and the study concluded that the impacts of caregiver stresses are modulated by coping techniques, social support, and appraisals.

In a study of 204 AD caregivers, Rosa et al. (2020) sought to examine the impact of coping and appraisal mechanisms as mediators between patients' behavioral issues and caregiver’s stress of the disease related fear. Alzheimer's carers were solicited from a Florida support network and completed self-report questionnaires on demographic data (age, gender, income, and relationship to the patient), coping strategies, proficiency, and fear in caring. Dependability measurements were recorded as α= 0.60 and 0.78; these measures assessed the caregiver's personal development and capacity to deal with caregiving circumstances. Depression and somatic problems were used to quantify

caregiver stress. To assess depression, the CES-D short form was employed. Somatic symptoms were assessed using the Bradford Somatic Inventory; the 21- item measure recorded bodily concerns like headache and stress (Zhang et al., 2019). According to the result of the research, the caregiver's assessment of satisfaction reduced the detrimental consequences of problematic behaviors. The study using Cross-sectional assessment method provided several insightful findings and conclusions; first, both stress and gain impact caregiver performance and should be investigated. The meaning or assessment associated with the behavioral issue Alzheimer's caregivers have an equal impact on outcomes as their behaviors. Second, the study's findings emphasized the necessity of tackling emotional stress from a strengths-based perspective.

Not all patients are adversely affected by caregiver stresses; the caregivers' sense of mastery is hypothesized to largely determine their perception in care and how they are affected. Personal mastery refers to a caregiver's perception that they are in charge of their situation and care outcomes. McAuliffe et al. (2020), sought to investigate the impact of personal control of caregiver fear and mental stability. The authors using a bias-corrected, accelerated bootstrapping method found that perceived burden was significant and directly (McAuliffe, 2020). Based on post hoc analysis, when mastery was poor the connection between problematic behaviors and mental instability were substantial, however, there was no statically meaningful link between problematic behaviors, fear, and mental instability when mastery was high (McAuliffe, 2020). In particular, the study concluded that a certain degree of personal competence might buffer caregivers from the detrimental impacts of caring; the research findings lend

credence to evaluating caregiver capabilities and examining strengths as potential moderators.

Fatigue is a bothersome condition that frequently leads to a worse quality of life and a lack of willingness to engage in ordinary physical activity. Many caregivers get exhausted following the psychological and physical strains of AD caring. According to a quantitative study that employed a conventional content analysis approach conducted by Ashrafizadeh et al. (2021), whose aim was to explain the experiences of family caregiver while caring Alzheimer's patients, seventy-five per cent of caregivers felt weariness. The study found that Fatigue among Alzheimer's carers was compared to non-caregivers based on their degrees of expertise. In the study, 73 Alzheimer's carers and 41 non-caregiving controls took part; the 30-item Multidimensional Fatigue Symptom Inventory assessed fatigue and how much the respondents reported "lively", "tensed", "heavy all over". Based on the Personal Mastery Scale used in assessing mastery, AD carers exhibited more weariness than non-caregivers. The study concluded that Personal mastery was proposed as a moderator in the association between caring status and weariness (Ashrafizadeh et al., 2021). Personal mastery exhibited no association with exhaustion on its own; however, the caring status and expertise interaction had a statistical significance link with fatigue. Alzheimer's caregivers with better mastery felt less weary and had more vitality and energy regardless of their caring condition.

There is scant evidence regarding the mental health of AD caregivers during the past COVID-19 pandemic. In a longitudinal study to assess the psychological effect of COVID-19 on AD caregiver’s health, Pierce et al. (2021), employed a probability sample

to track mental health during the pandemic to characterize health trajectories and pinpoint predictors of deterioration. Additionally, there is virtually little data on cross-country assessments of the mental distress of carers, even in northern Italy and southern Switzerland, two areas that were significantly affected by the first pandemic epidemic. Additionally, the few studies that were conducted on dementia caregivers during the disease outbreak varied in methodology and concentrated only on a few psychological well-being, primarily stress or caregiver burden. Mental illness was frequently not assessed using confirmatory factor scales. To support the design and delivery of suitable procedures and interventions designed to assist a large segment of the population for the present and in light of future disease outbreak crises, it is essential to expand and progress the present understanding of the impact of stressors on caregivers of people with dementia.

The incidence of physical sickness and mental health problems such as depression, anxiety, and stress among caregivers is higher than we previously assumed. according to a study by Pudelewicz et al. (2019), Italian caregivers were found to have 32% psychological illnesses and 56% physical illnesses. Moreover, 53% of the 200 caregivers in different research by Tentorio et al. (2020), who care for AD patients, the majority of their time is devoted to caring for their patients and little time is devoted to themselves. They feel that this has an impact on their own social lives. Additionally, 59% of them reportedly feel emotionally spent.

Occupational therapy is a treatment approach that is specifically designed to help AD patients accomplish daily tasks with their impaired cognitive function. A study by

Birkenhäger-Gillesse et al. (2018), examined how occupational therapy affected both AD patients and the people who cared for them; the study sought to influence the behavior of carers by including coping strategies and supervisory techniques in occupational therapy, whereas therapy for patients focused on cognitive and behavioral strategies. It has been demonstrated that occupational therapy is effective in lowering the load on caregivers and improving patients' life satisfaction.

Through behavioral therapies, the stress on caregivers can also be lessened. According to a study by Gautam et al. (2020), behavioral therapies might lessen psychological issues including anxiety and despair while also improving negative behavioral indicators. The development of technology has made it possible to carry out behavioral treatments electronically. The trial of "Mastery over dementia," which won the Alzheimer Disease International (ADI) award in 2010 for the "best promising psychosocial intervention for persons with dementia or their carers," provided evidence of this (Smith, 2019). It is interesting to note that telephone intervention is yet another strategy for dealing with behavior issues among caregivers. "Family Intervention Telephone Tracking- Caregiver (FITT-C)" has shown the effectiveness of virtual behavioral intervention (Pillemer et al., 2018). The intervention is conducted over the phone by skilled therapists who were knowledgeable about coping mechanisms, psychological support, and AD. In contrast, different research found that tele-support amongst five caregivers per group for an hour each week had very marginal advantages (Atoyebi, 2022); this may be because there are not enough qualified therapists or counselors to help them, as has been shown in an earlier study. However, this strategy is

highly cost-effective, and additional research should be conducted to examine its advantages. Many studies in the above literature review on AD caregiver inquiry provide extensive view of care-giving modifiers, but its association with caregiver burden is uncertain; this is a gap in knowledge that can be filled by exploring the experiences of fear in adult-child caregivers about their potential to inherit AD.

Summary and Conclusions

AD adult-child caregiver's burden develops due to a combination of variables. Stressors in the caring experience include disruptive behaviors, functional reliance, and mental retardation in the care receiver (Ashrafizadeh et al. (2021). Caregiver load is also linked to caregiver factors. The caregiving burden is caused by subjective views and the meaning associated with the caregiver's circumstance. AD information has been proved beneficial in the lives of Alzheimer's caregivers (Ashrafizadeh et al. (2021). It has been studied in connection to numerous elements of caring, but its association with caregiver burden is uncertain. As a result, there are scientific implications for studies looking at the link between AD awareness and adult-child caregiver burden. According to available literature, there is a link connecting various caregiver stresses and caregiver burdens (McAuliffe, 2020). Studies have also shown that moderator factors have an impact on such an association. Caregivers with a larger feeling of personal mastery and coping abilities, in particular, are better able to withstand the impacts of stresses and report reduced load, despair, and exhaustion (McAuliffe, 2020). The review of literature aided in the identification of a gap in knowledge hence acting as a foundation of the current study.

The following section is a prescription of an expropriate methodology that will be employed in the current study.

Chapter 3: Research Method

The purpose of this study was to explore the fear experienced by adult-child caregivers caring for a parent diagnosed with AD. Findings may help in improving the understanding of the fear of acquiring AD as experienced by adult-child caregivers and some of the important coping mechanisms employed by those caregivers. Adult-child caregivers confront behavioral and emotional issues similar to those of AD patients for whom they care (Pristavec, 2018). Some of the issues encountered include stress, lack of support, and social isolation. To improve the well-being of adult-child caregivers of persons with AD in various geographical regions and age groups, an interdisciplinary strategy must be adopted to address such problems (Pristavec, 2018). Equally, more studies on caregivers' difficulties and therapies for efficient coping techniques that will improve optimum well-being are needed. In this chapter, I cover the research design and its rationale. I also discuss the role of the researcher, the methodology, and qualitative approaches employed in the study, particularly data collection and analysis as well as issues touching on ethical procedures and trustworthiness.

Research Design and Rationale

I used a qualitative approach using grounded theory in exploring the general explanation of adult-child caregivers' fear, stress, well-being, social support, and coping mechanisms based on participants' perspectives. Using the approach, the following research questions will provide guidance in exploring the study's subject matter:

RQ1: How do adult-child caregivers of individuals with AD express fear of developing Alzheimer's themselves perceive their risk of inheriting AD?

RQ2: How do adult-child caregivers of individuals with AD expressing fear of developing Alzheimer's themselves manage their worry/fear of inheriting AD?

The use of a qualitative approach was critical in addressing the issues that adult-child caregivers of AD patients encounter. A quantitative approach as considered inappropriate for the study based on the present limitations in the literature on pressures affecting adult-child caregivers and lack of assistance. Surveys and semi structured interviews were used to collect data on the adult-child caregivers' scarcity of resources and the psychological variables that affect their actions. Better insights was obtained on the aspects that may lead to greater stress and a lower sense of well-being for the long-term carers through interviews and surveys.

A narrative research design, which focuses on individual stories (phenomenology) was considered but not choses; the approach is used in collecting tales and experiences of individuals or a group of people (see Dwyer, 2017). In such an approach, thorough sequencing interviews are used in creating themes. A researcher would need to acquire an extensive array of data from each participant to have a thorough knowledge of their lives, which is one of the underlying problems of the narrative research technique. The phenomenological approach focuses on explaining experiences (Williams, 2021); however, since I sought to provide detailed description of caretakers' fears and coping mechanism, grounded theory was considered a better approach. As a result, phenomenology was not used in this investigation because it potentially introduces a level of bias.

The grounded theory provides a more coherent theoretical explanation since it goes beyond explaining to producing and/or uncovering hypotheses for what will be observed (Charmaz & Thornberg, 2021). The approach aided in illustrating how practitioners might apply the research findings that would help in the improvement of the identified difficulties. Researchers can use grounded theory in focusing on the activities or actions to be performed, such as the implementation of frameworks to provide greater positive social support for adult-child caregivers of persons living with AD. As a result, since no contemporary theory exists to describe or comprehend the research questions addressed in this study, a qualitative methodology was used in explaining the assistance that adult-child caregivers require.

The key constructs of the grounded theory include codes, coding, and categories (Chun et al. 2019). As the approach was consistently employed through the study, the main element considered was theoretical sensitivity, which covered coding in a way that explained the subjects under study to derive a strong theoretical concept from the collected data. Equally considered was the theoretical sampling, which involves the parties to interview so that their responses aided in generating a theory. Finally, the composition of data between participants as considered; this was critical in arriving at a subject context to derive a strong theoretical foundation.

Role of the Researcher

As the key part of the study, I gathered data by interviewing participants. Rather than using standard questionnaires and other tools established by other researchers, I used invented open-ended interview questions. Although I am not affiliated with any of the

organizations from where I recruited participants, past background knowledge from family members offered a deeper grasp of the population under investigation. Consequently, I used methods including reflective journaling to facilitate objectivity reflection. Knowledge on the sensitivity of the matter aided in building rapport with the research respondents; this was vital in administering interviews and conducting surveys, as it will make the environment comfortable. A comfortable environment can aid in increasing participants' chances of sharing meaningful information (Carter et al. 2021). My experience also aided in understanding pertinent issues from participants' points of view.

Methodology

Grounded theory was used in deriving a broad interpretive model from procedures rooted in the respondents' responses. According to Silverio et al. (2019), the grounded theory is an approach developed from methodically collected and evaluated evidence via a continuous comparison process, which in this study included individual interviews and surveys. Surveys were used in validating interviews and were given out before the start of each interview in which the targeted adult-child caregivers who provided care to an individual with AD responded to issues of interest. The surveys include demographic data as well as the two open-ended research questions: (a) any fear of inheriting AD, and how do you describe your fear of acquiring AD? (e.g., effect on mental and physical health) and (b) what coping strategies do you consider to be effective in overcoming related stress and maintaining well-being? (e.g., hobbies, talking to people, or taking time by yourself).

Participant Selection Logic

Adult-child caregivers of people with AD who are afraid of developing AD themselves were the intended population for the study. As more emphasis is focused on patients with AD, their adult-child caregivers may experience more stress as a result of the individual's abstracted actions (Chang, 2019). This study's geographic location was the United States. I reached out to local AD organizations and used social media to recruit participants. For convenience purposes, interviews were conducted over video (videoconferencing).

Participants were recruited from a pool of adult-child caregivers who are caring for individuals living with AD. Individuals were chosen for sampling with intent, and a small sample of 12 participants was determined sufficient to aid in the development of a well-saturated theory. The collection of contextual data was achieved as the study enters the axial coding stage.

I conducted theoretical sampling by intentionally interviewing persons who can add to the study's conceptual framework. Initially, a uniform sample was interviewed to validate or disprove the circumstances under which the paradigm is maintained (see Kumar & Cavallaro, 2018; Jopke & Gerrits, 2019). Participants had to be adult-child caregivers who are over the age of 18 years, and at the time caring for a person with AD living in the United States. It was also a requirement that the participants speak English, comprehend all interview questions, could respond to them, and were afraid of developing AD. Participants were asked to complete a demographic survey and undergo

scheduled interviews after completing the survey; using Montréal cognitive assessment (MoCA) test, those with mental disabilities were barred from participating in the study.

Before the start of data collection, participants' consent was obtained; this involved communication between the researcher and the participants regarding the nature and the purpose of the study, the data to be collected, and their voluntary participation. The participants signed a consent form denoting their agreement to participate in the study. As the participants share their thoughts, I digitally recorded their responses with their consent to be transcribed later. To minimize the potential influence of bias I used a transcription service; however, I also listened to the recordings and conducted an independent transcription for verification of accuracy. Additionally, nonverbal cues such as facial expressions and body movements were noted to confirm and supplement the recorded spoken information; this was achieved through journaling.

Instrumentation

During the data gathering process, I was the primary observer. Journaling was also used in documenting observed expressions, respondents' reactions (nonverbal cues), and any notable events occurring throughout the data collection process. Interview questions were focused on adult-child caregivers' feelings of fear and coping techniques that would either increase their well-being or assist them to cope with the encountered problem. No data was gathered until the institutional review board approved the research and research participants give their consent.

Data Collection

Multiple phases of data gathering were employed, and data classifications were used to establish interconnections. The following sources were used in collecting data: journal entries, and tape-recorded interviews (see appendix for the semi structured interview questions). Each interview provided an opportunity to capture participants' impressions that increase fear of inheriting AD, and coping techniques utilized in dealing with the problems faced. absthe respondents will be assured that only information regarding their care experience would be collected. The method of data collection allowed for the examination of specific characteristics of respondents' behavior as well as reporting in ways that were both relevant to social science and not damaging to respondents. The chosen location for interviews was comfortable and accessible to the participants. Throughout the interview, comments were be captured as participants offered their ideas. Ensuring that the participants were calm as they communicate issues encountered was critical in creating trust between the participants and myself. If participants require debriefing or more help after each interview, a phone number was provided where they can call for assistance. I used an interview protocol with essential research questions and subquestions. Member checking was undertaken to facilitate the accuracy of transcribed data.

Data Analysis Plan

The data analysis will focus on the primary concerns of data collection including coding caregivers' notes for the perception of fear, stress, and coping mechanisms; coding interview notes; and comparison of notes for stress coping mechanisms. In

addition to notes, the continual practice of coding interview transcripts will be critical to data analysis. The transcription process will involve choosing the preferred transcription method, transcribing the audio using transcription software, adding time stamps and speaker designations, clarifying content where needed, and proofreading the transcription. It will necessitate reviewing and rereading the data to highlight and identify crucial, descriptive, or instructive issues that will arise for subsequent sorting and classification (Peel, 2020). Rereading the data will also allow for the identification of processes, as well as the qualities and aspects that define specific responses. The ultimate objective will be to create a theoretical framework taking into consideration the experiences of adult-child caregivers. The rich depiction that will arise will portray the experiences and the meanings that account for well-being and support for caregivers.

During the first data assessment, I will search for patterns and evidence that will aid in determining if all questions are answered. Following this conclusion, journal entries will be inserted into the Atlantis for coding; this technique will aid in identifying patterns of selected coping mechanisms employed by carers. A procedure of follow-up feedback will be planned to give perspectives on the participants' attitudes regarding any factors that lead to their capacity to adopt particular coping mechanisms that promote their well-being while caring for patients with AD. The categories will be deemed 'saturated' when no fresh ideas or concepts appear to be forming, and when no more negative examples are discovered that contradicted or undermined the suggested analytical framework; this will involve the use of coding reliability thematic analysis (Castleberry & Nolen, 2018).

Coding Paradigm

The initial phase in data analysis based on the grounded theoretical model is open or line-by-line coding. According to Sekiwu (2020), open coding entails breaking down data so that it can be inspected, contrasted, conceived, and classified. As open coding starts, a preliminary impression will be undertaken from the acquired data for it to be categorized or labeled. Data coding will be utilized to discover any conceptual recurrences and commonalities in the patterns of answers from participant experiences of issues encountered and course of action taken. As parallels in the emergent notions will be discovered, they will be classified. As the study's emphasis will be restricted throughout the first coding phase, it will be possible to pick which route to go in the subsequent data collecting to facilitate continued analysis. During axial coding, data will be reassembled in new ways so that links can be found between established categories. Finally, as the process of selective coding begins, fundamental categories will be chosen and connected to additional categories. Selective coding will enable the development of a more detailed narrative, allowing a framework for the study to arise from the thoughts and viewpoints expressed by the research participants.

Issues of Trustworthiness

Credibility refers to the precision with which collected data represents the numerous realities of the subject matter under study (Groenland & Dana, 2020). Transferability refers to the degree to which the results of a research can be transferred to other settings with other respondents (Groenland & Dana, 2020). On the other hand, dependability refers to the level of reliability and consistency of a research findings and

how the research procedures are documented, allowing others outside the research to audit and critique the research process.

One strategy to be used in ensuring credibility in the study will include triangulation of data, which is data collection from multiple sources aiding in shading light on emerging themes. Member checking is the other strategy to be used in ensuring credibility; this will involve summarizing what will be said after every interview while soliciting participants' views regarding the interpretation; this will take approximately one week to complete and will help in reviewing emerging themes (Groenland & Dana, 2020). In ensuring transferability, I will provide a detailed account of the research focus, the role of the researcher, and the basis of participants' selection as well as the context of data collection. Moreover, data collection and analysis strategies will be outlined in detail to provide an accurate and clear approach to the methods to be employed. In ensuring dependability, the study will have an audit of data by an external independent body to confirm that the appropriate methodology is correctly followed. Additionally, in ensuring confirmability, the audit trial will involve an experienced researcher confirming the study's findings.

Ethical Procedures

In conformance with ethical guidelines, Informed consent will be obtained from each participant prior to data collection. Before each interview, the goal of the study will be explained to respondents so that they are aware of the research intentions, and processes to be employed in the study. Respondents will be notified that they would willingly withdraw from the research at any time and with no repercussions. The

collected data will be stored electronically in a password protected folder for 5 years after which it will be destroyed using appropriate means. No other party will have access to the data other than the primary researcher, interested participants, and the dissertation committee: digital files will be stored in password-protected computer. Since the data collection will involve talking about sensitive issues, distressed participants will have their sessions rescheduled and repeated distress would lead to their disqualification. The participants will be reminded of their right to withdraw, and distressed participants will be provided with information regarding free or low-cost counseling. To minimize chances of research bias, the study will consider using multiple people in coding the data, have selected participants review the results, review finding with peer, and check alternative explanations.

Summary

This chapter explored the reason the study will choose a qualitative approach. The chapter went on to describe the specific qualitative approach that will be employed in the research study. Moreover, information regarding the data sources and considerations, as well as techniques of data collection and analysis are covered in the chapter. The chapter concluded with an explanation of how the study's trustworthiness and ethical considerations will be met through the study.

Chapter 4: Results

In this study, I investigated the fear experienced by adult-child caregivers caring for a parent with AD. In this chapter, I present the results of my study, providing insights into how caregivers assess their risk of inheriting AD and how they deal with their fear of acquiring the disease. The following research questions guided this investigation:

RQ1 How do adult-child caregivers of individuals with AD perceive their risk of inheriting AD?

RQ2: How do adult-child caregivers of individuals with AD who express a fear of developing Alzheimer's themselves manage their worry/fear of inheriting AD?

The arrangement of this chapter is designed to offer a full understanding of the results. The chapter begins with the setting, and contextual elements are next described, offering insight into personal or organizational situations that may have impacted participants' experiences and may have influenced the interpretation of research outcomes. Demographic information from surveys is explored to contextualize the results. The data gathering techniques used, including locations, frequencies, and duration, are specified to provide transparency into the process. I then discuss the complexities of data analysis, covering the processes used to progress from coded units to emergent themes and categories. Equally, cases that strayed from known trends are addressed.

My dedication to trustworthiness as crucial for the study's success, I detail the measures I used to assure credibility, transferability, dependability, and confirmability in the study results. Finally, the chapter concludes with a full examination of the findings

for each of the research questions. Direct quotes from transcripts and other pertinent data support the conclusions. Disputed situations are handled as needed to provide a complete picture of the findings.

Setting

The environment, human dynamics, and organizational settings that may have impacted the participants or their caregiving experiences at the time of the research are all considered setting and contextual elements in this study. Understanding such factors is critical for correctly understanding the study's findings. The United States was selected as the site for the study because of its diversified population and easy access to healthcare services. The specific qualities of the United States may have influenced the participants' caregiving experiences. The caregivers' stress levels and coping techniques may be influenced by the high expense of living in this location (Kate et al., 2013). Financial strains in a high-cost locale may raise stress, impacting general well-being.

In the context of AD care, the significance of organizational conditions is critical. The availability of support services, such as Alzheimer's support groups or in-home care programs, may have a substantial influence on adult-child caregivers' experiences. Changes in staff in local AD groups, such as Dignity Health Alzheimer's Assistance Group, might, for example, have impacted the resources and assistance accessible to caregivers. Budget cutbacks in healthcare organizations may also reduce the aid and resources available to caregivers, increasing their caring burden.

Individual caregivers' internal dynamics, in addition to environmental circumstances, play a crucial part in creating their caring experiences (Kuharic et al.,

2024). The caregiver's bond with the person who has AD is an important personal component. The degree of intimacy, emotional connection, and past family relationships may influence the caregiver's emotional reaction to the caring experience (Durán-Gómez et al., 2020). Participants' backgrounds, such as their health, work situation, and age, might also have a substantial impact on their caring stress and well-being.

Personal and organizational variables are dynamic and may have changed throughout the research period. Personal life dynamics, such as changes in marital status or work position, may have altered the participants' caregiving experiences (Zhu et al., 2024). Similarly, changes in local Alzheimer's support groups or government healthcare regulations throughout the research might have impacted the availability of services and assistance for caregivers.

The above elements must be included for a complete understanding of adult-child caregiver experiences in the setting of AD. When evaluating the study's findings, I had to consider individuals' particular circumstances and the shifting landscape of support services. My study provides comprehensive knowledge of the challenges experienced by caregivers as well as the coping techniques they use to improve their well-being while caring for people with AD.

Demographics

This section provides the demographics and participants' features that are relevant to the research. Twelve adult-child caregivers who are caring for parents with AD participated in the study. Such caregivers play an important role in their parents' lives and are critical in understanding the anxiety and coping methods associated with the

possibility of inheriting AD. Demographic information was gathered from participants via a survey.

The participants verified that they are adult children of individuals with AD; this was an important requirement for their participation in the research since it assured that they have firsthand experience with caring in the setting of AD. These participants would have begun on the difficult path of caring for their parents while dealing with the fear and anxiety of acquiring the condition themselves.

Participants' parents with AD ranged in age; this difference is significant because it may affect the severity of the illness, caregiving tasks, and the emotional effect on caregivers. The parental age range was between 55 and 90 years. It was evident that older parents need more specialized care, as their cognitive impairment was more advanced, resulting in higher stress and fear among caregivers.

Roughly 95% of the participants identified as female; this gender preponderance mirrors a wider trend in caring, in which women often serve as main caretakers for family members (see Arora et al., 2020). The gender-specific dynamic may have ramifications for the caring experience, particularly the emotional toll it may impose.

Approximately 13.45% of the participants reported having a disability; this is an important consideration since persons with impairments may have specific obstacles in caring for others and maintaining their health. Disabilities may impair caregivers' physical and emotional capacities, thereby exacerbating the stress and anxiety involved with caring (Palacio et al., 2020).

The marital status of the participants was varied, with the majority being married 63.33%. Other groups are single 11.67%, divorced 20.00%, widowed 1.67%, and other 3.33%. Since marital status may influence caring dynamics and support networks, it is an important demographic variable (Jones et al., 2019). For married caregivers, the participation and support of their spouses may be crucial, but single or divorced caregivers may face various obstacles.

The ages of participants varied, with the biggest share (40.83%) lying between the ages of 50 and 59. The age range of participants is significant since it influences their health, caregiving obligations, and coping techniques (Sit et al., 2020). Younger caregivers may have to combine caring with job and family duties, while older caregivers may be more concerned with the health consequences of their aging process.

Approximately 57.50% of participants were presently employed, while 42.50% were unemployed. Employment status is an important demographic feature because it affects the availability of time and resources for caring (Stanfors et al., 2019). Employed caregivers may face the challenge of managing a job and caring responsibilities, possibly leading to increased stress and emotional strain.

The household makeup of the participants varies, with diverse family configurations and living conditions. These dynamics may have had an impact on the availability of assistance and caregiving obligations. Participants may live with their spouses, children, or other family members, which might affect the allocation of caregiving chores and emotional support. The makeup of the family may also determine the degree of social connection and emotional reinforcement caregivers get.

Approximately 44.17% of individuals reported using outside caregiving services; this includes resources and support gained from outside sources to help with caring. The use of caregiver support is an important aspect since it represents the amount of external assistance in handling caring obligations; this help might take the form of professional caregivers, support groups, or respite care, and it is critical to recognize the resources available to caregivers to deal with the issues they experience (Liu et al., 2020).

The above demographic factors offer vital insights into the different conditions of the adult-child caregivers participating in the research. The demographics are critical for understanding the study's results and their implications for caregiver experiences in the setting of AD. It emphasizes the intricate interaction between caring, personal qualities, and environmental variables that impact caregivers' concern about inheriting AD and their coping mechanisms. The demographics stage the setting for a thorough examination of the participants' experiences and viewpoints.

Data Collection

The data-gathering procedure was broadly consistent with the strategy given in Chapter 3. However, based on the geographical dispersion of the participants and the sensitive nature of the study, videoconferencing was selected as the main technique for conducting interviews. I would have liked to have included in-person interviews, but videoconferencing guaranteed the comfort and accessibility of the participants. Equally, the population sample was decreased from the anticipated 12 participants; this was considered necessary based on the time constraint.

The differences in data collection were due to abpractical issues such as participant location and the sensitive nature of the study. I opted to conduct interviews using videoconferencing. This method provided the participants with increased accessibility and convenience. It also respected the delicate nature of the study, as many caregivers may have found traveling to an in-person interview financially and emotionally difficult. While this was a deviation from the original plan, it was a pragmatic move that valued the participants' well-being and comfort. I guaranteed that adult-child caregivers could participate more easily by tailoring the data-collecting procedure to the conditions, eventually adding to the quality and depth of the data acquired for the study.

A few unique conditions arose throughout the data-gathering process, which should be noted. Based on the nature of the research, three participants experienced difficulty when expressing their AD experiences and fear. In such circumstances, interviews were postponed providing participants with a break and a chance to process their feelings. In addition, the research supplied a phone number for participants to contact me if they needed support or debriefing; this precaution was taken to guarantee that participants' emotional well-being was upheld and that they were not left alone in times of hardship. Such atypical conditions highlight the study's sensitive and emotionally intense character. Caring for those with AD while also dealing with the fear of inheriting the disease may be draining for those involved. My responsibility was not only to gather data but also to preserve the well-being of the participants during the data-collecting process. As a consequence, handling any emotional issues that participants

could face during interviews was given great thought; this method intended to provide participants with a secure and supportive setting where they could freely discuss their views and experiences.

Data Analysis

In the realm of AD caregiving, understanding the emotional experiences, coping strategies, and support needs of adult child caregivers of parents diagnosed with the debilitating illness is paramount. To glean insights into such aspects, a qualitative approach involving interviews was undertaken. In this section, I explain the process used for data analysis, the emergence of specific codes, categories, and themes, and the consideration of discrepant cases in the inductive analysis.

Iterative qualitative data analysis entails progressing from raw data to discovering patterns, categories, and, finally, themes. In this study, I used an inductive technique, allowing the themes to arise spontaneously from the participants' narratives. The transcription of the interviews was the first step in gaining a full grasp of the data. After transcription, I initiated open coding; during this stage, data segments were divided into little components called codes that represented unique thoughts or ideas. The codes were not predetermined but were allowed to arise immediately from the remarks of the participants. I extensively evaluated each interview to construct a coding system, and open codes were given to pertinent extracts. For example, answers indicating fear of inheriting AD resulted in the development of the 'Fear of Inheriting AD' code.

I employed continual comparison, a method that involves comparing fresh data segments with previous codes (Morgan & Nica,2020), as the coding process advanced

this method proved useful in refining codes and developing the foundations of categories. The 'Coping Strategies' code, for example, arose as a result of participant responses indicating different coping techniques, such as indulging in hobbies or seeking social support. The next stage was to arrange the codes into bigger categories to contain similar codes as they were collected. I revised and condensed categories after the first classification. For example, the category 'Coping Strategies' had codes for emotional coping, social assistance, and therapeutic activities. Furthermore, the step required a thorough analysis of divergent examples to prevent neglecting unique discoveries. If a participant's response deviated considerably from the emerging pattern, it was considered a unique instance and examined for its contribution to the research. Finally, the most important categories were raised to the level of themes, which embodied the data's overall concepts. I thoroughly examined and revised the themes to ensure they appropriately reflected the experiences of the participants.

Table 1

Table 1 presents the key themes, categories, and corresponding quotes derived from interviews with adult-child caregivers regarding their fear of inheriting Alzheimer's disease (AD) and the coping strategies they employ to manage this fear.

Themes, Categories, and Quotes

Themes	Categories	Quotes
Fear of inheriting AD	Emotional burden	"I can't help but feel a deep sadness when I think about the possibility of getting Alzheimer's. It's heartbreaking."
	Genetic risk	"Knowing that Alzheimer's runs in my family makes me feel like a ticking time bomb. I can't escape the genetic risk."
	Constant worry	"My fear comes and goes. I think about it, but not a lot because I'm too busy."
	Impact on mental health	"The fear of inheriting Alzheimer's has taken a toll on my mental health. I often feel anxious and stressed."
	Impact on physical health	"The stress from the fear of inheriting Alzheimer's has caused physical symptoms. I've had trouble sleeping and digestive issues."
Coping strategies	Engaging in hobbies	"Engaging in my hobbies, like painting, helps me take my mind off the fear of Alzheimer's. It's therapeutic."
	Seeking social support	"Spending time with friends and family is my refuge. It helps me feel supported and less anxious."
	Alone time	"Taking time for myself, whether it's reading a book or just sitting in silence, is essential. It calms me."
	Spirituality and prayer	"Praying and attending church regularly give me hope and strength to face the fear of Alzheimer's."

Themes	Categories	Quotes
	Therapeutic activities	"Listening to soothing music, practicing yoga, and meditation have become part of my daily routine to cope."
Need for more support	Desire for respite care	"I wish I could get some respite care, even for a day, to recharge and address my own health."
	Information and resources	"More information about Alzheimer's, its risks, and prevention strategies would help me make informed decisions."
	Support networks	"Having a support network of friends and fellow caregivers who truly understand the challenges is invaluable."
	Family involvement	"I wish my family could better understand the exhausting nature of caregiving and offer more assistance."

Category 1.1: Emotional Burden: Most participants in this study expressed the emotional burden of fearing they might inherit AD. The fear itself was emotionally taxing, as one participant noted, "My fear is constant, and it takes my sleep away." The emotional weight of this fear loomed large, affecting caregivers' daily lives.

Category 1.2: Genetic Risk: An underlying theme was the genetic risk associated with AD, especially when there was a family history. One participant highlighted this concern by noting, "With both parents being diagnosed with it, yes, it scares me." The inheritance of the disease from parents was a prominent source of fear.

Category 2.1: Engaging in Hobbies: To cope with their fear of inheriting AD and emotional distress, participants note that they frequently engaged in hobbies; reading, listening to music, and engaging in outdoor activities were cited as effective strategies. One participant stated, "I read at night and take walks with my mom in her wheelchair."

Category 2.2: Seeking Social Support: Seeking support from friends and family was another prominent coping strategy that emerged. Engaging in conversations and sharing their experiences with others played a significant role in alleviating the caregivers' emotional burden. A participant noted, "My sister is a godsend. We talk nearly every day."

Category 2.3: Alone Time: Participants also valued alone time as a coping strategy. Taking time for self-care to most caregivers was as essential to maintain emotional well-being. For example, one participant noted, "I have set time for a meal out once a week," one participant described.

Category 2.4: Spirituality and Prayer: Spirituality and prayer was identified as a source of solace for some caregivers. Caregivers turned to faith to find strength in dealing with the fear of Alzheimer's, as was noted by one participant that, "I give my fear to Jesus Christ".

Category 2.5: Therapeutic Activities: Therapeutic activities, such as meditation and counseling, played a vital role in some participants' coping strategies. One participant noted, "antidepressants and local support group"; this demonstrates the significance of professional help.

Category 3.1: Desire for Respite Care: Several participants expressed the need for respite care to alleviate the constant caregiving burden. "If I had more resources and a better understanding of the genetic factors of AD," one participant emphasized.

Category 3.2: Information and Resources There was a call for more information and resources to assist caregivers; this included access to educational materials and

awareness programs. Participants believed that a better understanding of the disease would contribute to improved caregiving.

Category 3.3: Support Networks Establishing support networks for caregivers was deemed crucial. Participants acknowledged the importance of interacting with individuals who shared similar experiences; they sought more accessible support groups and platforms.

Category 3.4: Family Involvement The need for increased family involvement and assistance was emphasized, especially for those who felt overwhelmed by the caregiving role. Participants hoped for more collaboration and shared responsibilities.

The researcher thoroughly considered discrepant cases throughout the analysis procedure. While the majority of participants had similar experiences, others had distinct viewpoints. Discrepant situations were accounted for in the study by emphasizing participants' distinguishing traits, resulting in a well-rounded picture of the broader environment.

This study's data analysis method was inductive, starting with open coding and moving to discovering categories and themes. The emerging themes of 'Fear of Inheriting AD,' 'Coping Strategies,' and 'Need for More Support' summarized caregivers' emotional burdens, coping methods, and support needs. Various instances were combined to offer a complete picture of the diverse experiences of the group of adult child caregivers. Finally, the results will help to shape the creation of more effective support systems for caregivers of Alzheimer's patients.

Evidence of Trustworthiness

In qualitative research, maintaining trustworthiness is vital to establishing the reliability and validity of the results. In this study, the researcher applied many ways to strengthen the credibility, transferability, dependability, and confirmability of the research, as mentioned in Chapter 3.

Credibility refers to the extent to which research finding accurately represents the participants' experiences. To establish credibility, the researcher utilized prolonged engagement, member checking, peer debriefing, thick description, and negative case analysis. The researcher-maintained contact with the participants for a lengthy period; this way, she could create rapport with each participant, obtain a better knowledge of their experiences, and limit the likelihood of surface-level responses by doing repeated interviews. The researcher held member-checking meetings during which she discussed early results with the participants; this procedure allowed them to confirm, explain, or provide new information about their experiences. The member-checking sessions were beneficial in evaluating the accuracy of the interpretations. Equally, throughout the data analysis process, the researcher solicited comments from colleagues with qualitative research expertise; this outside viewpoint helped the researcher to confirm the responses and guarantee that she had all the alternate answers. To boost the credibility of the results, the researcher gave extensive explanations of the study setting and participants; this contained specific background information about the participants and a thorough explanation of the data-collecting procedure, contributing to a complete knowledge of the study context. Finally, the researcher aggressively sought and evaluated anomalous

instances, paying particular attention to individuals who had opposing perspectives or experiences, as mentioned in the Data Analysis section. The researcher confirmed that the conclusions are not skewed toward a single point of view by integrating most responses into the study.

Transferability refers to the extent to which the study's findings can be applied to similar contexts or populations. To enhance transferability, the researcher implemented strategies including purposeful sampling, detailed description, and context information. The researcher chose people with various experiences and backgrounds using purposeful sampling; this technique sought to elicit diverse viewpoints from adult children caring for parents with AD. By doing so, the researcher enhanced the possibility that the results would apply to a larger community of caregivers. The research also included extensive explanations of the participants' experiences, circumstances, and data-collecting procedures; these facts were included to provide readers with a thorough knowledge of the study background; this was further supported by the wide use of direct quotes from participants. In addition to characterizing the individuals, the researcher supplied information regarding caregiving settings and family ties so that readers can assess the applicability of the findings by considering the contextual information provided.

Dependability relates to the consistency and stability of the research process and findings over time. To establish dependability, the researcher implemented an audit trail, research reflexivity, and data saturation strategies. Throughout the study process, the researcher kept a detailed audit trail; this contained thorough documentation of data collecting, coding, and analysis techniques to guarantee the openness and traceability of

the study approach. The researcher also participated in reflective practices, constantly questioning assumptions, prejudices, and preconceptions. Based on the researcher's self-awareness, she made the required improvements to data gathering and analysis methods, assuring consistency in the study. Finally, during the data-gathering phase, the researcher checked data saturation; she kept doing interviews until no new themes or insights arose, indicating that she had thoroughly probed the individuals' experiences.

Confirmability refers to the neutrality and objectivity of the research findings. In the study, the researcher employed different strategies to enhance confirmability, these included research positionality, consistency in data analysis, and external review. The researcher freely recognized her viewpoints and opinions on the study issue; she hoped that by being open about her origins, readers could assess how her subjectivity may have impacted the study process and conclusions. The researcher also used a consistent and systematic approach to data analysis. She recorded the whole coding and categorizing procedure, as discussed in the Data Analysis section, to ensure that the conclusions were obtained from the data rather than from researcher bias. Finally, the researcher enlisted the help of external reviewers and qualitative research professionals to examine the methodology and results critically; this external viewpoint aided in identifying and mitigating possible biases, as well as contributing to the research's neutrality.

This study used different strategies to enhance the trustworthiness of the research. Through prolonged engagement, member checking, peer debriefing, thick descriptions, and negative case analysis, the researcher established credibility. Purposeful sampling, rich descriptions, and contextual information supported transferability. Dependability was

ensured through an audit trail, researcher reflexivity, and data saturation monitoring, while confirmability was strengthened through researcher positionality, consistency in data analysis, and external review. These strategies collectively contribute to the rigor and reliability of our qualitative research findings, promoting confidence in their validity and applicability.

Results

Research Question 1**:** How do adult-child caregivers of individuals with AD perceive their risk of inheriting AD? seeks to explore the perceptions of adult-child caregivers of individuals with AD regarding their risk of inheriting the same condition. Understanding such perceptions is critical as it sheds light on the emotional, psychological, and practical challenges that such caregivers face.

The research question is of paramount significance for several reasons. First, AD is a complex and devastating condition that affects not only patients but also their families, especially adult-child caregivers. These caregivers frequently find themselves thrust into the job of caring for and supporting their loved ones, which may be emotionally and physically taxing. It is critical to understand how they view their own risk of inheriting the condition in order to create suitable support measures. Secondly, familial AD, which has a genetic component, can lead to a heightened sense of vulnerability among caregivers who may fear they could also be at risk (Culberson, 2023). Their perceptions of this risk can influence their decisions regarding healthcare, future planning, and even family dynamics.

Within the context of Research Question 1, the first subtheme that emerged relates to caregivers' awareness of the genetic factors associated with AD. Caregivers often expressed profound fear about the condition's genetic origin, as shown by the following quotation: "I know it runs in the family". "My grandmother had it, my father had it, and now my mom has it. It's hard not to worry about whether I'll get it too". Such remarks emphasize the significant influence of family history on caregivers' perception of their own risk. Subtheme 1.1 discusses the frequency of AD in families, the fear of hereditary transmission, and the necessity for genetic testing or counseling. The findings highlight the importance of this subtheme by demonstrating the considerable effect of family history on caregivers' risk perceptions.

Subtheme 1.2 investigates the impact of caregivers' contacts with healthcare experts and the information gained on their assessment of AD risk. Caregivers stated how medical consultations shaped their awareness and worries about their risk. One caregiver mentioned, "When I talked to the doctor, they explained the genetic component. That's when it really hit me that I should be concerned about this". The subtheme emphasizes the crucial role of healthcare providers in teaching caregivers about AD risk factors and the influence such knowledge may have on caregivers' perspectives. Subtheme 1.2 highlights the significance of good communication with healthcare practitioners, the influence of medical knowledge on caregivers' fear, and the function of genetic counseling in offering clarification.

Subtheme 1.3 explores the emotional toll of caring and how it influences caregivers' perceptions of their own risk. Caregivers often showed concern about the

emotional cost of AD caring, which impacted their risk assessment. One caregiver shared, "Seeing what my mom goes through is terrifying, and I can't help but think about my own future". The subtheme summarizes insights including emotional strain that caregivers experienced, the impact on their perceived risk, and the need for emotional support and counseling.

Subtheme 1.4 focuses on the social dimension of caregivers' risk perception. It explores how caregivers' family dynamics, peer interactions, and societal attitudes affect their perception of inheriting AD. Caregivers highlighted the role of discussions with family members and friends in shaping their outlook. The subtheme concludes by summarizing the key points discussed, which include the influence of social interactions, family discussions, and societal stigma on caregivers' risk perception.

Among the above subthemes, there were a few instances when caregivers did not seem to be too concerned about their risk despite a considerable family history of AD. Such is an interesting disparity that might be attributed to individual coping techniques or a lack of knowledge.

Research Question 2: How do adult-child caregivers of individuals with AD who express a fear of developing Alzheimer’s themselves manage their worry/fear of inheriting AD? addresses the strategies and mechanisms that adult-child caregivers of individuals with AD employ to manage their worry and fear of inheriting the condition. The question delves into the psychological and practical aspects of caregiving, highlighting caregivers' coping strategies and emotional management. Consequently, the question is of great relevance within the broader context of this study.

Understanding how caregivers deal with the fear of inheriting AD is critical for a number of reasons. First, caregivers bear a considerable emotional burden, and their ability to control this fear may have a big influence on their quality of life and ability to offer good care. Second, caregivers often act as role models for family members and friends who are concerned about their risk. By investigating how caregivers cope with their fears, the study gathers insights that might possibly be shared with others, adding to a larger knowledge of coping techniques for those at risk of the disease.

Subtheme 2.1 examines the role of knowledge and education in assisting caregivers in coping with the fear of passing on AD. Caregivers emphasized the importance of having access to precise and trustworthy information in easing their concerns**.** For example, one caregiver stated, "Understanding the science behind Alzheimer's and the latest research has lessened my fear." The subtheme summarizes the key points within the context of Research Question 2, such as the importance of knowledge, the impact of information on caregivers' fears, and the need for accessible educational resources.

Subtheme 2.2 investigates the support networks and social interactions on which caregivers depend to alleviate their fears. Caregivers often mentioned the need to interact with support groups, therapists, and other caregivers who are dealing with similar issues. A caregiver mentioned, "Talking to others who are going through the same thing makes me feel less alone in this". The subtheme offers a comprehensive picture of how social connections and support systems play a crucial role in coping with anxiety and stress

associated with inheriting AD. The major insight includes the relevance of sharing experiences, the impact of peer support, and the significance of sharing experiences.

Subtheme 2.3 investigates the influence of self-care and stress management on caregivers' abilities to handle their fear of inheriting AD. Caregivers typically mentioned participating in self-care methods such as exercise, mindfulness, and meditation as coping mechanisms. A caregiver shared, "Taking time for myself helps me stay grounded". The subtheme outlines the essential aspects linked to self-care, stress management, and its influence on fear reduction, highlighting the significance of caregivers looking after their well-being.

Subtheme 2.4 looks on how family dynamics and communication affect caregivers' abilities to handle their fears. Caregivers spoke about how open and supportive communication within the family could assist with alleviating fear. A caregiver mentioned, "We sit down and discuss our worries openly. It's a relief to know we're all on the same page". The subtheme summarizes significant insights regarding the importance of family discussions, honest communication, and the impact of familial support structures in managing fear and worry.

There was a case in the data when caregivers did not seem to adequately manage their fear of inheriting AD. Understanding these non-confirming examples is critical for recognizing the range of caregiver experiences and may provide insights into areas that need extra assistance or intervention. Possible interpretations for such cases need further investigation. Such instances may challenge the predominant trends and offer valuable perspectives on the difficulties caregivers face in managing their fear of inheriting AD.

This part compares the important findings from Research Questions 1 and 2. The two research questions investigated adult-child caregivers of individuals with AD's opinions of their risk of inheriting the disease (Research Question 1), and how they manage their anxiety and fear of inheriting AD (Research Question 2). Although the research questions cover different elements of caregivers' experiences, commonalities and variations arose, offering insight on the varied nature of the caregiver role.

Research Question 1 revealed that caregivers often sought knowledge and information to understand their risk of inheriting AD, offered a feeling of empowerment and control. As a result, caregivers sought ways of dealing with their fears. Research Question 2 emphasized the importance of information, indicating that caregivers used education to lessen their fear. Furthermore, Research Question 2 revealed the critical significance of social connections and peer support in reducing anxiety, which was consistent with the findings of Research Question 1 However, while Research Question 1 primarily focused on the role of knowledge and education in caregivers' perceptions, Research Question 2 delved into the emotional and psychological aspects, such as self-care practices and open family communication. Such strategies, as revealed in Research Question 2, aided caregivers in managing their fear.

Summary

In summary, the findings from the two research questions highlight the complex interplay between knowledge, social support, and emotional well-being in the lives of adult-child caregivers of Alzheimer's patients. This research emphasizes the complexities of caring in the setting of AD. It highlights not only the necessity of knowledge and

information but also the critical function of social support and emotional well-being in the lives of caregivers. Recognizing and resolving such issues may result in more complete and successful assistance for caregivers and, by extension, those living with AD. After thoroughly examining the experiences of adult-child caregivers of persons with AD and the significant insights garnered from our study this study will proceed to Chapter 5: Interpretation of the Findings. In the chapter, the study will go further into the ramifications of the research and present a nuanced interpretation of the findings. By doing so, the researcher will provide a more comprehensive understanding of the importance of the research finding, both within the research framework and in the larger context of AD care. The researcher hopes that by providing this perspective, she might add to the continuing discussion about caring for AD patients and its diverse effects on caregivers.

Chapter 5: Discussion, Conclusions, and Recommendations

In this chapter, I discuss the interpretation of findings, providing a complete analysis that sheds light on the study's larger ramifications. The goal of this study, which was to investigate the views and coping techniques of adult-child caregivers of people with AD, has been reviewed, with a fresh emphasis on extracting meaning from the extensive dataset obtained throughout the research. The study results are a collection of viewpoints and coping techniques from adult-child caregivers who care for their parent with AD. Each coded unit and thematic emergence helped provide a comprehensive picture of the challenges, resilience, and coping mechanisms associated with Alzheimer's caregiving.

The major purpose of this research was to discover experiences among adult-child caregivers navigating the challenges of AD (Sharif et al., 2020); thus, knowing their perspectives is critical for designing support systems and solutions. Through this study, I sought to capture participants' experiences to gather information on the effect of caring for those with Alzheimer's.

The key findings that emerged from my data analysis is embedded within the narrative. The caregivers' narratives revealed profound insights into their fears of inheriting Alzheimer's, their diverse coping strategies, and the need for more support. The findings are not isolated revelations but connect with a broader context, echoing and sometimes challenging existing literature. In this interpretive exploration, the summary of key findings provides insights to the themes that define caregivers' experiences in the context of AD.

Caregivers' awareness of Alzheimer's genetic factors revealed significant fear rooted in family history (Subtheme 1.1). Their apprehension highlighted concerns about hereditary transmission, fostering the necessity for genetic testing. Healthcare consultations (Subtheme 1.2) profoundly shaped their risk perceptions, emphasizing the role of healthcare providers in imparting knowledge. Emotional strain (Subtheme 1.3) from caregiving amplified their risk awareness, underscoring the need for emotional support. Subtheme 1.4 emphasized how social interactions and societal stigma affected caregivers' outlook. These findings elucidate the profound impact of family, healthcare interactions, emotional strain, and social dynamics on caregivers' perceptions of AD risk.

Interpretation of the Findings

This section marks the transition from presenting raw data to a nuanced understanding of the study's significance. The study, crafted to explore the multifaceted experiences of adult-child caregivers of individuals with AD, is reintroduced to illuminate the broader implications derived from the gathered data. By revisiting the study's purpose, I present meaningful insights from the narratives provided by caregivers.

The key findings encapsulate the caregivers' fears, coping strategies, and their articulated need for enhanced support. Such findings, as presented in Chapter 4, are not isolated views but interconnected components of caregiver experiences. The interpretation process is underscored as essential for situating findings within the broader context of existing literature and theoretical frameworks. By contextualizing the findings, I contribute not only to the field of Alzheimer's caregiving but also to the larger discourse on health, resilience, and support systems.

The congruence reinforces the universality of some parts of the caregiving experience, stressing emotional complexities as a fundamental component in the narratives of those caring for people with AD. However, the comparative analysis revealed variations, providing insights into the current unique cohort's peculiarities. Such contrasts highlight the subtle differences in participants' caring experiences, highlighting the distinguishing characteristics that set them apart in the larger landscape of Alzheimer's caregiving research (see Martin et al., 2020; Teixeira et al., 2019). My study contributes significantly to the current conversation on caring by methodically uncovering such consistency and discrepancies.

The emotional pressures shown in the findings are consistent with previous research, confirming the recurring theme of caregivers bearing an emotional burden across several studies (see Martin et al.,2020). Anxiousness and fear reoccur in numerous caregiving narratives, suggesting a similar emotional landscape traveled by caregivers faced with the challenges offered by AD (Mruck & Mey, 2019). Furthermore, the research provides new insights into the coping processes used by caregivers, shedding light on the many tactics that include indulging in hobbies, seeking social support, isolation, spirituality, and therapeutic activities.

While reviewing the literature, the research allowed me to identify similar narratives and the uniqueness of my participants' experiences. This detailed comparative study broadens the current knowledge of Alzheimer's caring by recognizing similarities and distinctive characteristics, resulting in a more holistic and refined grasp of the numerous components of the caregiving journey.

In summary, this thorough review of the literature not only affirms the emotional foundation of Alzheimer's caregiving but also reveals nuanced variances among caregiver narratives. The consistency with past studies confirms the emotional pressures caregivers face, stressing the recurring theme of carrying a significant emotional burden (Rosa et al. 2020; Zhang et al., 2019). The recurring themes of fear and worry in many caregiver experiences highlight a shared emotional landscape, supporting the universal issues faced by those navigating Alzheimer's caregiving. At the same time, the study serves as a torchbearer, revealing the uniqueness of the current cohort's experiences. Through the study results, I identified varied strategies of coping mechanisms, ranging from indulging in hobbies to seeking spiritual solace (see Atoyebi, 2022; Pillemer et al., 2018; Smith, 2019). The rigorous comparison analysis confirms known discoveries and carves out a distinct place for the caregivers in this study, adding a richer, more nuanced understanding of the various facets of Alzheimer's caregiving to the greater scholarly discussion.

My study provides new insights into the current body of knowledge. I presented caregivers' voices by offering a detailed and granular analysis of their fears, coping techniques, and complex support requirements. It goes beyond the traditional bounds of caring research, providing a more comprehensive knowledge of the numerous characteristics inherent in the caregiver experience.

The transactional model of stress and coping (Lazarus & Folkman, 1984, as cited in Nezlek, 2008) provided the theoretical foundation for my study, allowing the complex interplay between caregivers and the various challenges AD offers to be identified. The model acted as a conceptual framework, directing the current investigation of caregiving as a dynamic, transactional process marked by the continual interaction of stressors and coping techniques (Smith, 2013).

According to Lazarus and Folkman's (1984) concept, individuals engage in a cognitive assessment of stresses, and this appraisal influences their subsequent coping behaviors. Caregivers in the study face stressors such as the fear of inheriting AD, and their subjective assessment of these stressors impacts the coping techniques they apply. The model's emphasis on the personalized nature of stress responses connects strongly with the unique problems of caregiving. Furthermore, the transactional model emphasizes the bidirectional character of the caregiver-care-receiver interaction, emphasizing that the caregiver's assessment of stressors is dynamic and changes over time (Falzarano & Siedlecki, 2020). The dynamic viewpoint is consistent with the developing nature of Alzheimer's caregiving, in which challenges and coping techniques are fluid and responsive to the disease's changing terrain.

I used Lazarus and Folkman's transactional model to investigate the varied experiences of caregivers. It was possible to get a greater knowledge of how caregivers negotiate the complicated terrain of Alzheimer's caregiving by accepting the model's key principles of cognitive appraisal and coping as dynamic processes, providing vital insights into the subjective and changeable character of their experiences.

The findings aligned with the expectations made by the transactional model of stress and coping. Caregivers described emotional load coincides with the model's core concept, emphasizing the subjective and customized assessment of stressors. The accounts of the caregivers depicted the dynamic process of cognitive evaluation, in which the fear of inheriting AD becomes a personal and emotionally charged stressor.

The coping techniques used by caregivers, as discovered in the study, are a clear parallel to the transactional model's notion that people use various coping mechanisms to deal with the complexities of stress (see Rosa et al., 2020). The caregivers' repertoire of coping techniques, including hobbies and seeking social support, reinforces the model's claim that coping is a complex and adaptive process (McAuliffe et al., 2020). The alignment strengthens the model's robustness in capturing caregivers' various techniques to address the emotional issues associated with Alzheimer's caregiving.

Despite the expected alignment, the research revealed several surprises that add to the narrative. The multifarious significance of spirituality and prayer as coping mechanisms added a complication not expressly stated in the original concept; this unanticipated component implies that caregivers' coping methods extend beyond the model's basic framework, emphasizing the need for a more nuanced understanding of how individuals negotiate the emotional terrain of caregiving. In that regard, the study contributes to a more comprehensive understanding of the stress and coping dynamics inherent in Alzheimer's caregiving by providing insights into caregivers varied and sometimes unexpected coping mechanisms.

In line with the transactional model of stress and coping, my research connects with the broader conceptual framework based on caregivers' holistic well-being. The conceptual framework, which is based on the biopsychosocial model, a theoretical approach that contends health outcomes are influenced by biological, psychological, and social variables, provided a comprehensive lens through which to examine the various experiences of caregivers (Saxena et al., 2022). This concept shows caregiving as an intricate interplay of numerous factors that influence the caregiver's overall well-being rather than as a collection of discrete stresses and coping techniques.

The motifs discovered in the study are inextricably linked to the biopsychosocial model's tenets. Caregivers' emotional load represents the psychological dimension, demonstrating the deep influence of caregiving on their mental and emotional states (Pristavec, 2018). Simultaneously, the observed coping techniques, ranging from hobby participation to seeking social support, incorporate social and psychological features, underlining the interdependence of individual coping mechanisms and broader social support networks.

Furthermore, the conceptual framework indicated caring as a dynamic and comprehensive experience echoes the biopsychosocial model's hypothesized interaction of biological, psychological, and social components (Saxena et al., 2022). Caregivers' emotional toll is not considered in isolation but as a symptom of the intricate interaction of numerous factors contributing to their total well-being (Cai et al., 2021).

Through the conceptual lens, I linked the complexities of Alzheimer's caregiving and a broader knowledge of health and well-being. The findings contribute to a richer

conceptualization of the caregiver experience by recognizing the interconnections between biological, psychological, and social elements, going beyond singular stressors, and coping mechanisms to embrace the holistic complexity inherent in the caregiving journey.

This study contributes to the transactional model of stress and coping by elucidating complex features of the caring experience. While the model depicts the dynamic interaction between stresses and coping strategies (Sousa & Veronese, 2020), discovering spirituality as a significant coping mechanism broadens the model's scope. Spirituality, deeply woven within caregivers' coping repertoire, emerged as a critical component influencing their assessment of stresses, bringing a dimension not expressly addressed in the original model. Furthermore, the findings contribute significantly to the broader conceptual framework based on the biopsychosocial model. The complex examination of emotional burden and coping techniques is consistent with the model's key premises, expanding our understanding of the linked biological, psychological, and social elements influencing caregivers' well-being (Harris, 2009). Incorporating the findings refines and expands theoretical and conceptual frameworks, resulting in a more thorough and holistic understanding of the complex interplay between caregivers and the challenges posed by AD.

Within the framework of Lazarus and Folkman's transactional model, I identified connections between caregivers and the challenges provided by Alzheimer's. The findings confirmed the model's relevance to the complicated caregiver experience by identifying emotional strain and coping methods that align with theoretical assumptions.

On the other hand, the unanticipated appearance of spirituality as a crucial coping technique adds complexity to the understanding, implying that the caring journey includes components not fully encompassed by the original model.

Limitations of the Study

Ensuring the credibility of qualitative research is an ongoing challenge, and despite the rigorous procedures used in the current work, certain limitations must be acknowledged. Despite the researcher's best efforts, credibility, or the amount to which the findings correctly reflect the participants' experiences, they faced inherent challenges. For starters, the dynamic nature of caregiving experiences makes it impossible to capture a static representation. Caregivers' opinions may have changed over time, impacted by the advancement of AD in their loved ones or changes in their circumstances. While longer engagement and member-checking sessions were held, the study's temporal aspect limited the depth of insight acquired over an extended period.

Furthermore, the study's narrow focus on a demographic of adult-child caregivers of Alzheimer's patients may restrict the findings' applicability to larger caregiving communities. Since each caregiving scenario is unique and influenced by characteristics such as cultural background, socioeconomic level, and disease severity, the findings may not be universally applicable.

Despite the efforts to improve dependability through standardized data analysis methodologies and peer debriefing, the interpretative nature of qualitative research involves inherent subjectivity (Stahl & King, 2020). Despite the efforts to maintain

reflexivity and minimize preconceptions, the researcher's opinions and prejudices may have influenced the interpretation of data.

Due to the emotive nature of the topic, ensuring that the findings are founded in the facts rather than the researchers' predispositions presented challenges. The other challenge was the possibility of accidentally influencing findings to match existing conceptions or expectations inherent in qualitative research on emotional charges, thus prompting ongoing reflection on the researchers' role in shaping the narrative.

Moreover, while held in check through reflexivity was ensured, the researchers' emotional involvement added another degree of complication. Emotional engagement can be a double-edged sword, increasing understanding of individuals' experiences while clouding judgment. Balancing empathy with analytical rigor is a constant problem in qualitative research.

Despite the limitations, this study adds to understanding caregivers' experiences in the context of AD. Acknowledging these limitations emphasizes the importance of cautious interpretation and application of the findings. Future research efforts can expand on the current findings, developing approaches to solve these constraints and significantly enriching the common knowledge on Alzheimer's caregiving experiences.

Recommendations

This study's analysis of Alzheimer's caregiving uncovers a complicated web of experiences, pointing to future research routes that can greatly contribute to understanding caregiving dynamics. A longitudinal assessment of caregivers' experiences is important for future research. A long-term investigation could provide deep insights

into the dynamic nature of caregiving. Understanding how views, coping strategies, and support requirements change as the disease develops would provide a more complete picture of the caring journey. A longitudinal study would capture the intricacies of caregivers' experiences while addressing changing problems and adaptive solutions over time.

Another intriguing area for future investigation is cultural factors. Cultural variables significantly impact people's views, coping techniques, and support preferences. A cross-cultural investigation could reveal whether caregiving experiences are universal or culturally distinct. Such studies would not only improve the current understanding of the global effect of AD. However, they would also pave the way for culturally tailored interventions that meet the requirements of varied caregivers.

The function of technology in assisting caregivers is an important subject for research. Understanding the influence of technological treatments on caregiver well-being is becoming increasingly important as technology is increasingly integrated into healthcare. Such a study might examine the effectiveness of Apps, online support groups, or virtual respite care in reducing caregiver load. Such an investigation is especially significant in light of a rapidly digitizing healthcare scene.

Examining caregiver experiences at various stages of the caring trajectory provides another option for fruitful investigation. While such a study gives a picture of caregiver experiences, a more in-depth examination of the particular problems and needs at each stage, for example, early diagnosis, intermediate stages, and probable end-of-life care scenarios, can generate targeted treatments tailored to each stage.

Furthermore, future research must incorporate the opinions of healthcare professionals and policymakers; understanding the ordeals they perceive in assisting caregivers and identifying systemic barriers to effective caregiving can provide a more complete picture of the caregiving landscape. Such study direction can provide valuable insights that can be used to create policy suggestions, ultimately improving overall caregiver support structures.

In summary, the suggested study avenues highlight the dynamic and complex nature of Alzheimer's caregiving experiences. Researchers can contribute to a more nuanced knowledge of caregivers' needs, inform the development of focused interventions, and advocate for policies that assist caregivers throughout their journey by diving into the identified areas.

This study's consequences are significant, providing actionable insights for healthcare professionals, support organizations, and policymakers involved in Alzheimer's care support. Adopting a holistic and tailored approach to caregiver support is a top recommendation for healthcare practitioners. It is critical to recognize the unique nature of each caregiving circumstance. Interventions tailored to specific needs and preferences can considerably improve the effectiveness of support programs; this suggests a move away from general techniques and toward tailored strategies that recognize the variety of issues caregivers confront.

Spirituality's designation as a coping mechanism pushes for a broader viewpoint on caring support. Healthcare experts should look into several ways to help. It is critical to incorporate spiritual care into interventions, such as providing access to chaplaincy

services or promoting discussions about the significance of faith in coping. This addition addresses a previously unnoticed aspect of caregiver demands, providing a more holistic support system.

The findings highlight the significance of early intervention and ongoing support throughout the caregiving journey. From the beginning of caregiving, programs that provide education, coping techniques, and respite care can give caregivers the tools they need to handle the obstacles that may develop. This proactive approach acknowledges caregiving as a dynamic activity that necessitates changing techniques and resources.

Support groups are critical in linking caregivers with resources and developing a feeling of community. According to the findings, such organizations should broaden their assistance services. Aside from information, channels for social connection, emotional expression, and spiritual support should be included. Creating a complete support network addresses caregivers' various needs and fosters a more holistic caregiving experience.

Policymakers are encouraged to use the study's findings to advocate for comprehensive caregiver assistance policies. Priority should be given to raising understanding of caregivers' diverse requirements; this includes advocating for additional financing for support programs and incentives for healthcare institutions to develop caregiver-friendly procedures. Policymakers have the power to create an atmosphere that not only acknowledges but also actively supports caregivers.

In summary, the findings of this study underline the importance of a diverse and personalized approach to Alzheimer's caring assistance. Bridging identified research gaps

and implementing personalized interventions necessitates collaborative efforts from researchers, healthcare professionals, support organizations, and policymakers. By implementing the recommendations, the field will be able to dramatically improve the well-being of Alzheimer's caregivers while also contributing to a greater public understanding of caregiving as an essential component of dementia care.

Implications

At the core of positive social change emanating from this study is the empowerment of individual caregivers. The nuanced understanding garnered through this research serves as a beacon, illuminating caregivers' diverse needs and experiences. Armed with this comprehensive insight, caregivers are poised to traverse the intricate landscape of Alzheimer's caregiving with improved well-being and a heightened sense of agency. The shift is transformative, positioning caregivers not merely as support recipients but as active agents navigating the challenges of caregiving with newfound clarity.

The study's implications ripple through familial realms, offering avenues for enhanced family dynamics and relationships. The personalized approach advocated for in caregiving support becomes a catalyst for fostering unity within families grappling with Alzheimer's challenges. Familial bonds strengthen as communication improves, coping strategies are shared, and a deeper understanding of each other's experiences unfolds. This strengthens the fabric of family dynamics, supports the caregiver, and creates a network of resilience that can withstand the challenges inherent in Alzheimer's caregiving.

On a societal level, the study accentuates the integral role of caregivers within the broader healthcare landscape. The increased awareness of the multifaceted nature of caregiving, propelled by this research, can catalyze policy changes. These changes advocate for enhanced resources and support structures, recognizing caregivers' indispensable role in the well-being of individuals affected by Alzheimer's. The societal perception of caregivers undergoes a transformative shift, evolving to appreciate their invaluable contributions. This recognition extends beyond individual caregiving situations, influencing societal attitudes towards caregiving.

The positive social change catalyzed by this study transcends individual, familial, and societal dimensions. Empowering individual caregivers with a nuanced understanding of their experiences creates a ripple effect, fostering stronger familial bonds and reshaping societal perceptions. The study's legacy lies in its potential to instigate a holistic shift in the Alzheimer's caregiving paradigm, recognizing caregivers not just as silent heroes but as dynamic agents of change within the intricate tapestry of healthcare and societal well-being.

The methodological underpinnings of this study resonate with significance in the qualitative research domain. The in-depth exploration of caregivers' experiences, facilitated by extensive interviews and meticulous thematic analysis, stands as a testament to the richness and depth achievable through qualitative methodologies. The methodological journey outlined in this study serves as a guidepost for researchers embarking on similar inquiries, offering insights into strategies that enhance the credibility, transferability, and dependability of qualitative research endeavors. The

emphasis on prolonged engagement, member checking, peer debriefing, thick descriptions, and negative case analysis provides a robust methodological scaffold, elevating the quality and rigor of qualitative studies exploring nuanced phenomena.

Within the theoretical realm, this study casts profound implications on the Transactional Model of Stress and Coping. By unraveling the intricate dimensions of caregiving experiences, such as the unexplored role of spirituality as a coping mechanism, this research extends the boundaries of the theoretical framework. This study's revelations enrich the transactional model, which traditionally focused on stress appraisal and coping responses. The theoretical implications transcend the specific context of Alzheimer's caregiving, hinting at the model's adaptability and relevance in comprehending the diverse responses of individuals facing various challenges. This nuanced understanding of caregiving experiences contributes to the ongoing evolution and refinement of stress and coping theories.

Empirically, this study elevates the granularity of the existing body of knowledge on Alzheimer's caregiving. The research provides a nuanced account of the caregiving landscape by identifying specific themes, coping strategies, and support needs. This empirical depth contributes to the comprehensive understanding of caregivers' experiences and serves as a foundation for future investigations. Researchers can leverage these empirical insights as a springboard for exploring related nuances or delving into specific aspects that warrant further investigation. The study's empirical contributions, encapsulated in a rich synthesis table, present a valuable resource for researchers seeking to build upon or validate these findings in diverse caregiving contexts. As such, this

research is not only an empirical contribution but also a catalyst for future empirical inquiries into the multifaceted domain of Alzheimer's caregiving.

The practical recommendations derived from this study resonate as pivotal guidelines for shaping caregiver support programs, interventions, and policies. Healthcare professionals at the frontline of caregiving support are encouraged to adopt a personalized and holistic approach. Recognizing and addressing each caregiver's unique needs becomes paramount in effectively tailoring interventions. Integrating spirituality as a coping mechanism, a salient revelation from this study, should be considered a vital component in the available support strategies. Healthcare professionals are urged to move beyond standardized approaches, embracing a nuanced understanding of caregivers' diverse coping mechanisms.

Support organizations, which serve as vital links between caregivers and resources, should respond to the urge to diversify their offerings. Such organizations must widen their scope to include various facets of caregiver requirements and disseminate informational resources. Support programs should include avenues for social connection, emotional expression, and spiritual support. Support groups can address caregivers' holistic well-being more effectively by acknowledging the complex nature of caring experiences.

Policymakers have a critical role in turning research findings into meaningful policies. The study's conclusions urge policymakers to use the research's detailed understanding to advocate for comprehensive caregiver support programs. Such an advocacy involves a focus on greater financing for programs that serve the multiple needs

of caregivers. Policymakers can build a strong support infrastructure by promoting legislation recognizing and supporting the various facets of caregiving.

In summary, the findings of this study extend beyond academic discourse, promoting beneficial societal change at multiple levels. The study recommends a holistic, individualized, and nuanced approach to Alzheimer's caregiving, from individual caregivers dealing with the problems of the disease to families navigating these intricacies and the broader societal landscape. The guidelines serve as a road map for practitioners, support organizations, and legislators to improve the well-being of Alzheimer's caregivers while also contributing to a greater societal understanding of caregiving as an essential component of dementia care.

Conclusion

This study has revealed significant insights that resound throughout human experiences, familial relationships, and social paradigms by traversing the multifaceted landscape of Alzheimer's caregiving. The caregiver's journey rises into the light, intricately braided with emotional loads, coping mechanisms, and a strong need for comprehensive support, which is often buried in the shadows of the disease's problems.

The recognition of the multidimensional nature of Alzheimer's caregiving is at the center of this investigation. Caregivers whose accounts have been masterfully weaved into the fabric of this study struggle with emotional burdens, seek various coping techniques, and issue a resounding request for help reflecting their lives' complexities. The emotional cost, inextricably linked to the fear of inheriting Alzheimer's, becomes a palpable thread that connects such accounts. Coping techniques that emerge from the rich

tapestry of caregiver experiences go beyond traditional treatments. Caregivers use a range of coping techniques to overcome the challenges of AD, from hobbies and social support to the often-ignored facet of spirituality. Spirituality as a coping mechanism provides a complex layer to the understanding, underlining the significance of recognizing and implementing various coping techniques into assistance programs.

This study is a call to action for caregivers, healthcare professionals, support organizations, and policymakers rather than an academic undertaking. The methodological rigor in qualitative research and the theoretical insights provided using the Transactional Model of Stress and Coping contribute to the academic debate on Alzheimer's caregiving. Furthermore, the recommendations derived from these insights serve as a guidepost for those involved in the practical aspects of caregiver assistance, pointing the way toward a more holistic and customized approach.

The overarching message of this study is compassion. Alzheimer's caregiving, with its challenges and accomplishments, necessitates a compassionate response, one that understands each caregiver's unique journey and strives to provide individualized, comprehensive assistance. The positive social change anticipated from this study is found in the scholarly contributions and the potential to redefine the caregiving landscape, encouraging a future in which caregivers are genuinely seen, heard, and supported on their journey.

The findings have far-reaching ramifications. To better assist adult-child caregivers, educational tools and instructional programs that help them develop a deeper awareness of AD and its risk factors are critical. Furthermore, establishing and supporting

social support networks and therapy may reduce caregivers' emotional burdens and fears. By fulfilling such requirements, caregivers' well-being may increase, which may have an advantageous effect on the quality of care they offer to persons with AD.

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Appendix A: Adult-Child Caregiver Survey

Please complete questions including Question 1

1. I am an adult child of a parent who is currently diagnosed with AD disease.

   _____ Yes

   _____No

2. My parent who is diagnosed with Alzheimer's disease is _____ years of age.

3. Please identify your gender

   _____ Male

   _____ Female

   _____ Other

4. Do you have any disability?

   _____ Yes

   _____ No

5. Please identify your marital status

   _____Single

   _____Married

   _____Divorced

   _____Widowed

   _____Other

5. Please identify your age range

   _____Under 20

   _____20-29

_____30-39

_____40-49

_____50-59

_____60-69

_____70 or older

6. Are you currently employed?

_____Yes

_____No

7. Please identify your employment

_____full-time

_____part-time

_____student

_____other

8. Who else lives with you _____.

9. Are you currently using outside caregiver support?

_____Yes

_____No

10. do you have any fear of inheriting Alzheimer's disease?

11. How do you describe your fear of acquiring Alzheimer’s disease? (e.g. effect on mental and physical health),

12. What coping strategies do you consider to be effective in overcoming related stress and maintaining well-being? (e.g. hobbies, talking to people, or taking time by yourself).

13. What do you believe would help you use more effective coping strategies in caring for an individual with Alzheimer's disease?

Appendix B: Research and Interview Questions

Research Question 1: How do adult-child caregivers of individuals with Alzheimer's disease perceive their risk of inheriting Alzheimer's disease?

1) Do you think your relationship with the patient may lead to you developing Alzheimer's disease?
2) What would you say of your risk of developing AD?

Research Question 2: How do adult-child caregivers of individuals with Alzheimer's disease who express a fear of developing Alzheimer's themselves manage their worry/fear of inheriting Alzheimer's disease?

1) What coping strategies do you use in managing your fear of developing AD?
2) How do you understand strategies for coping with fear of developing Alzheimer's disease?