THE LIVED EXPERIENCES OF INDIVIDUALS IN EARLY-STAGE ALZHEIMER’S DISEASE: A QUALITATIVE STUDY

by

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DEDICATION

This research is dedicated to God and persons living with dementia—past, present, and future.

“When I stand before God at the end of my life, I would hope that I would not have a single bit of talent left, and could say, I used everything you gave me.”

- Erma Bombeck
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about this illness, and I want to continue helping others impacted by Alzheimer’s disease,
and educate the world about this complicated illness.

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in completing this journey.

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laughing till we cried, and telling me to just keep swimming- God planned your presence in my life.

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ABSTRACT

J. HEUER
THE LIVED EXPERIENCES OF INDIVIDUALS IN EARLY-STAGE ALZHEIMER’S DISEASE: A QUALITATIVE STUDY
Under the direction of W. DAVID LANE, Ph.D.

The number of individuals diagnosed and living with Alzheimer’s disease (AD) is increasing, and the disease is considered a public health crisis. To date, the majority of the research has focused on the medical aspects of the illness and caregiving. Researchers have noted a significant gap in the literature- the perspective of the person living with the disease. This qualitative study sought to fill this gap and understand the lived experiences of individuals living in early-stage Alzheimer’s disease. Semi-structured interviews were used to explore various aspects of living in the early-stage from their general experiences living with the illness, perceptions of family, friends, and others because of the disease, as well as encounters with the medical community. Interviews were coded using In-Vivo and Descriptive Coding. An external auditor was involved in building the trustworthiness of the research and findings by the researcher. The themes that surfaced from this study challenged previous research and the mentality that the medical community, caregivers, and society believe that individuals with the disease are inhuman, incapable, and unable to share their experiences with the disease. Participants in this study were not only able but willing to articulate their story of living in the early-stage of AD and encourage x
others to share their journey. Also, the individuals shared examples of how they are capable of caring for themselves and engage with life, find solutions to the challenges the disease brings, are concerned about the impact of the disease on others, and questioned the disconnect they experienced with the medical community. The findings from the study presented an opportunity for future research to explore additional coping skills, such as technology, for individuals in the early-stage to use to meet the daily challenges the disease presents. This research also highlighted the importance of the readiness of the counseling profession to work with individuals with dementia. This study also addressed the medical community’s need to acknowledge its disconnect in the social aspect of working with persons with the illness. This study ultimately answered the call for qualitative research that explored the lived experiences of individuals in early-stage Alzheimer’s disease.

Keywords: Alzheimer’s disease, early-stage, caregiving, research, qualitative
CHAPTER 1

INTRODUCTION TO THE STUDY

Imagine sitting at your desk at the job you have been working at for ten years. You start fumbling with the papers on your desk because at this moment you do not remember how to do your job. Imagine walking around your house you have lived in for 20 years, and suddenly you do not remember where the bathroom is. Imagine driving to the same grocery store you have shopped at for five years, and now you cannot remember how to get there. What is this story about? These are the lived experiences of nearly 50 million individuals worldwide who live with Alzheimer’s disease (AD) or related dementia (Alzheimer’s Disease International, 2017).

A man who attended a weekly support group for people in early-stage dementia shared,

We were all going along quite productively in our lives until we were confronted by memory loss, confusion, nervousness, loneliness, and isolation. It’s as if you’re reading a book and someone has torn the pages out. (Snyder, 2009, p. 3)

His words capture the essence of the symptoms someone may feel when he or she experiences a form of dementia—memory loss, confusion, nervousness—a feeling that something is missing (Snyder, 2009).

Dementia is not a normal part of aging or disease (World Health Organization, 2018). It is a category of symptoms related to a decline in memory, thinking, an behavior (DSM-V, 2013). Alzheimer’s disease (AD) is considered to be the most common form of
dementia (Alzheimer’s Association, 2018). Memory is typically the first (DSM-V, 2013). Alzheimer’s disease (AD) is considered to be the most common form of dementia (Alzheimer’s Association, 2018). Memory is typically the first area impacted by the AD (National Institute of Health, 2018). The illness is progressive, cannot be slowed or stopped, and there is no cure (Alzheimer’s Association, 2018).

In 2006, Douthit indicated that the rising rate of AD would increase the demands on the medical field, healthcare professionals, and resources to support individuals and caregivers. At that time, 26.6 million people worldwide were living with AD (Rocca et al., 2010). Douthit added that the number of aging baby boomers could significantly contribute to the number of individuals living with the disease. Since 2006, the number of persons with AD has nearly doubled (Alzheimer’s Disease International, 2017).

These statistics illustrate the global impact of the disease and how vital the voices are of individuals living with Alzheimer’s. However, Beuscher and Grando (2009) noted the reality of living with the illness has a track record of being lost in the research. Snyder (2009) stated, "the person diagnosed with it can live in the shadow- an autobiography that continues to unfold with no one writing the narrative" (p. 3). Understanding the reality of what life is like with AD would enhance the support, care, and dignity that persons with the disease should receive.

Background

In 1906, Alois Alzheimer discovered the illness (Alzheimer’s Association, 2018). Over the past 113 years, the perspective and meaning of Alzheimer’s have come from
medical research and the impact of the disease on caregivers (Roberts, McLaughlin, & Connell, 2014; Zeilig, 2013). The literature has focused heavily on the biomedical factors of the illness—biology, symptoms, treatment (Bahro, Silber & Sunderland, 1995; Cotrell & Schulz, 1993). Also, it is well documented within the literature the significant impact on a caregiver's social, mental, and physical well-being (MacQuarrie, 2008; Sorensen, Waldorff, & Waldemar, 2008). Keady and Nolan (1996) reinforced, “there has probably been more research into the needs of family members caring for a person with dementia than in any other fields” (p. 15).

During the 1990s foundational work in the medical field took place to understand the causes, symptoms, behaviors, and treatment of the disease (Shriver, 2009). During that time Cotrell and Schulz (1993) observed that there was one area not being considered by researchers—the perspective of individuals with AD. Bahro, Silber, and Sunderland (1995) also noticed the lack of phenomenological studies from the subjective experiences of persons with the illness. The authors presented a series of questions regarding the reality of persons living with AD, “What is their perception of the disease? In what ways are they all aware of it? What explanations do patients offer for their diminished abilities? What is their outlook for the future?” (p. 41).

One of the presenting issues found throughout the literature is the stigma of individuals with Alzheimer’s (Swaffer, 2014). Stigma with regards to persons with the disease equates to being negatively labeled (Swaffer, 2014), such as helpless (Dementia Action Alliance, 2016), objectified (Harris, 2002), and deemed unable to share their own
experiences due to a diagnosis of Alzheimer’s disease (Snyder, 2009). Often individuals with Alzheimer’s are “negatively labeled” and this impacts the desire to seek a diagnosis, resources, or participate in research (Swaffer, 2014). Ultimately, it appears this is one of the critical factors in the experiences of individuals in the early-stage of the disease to be missing from the research.

Statement of the Problem

Over twenty years later, researchers are still asking for first-hand accounts of individuals living with the illness (Beuscher & Grando, 2009). One of the issues is a fundamental bias that persons with AD are limited or unable to share their experiences due to the disease’s impact on memory (Robinson, Giorgi, & Eckman, 2012; Snyder, 2009). When a person receives a diagnosis, it is not uncommon that other people immediately view him/her as helpless and dependent (Dementia Action Alliance, 2016). According to Herskovits (1995), individuals with AD are frequently “objectified, and viewed as shells of their former selves” (Harris, 2002, p. xv). Unfortunately, an individual is often seen as the disease (Fazio, Seman, & Stansell, 1999), rather than a human experiencing an illness (Usita, Hyman, & Herman, 1998).

Consequently, the individuals who surround the person with the disease are the primary storytellers of living with Alzheimer’s (Chatterji, 1998). Without the voices of persons who experience the disease, the medical community and those who interact with a person with the illness will continue to be the primary narrators on living with AD.
More importantly, knowledge of the most significant needs of individuals with Alzheimer’s disease will remain unheard.

Another issue that exists in perpetuating the barrier of stigma is what Gitlin and Hodgson (2018) described as a cycle of despair that permeates throughout the medical profession. These authors described how this cycle impacts the welfare of individuals with the disease. The cycle places significance on a cure. With no cure to date, healthcare professionals feel there is nothing that can be done and communicates this with the individuals with AD. In turn, the persons with the disease receive no support or resources, which creates a sense of hopelessness surrounding the illness and ultimately reduces the quality of life of the individual living with Alzheimer’s.

**Purpose of the Study**

The mission of this research was to gain greater insight into the experiences, feelings, and preferences of persons living in the early-stage of AD. Considering the increasing rate of individuals with Alzheimer’s (Alzheimer’s Association, 2018) and the number of individuals who will interact with persons with the illness, the purpose of this study was to increase awareness of the personal journey of living in the early-stage of the disease. This research aimed to answer the call to conduct qualitative research and bridge the gap in the literature by performing in-depth semi-structured interviews with individuals who are living with AD.
Significance of the Study

By 2025 the number of individuals over the age of 65 with AD living in the United States is expected to rise from 5.5 million to 7.1 million (Alzheimer’s Association, 2018). According to the Alzheimer’s Association (2018), this number is expected to triple to 13.8 million by 2050. In light of these statistics, to know the first-hand accounts of living with the disease is significant for several reasons. First, Beuscher and Grando (2009) noted that this information would assist researchers and clinicians in finding interventions to improve the well-being and quality of life for people living with the disease. Second, highlighting the lived experiences of individuals with Alzheimer’s works towards increasing empathy and understanding from the communities that work with persons with AD. Third, and even more importantly, this research aids in decreasing the stigma of the illness and emphasizing the value and personhood of individuals living with Alzheimer’s (Beuscher & Grando, 2009).

Theoretical Framework

A qualitative methodology was used to explore the lived experiences of individuals in the early-stage of AD. Qualitative research examines a phenomenon where “researchers are interested in observing how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences” (Merriam, 2009, p. 13). Beuscher and Grando (2009) explained that qualitative research captures the purposeful meaning of life experiences of persons with the disease. Beard, Fetterman, Wu, and Bryant (2009) highlighted that the initial perceptions of AD originated from a
socio-cultural context, leaving out the narratives of individuals living with the disease. Furthermore, these researchers recommended that future “research should incorporate the perspectives of those most intimately affected by the condition” (p. S48).

Within the spectrum of qualitative research, phenomenological research seeks to understand the essence of an experience (Christensen & Brumfield, 2010). The participant, not the researcher, is considered the expert of his/her own experience (Christensen & Brumfield, 2010). A method of phenomenological research is Transcendental Phenomenology (TPh). TPh approaches a phenomenon without any preconceived notions allowing the true meaning of the experience to emerge naturally (Moustakas, 1994). TPh is the philosophy that was used to capture the perceptions of persons living with the illness in this study. With TPh the researcher sets aside his/her thoughts and opinions to solely focus on the participants’ experiences (Moustakas, 1994). The result is the capturing of the authentic meaning of living with Alzheimer’s.

Research Questions

The overarching question in this study: What are the lived experiences of individuals in early-stage Alzheimer’s disease? The following sub-questions guided this study:

1) What is your experience of living in early-stage Alzheimer’s disease?

2) How do you feel family, friends, and others perceive you because of the disease?
3) What is your experience with the medical community in being treated for Alzheimer’s disease?

Definition of Terms

Dementia. Dementia is a neurocognitive disorder that impacts an individual’s cognitive and functional abilities (DSM-V, 2013). The core feature of dementia is a decline in cognitive functioning which affects performance in one or more cognitive domains: “complex attention, executive function, learning, memory, language, perceptual-motor, or social cognition” (DSM-V, 2013, p. 602). The disorder interferes with an individual’s memory, thinking and behavior (Alzheimer’s Association, 2018). Dementia hinders the ability to perform activities of daily living, such as planning and organizing, completing familiar tasks, and decreased judgment in areas such as money (Alzheimer’s Association, 2018; DSM-V, 2013).

Alzheimer’s disease. Alzheimer’s disease (AD) is the most common form of dementia (Alzheimer’s Association, 2018). With AD there is a “decline in memory and learning” (DSM-V, 2013). The disease creates a continuous and progressive decline in cognition functioning (DSM-V, 2013). Symptoms of AD may include memory loss, difficulty with conversations and word finding, challenges with visual-spatial relationships, changes in personality and mood, and decreased judgment (Alzheimer’s Association, 2018; Alzheimer’s Disease International, 2017).

Early-stage Alzheimer’s disease. Early-stage Alzheimer’s disease, also known as a mild form of the disease, is the stage when a person functions independently but may
experience difficulty in remembering recently learned information, word finding, decreased concentration, misplacing items, getting lost, and challenges at work (Mittelman, Epstein, & Pierzchala, 2003).

Lived experiences. The phenomenon of living in early-stage Alzheimer’s disease through the exploration of individuals’ thoughts, emotions, self-perceptions, and social interactions. According to Starks and Trinidad (2007), the essence of phenomenology revolves around the meaning and commonality of the experience of an event.

Challenges. Alzheimer’s disease’s impact on a person’s life, including his or her ability to perform activities of daily living in various settings and engagement in interpersonal relationships.

Loss. A loss in individuals with Alzheimer’s disease will be defined based on a qualitative study performed by Ahlstrom (2007) regarding experiences of loss in individuals with severe chronic illnesses. This experience includes losses related to the impact of the disease on a person’s physical, emotional, and social aspects of his/her life including loss of bodily functions, relationships, individuality, life imagined, and identity. Ahlstrom (2007) added that loss of identity includes “the loss of human worth, dignity and a changed self image” (p. 76).

Sources of support. Sources of support for individuals in early-stage Alzheimer’s disease may include family, friends, caregivers, support groups, religion, spirituality, and healthcare professionals.
Stigma. An individual with Alzheimer’s disease being negatively labeled (Swaffer, 2014), such as helpless (Dementia Action Alliance, 2016), objectified (Harris, 2002), and deemed unable to share his/her own experiences due to a diagnosis of Alzheimer’s disease (Snyder, 2009).

Delimitations

A delimitation of this qualitative study was the inclusion of participants with a specific diagnosis of early-stage Alzheimer’s disease. Purposive sampling was particular to this study due to the significant gap in the literature that calls for future phenomenological studies on individuals in the early-stage of the illness (Bahro, Silber, & Sunderland, 1995; Beard, Fetterman, Wu, & Bryant, 2009). The researcher asked individuals who were known to be in the early-stage of Alzheimer’s disease.

Assumptions

The assumptions of this study included:

1) The participants were honest in their diagnosis of early-stage AD.

2) The participants answered the interview questions truthfully.

3) The participants anonymity and confidentiality were preserved.

4) The participants were volunteers who could withdraw from the study at any time with no ramifications.

5) The findings from this study added to the research on the lived experiences of individuals in the early-stage of AD.
Organization of the Study

Chapter One presented an introduction to the proposed research study, a statement of the problem, and the purpose of exploring the lived experiences of individuals in the early-stage of AD. This chapter also provided the theoretical framework, the significance of the study, the background of the problem, the research questions, definition of terms, delimitations, and assumptions of the study. Chapter Two presents a review of the literature related to the phenomenon of persons in early-stage Alzheimer’s disease. Chapter Three presents the methodology of the study. Chapter Four discusses the findings of this research. Chapter Five addresses a discussion of the findings, implications for practice, recommendations for future practice, and a conclusion of the study.
CHAPTER 2
LITERATURE REVIEW

History of Alzheimer’s Disease Research

Since Alois Alzheimer discovered Alzheimer’s disease (AD) in 1906 (Alzheimer’s Association, 2018), the scientific community and governments around the world have focused research efforts on the illness due to its current and expected global impact (Roberts & Tersegno, 2010; Ryan, Rossor, & Fox, 2015). Alzheimer was working with a woman in her 50’s who had symptoms of “memory loss, disorientation, hallucinations and delusions,” paranoia, and language problems (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011, p. 275). What he found in her brain during the autopsy were predominant markers of what is known today as the primary markers of AD— the death of nerve cells, “and the presence of amyloid plaques and neurofibrillary tangles” (p. 277). At the time of Alzheimer’s findings, the disease was still considered senile dementia (Cipriani et al., 2011). In 1910, Emil Kraepelin, a fellow researcher who worked with Alzheimer, named the illness “Alzheimer’s disease” (Maurer, Volk, & Gerbaldo, 1997; Small & Cappai, 2006).

Selkoe, Madelkow, and Holtzman (2012) noted that for 60 years after the discovery of the disease little progress was made in understanding the illness. However, in 1963, seminal work was published on caregiving. Grad and Sainsbury were the first researchers to introduce the impact of stressors on caregiving. Their research centered
around the impact of community care versus traditional care for individuals with a psychiatric illness. Traditional care consisted of individuals staying at a hospital for as long as they needed attention. Community care involved individuals receiving care on an outpatient basis and time-limited hospital stays. Grad and Sainsbury found that caregiver stress increased for the individuals who received care in the community due to his/her need for increased attention needed by the caregiver. Also noted in this study was the impact of caregiving on mental and physical health, social and leisure activities, children in the family, household routine, income, and employment. Mental health ranked highest on the list with the majority of participants admitting to excessive worrying about the individual with the illness. The study also revealed how the role of the patient’s clinical features and the duration of the disease impacted caregiver burden. Although Alzheimer’s disease is a neurocognitive disorder, and not a mental illness (American Psychiatric Association, 2013), this study highlighted the impact of caregiving for someone who needs increased care while living at home.

A few years after Grad and Sainsbury investigated caregiving and stressors, Hoenig and Hamilton studied different types of caregivers. The authors noted two categories of burden in their research: objective and subjective (Marshall, Neumann, Pitt, & Cammer, 1972). There are two types of objective burden: (1) the impact of caregiving on the household- i.e. finances, health, the family unit, children, and (2) “the presence of any abnormal behavior in the patient likely to disturb others: noisiness, wandering at night, presenting a danger to himself or others, requiring nursing or physical care” (Marshall et al., 1972, p. 43). Subjective burden refers to the “mental health and
subjective distress among family members” (Reine, Lancon, Simeoni, Duplan, & Augier, 2003, p. 137). Grad and Sainsbury (1963) and Hoenig and Hamilton (1966) were the first researchers to develop “burden scales for caregivers of severely mentally ill patients, and a number of authors further developed instruments trying to distinguish between “objective” and “subjective” burden” (Reine et al., 2003, p. 137).

In the mid-1960s interest in AD increased after foundational research was published on the examination of the cells and nature of the disease (Selkoe et al., 2012). Along with this foundational research, measurement scales such as The Cambridge Mental Disorders in the Elderly (CAMDEX), were created to measure the cognitive and functional decline in adults (Estabrook, Sadler, McGue, & Denmark, 2015; Kahn, 2016). With measurement scales in place and new scientific findings of the disease increasing, research funding for AD reached a pivotal moment in 1974 with the establishment of the National Institute on Aging (NIA) (National Institute of Aging, 2018; Selkoe et al., 2012). The NIA is the primary federal agency that supports research of the disease (Alzheimer’s Association, 2018; National Institute on Aging, 2018). Dr. Steven DeKosky with the University of Pittsburgh School of Medicine explained in the documentary, The Alzheimer’s Project,

Serious and focused research on Alzheimer’s disease began when the National Institute of Aging and a variety of researchers, brain researchers, realized that what we had been calling dementia or senile dementia or hardening of the arteries or arteriosclerosis in late life that everyone just called dementia actually in the vast majority of cases was Alzheimer’s disease. Which before this we had thought had been this very uncommon disorder that occurred in your 40s and 50s in rare cases. (Shriver, 2009)
Two years after the development of the NIA, AD was recognized as the most common form of dementia (Ryan et al., 2015).

Dr. John Morris from the Washington University School of Medicine noted that significant advancements in understanding the disease took place in the 1980s (Shriver, 2009). Morris further explained in the documentary, *The Alzheimer’s Project*, that progress was also made in how to diagnose the illness, how AD begins in the brain, “how it changes brain cells, damages brain cells, and results in its clinical phase dementia, loss of memory and thinking ability. A tremendous number of tools have helped this remarkable advance” (Shriver, 2009). Researchers identified two key hallmarks of the disease, plaques and tangles, which are responsible for nerve cell damage and tissue loss inside the brain (Hoffman, Froemke, & Golant, 2009; Shriver, 2009). Plaques are abnormal clusters of brain fragments that build up between nerve cells and impact their ability to function (National Institute on Aging, 2018). Tangles are tangled nerve fibers that form inside neurons and lead to the loss of communication in nerve cells where they eventually die (Whitbourne & Whitbourne, 2017). Neurons assist in communication in the brain, and plaques and tangles kill this process (Hoffman et al., 2009). Hence, the plaques and tangles of Alzheimer’s disease progressively limit a person’s ability to function due to the destruction of the brain’s ability to process memory, language, and behavior (Ihara, Nukina, Sugita, & Toyokura, 1981).

Also, in the 1980s, the desire for increased research by the NIA fueled the establishment of Alzheimer’s Disease Centers at medical facilities across the United States (U.S.) (National Institute on Aging, 2018). The goal of these centers is to improve
diagnosis of the disease, to find a cure, and to find a way to prevent the illness (National Institute on Aging, 2018). Just as the Alzheimer’s Association noted the strengthening of research in the 1980s, Tanzi (2012) described the 1980s and 1990s as being the modern era of genetic discoveries surrounding AD. In 1984, researchers Glenner and Wong identified a genetic link to the disease by recognizing the first gene associated with a familial form of Alzheimer’s (Tanzi, 2012).

Three years later another scientific breakthrough in genetic research surfaced when Scientists discovered the first gene associated with a rare inherited form of AD (Alzheimer’s Association, 2018). The significance of this finding involves the gene located on chromosome 21 (Wiseman et al., 2015). Individuals with Down syndrome have an extra copy of chromosome 21 (NIA, 2017). According to the National Institute on Aging (2017), “50 percent or more of people with Down syndrome will develop dementia due to Alzheimer’s disease as they age” (p. 3). Wiseman et al. (2015) noted that individuals with Down syndrome are more susceptible to early-onset AD.

Along with the introduction of genetic linkage studies (Tanzi, 2012), the NIA was on the precipice of launching the first drug trial to target symptoms of the disease (Alzheimer’s Association, 2018). In 1993 the Food and Drug Administration (FDA) approved Tacrine the first drug to treat the symptoms of the illness in the United States (Crismon, 1994). Additional drugs became available throughout the 1990s for the treatment of Alzheimer’s, which included the licensing of Aricept in 1997 in the United Kingdom (Jackson, 2014). As of 2009, more than 90 drugs were being tested in clinical trials (Hoffman et al., 2009). Several drugs are approved to treat the symptoms of
Alzheimer’s; however, none prevent, modify the progression, or cure the disease (National Institute of Aging, 2018).

Besides a genetic link, the focus on disease risk factors is an area that researchers continually investigate (Hoffman et al., 2009). During the 1990s, researchers identified the first Alzheimer’s risk factor gene (Alzheimer’s Association, 2018). As research has progressed, age is known to be the number one risk factor for the disease (Guerreiro & Bras, 2015). Along with age and genetics, other risk factors include psychological factors, education, environment, health, lifestyle (Imtiaz, Tolppanen, Kivipelto, & Soininen, 2014), and brain injuries (Lye & Shores, 2000).

In 1999 scientific research showed promise when an Alzheimer's vaccine was proven successful in transgenic mice (Alzheimer’s Association, 2018; Morgan et al., 2000). A vaccine with beta-amyloid prevented memory loss and reduced amyloid deposits, a hallmark of AD, in the brain of the mice (Morgan et al., 2000). Morgan et al. (2000) stressed that this vaccine might prevent and treat the illness. Shriver (2009) expressed that using an animal model for the disease has a significant impact on expediting the development of drugs that alleviate symptoms of the disease and may be able to prevent the advancement of AD in individuals.

Genetics research continued to progress between 2000 to 2009 when the NIA established The National Alzheimer’s Disease Genetics Study (Hoffman et al., 2009). The study investigates the genetic link of late-onset Alzheimer’s in 1,000 families (Hoffman et al., 2009; NIA, 2018). Along with the genetics study the Alzheimer’s Disease Genetics Initiative was launched to investigate genetic variations of AD in
individuals (Hoffman et al., 2009). This initiative is considered to be the first international collaboration on AD genetics and involves universities from the United States to Europe (Alzheimer’s Association, 2018). Hoffman et al. (2009) reported: “the discoveries from these initiatives should provide important clues to the Alzheimer’s disease process and, ultimately, reveal potential targets for drugs and other interventions” (p. xiv).

Morris (2009) explained that the 1980s was a decade of trying to understand what the disease represents, and the 1990s was a time of discovering treatments that helped with the symptoms of Alzheimer’s (Shriver, 2009). Now as the science behind Alzheimer’s moved into the 2000s, Morris noted that this decade was a time to “understand that the illness to be effectively treated is going to require agents that get at the underlying cause of the disease” (Shriver, 2009). On an international level, in 2004 at the Alzheimer’s Association International Conference on Alzheimer’s Disease (AAICAD) researchers shared groundbreaking news of the possibility of a new way to detect, diagnose, monitor the disease, and develop new drugs for Alzheimer’s (Alzheimer’s Association, 2018; Hoffman et al., 2009; Johnson, 2006). An imaging agent called Pittsburgh Compound-B (PiB) is used during a positron emission tomography (PET) to detect amyloid plaque deposits, one of the hallmarks of AD (Bacskai et al., 2007). After developing and testing PiB, research has found that the imaging agent can be used for measuring amyloid deposits (Price et al., 2005) and early detection of the disease. However, the agent is not to be used solely to diagnosis the disease (Alzheimer’s Association, 2018).
The focus on early detection of Alzheimer’s continued in the 2000s as the NIA established the Alzheimer’s Disease Neuroimaging Initiative (ADNI) (Alzheimer’s Disease Neuroimaging Initiative, 2013; Hoffman et al., 2009). This initiative focuses on using biomarkers for detecting and monitoring the illness (Alzheimer’s Disease Neuroimaging Initiative, 2013). Strimbu and Tavel (2010) defined biomarkers as “objective, quantifiable characteristics of biological processes” (p. 464). The author’s further explained, “biomarkers play a critical role in improving the drug development process as well as in the larger biomedical research enterprise” (p. 465). Gustaw-Rothernberg et al. (2010) explained that researchers could look to AD biomarkers to hopefully predict the early stages of the disease. ADNI advocates for the development of new methods of diagnosing the disease such as biomarkers and continues to update and expand their data (Alzheimer’s Disease Neuroimaging Initiative, 2013). This initiative also laid the groundwork for standards to obtain and interpret brain images (Snyder & Carrillo, 2016).

On a global scale, in 2008 the Alzheimer’s Association formed the International Society to Advance Alzheimer’s Research & Treatment (ISTAART) (Snyder & Carrillo, 2016). Along with the international outreach of the Alzheimer’s Disease Genetics Initiative (Hoffman et al., 2009), ISTAART continues the collaboration efforts of researchers worldwide. Currently, 60 countries are part of ISTAART, and the focus is on “the rate of progress of Alzheimer’s and dementia research” (Alzheimer’s Association, 2017, p. 839).
Cummings, Lee, Mortsdorf, Ritter, and Zhong (2017) expressed, “there is an urgent need to develop new treatments for Alzheimer's disease (AD) and to understand the drug development process for new AD therapies” (p. 367). Clinical trials are one avenue that researchers who study Alzheimer’s find ways for early detection of the disease and know if a particular treatment is effective (NIA, 2018). To push forward in understanding more about the illness, in 2010 the Alzheimer’s Association and the Coalition Against Major Diseases (CAMD) established the first clinical trial database (Alzheimer’s Association, 2018). According to the Alzheimer’s Association, as of 2018, researchers were conducting more than 250 drug and non-drug related studies. And per the Alzheimer’s Drug Discovery Foundation (2018) as of 2017, there were 126 drugs in development.

In 2007 the Centers for Disease Control and Prevention (CDC) identified AD as the sixth leading cause of death (Xu, Kochanek, Murphy, Tejada-Vera, 2010). Between 2000 to 2010 the death rate from the illness increased by 39% from the year 2000 (Tejada-Vera, 2013). Tejada-Vera (2013) reported as of 2013 the disease ranked as the fifth highest cause of death for individuals 65 and older. As of 2018, the NIA is stating that recent estimates indicate that Alzheimer’s is the third foremost cause of death (NIA, 2018). According to Wortmann (2012), “Alzheimer's disease and other dementias are a global health challenge and are exceptional in size, costs and impact” (p. 40).

Due to the impact of the disease researchers continue to explore the science behind the disease process of Alzheimer’s (Roberts & Tersegno, 2010; Ryan et al., 2015) such as biomarkers (Gustaw-Rothernberg et al., 2010). Just as the ANDI explores this
aspect of science, Jack et al. made significant progress concerning biomarkers of the illness in 2010 (Jack et al., 2010; Alzheimer’s Association, 2018). Their model correlates the stages of AD to biomarkers and the severity of clinical symptoms (Jack et al., 2010). According to the Alzheimer’s Association (2018), Jack et al.’s model is at the center for current and new research in AD biomarkers. Gustaw-Rothernberg et al. (2010) reiterated the worldwide health crisis of the disease and how “sensitive and reliable biomarkers are needed to execute early and accurate clinical diagnosis” (p. 17).

Research published by Jack et al. in 2010 highlighted how important biomarkers are in diagnosing the disease, and one year later the NIA proposed new guidelines in this process (Schott & Petersen, 2015). Up to this point, clinicians were using diagnostic criteria established in 1984 when biomarkers did not exist and results relied on an autopsy of the brain for diagnosis (NIA, 2018). Schott and Petersen (2015) reported before this change, Alzheimer’s was diagnosed based on the impact of memory loss of an individual’s ability to perform activities of daily living. Some of the distinguishable changes in criteria included: the disease progressing through three stages rather than one stage, focusing on other impairments of the illness rather than solely memory loss, recognizing the differences between Alzheimer’s and other forms of dementia, and acknowledging the use of biomarkers in diagnosing the disease (NIA, 2018).

To delay the progression of Alzheimer’s biomarkers, the National Institute of Health (NIH) launched the first-ever clinical prevention trial of the disease in 2012 (NIH, 2012). The study investigated a large family from Columbia who is at higher risk to get the disease due to a genetic mutation. The family starts typically to experience symptoms
of the disease around the age of 45. The trial focused on the prevention of Alzheimer’s by use of anti-amyloid antibody treatment. The NIH (2012) noted that the trial had three goals: (1) decrease the chance of family members getting the disease’s symptoms, (2) maintain cognitive abilities, and (3) limit the advancement of biomarkers of AD. This trial was part of the U.S. National Alzheimer’s Project Act (NAPA). NAPA, created in 2012, involves U.S. plans to address the disease and assist families that are impacted by the illness.

In 2013 efforts to understand Alzheimer’s continued on a global scale. First, researchers from around the world identified 11 new genes that impact the risk of developing AD (NIH, 2013). According to the NIH (2013), at that time this was considered the largest genome-wide study of the disease. The research involved scientists from around the world who worked with 74,000 older adults from 15 countries. Individuals either had late-onset of the illness or did not have the disease. The study was part of the International Genomics of Alzheimer’s Project (IGAP) and researchers identified 11 new genes associated with AD.

Second, the G8 Dementia Summit met for the first time in London (Alzheimer’s Association, 2018; Department of Health and Social Care, 2014). Health ministers, research participants, pharmaceutical companies, and charities from the eight countries—France, Germany, Italy, United Kingdom, Japan, U.S., Russia, and Canada—met to address the global health crisis, fight the disease, and increase partnerships to find a cure by 2025 (Alzheimer Society of Canada, 2017). There was a consensus at the Summit that AD research is underfunded (Mitchell, 2017). Researchers identified three goals at the
Summit: “stimulate greater investment and innovation in dementia research, improve the prevention and treatment of dementia, and improve quality of life for people with dementia” (Department of Health and Social Care, 2014, p. 1). According to Mitchell (2017), progress has been made to achieve these three goals including the development of The World Dementia Council and the Dementia Discovery Fund.

Ganguli, Dodge, Shen, Pandav, and DeKosky noted in 2005 the underreporting of deaths of AD on death certificates. In 2014 the U.S. reported that information surrounding AD deaths were much higher than indicated on death certificates (James, Leurgans, Herbert, Scherr, Yaffe, Bennett, 2014). James et al. (2014) performed a study to assess deaths related to AD in the United States. Two studies included 2,566 participants 65 years and older without dementia: the Religious Orders Study and the Rush Memory Aging Project. The Religious Orders Study included older Catholic nuns, priests, and brothers from across the United States. Participants from the Religious Orders Study included individuals from retirement communities and subsidized senior housing facilities across Illinois. “In both studies, participants without known dementia at baseline agreed to annual detailed clinical evaluation and brain donation at the time of death” (p. 1046). The results of the study indicated that participants who developed Alzheimer’s significantly impacted mortality.

In March 2018, the United States Congress approved, and President Donald Trump signed into law a $414 million increase in research funding for the disease (Alzheimer’s Association, 2018). According to the Alzheimer’s Association (2018), this boosts research funding for the United States government to $1.8 billion. Harry Johns,
Chief Executive Officer (CEO) for the Association, expressed, “On a global level, clinical trials are always in progress, research continues to advance, and advocacy for funding AD research is pursued in hopes of finding a cure for the disease” (Alzheimer’s Association, 2018, p. 2).

Caregiving

Just as Professor Tom Kitwood once said, “When you’ve met one person with dementia, you’ve met one person with dementia” (Social Care Institute for Excellence, 2015, p. 1), Kriseman (2014) shared “Caregiving will never be one-size-fits-all” (p. 1). Caregivers of persons with Alzheimer’s are sometimes called “the invisible second patients” (Brodaty & Donkin, 2009), or “the hidden victims” of the illness (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Hodgson and Cutler (1994) expressed that individuals who care for persons with the disease are considered to be a different subset of the caregiving population. These author’s noted that the research on Alzheimer’s caregivers presents as a distinct topic separate from the literature on caring for individuals who do not have the disease.

The needs of caregivers are in the spotlight due to the increasing number of individuals who are being diagnosed and currently have Alzheimer’s (Hepburn, Tornatore, Center, & Ostwald, 2001). Keady and Nolan (1996) reported that caregiving, more than any other field of study, has received significant attention in research. Hepburn et al. (2001) explained, “Family caregiving is an integral part of the care system for persons with dementing disorders, such as Alzheimer’s disease” (p. 450).
According to the Alzheimer’s Association (2018), at least 16.1 million informal caregivers provide care for individuals with Alzheimer’s disease or related dementias (ADRD)’s in the United States. Informal caregivers are unpaid caregivers, such as family and friends (Family Caregiver Alliance, 2018). According to Gaugler, Jutkowitz, and Peterson (2017) “the brunt of dementia care is not borne by hospitals, nursing homes, or other professional providers but by families” (p. 37).

Most individuals with this disease and his/her caregiver(s) live in the community (Brodaty & Donkin, 2009). The demographics of informal caregivers consists mostly of spouses, who are also elderly (Clyburn et al., 2000), and children. The majority are female (Brodaty & Donkin, 2009). In 2009, Martin-Carrasco et al. reported that on average caregivers spend 70 hours per week addressing the needs of a person with the disease. Due to the lifespan of a person diagnosed with AD, a caregiver can spend three to 20 years, the average is eight to ten years, caring for someone with the illness (Alzheimer’s Association, 2018; Zanetti, Solerte, & Cantoni, 2009).

The Caregiver Career

Caregivers for individuals with the disease are considered “the greatest resource” in the healthcare system (Clyburn et al., 2000). The care provided by caregivers is significant to the point it is called the “caregiver career” (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Frank, 2007). This career involves being concerned about the well-being of the person with the disease, learning about Alzheimer’s, locating medical care, assisting with activities of daily living, finding respite and support, handling legal and financial issues, planning for the future, and advocating for the individual with the
illness (Esandi, Nolan, Alfaro, & Canga-Armayar, 2018; Family Caregiver Alliance, 2018; NIA, 2018). Brodaty and Donkin (2009) explained,

> Without caregivers, people with dementia would have a poorer quality of life and would need institutional care more quickly, and national economies would be swept away by the advancing demographic tidal wave. (p. 217)

In general, family caregivers of persons with ADRD provide more extensive activities of daily living, instrumental activities of daily living such as shopping and finances, and a range of other care needs (Alzheimer’s Association, 2018). According to the Alzheimer’s Association (2018), when compared to non-caregivers, twice as many dementia caregivers indicate financial, emotional, and physical changes. Gaugler et al. (2017) explained care for individuals with the illness is considered non-normative because caregivers are also dealing with the behavioral symptoms of the disease.

### Caregiver Well-Being and Burden

A primary focus in the literature has been on caregiver well-being and burden (Alwin, Oberg, & Krevers, 2009; Frank, 2007; Schulz & Sherwood, 2008; Sorensen et al., 2008). The caregiving experience may impact an individual’s physical health, psychological/mental health, financial resources, and social participation (Frank, 2007; George & Gwyther, 1986). Caregivers express there are both positive and negative aspects of caring for a person with AD (Brodaty & Donkin, 2009). Frank (2007) noted that caregiver well-being equates to a positive caregiving experience and caregiver burden relates to a negative experience. A positive experience includes sharing time and activities, reciprocity in the relationship, “spiritual and personal growth, increased faith, and feelings of accomplishments and mastery” (p. 218). However, Brodaty and Donkin
(2009) pointed out the experiences “are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship” (p. 217). Much of the literature discusses the negative impact of caring for someone with AD (Clyburn et al., 2000).

Caregivers struggle to not only meet the demands of caring for a person with Alzheimer’s but also to maintain balance in his/her life as they face everyday demands of career, relationships, and own well-being throughout the progression of the disease (Brodaty & Donkin, 2009; Cooke, McNally, Mulligan, Harrison, & Newman, 2000; Lilly, Robinson, Holtzman, & Bottorff, 2012; Wang, Chien & Lee, 2012). The role of caregiver is often complex, dynamic with “no endpoints” (Gaugler et al., 2008), and intense (Frank, 2007). Some caregivers adjust to this role in “stride” and some “develop distress” (Brodaty, Gresham, & Luscombe, 1997). How a caregiver adjusts to his/her role is essential, because research shows the well-being of the caregiver directly impacts the quality of life of the individual with Alzheimer’s disease or dementia (Charlesworth et al., 2011; Granello & Fleming, 2008; Martin-Carrasco et al., 2009). Schulz and Sherwood explained:

Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance. (2008, p. 1)

These authors pointed out that this type of caregiving is considered a significant public health crisis.
There are factors related to caring for a person with AD that impact a caregiver’s physical and mental health (Brodaty & Donkin, 2009; Brodaty et al., 1997; Frank, 2007; Schulz & Sherwood, 2008). These issues include the behavioral symptoms of a person with Alzheimer’s, changes in cognitive functioning, duration of caregiving, role changes and strain, changes in intimacy, functional limitations, social interactions, and activities, if the person with AD and the caregiver live together, and negative emotions such as depression, stress, and isolation (Frank, 2007; Schulz & Sherwood, 2008). These situations take a toll on the physical and psychological health of a caregiver, more so than non-ADRD caregivers and caring for someone with a physical disability (Schulz & Sherwood, 2008). Schulz and Sherwood (2008) stated that the impact on ADRD caregivers is significant due to individuals with the disease requiring more care and attention than other individuals with chronic health issues.

Caregiver’s Health

According to Vitaliano, Zhang, and Scanlan (2003), the exposure to the chronic stress of the disease and intense caregiving can increase the likelihood that a caregiver will experience “psychosocial distress and risky health behaviors” (p. 947). These authors noted how the chronic stress for caring for someone with Alzheimer’s impacts the mental health and social aspects of a caregiver’s life and then leads to stress hormones. Vitaliano et al. (2003) also found that caregivers had a 23% higher amount of stress hormones than non-caregivers.

Physical health. Due to this level of stress, there are numerous areas of a caregiver’s physical health that are impacted by caring for a person with AD (Brodaty &
Donkin, 2009; Clyburn et al., 2000). An individual may experience the following health issues: increased visits to the doctor and use of the healthcare system, not taking care of his/her physical health, not taking preventative health measures (Brodaty & Donkin, 2009; Clyburn et al., 2000), increased use of medications (Brodaty & Donkin, 2009), especially psychotropic medications (Clyburn et al., 2000), cardiovascular issues, lowered immune system, increased use of alcohol and nicotine (Brodaty & Donkin, 2009), and poor sleep (Brodaty & Donkin, 2009; Vitaliano et al., 2003). In general, caregivers rate his/her overall health as poor (Brodaty & Donkin, 2009; Clyburn et al., 2000).

In 2003 Vitaliano et al. performed a meta-analysis of 23 studies evaluating the impact of caregiving for a person with dementia on a caregiver’s physical health. The studies included 1,594 caregivers of persons with dementia and 1,478 non-caregivers. The results of the study found an increased risk for health problems for caregivers of individuals with dementia, especially with increased stress hormones and overall adverse reported health.

Mental health. Depression, stress, isolation, and grief are universal emotions experienced by a caregiver of an individual with Alzheimer’s disease (Cuijpers, 2005; Vitaliano et al., 2003). These emotions take a toll on a caregiver’s psychological health and in turn, can impact his/her physical health (Vitaliano et al., 2003). The most common emotion noted throughout the literature is depression (Cuijpers, 2005; Clyburn et al., 2000; Etters, Goodall, & Harrison, 2008). In 2006, the Alzheimer’s Association reported that 80% of caregivers experience stress and almost half experience depression (Etters et
al., 2008). According to Cuijpers (2005), in a study of 176 caregivers, 22.3% of the participants experienced a depressive disorder. This author also noted that depressive disorders are three to 38 times higher than non-ADRD caregivers. Mausbach, Patterson, and Grant (2008) explained that an increase in depression for caregivers is not uncommon due to the various factors of caring for a person with the disease, these include behaviors of the patient, increased cognitive issues, need for assistance with activities of daily living, and psychiatric problems of the patient. Depression and caregiving for individuals with AD is an important topic because this can impact a caregiver’s ability to function daily and maintain self-care throughout the disease (Cuijpers, 2005). The level of negative emotions a caregiver experiences, such as depression (Cuijpers, 2005), burden (Clyburn et al., 2000), isolation (Hepburn et al., 2001; Charlesworth et al., 2011), loss of self (Skaff & Pearlin, 1992), and failure (Karner & Bobbitt-Zeher, 2006) may also impact the quality of life of the person with the disease and possible early nursing home placement (Etters et al., 2008).

The Social Toll

Caregivers of individuals with AD often run the risk of feeling isolated (Hepburn et al., 2001; Charlesworth et al., 2011), due to limited time and opportunity to socialize and maintain relationships with family and friends (Charlesworth et al., 2011; Croog, Burleson, Sudilovsky, & Baume, 2006). The stigma of the disease is also an issue which may prevent people from engaging with the person with Alzheimer’s and his/her caregiver (Charlesworth et al., 2011). According to Bergman-Evans (1994), spousal caregivers have an increased risk of loneliness due to “loss of companionship of their
other, forced social isolation, increased responsibility, and the emotional burden of caregiving” (p. 6). The author explained that the caregiver often spends more time at home due to the increased needs of an individual with the illness which in turn decreases contact and participation in the community. Bergman-Evans also noted that isolation increases in the caregiver because of the change in the relationships with the person with AD due to the impact the disease has on his or her ability to engage socially. The Family Caregiver Alliance (2018) reported that depression experienced by caregivers is often a result of feelings of loneliness and isolation. Caregivers can experience feelings of being “forgotten” (Lilly et al., 2012) due to alienation from friends and other family members (Mitrani & Czaja, 2008). Spousal-caregivers are especially prone to experience this level of isolation because his/her primary social network is often the spouse who is living with the disease (Sanders, Ott, Kelber, & Noonan, 2008). Loneliness is also attributed to caregivers feeling that no one understands what he/she is experiencing and feeling he/she are alone in caring for an individual with AD (Family Caregiver Alliance, 2018). Croog et al. (2006) researched the caregiver burden involving 199 spouses of persons with the disease. The study indicated that social deprivation was one of the issues by spousal caregivers.

Relationship Changes

Role changes play a part in the loneliness and isolation as Skaff and Pearlin (1992) noted that caregivers become engulfed in the role of caring for an individual with AD. “As persons with Alzheimer’s disease (AD) lose their ability to make decisions, someone else has to make decisions for them” (Hirschman, Xie, & Feudtner, 2004, p. 1).
Caregivers step in to make decisions that the person was normally able to do, thus leading to feelings of being overwhelmed (Alzheimer’s Association, 2018). As caregivers immerse themselves in the role of taking care of the needs of an individual with the illness they feel a “loss of self” or loss of identity (Skaff & Pearl, 1992).

Karner and Bobbitt-Zeher explained that AD impacts both the person with the disease and the caregiver. The authors described, “one becomes ensfolded in dementia, the other transformed into a caregiver” (p. 549). These researchers noted that the dyad between an informal caregiver and person with dementia occurs within a pre-existing relationship. Within this partnership the caregiver is renegotiating his/her place in the relationship as the person with the disease is declining cognitively (Karner & Bobbitt-Zeher, 2006). Karner and Bobbitt-Zeher shared that this readjustment takes a toll on the emotional well-being of the caregiver. These authors performed a qualitative study with 20 family caregivers. Karner and Bobbitt-Zeher explored areas such as caregivers’ reflections on his/her experiences, support services, and expectations of caregiving. Through this research, the authors found that the emotional aspect of caregiving was more difficult than the physical point of caring for the person. The results of this study also indicated that because the partner is becoming increasingly absent due to cognitive loss, “the family member must transform his or her identity into that of a “caregiver” (p. 566).

Intimacy with Couples

One area noted in the research on caregiving is the impact of the disease on intimacy among couples (Forsund, Skovdahl, Kiik, & Ytrehus, 2014; Harris, Adams,
Harris et al. (2011) performed a qualitative study with ten caregivers seeking their perspective on intimacy and ADRD. The caregivers expressed that the quality of the relationship before the disease played a role in how the disease impacted intimacy after the diagnosis. The authors shared that ADRD placed stress in the “closeness and connection within the couple” (p. 950). Some caregivers also acknowledged that one of the important factors is the adjustment to the role “while maintaining an emotional as well as physical connection to their partner” (pp. 956-957). The results of the study showed that for other participants, negative emotions such as hurt and feeling overwhelmed, impacted their ability to be intimate with their partners. The theme of uncertainty also surfaced for some of the caregivers. The ambiguous nature of the disease progression brought up “feelings of resentment, a sense of burden, and physical and emotional stress” (p. 957). Ultimately, the results of the study indicated that the quality of the relationship prior to the disease greatly impacted a caregiver’s experience of ADRD with his/her partner.

Forsund et al. (2014) also explored the loss of couplehood as experienced by the caregiver. The researchers found themes of separation from the partner and a loss of sense of self to be relevant to the caregiver’s reality of a spouse with dementia. The participants expressed feelings “to the loss of the shared past and future” (p. 121), although the caregivers also expressed that there were momentary feelings of couplehood throughout the disease with “connectedness, reciprocity, and interdependence” (p. 121). Overall, Forsund et al. reported that the topic of loss in couplehood is multidimensional.
with caregivers feeling both loss and connectedness depending on how the disease was impacting their partners at the moment.

Grief

Due to the changes in the role and the relationship between the caregiver and the person with Alzheimer’s, the caregiver often feels grief (Alzheimer’s Association, 2018; Frank, 2007). A type of grief associated with the disease is ambiguous loss (Boss, 2009). Boss (2009) described ambiguous loss as a situation where there are a physical presence and psychological absence. In this type of loss, the person someone cares about is psychologically absent or emotionally or cognitively missing (Boss, 2009). Frank (2007) added, “Schulz and colleagues (2003:1941) found this loss so profound as to suggest that bereavement “affects many caregivers before death occurs’” (p. 559). Karner and Bobbitt-Zeher (2006) performed a qualitative study with family caregivers and discussed the topic of losing themselves throughout the changes and transformation of the disease. One participant shared,

At first it was hard for me to accept her condition because it was like this is someone I don’t even know anymore…she’s just different…They look at her like she’s crazy or something, which she’s not, she’s just…that is just the way it is…[But] the difficult part for me because I have always been obedient and I have been and she is still my mom. (p. 559)

This caregiver speaks to the topic of role changes and the multidimensional aspects of loss during the progression of the disease (Karner and Bobbitt-Zeher, 2006).

Coping Strategies

Researchers have focused on interventions to assist a caregiver in decreasing caregiver burden and adjust to the role of caring for a person with dementia (Ducharme et
To counteract the stress and negative emotions associated with the caregiver experience (Wang et al. 2012; Lilly et al., 2012), an extensive amount of research points to support groups as a form of “respite” for caregivers (Kansas, 2006; Laakkonen, Holtta, Savikko, Strandberg, Suominen, & Pitkala, 2012). Connection, education, and opportunity—the three common support group qualities that caregivers seek (Brodaty et al., 1997; Sorensen et al., 2008; Alwin et al., 2010; Charlesworth et al., 2011). A consistent finding throughout the literature suggests that caregivers desire to “exchange experiences” and gain knowledge about dementia (Grabel et al., 2010; Lilly et al., 2012; Morrow-Odom & Robbins, 2012).

Connection. “Support can be achieved in many ways, but it typically comes from creating a common bond and common ground among group members” (Morrow-Odom & Robbins, 2012, p. 81). This bond and peer support generated from these groups provides a sense of universality and decreases isolation for caregivers (Sanders et al., 2008). Caregivers are looking for a sense of community and sharing their experiences (Winslow, 2003; Reynoso-Vallejo, 2009). Golden and Lund (2009) noted “sameness” as one of the main themes in support groups (Morrow-Odom & Robbins, 2012). This “common bond” and desire to relate in the group process captures the essence of universality, a therapeutic factor in the group process (Yalom, 2005). Throughout the literature on caregivers and support groups, this sense of universality attributed to decreased feelings of loneliness, created moments of laughter with other caregivers, provided emotional support, brought awareness to coping skills, and increased a sense of peace in meeting the demands of caring for persons with the disease (Charlesworth et al.
2011; Sorensen, et al., 2008; Wang et al., 2012; Winslow, 2003). Universality is best exemplified by the words of one caregiver who stated, “I feel I’m not alone in the world with this on my shoulders...to tell people who understand...I think it’s good therapy” (Winslow, 2003, p. 344). Sharing experiences with other caregivers in support groups helps to normalize experiences, instill hope, and awareness that they are not alone if other caregivers are encountering similar situations (Toseland & Rossiter, 1989 as cited in Wang et al., 2012).

Brodaty et al. (1997) studied the experiences of individuals with dementia and their cohabitating caregivers who participated in a 10-day caregiver-training program. In this program, caregivers participated in groups and shared their experiences. The researchers noted that throughout this intervention connections strengthened among caregivers, and caregivers desired to spend time with each other and share the knowledge they gained from the program. After the program ended the caregivers reported they continued to meet other caregivers. Studies also pointed to caregivers finding value in giving back to their peers (Sanders et al., 2008). Sanders et al. (2008) noted, “it was not unusual to find that the caregivers appreciate the ability to “give back” to other caregivers through advice, recommendations, and serving as an emotional presence” (p. 514). Cooke et al. (2001) noted in their research that due to the benefit that caregivers find in sharing experiences there had been an effort to increase social components to interventions, such as support groups, social support, social skills, and social activities. One can conclude that caregivers desire continuous support and connection throughout the progression of the disease.
Education. Brodaty et al.’s (1997) model of the effects of dementia on caregivers showed that lack of knowledge and limited coping skills are factors that can exacerbate the challenges of caring for individuals with dementia. According to a meta-analysis performed by Chien et al. (2011), psychoeducational groups are beneficial on multiple fronts. These groups provide information about dementia, support from peers, and improve caregivers psychological and emotional well-being (Chien et al., 2011). Psychoeducational groups provide the caregiver with education on the disease, coping skills, techniques, strategies, resources, and suggestions in performing the role of caregiver for an individual with Alzheimer’s or dementia (Hepburn et al., 2001; Winslow, 2003; Sanders et al., 2008, Grabel et al., 2008). The results from varying studies show that when caregivers know about the illness, the effectiveness of their care increases and their level of stress decreases (Cooke et al., 2001; Granello & Fleming, 2008).

Two programs that incorporated education into their interventions were the Minnesota Family Workshop (MFW) (Hepburn et al., 2001) and the Psychoeducational Intervention Program (PIP) (Martin-Carrasco et al., 2009). Participants in the MFW received information and were trained on problem-solving, role clarification, and provided homework assignments to apply the knowledge from the workshop to their daily lives (Hepburn et al., 2001). The researchers found that this workshop proved beneficial in outcome scores related to the caregivers’ “depression, burden, and reaction to their care receiver’s problem behaviors” (p. 454).
Caregivers who participated in PIP received information on managing stress, strategies for dealing with challenging behaviors from individuals with the disease, and improving their fulfillment in life (Martin-Carrasco et al., 2009). The results from this intervention program indicated a reduction in “the levels of burden, improving the quality of life in relation to health and rates of psychiatric morbidity” in caregivers (p. 497). Extrapolating from the research, it appears that psychoeducational groups are beneficial to the health of caregivers and strengthens their coping skills to meet the demands of this role.

Caregivers want to ensure the quality of care to the care-recipients however this often comes with a price to their well-being. Caregivers are requesting continued support “to manage the clinical multiyear course of” Alzheimer’s disease (Gaugler et al., 2008, p. 426). However, Lilly et al. (2012) noted, “caregivers wait too long to reach out for help” (p. 110). Caregivers often will use services only when there is a need (Grabel et al., 2010), despite the benefits of early use of interventions (Sorensen et al., 2008).

Individuals in Early-Stage Alzheimer’s Disease

Extensive research exists about the caregivers perspective of AD (Keady & Nolan, 1996; Stokes, Combes, & Stokes, 2014), however, Cotrell and Schulz (1993) noted that many consider the narrative of persons living in early-stage Alzheimer’s to be the most crucial information missing in the treatment of the disease. To date, research has explored various aspects of Alzheimer’s disease including biology, symptoms, treatment and the impact of the disease on individuals caring for persons with AD (Bahro et al., 1995). Parsons-Suhl, Johnson, McCann, and Solberg (2008) noted that studies regarding
the medical aspects of the disease have helped to improve the lives of persons with the illness. However few studies have focused on understanding the experiences of individuals in the early-stage of AD.

Snyder (2001) shared, “oversight in exploring and honoring the subjective experience of Alzheimer’s is rooted in a prevailing bias that persons with the disease have little insight into their condition,” and are assumed to be, “poor informants of their circumstances” (p. 9). Due to these factors, the narratives of individuals in the early-stage of Alzheimer’s remain silenced. There appear to be a variety of answers to the lack of first-hand accounts from the person afflicted with AD. First, individuals with the disease are not often given enough credit in their abilities to communicate (Snyder, 2009), resulting in overlooking their voices (Johannessen & Moller, 2011). Next, a person in the early-stage may be reluctant to share his/her experiences due to “real or perceived memory losses” (Usita, Hyman, & Herman, 1998). Third, the medical field has focused on the disease aspect of AD and not on the lived experience (Dementia Action Alliance, 2016). MacQuarrie (2008) observed, “a wealth of information about the biomedical aspects of the disease stand counterpoint to the lack of systematic inquiry around the lived experiences of people with AD” (p. 430). The author further explained that with the medical understanding of Alzheimer’s there is a tendency to equate and stigmatize the person as the illness, rather than the human experience of living with the disease.
Stigma

In other parts of my life dignity has taken a battering from people who will cross the road to avoid me, who refer to me as ‘that woman with Alzheimer’s’ and not my name, and who don’t look at me in the face while talking to me: subtle things but heartbreaking. (Morgan, 2011, p. 281)

When a person receives a diagnosis of AD, there is a tendency to think of the individual as the disease stages and deficits instead of a human experiencing Alzheimer’s (Fazio et al., 1999). Swaffer (2014) noted that the impact of the stigma of dementia is a prevalent topic in the literature. Stigma refers to “persons being negatively labeled, a loss of status and power, discrimination and stereotyping” (Link & Phelan, 2001 as cited in Swaffer, 2014, p. 709). The consequences for a person with AD experiencing stigma include his/her reluctance to get a diagnosis, seek support, or participate in clinical research studies (Batsch & Wortman, 2017; Swaffer, 2014). Batsch and Wortman (2017) identified stigma as a barrier where people will not get the help they need. These authors explained that because of stigma people are walking around that do not even know they have the disease. Batsch and Wortman also addressed the fact that studies acknowledge the opinions and thoughts on stigma by professionals, caregivers, and society. However, individuals with dementia are rarely part of the conversation which leaves a vital part of the issue unheard.

Swaffer (2014) indicated that there are two types of stigma. External stigma which comes from society and internal stigma where the individual with the disease experiences shame about him/herself. With internal stigma, a person feels they are ‘less of a person’ because of the impact of the disease on an individual’s behavior. Mitchell,
Dupuis, and Kontos (2013) explored how words and images from health care literature, public discourse, and policy impact the external and internal stigma related to dementia. These authors pointed out that these words and images contribute to a ‘violent interrelating’ and ‘othering’ of individuals with the disease. Mitchell, Dupuis, and Kontos pointed out how this level of communication “imposes a suffering of personhood” (p. 1).

These authors provided titles from literature and social media that intensify the fearfulness and negative messages associated with dementia. For example, Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer’s. Per Mitchell, Dupuis, and Kontos, this book by Cooney (2004) focused on “the gruesome portrayal of a medical diagnosis” (p. 2). Another example is The Living Dead: Alzheimer’s in America by Lushin (1990). Zeilig (2013) reported a tendency to compare individuals with AD to zombies and a connect diagnosis to a living death. Behuniak (2011) discussed that the stigma associated with AD is specific to dehumanization based on hatred and fear. The author identified that throughout the literature individuals with the disease are compared to zombies. Behuniak expressed that this is significant because the metaphor perpetuates the societal belief of disgust and dread that separates and dehumanizes individuals with Alzheimer’s.

The concepts of ‘the living dead,’ social death, or death of self is all too common within the world of individuals with dementia (Dementia Action Alliance, 2016; Mitchell, Dupuis, & Kontos, 2013). Sweeting and Gilhooly (1997) performed an exploratory story of 100 caregivers of individuals with dementia. One-third of the caregivers reported that there were indications by their beliefs and the sufferers’
behaviors that the individual was socially dead, meaning the person was unable to engage socially, however biologically the body is still alive. Some of the caregivers reported that they thought about or wished the person were physically dead. In 1982 Pitt shared:

Twenty-five years ago it was quite acceptable to write about the ‘death of the self’ of a person with dementia, label dementia as a ‘tragic disorder’ and describe the years between awareness and bodily death as ones whereby ‘a smudged caricature disintegrates noisily and without integrity. (Keady, Williams, and Hughes-Roberts, 2007, pp. 343-344)

Thirty-seven years later the topic of social death and dementia is still discussed in the literature.

Zeilig (2013) indicated that the language of the medical community reinforces the sense of dread and fear associated with Alzheimer’s and dementia. This author reported that dementia had been called the “silent tsunami” or “slow-moving” tsunami. Zeilig expressed, “there is a sense of an unstoppable force of nature coupled with quiet stealth...the silence is particularly something that we cannot anticipate” (p. 260).

The idea of social death, the myth that individuals with Alzheimer's are cognitively unable to share their stories, and the shame individuals feel because of their diagnosis are main factors as to why narratives remain unheard (Batsch & Wortmann, 2017). Johannessen and Moller (2011) agreed that stigma coupled with the primary focus on the caregivers perspective and the medical aspects of the illness overshadow the voices of persons with AD.

Studies about Individuals in Early-Stage Alzheimer’s Disease

Parsons-Suhl et al. (2008) performed a qualitative study where they found that AD is not just memory loss, rather an experience of meaning found in every day for
persons in the early-stage of the illness. The participants in their study were 12 individuals with either early-stage Alzheimer’s disease or mild cognitive impairment (MCI). Persons with MCI struggle with memory loss more than the average person; however it is not as severe as AD (National Institute on Aging, n.d.). The results of the study showed that the process of memory loss is frightening and life-changing for individuals in early-stage AD. The authors emphasized the importance of healthcare workers understanding, valuing, and not discrediting the person with Alzheimer’s. The authors concluded, “Individuals with AD have a lot to teach us about forgetting” (p. 41).

Robinson et al. (2012) reiterated what many researchers are expressing regarding knowledge of who the person is who lives in early-stage AD:

the needs as experienced by those who are living through the early stages of the disease is still poorly understood, and the care they receive is far from being well developed. These patients are only beginning to receive recognition outside the field of medical research and it is only recently that the care they receive has become an issue of concern in society. (p. 217)

The authors further explained that the care individuals with AD receive are often inadequate because the healthcare professional does not know the needs and essence of the person with Alzheimer’s. Up to now, according to Gitlin and Hodgson (2018), a cycle of despair has been perpetuated throughout the medical community and passed onto individuals with the disease and their caregivers. These authors noted the continuous emphasis on a cure. However, due to the lack of a cure medical professionals share there are limited possibilities in their treatment, and there is a lack of support for care and resources. In turn, this permeates a hopeless state that surrounds living with Alzheimer’s disease and ultimately reduces the quality of life.
Robinson et al. (2012) explained that the misunderstanding of the person with Alzheimer’s could have long-term consequences on him/her in how they “personally adjust in a meaningful way to the disease and its effects” (p. 234). In 2018, Gorska, Forsyth, and Maciver performed a meta-synthesis of qualitative research on the lived experiences of those living with dementia. In the authors’ review, they found studies related to themes such as living with change, coping strategies, and sociological and environmental factors. They noted that although their review was necessary, they recognized the need for further research from the subjective experience of individuals with dementia. This study highlighted the need for qualitative research specific to the lived experiences of individuals in the early-stage of AD. Without this research, it appears an aspect of understanding the disease will remain missing. Exploring the experiences of persons in the early-stage of the illness will help to foster knowledge of the sense of living with the disease, enhance empathy, and improve the support and care when interacting with individuals with the disease.

Conclusion

The purpose of this literature review was to aid in the understanding of the history of Alzheimer’s disease, the impact of the illness of caregivers, and the gap in the research that remains regarding the lived experiences of individuals in the early-stage of the disease. It is clear from the literature that there is extensive research on the medical aspects of the disease. Due to the impact of the disease on caregivers, it seems appropriate that there is a wealth of information on the role of caregiving. However, there is a paucity of research that addresses the narratives of those experiencing AD first hand.
This study was undertaken to fill this gap in the literature. Through careful exploration of the lived experiences of those in early-stage AD, medical personnel, helping professionals, caregivers, and family members may gain a deeper understanding of the needs of those diagnosed with AD. This understanding will, in turn, translate into action and advocacy on the part of those caring for individuals diagnosed with Alzheimer’s disease.

Chapter Three will present the methodology of the study. This section will include the research design, research questions, participant information, and setting of the study. This chapter also contains data collection and analysis procedures, as well as the limitations of this research.
CHAPTER 3

METHODOLOGY

The purpose of this chapter is to explore the methodological approach utilized in this study. Presented first is the research design followed by the research questions, setting, and participants involved in investigating the phenomenon of the lived experiences of individuals in the early-stage of Alzheimer’s disease (AD). Of particular focus is the role the researcher played in the data collection process. This chapter will also address the procedures used to analyze the data. This chapter will conclude with the ethical implications and limitations of this study.

Research Design

This study sought to understand the lived experiences of individuals in the early-stage of AD. The goal was to approach this without any preconceived ideas and to capture the essence of the moment and the meaning behind the experience from the subjectivity of the person with the disease. To explore the phenomenon, the story or experience of living in the early stages of AD, a qualitative approach was used. Seidman (2013) stated, “telling stories is essentially a meaning making process” (p. 7). Qualitative research is exactly this, discovering the meaning behind the phenomenon (Merriam & Tisdell, 2016). Merriam and Tisdell (2016) added, “qualitative researchers are interested in understanding how people interpret their experiences, and what meaning they attribute to their experiences” (p. 6). This research study sought to understand the perspective
rather than quantify the perception of individuals with the illness. The goal was to perform a qualitative study of individuals in the early-stage of Alzheimer’s disease in order to add to an essential piece to the literature that has been missing, the subjective experience of persons with the disease. A genre within a qualitative approach is phenomenological research. From early research, Van Kaam noted the philosophy behind this category of study is the idea of participants “really feeling understood” (Moustakas, 1994).

A subject, perceiving that a person co-experiences what things mean to the subject and accepts him, feels, initially, relief from experiential loneliness, and gradually, safe experiential communion with that person and with that which the subject perceives this person to represent. (van Kamm, 1966, p. 325-326 as cited in Moustakas, 1994, p. 12)

In other words, a researcher accepts the participant as they are in the moment of sharing his or her perceptions (Moustakas, 1994).

The idea of acceptance of the individual in the here and now is the core of what is known to be Husserl’s Transcendental Phenomenology which emerged in 1975 (Moustakas, 1994). Through Transcendental Phenomenology, Husserl “pointed to a new way of looking at things, a return to things as they actually appear” (p. 45). In other words, this approach is the study of things as they exactly are without “perception, judgment, experience, and thought” (Moustakas, 1994, p. 46). The researcher’s role is to be objective and approach a subject “freshly and naively,” construct “a question or problem to guide the study,” and “derive findings that will provide the basis for further research and reflection (p. 47).

Moustakas (1994) stated, “meaning is at the heart of a transcendental phenomenology” (p. 56). Researchers have been calling for more qualitative studies that
explore the meaning behind living with Alzheimer’s, especially in the early-stage (Beuscher & Grando, 2009). The purpose of this research was to make meaning of the perspective of the person living with Alzheimer’s as he/she shares at the moment.

Research Questions

The overarching question in this study: What are the lived experiences of individuals in early-stage Alzheimer’s disease? The following sub-questions guided this study:

1) What is your experience of living in early-stage Alzheimer’s disease?

2) How do you feel family, friends, and others perceive you because of the disease?

3) What is your experience with the medical community in being treated for Alzheimer’s disease?

Participants

Before the selection of the participants, the researcher requested approval for this study by the Institutional Review Board (IRB) (Appendix A). “This process requires the preparation of an application in which research questions, methods, and instruments of data collection, and participant sample are detailed. The IRB requires an in-depth discussion of the steps taken to protect human subjects” (Galletta, 2013, p. 40). When an individual with the illness decides he/she would like to be part of a study researchers are required to take into account multiple factors (Alzheimer’s Disease & Associated Disorders, 2004). The application had to identify the individuals participating in this study are a vulnerable population due to having cognitive impairment. Also indicated in
the application were the protective measures that were in place to ensure the safety of the potential participants in this study, such as participation being voluntary and they could withdraw at any time, the potential risks and discomforts, and the steps to take in case of injury.

When an individual with the illness decides he/she would like to be part of a study researchers are required to take into account multiple factors (Alzheimer’s Disease & Associated Disorders, 2004). Alzheimer’s Disease & Associated Disorders (2004) identified five areas that the researcher takes into consideration. First, individuals with cognitive impairment are a vulnerable population. Second, screening and assessment procedures are to be utilized for the “individual to understand the nature of the research and the consequences of participation in the protocols” (p. 171). Third, the researcher should reassess the participant’s consent to take part in the study throughout the process. Fourth, “if capacity is impaired, permission from a proxy and assent from the individual is required unless the IRB waived the requirement” (p. 171). The proxy is considered the individual’s legally authorized representative, including legal guardian, research agent, health care agent, or a family member. Finally, the research requires documentation throughout the entire process.

This research sought out individuals who were known to be in the early-stage of Alzheimer’s. Purposive sampling was used due to the significant gap in the literature that calls for future phenomenological studies specific to individuals in this stage of the illness (Bahro et al., 1995; Beard et al., 2009). Ultimately six participants were chosen to participate in the research. Once the individual verbally confirmed they were living in the
early-stage of the disease, this researcher and the participant discussed the informed consent (Appendix D). Once the participant understood their involvement in the study the informed consent was signed. None of the participants required a proxy to be part of the study.

Next, to validate the five areas and assess for the cognitive capacity of the individuals to participate in the study, the researcher was required by the IRB to administer the Mini-Mental State Examination (MMSE) (Appendix B). The MMSE “asks a patient a series of questions designed to test a range of everyday mental skills (Alzheimer’s Association, 2018, p. 1). The screening test was published in 1975 by psychiatrist Marsal Folstein (Getz, 2018). The goal of the MMSE is to provide “a brief screening test that quantitatively assesses the severity of cognitive impairment and documents cognitive changes occurring over time” (Tombaugh & McIntyre, 1992, p. 922). The test evaluates “orientation, word recall, language abilities, attention and calculation, and visuospatial ability” (Getz, 2018, p. 1). A score of 24 to 30 suggests mild to no cognitive impairment, 18 to 23 indicates mild cognitive impairment, and 0-17 suggests severe cognitive impairment (Mega, Cummings, Fiorello, & Gornbein, 1996). According to Tombaugh and McIntyre (1992), reliability and construct validity of the MMSE is satisfactory. The MMSE is an assessment to be used as part of the diagnostic process and is not a tool to officially diagnose dementia (Crum, Anthony, Bassett, & Folstein, 1993; Tombaugh & McIntyre, 1992). Participants who scored between 18 to 30, mild to no cognitive impairment, were only considered to participate in this research.
Inclusion criteria for this study included participants who scored between 18 to 30, mild to no cognitive impairment. Also required was a diagnosis of Alzheimer’s disease per the DSM-V, “awareness of diagnosis, ability to provide informed consent, and sufficient language abilities to participate in a semi-structured interview” (Matchwick, Domone, Leroi, & Simpson, 2014, p. 270). After the individual and researcher signed the informed consent and the participant scored within the range of mild to no cognitive impairment on the MMSE, this research facilitated the semi-structured interviews.

Setting

This research provided participants with three options to choose where they would like the interview to take place: telephone, face-to-face, or through a telephone/video conference services such as Facetime and Zoom. The telephone/video conference services allowed individuals to choose the setting where they would feel most comfortable during the interview when discussing their lived experience with Alzheimer’s. Four participants chose their interviews to be face-to-face, another individual selected the telephone/video service Facetime, and another participant preferred using Zoom Video Conferencing. Facetime and Zoom allowed for the inclusion of participants not located in the geographic region of this researcher.

Data Collection

This researcher performed semi-structured interviews. A semi-structured interview is a tool that uses questions as prompts to fully engage the individual to explore his or her experience (Galletta, 2013). Based on participant responses, additional open-
ended questions were asked to clarify statements regarding the lived experiences of individuals in this study. The interviews were recorded using a digital recording device.

Data Storage

The collected data- MMSE’s, informed consents, and transcribed interviews- was stored confidentially due to the sensitivity of the information. This researcher only had access to recorded conversations. Before the data was stored, it was anonymized where the researcher assigned pseudonyms to the participants to ensure confidentiality. Data was stored separately in various places, a locked safe and a computer that is password protected.

Data Analysis

In a phenomenological research method, there is a process for analyzing the data. Von Colaizzi (1978) noted several steps in evaluating the interviews in a qualitative study (Heppner & Heppner, 2004). These include getting a sense of the whole, extracting significant statements, and formulating meanings. Also involved are clustering themes, exhaustive description, and final validation.

This researcher first listened to the interviews and transcribed the participants’ words verbatim. Also taken into consideration were nonverbal cues. Between the nonverbal cues and re-reading the words of the interviewees, an attempt was made to utilize First Cycle coding with Descriptive and In-Vivo Codes (Saldana, 2009). Descriptive Codes entailed this researcher reading a participant’s experience and capturing what was said using a word to summarize the statement (Saldana, 2009). With In-Vivo Codes, this researcher used quotation marks to capture the participant’s exact
words (Saldana, 2009). After this researcher completed First Cycle coding the Descriptive and In-Vivo Codes were compared to find similarities and differences among the participants’ experiences. From this process, significant themes emerged surrounding the research.

Once the interviews were transcribed and coded, an external auditor was involved in ensuring this researcher captured and summarized the participants’ experiences. According to Cohen and Crabtree (2006), an external auditor is not a member of the research team and evaluates the accuracy of the research and “whether or not the findings, interpretations and conclusions are supported by the data” (p. 1). This researcher provided the external auditor with transcribed and coded interviews with no identifying information about the participants. The external auditor provided insight for this researcher into the overall data analysis and larger themes expressed by the individuals in discussing their lived experiences with Alzheimer’s disease. Overall this researcher and the external auditor agreed on the findings of the study.

In addition to the data gained from the research field notes from observations were used to track nonverbal cues of the participants during the interviews. Also, a journal was used during the experience to record any personal thoughts and reflections of the experience. Final evaluation of the data analysis took place once member checks were completed. Three participants agreed with the findings. Two participants shared they did not remember the interview but felt the findings were what they would have said. One participant was contacted twice, once through email and once through telephone where a voicemail was left. The participant did not return the email or telephone call.
Role of the Researcher

The researcher in qualitative research has a unique role as they are the main instrument in gathering data in the study (Heppner & Heppner, 2004; Morrow, 2005). Morrow (2005) noted, “the qualitative investigator considers a number of particular concerns that emerge from the qualitative endeavor itself” (p. 253). This author noted these concerns include subjectivity, ‘adequacy of data,’ and interpretation” (p. 253). To alleviate these concerns, this researcher maintained the authenticity of the results of this study through various protective factors. Heppner and Heppner (2004) provided the following recommendations:

As a qualitative researcher, you “bracket” your own assumptions, take field notes, write reflexive journals and tell your readers what your “filters” are. The lived experiences of the participants are what you focus on, and researchers are the instruments in this discovery process with the awareness that your worldviews shape your understanding and interpretations of the phenomena under analysis and the stories you narrate. (p. 137)

This researcher maintained an etic perspective by allowing the participants to determine the meaning of the experience of living in the early-stage of the disease. Only then did this researcher derive the essence of this phenomenon.

Trustworthiness

A crucial factor in performing this study was establishing the trustworthiness of the research and data. To constitute trustworthiness, Guba and Lincoln (1994) noted that the foundation of qualitative research must have credibility, dependability, confirmability, and transferability. To provide credibility, this study was conducted in the same manner as other phenomenological studies (Connely, 2016). Credibility is one of
the most critical criteria in qualitative research (Guba & Lincoln, 1994). To ensure
credibility, this study focused on the various individuals’ experiences and perspectives of
living in the early-stage of AD using thick description. Thick description “establishes the
significance of an experience, or the sequence of events, for the person or persons in
question. In thick description, the voices, feelings, actions, and meanings of interacting
individuals are heard” (Denzin, 1989, p. 83).

From these experiences, this researcher interpreted the meaning from the first-
hand accounts of living with the illness (Morrow, 2005). To ensure a higher level of
credibility, this researcher asked an external auditor to review the findings of the study.
According to Cohen and Crabtree (2006), this helps to enhance the accuracy and
credibility of this research. The external auditor was not a member of the research team
and did not have access to participant information. To ensure the accuracy of the findings
of the study, the external auditor evaluated the transcribed interviews and themes.

Credibility was also established by performing participant checks (Morrow,
2005). Participant checks involved discussing the results of the interviews with each
participant (Morrow, 2005). Three participants agreed with the findings; two shared that
they did not remember the conversations but felt the findings reflected what they would
have said, and two attempts were made to contact one participant who did not return this
researcher’s phone call or email.

Another criterion to develop trustworthiness in qualitative research is through
dependability deals with “the way in which a study is conducted should be consistent
across time, researchers, and analysis techniques” (p. 94). In other words, researchers can repeat the study, and the results would be consistent through time (Morrow, 2005; Petty et al., 2012). According to Petty et al. (2012), this involves an audit trail of the data. Morrow (2005) explained an audit trail consists of “a detailed chronology of research activities and processes; influences on the data collection and analysis, emerging themes, categories, or models, and analytic memos” (p. 252). To meet this criterion, this researcher utilized field notes and a journal.

Confirmability is another factor that ensures trustworthiness in qualitative research (Morrow, 2005). Confirmability involves inquiry based on the study and not on researcher bias (Petty et al., 2012). This study applied transcendental phenomenology to understand the true nature of the participants’ experiences rather than the subjectivity of this researcher.

Limitations

There were limitations to this research. First, only six individuals in the early-stage of Alzheimer’s disease participated in this study. The number of participants was non-exhaustive and did not represent the entire population of individuals in the early-stage of Alzheimer’s disease. The second limitation was the researcher was the primary data instrument. In hopes of alleviating this limitation, this study established trustworthiness through various techniques such as audit trails, an external auditor, and participant checks. A third limitation included the unpredictability of environmental distractors out of the control of this researcher and participant. Another barrier included a participant unable to be reached to verify findings of her interview and two participants
did not remember the conversations. However, the researcher collected the interview through a digital audio recording device, and an external auditor reviewed the transcribed and confirmed these researcher findings.

Summary

This chapter presented a research agenda composed of a phenomenological approach to explore the lived experiences of individuals in early-stage AD. A detailed methodology was introduced, including the rationale for the use of a qualitative research design to capture the phenomenon of individuals in the early-stage of the illness. Also included, were the sampling methods used to recruit participants, as well as, the assessments used to verify the eligibility of individuals to participate in this study. This chapter also included the data collection and analysis process, the use of an external auditor and member checks to ensure credibility, role of the researcher, trustworthiness, and limitations of the study.

Chapter Four presents the findings of this study. These findings include the major themes deducted from the participants’ experiences living in the early-stage AD. Also included will be the individuals’ perceptions of families, friends, and others due to the impact of the disease. Lastly, the participants will discuss their experiences with the medical community.
CHAPTER 4

FINDINGS

Alzheimer’s disease (AD) is a brain disease that impacts many areas of an individual’s daily functioning - memory, thinking, behavior, judgment, body movement (DSM-V, 2013). Currently, nearly 50 million people living with Alzheimer’s disease or related dementia (ADRD) (Alzheimer’s Disease International, 2017). This number is expected to triple by 2050 (Alzheimer’s Association, 2018). The increase in individuals with ADRD’s is expected to require increased efforts in understanding the disease by those in the medical profession as well as the development of added resources (Douthit, 2006). Primarily what we know about the disease comes from the medical and caregiver perspective (Roberts, McLaughlin, & Connell, 2014; Zeilig, 2013). Researchers are calling for studies that focus on learning about AD from the individuals living with the disease (Beuscher & Grando, 2009). The purpose of this study was to add to the research by exploring the experiences of individuals who live in the early-stage of Alzheimer’s, as well as increase awareness and insight into the world of living with the disease. The research question this study was trying to answer is, “What is the experience of living in the early-stage of Alzheimer’s disease?” This chapter discusses the findings of the data analyses and emerging themes from this study.
Participant Demographics

Six participants shared their experiences living in early-stage Alzheimer’s disease. Of the six participants, three were male, and three were female. Five participants were Caucasian, and one individual was African-American. At the time of the interviews four participants resided in Georgia, one individual lived in Florida, and another participant lived in the United Kingdom. The participants’ ages ranged from 54 to 76 years old, and the average age was 63 years old. All the participants met the requirement of passing the Mini-Mental State Examination (MMSE), with a qualifying score from 18 to 30. The scores ranged from 20 to 29, with an average score of 25. Each participant was assigned a pseudonym to protect confidentiality: P1, P2, P3, P4, P5, and P6.

The Experience of Living in Early-stage Alzheimer’s Disease

The participants were asked to describe their experience of living in early-stage Alzheimer’s disease. Three themes emerged from this question. The first theme was speaking about the diagnosis. The second theme surrounded challenges the individuals face. The third theme was the concept of time.

Speaking about the Diagnosis

Consistently among the participants was the theme of speaking about the diagnosis of Alzheimer’s disease (AD). The topic of sharing about having AD ranged among the individuals regarding the context of talking about their diagnosis. P1 expressed gratitude for being given the opportunity to share his experience and use his voice to help others, speak on behalf of individuals with the disease who can no longer talk and educate others. “Everywhere I go…people come up to me afterwards, and they
say, ‘You know we’ve heard from the neurologists, and we’ve heard from care partners, but we don’t hear from people like you.’” P1 speaks because it keeps him engaged and believes through the diagnosis he found his mission in life. Unlike P1’s experience of actively sharing his journey, P2 shared that he does not think friends know he has the disease, and he has not focused on sharing his diagnosis with others.

P3 pointed out that talking about the disease is an opportunity for her to educate others and help them understand AD from her perspective. She expressed, “when people don’t understand it you don’t explain to them they’ll never understand.” P3 shared that educating everybody has been “a huge learning curve” as she provided this example of an opportunity to share knowledge about the disease:

...before my book came out um I even have people crossing the street because they didn’t know how to talk to me. Um…they suddenly think that you’re different today than you were yesterday when they knew you and talked to you…I had one old gentleman that used to talk to me everyday on his way to get the newspaper then suddenly I had a feature in the newspaper and he suddenly crossed the street because he suddenly didn’t know how to talk to me even though he talked to me the day before so I the next time I saw him cross the street I crossed the street as well so he couldn’t avoid me and had to talk to me and once he understood then he was ok.

Just as P1 and P3 are open about sharing their experiences, P4 expressed that she has never been shy about her diagnosis; however she feels the need to weigh the pros and cons of telling others. At times she is cautious about letting others know about her AD. She has experienced others treating her differently in terms of others trying to make decisions for her. P4 has also found that conversations are directed towards her husband even when she is in the same room with him.
At the beginning of her journey, P5 did not share with others about her disease. However, she decided to tell her story to her local newspaper. She hopes that by sharing her story, others will be encouraged to come forward and share their lived experience. She believes other people fear to share their diagnosis due to stigma and fear, such as losing a job. When reflecting on his preference for sharing his diagnosis, P6 reported that he is relatively open about having Alzheimer’s, but he wants to be the one who chooses to tell others about his AD.

Challenges

Challenges were the second central theme the participants discussed concerning the experience of living with the disease. These challenges related to the impact of Alzheimer’s on the participants daily lives, how this contributes to emotional struggles, and despite these challenges, the individuals in this study found a solution through technology.

Impact on daily life. The participants spoke to the challenges the disease presents to their daily life which contributes to emotional struggles the individuals face. Several of these struggles include reading, environmental stressors such as noises, losing items such as keys, not being able to enjoy hobbies they once could, and not being able to make plans. P5 shared the challenge of remembering how to put makeup on in the morning. Due to her struggles with forgetting she shared that she is working harder to listen closer to pick out things to remember. She added, “I’m thinking all the time, please don’t let me forget.”
Emotions. The participants spoke about a range of emotions, from gratitude to frustration, due to the impact of Alzheimer’s. Emotions included the unpredictability from one day to the next, concern regarding the effect of the disease on others, and isolation. P1 expressed multiple times feelings of loneliness and the struggle with having to do things on his own. He started the conversation by saying, “it’s the most difficult thing I’ve ever done in my life.” Another participant expressed a sense of loss in that living with Alzheimer’s is “not what I imagined life would be.” One individual related to a sense of unexpectedness of being diagnosed as he said, “I didn’t raise my hand for this assignment.” P5 shared the one emotion that stays with her is confusion. This participant described the experience of living with the disease is like waking up from a bad dream. Another participant shared a sense of gratitude that her Alzheimer’s has not progressed as quickly as others with the disease.

Technology. Despite the hardships and challenges, two participants found a way to adapt through technology. These individuals use a device called Alexa, a voice service created by Amazon. The individuals shared that the service helps to orient them to the day. One individual explained, “if I don’t have Alexa I don’t know I’m like, ‘Alexa what day is it?’ ‘Alexa, what’s the temperature outside?’ Alexa keeps me focused.”

Sense of Time

A third major theme when the participants reflected on their experience of living in early-stage Alzheimer’s disease was a sense of time. This related to living in the present moment. P1 shared, “I try not to think of what my life is going to be when I get to that point. So what I do now is I don’t look, I try not to look past today.” P3 had the same
approach to living with AD. “I never dwell on the future because I’ve got no control over
the future. So I just enjoy today and keep looking for new challenges and new
adventures.” The same was true for P4 as she shared about just living in the moment,

You just have [sic] decide how you’re going to live once you’ve been diagnosed
with something like this and then just move forward…I’ve come to accept the
things that I can’t do anymore…cherish those ones that I can…you know at this
point there’s nothing else I can do.

P5 expressed concern throughout the interview about how much time she has left
because of the disease. Her fear surrounds the idea of not wanting to be a burden to
others, as well as, losing her individuality and not being able to do the things she enjoys.
“I don’t know what to say about death, and the fear of death and I just don’t want to be a
burden. But I fear losing my individual.” She also shared a story about her husband
asking if she was going to put up a Christmas tree in 2018. She explained, “I thought yes
there was my first thought I may not put up a Christmas tree. And then I thought I
probably will put up a Christmas tree cause I can count my Christmases now.”

Amidst a sense of time, the participants shared an acceptance of the disease. P5
expressed, “It is what it is. And I say that all the time and I know that’s the craziest thing
to say but…it is what it is.” The same was true for P1 who not only shared an acceptance
of having Alzheimer’s but also enthusiastically stated his motto, “I have Alzheimer’s, but
it doesn’t have me.” He spoke of not letting the disease define him. Three other
participants spoke further to acceptance and expressed gratitude for where they currently
are in the disease. P2 recognized, “I’m still on the good side of things,” and “there’s
people a whole lot worse off than I am.” P4 feels fortunate that her AD has not
progressed as quickly as others. P6 added, “you need to remember is everybody’s got something...got something they’re battling.”

The Perceptions of Family, Friends, and Others

The second question in this study asked the participants how they believed that family, friends, and others perceive them because of the diagnosis of Alzheimer’s disease. When it comes to the participants’ experiences with perceptions of family, the individuals spoke more to the emotions associated with the impact of the disease on their loved ones. Regarding perceptions of friends, individuals spoke of loss, support, and connection. When responding to the question regarding other’s perceptions of the participants due to the disease the main theme that emerged was an overall misperception of the individual in the early-stage of Alzheimer’s.

Perceptions of Family

When it comes to the participants’ experiences with perceptions of family, the individuals spoke not of how the family views them because of AD. Instead, the primary theme that surfaced was their concern about the impact of Alzheimer’s on their family. The individuals also shared their families struggle with acceptance of their diagnosis, as well as not wanting to be a burden on their loved ones.

Concern. Throughout the interview, P2 expressed concern regarding the impact of the disease on his spouse, “biggest thing is I hate for her having to deal with this...” P3 also related to a sense of concern for her family. She shared that even though she has the disease, she’s still a mum and wants to know what is upsetting her daughters. She shared that her daughters are amazing and how she could not do this without them. This
participant explained that the most significant learning process and how they have gotten to this point is due to talking about the disease and learning to be open to help and support each other.

P4 expressed concern in terms of wanting to protect her family from the disease. “I try to hide what I can from them…but you know there are times when I have to say this is what’s going on…” She shared at the beginning of being diagnosed she did not tell her son about the diagnosis because she did not want to worry him. P4 spoke of her husband experiencing depression because of her diagnosis and believes her son did as well. Her son described Alzheimer’s as “his mom being on death row and being innocent of her crime.” She shared that her husband described Alzheimer’s like they are on the Titanic and the family surviving and she does not.

Acceptance. P5 shared her concern about how her family is struggling to accept her diagnosis. She shared that her father had AD which is making it difficult for her mother to come to terms with her Alzheimer’s. The participant explained that her daughters are having challenges but are slowly understanding the disease.

I think that they really don’t know how to take it. I I know my husband is there little by little accepting it um it’s not as hard for them to accept. It’s probably normal cause my father had it. And so we’ve seen it. And we know what it is. Um I know my mom is very was very hard in accepting it and I guess because she had seen you know she was there with my father from day one. So she it was very hard for her. But I think that their that…slowly but surely understanding that it’s gonna happen…they’re going to accept it cause it’s something they have to but they don’t want to accept it.

P1 added that he understands the challenges it takes to be a care partner and care for someone with Alzheimer’s. He became tearful as he shared how the struggles of the
disease ultimately led to a divorce from his wife. This participant further described the relationship with his family as nonexistent, except for his oldest sister. He shared that his two older brothers think he is faking the disease. He further explained that he believes his brothers are scared because “they may see themselves developing this…as they go further along.”

Burden. Two participants shared the concern regarding not wanting to be a burden to their family. P4 feels that her husband is experiencing more of the changes because of the disease as she shared that her husband says, “she’s here, but she’s not here.” This participant feels that her part in having Alzheimer’s is easier because the hard part for her family has to deal with her. She expressed, “I don’t want it to be that way but what are you going to do.”

P5 expressed a similar experience when a doctor said, “‘don’t worry about it because you aren’t the person who will have the problem…the caregiver is.’” In response to this doctor’s advice, the participant shared, “…I don’t want to be a problem to anybody…it didn’t make me feel any better. It made me feel worse because I know that my husband would have a problem with trying to get somebody to take care of me.”

Perceptions of Friends

When the research participants shared about perceptions friends, have of them due to the disease three themes were shared: loss with a subtheme of depersonalization, support, and connection.

Loss. The theme of loss surfaced when the participants spoke of the perception friends had of them due to a diagnosis of Alzheimer’s disease. P1 started by sharing
“stigma just sucks...they’ve lost a friend...because they tend not to talk to me.” He shared about the loss of communication due to Alzheimer’s and that he has very few friends. P3 and P4 also had similar experiences in terms of loss of friendships. Concerning the perception of her friends, P3 admitted that some “just left.” When reflecting on her experiences with friends, P4 shared about the impact of the disease on some of her relationships,

...friends I thought were friends were no longer friends...once I told them I had the disease. And that bothered me because I’d known people that had the disease you know and it’s a sickness you know but they just treated me like I had the plague.

Depersonalization. Amidst this sense of loss, the individuals spoke to depersonalization. There was a sense that friends no longer thought they were capable of performing specific functions, such as understanding conversations. P1 shared that a friend he has had since the age of five does not talk to him because he is worried that if he asks the participant a question, the participant will not comprehend. This individual responded to his friend that if he does not understand he will ask a question and added, “don’t just toss me aside.”

P3 shared one of the reasons she started writing her blog was to prove that she was still capable of living life and doing things for herself. She explained,

To show them I was still capable because I can type and so the dementia never entered my world. I can type words quicker than I can think and speak them so that showed them that my intellect was still intact and they gradually came back.

P4 also experienced being treated differently because of the disease,

...and as soon as I told them I was like a different person. They didn’t want to talk to me, they wanted to talk to my husband instead you know and I’d be in the same
room and they’d want to have a conversation with him and not me and it was like I just couldn’t think for myself …it’s like I had this big ‘A’ on my forehead.

This participant also shared how a friend would come over to her home and pick out clothes for her.

Support. Despite challenges with some friends, the majority of the participants felt their closest friends have stuck by their side throughout the journey living with AD. P3 shared that her best friends have always been there for her. P4 reflected on other relationships and expressed that her real friends were supportive and wanted to know what they could do to help. P5 had a similar experience and shared throughout the interview how her close friends have been supportive. P6 described his friends’ perception of the participant is to not bother him. However, he also explained that this happened a little bit and his friends have come forward and taken him to lunch.

Connection. P2 explained that he had found a sense of connection with those with the disease which he met through a support group. “...it’s a group of people that get together that have the same problem…comradery and the fellowship there cause everybody shared in the same problem. There’s just a good positive thing…” P3 shared a positive of the disease is “I met made friends I would never met in a million years…so that’s been a very big plus.” P4 added that because of the blog she writes, “I was able to meet a lot of other people that were in my same situation.”

Perceptions of Others

When responding to the question regarding other’s perceptions of the participants due to the diagnosis the individuals shared a struggle with the overall feeling of others
depersonalizing them as a human being. This feeling took away the sense of personhood leaving them feeling as if they did not exist as a human being and were incapable of living life.

P1 explained that the perception he feels that society and other people have of him is that he does not matter and he can no longer do anything.

Just don’t forget that we we’re still people…you know. I call it “still alive inside,” that yeah we’re not exactly the person that we used to be…but because of that don’t discount us. Don’t act as if we can’t have a conversation, include us. And if there’s something that we don’t understand or that we need help with then we’re gonna ask, because we still have that ability…you know.

P1 sighed as he explained, “there’s so many barriers because of the misunderstanding of Alzheimer’s.” In response to stigma, P5 said, “I think that they feel sorry for me. Because if you knew me before then it’s hard to know me like this now.”

P1 and P6 spoke to AD being an invisible disease or disability. P6 felt, “it would be so much easier if Alzheimer’s was visible.” P1 expressed, “...when somebody has a broken arm or broken leg they have a cast. If you have a cut you have bandages…you tell somebody that you have Alzheimer’s then they go… ‘Oh’.”

P6 spoke of stigma coming from the general population and is embarrassed by the lack of support for Alzheimer’s. P3 described stigma and Alzheimer’s disease (AD) as coming from a source of fear. She feels that people are fearful of the disease because they are focused on loss,

...they think of all the negatives what you can’t do…what you um no longer have instead of what you can do and what um you still have. So they think of the negatives instead of the positives.
She shared, “it’s a bummer of a diagnosis to get, but there’s still a way to live with it.” P3 explained that part of living with the disease means talking about her experiences so others can understand. She shared that if you do not explain Alzheimer’s disease people will never understand the illness. Eventually, this participant had to move to a quiet town where people do not ignore her and go out of their way to help her. P3 expressed that people are in the old stigma and vision of dementia, including the media. She noted that the media focuses on the negatives and emphasizes that individuals with the disease are not capable of doing things. This participant said that this message is going to bring your mood down and you are going to start to think that you are not capable and are worthless.

P4 spoke to the topic of being treated differently by others. She shared that people would think that she could not think for herself and they would make decisions for her. This participant noted that people would assume she would not want to do something. P4 added that when she and her husband start talking all questions are addressed to him. She also described a time when she and her brother visited a memory care unit to consider options in her future care. The staff asked who the person was for whom they were looking at the memory care unit. At first, P4 was hesitant to share they were taking the tour for her. However, when she decided to let the staff know about her diagnosis, P4 described this reaction:

After that point they never addressed another question to me they addressed it to my brother…and I told him I don’t want to stay at a place like that…If they can’t treat me nice now, how are they going to treat me when I get here? …that was somebody who should have known better…several people did that.
Experience with the Medical Community

The participants spoke to the experience of the medical community as one where there is a loss of communication. This loss of connection equates to a feeling of sterility from the medical profession as the focus is on medication rather than providing support and dialogue about the diagnosis. As P1 shared about his experience with the medical community, he dusted his hands off to represent the professionals doing their job but having no interest in the outcome. He described his experience as his doctor gave him the diagnosis, walked out of the room, and came back with a nurse and two prescriptions and said, “here’s prescriptions for Aricept and Namenda come back in six weeks.” He further described this approach as usual for many people living with Alzheimer’s.

P3 noted that her experience with healthcare professionals is one that does not bring hope. She shared that clinicians use negative language surrounding dementia, misunderstand the reality of the disease, and recommend a ‘tablet’ which might be helpful. She noted that they need to learn about Alzheimer’s disease from the social aspect rather than just a textbook.

P4 shared that currently, she is on her third neurologist since her first two retired. She explained there is not much they can do for her and said the solution from medical professionals is, “take two aspirin and see me next week.” She feels she has a greater awareness of up to date information on the disease than her current doctor. She feels this is due to the number of neurological disorders that clinicians have to handle. However, when she tries to share the latest information with her neurologist, he discounts her information or says, “oh that’s just hogwash,” when in fact she shared that she finds the
information from recognized sources. She stated, “there’s not even a dialogue.” P4 added that the medical profession provides no support as she offered this example,

    when my friends go to the doctor with their spouses that have Alzheimer’s…they’re more confused when they leave because they don’t know next steps they don’t know what to expect you know because they’re not given any guidance…that’s frustrating.

    P5 also expressed similar frustrations with her current care in that she has not received any support from medical professionals. She reported she has never met her current neurologist since her first one retired, “I’ve never met the new one. I don’t know who he is. I’ve never met him.” The participant explained that there are limited neurologists in her area and so individuals have to see the physician’s assistant (PA). P5 started to raise her voice as she shared her experience with the PA, “... and the PA she doesn’t know what she’s talking about. God knows I feel sorry for her…” The participant added that the PA responded to her and said, ‘I’m just the PA.’”

    Two participants did not have the same negative experiences as most of the individuals in this study. P2 shared that his experience with medical professionals has been good and he enjoys going to see his doctors. P6 expressed that there is a lot of variety and differences between practitioners and neurologists, and he feels fortunate to have found the doctors that he needs.

Conclusion

This chapter detailed the findings of the research question, “What is the experience of living in the early-stage of Alzheimer’s disease?” Through this question, the participants were asked to reflect on three areas pertaining to living with the diagnosis
of AD: 1) Their general thoughts on living in the early-stage of the disease, 2) their beliefs on family, friends, and others perception of them because of the diagnosis of Alzheimer’s disease, and 3) their experience with the medical community.

Concerning the first question three themes surfaced. The initial theme revealed the experience each of the participants has in sharing their diagnosis. The second theme captured the challenges the individuals experience due to the disease. The subthemes that emerged from the struggles the participants’ experience include the impact of Alzheimer’s on their daily life, the emotions that come from the challenges, and how technology is helping to ease the daily struggle with AD. The third theme the participants expressed involved a sense of time. The individuals share how they are focused on the present moment and have found acceptance in living with the disease.

Regarding the second question of perceptions of friends, family, and others, several themes emerged. Concerning family, the participants spoke to the concern of the impact of the disease on their loved ones rather than the perception of individual because of the illness. In terms of friends the themes of loss with a subtheme of depersonalization, support, and connection surfaced. In speaking about the perception of others, emotions of feeling helpless and incapable surfaced about the theme of depersonalization.

When the participants discussed the third question with their experience with the medical community the individuals spoke to the loss of communication. The participants shared about a disconnect between giving a diagnosis and discussing in more detail about living with Alzheimer’s. Also shared was the lack of support the participants have found with the medical profession.
Chapter Five will outline the findings of this study. This information will include a summary, interpretation, and implications. Also discussed will be a discussion of future research.
Alois Alzheimer discovered Alzheimer’s disease (AD) in 1906 (Alzheimer’s Association, 2018). Since that time knowledge about the disease is predicated on medical aspects of the disease and caregivers first-hand accounts of caring for someone with the illness (Roberts, McLaughlin, & Connell, 2014; Zeilig, 2013). Researchers have called attention to a missing piece in what is known about the disease the narrative of the individual living with Alzheimer’s (Beuscher & Grando, 2009). Stigma, also defined as being negatively labeled because of the illness, has played a significant role in preventing individuals living with AD in telling their stories (Swaffer, 2014). Stigma has also been a factor in persons with the disease seeking a diagnosis and locating resources for support.

The purpose of this study was to begin to fill this gap in research and highlight the lived experiences of individuals who live in the early-stage of Alzheimer’s disease. To capture this phenomenon participants in this study were asked to reflect on three questions:

1) What is your experience of living in early-stage Alzheimer’s disease?

2) How do you feel family, friends, and others perceive you because of the disease?
3) What is your experience with the medical community in being treated for Alzheimer’s disease?

To capture the essence of living in the early-stage of AD this research utilized a phenomenological approach. The application of Transcendental Phenomenology allowed for the findings to reflect the subjective experience of the participants. Six participants were purposefully selected to share their narratives of living with the illness. This study utilized semi-structured interviews. After verbatim transcription of the interviews was complete, In-Vivo and Descriptive Codes were used to code the transcriptions to identify themes. An external auditor reviewed the findings to ensure the accuracy of the results of the study. The external auditor provided insights into broader topics of the research and overall agreed with the significant conclusions found in the research. Lastly, participants were asked to review the findings and accuracy of the data analysis.

Research Question One

Research question one asked the participants about their overall experience of living in the early-stage of AD. Three themes emerged and included speaking about their diagnosis, challenges faced by the individuals due to Alzheimer’s, and a sense of time.

Sharing the diagnosis. Regarding sharing their diagnosis, overall the participants were open to telling their journey with the disease. Researchers have noted that there is a bias. This prejudice towards individuals with Alzheimer’s is that they are limited or unable to share what life is like living with AD (Robinson, Giorgi, & Eckman, 2012; Snyder, 2009). However, all six participants in this study were able to articulate the multidimensional experience living in the early-stage from their thoughts, feelings, and
perspectives. Cotrell and Schulz (1993) expressed that the person with the disease is the missing piece in fully understanding the disease. P3 spoke to the three elements needed to understand the disease: medical information, the caregiver’s perspective, and the narrative of the individual with AD. She emphasized that without one of these pieces a full picture of the illness is incomplete. Her experience validated what Cotrell and Schulz concluded, without the narrative of these participants an essential aspect of knowledge about Alzheimer’s is unknown.

P1 shared enthusiastically about being given the opportunity to tell his story. He also noted how people would come up to him and recognize that they have heard from the medical profession and caregivers, but they have not heard from people living with the disease. Batsch and Wortman (2017) expressed conversations about the disease often exclude individuals living with AD. These researchers added that medical professionals, caregivers, and society dominate discussions about stigma concerning Alzheimer’s disease. According to P1’s experience with others wanting to hear his story, this could point to a breakdown in stigma where not only researchers want the stories of individuals with the disease, but people are beginning to understand the value of the narrative of persons living with Alzheimer’s. P3 shared that she moved to a different town because of the struggles of the perceptions of others due to the disease and how her new town has become more dementia friendly and engaged with her. The results of this study appear to point to people wanting more than just the knowledge of the medical profession and the perspective of caregivers. This desire may mean people are beginning to embrace the experience of a person living with Alzheimer’s.
Beuscher and Grando (2009) highlighted the value of a qualitative study exploring the phenomenon of living with Alzheimer’s. The researchers emphasized that this type of research would help to decrease stigma and underline the worth of a person living with the disease rather than the individual as the disease. Swaffer (2014) indicated that due to the stigma of the disease individuals may be unlikely to speak about their diagnosis or participate in research. As noted, the majority of the participants in this study are open about their diagnosis and did not hesitate to participate in this study and tell their story. P3 frequently shares her story to educate others. As mentioned previously she approached a gentleman who avoided her because of the diagnosis. It appears based on her story, and once the gentleman gained knowledge about the disease, his relationship changed with the participant. This example may mean that the power of the narrative of individuals in early-stage Alzheimer’s from their perspective may help break down the stigma of participant disability. In other words, the direction may move towards the focus on an individual’s ability to bring forward the true essence of understanding the human aspect of living with the disease.

P4 shared she is generally open in sharing her diagnosis, but in terms of stigma, she explained that she weighs the pros and cons of telling others she has Alzheimer’s. She explained there is a tendency for others to think she is different as soon as they find out she has AD. P4 added that this difference equates to people thinking she is unable to make her own decisions or is incapable of doing things for herself. Although the concept of stigma is ever present, P5 decided to share her diagnosis in hopes that others would start to open up about their journey. She acknowledged that people are afraid to tell their
story for fear of losing things such as a job. Researchers pointed to stigma as a barrier to individuals sharing their story with AD (Batsch & Wortman, 2017; Swaffer, 2014). However, this study’s conclusion is there are individuals in early-stage Alzheimer’s disease who are willing to defy stigma and educate others regardless of the common thread of negativity and fear that a diagnosis brings.

Another discrepancy in this phenomenon is the perception by the caregiver of the capabilities of the individual with the disease sharing his/her journey (Chatterji, 1998). Often this relates to a caregiver telling the story of the individual with the disease. In the interview with P6, he wanted his caregiver to sit in on the interview. During the interview, this researcher observed that his caregiver frequently jumped in to share her own story and experience as well as the experiences P6 has with the disease. At one point, the caregiver answered a research question for P6. However, the parameters of the research were revisited with both the participant and the caregiver that the experience with the question needed to come directly from P6. The conversations and research questions were pointedly redirected back to the participant. After this, P6 answered the research question from his perspective.

Capabilities. An overall theme in this study showed that individuals in the early-stage are questioned about their capabilities to live daily life. According to The Dementia Action Alliance (2016) and Fazio et al. (1999), a diagnosis of AD can mean an individual is often considered helpless and cannot care him/herself. However, the participants in this study were not only fully functioning in their ability to participate in life, but they were also fully capable of sharing their journey in early-stage Alzheimer’s and are active in
efforts to advocate on behalf of the disease. One participant frequently travels to share his story and lives on his own, a second participant still drives to attend support groups, two participants write blogs, one individual plays Pickle Ball, another participant often visits Hobby Lobby to make art for other people, and one individual actively exercises at the gym. The majority of the individual in this study choose to participate in advocacy events regarding Alzheimer’s disease. The findings regarding the participants in this study ability to live life directly contradict the stigma that individuals with Alzheimer’s disease are helpless and unable to care for themselves.

Acceptance despite challenges. The second theme related to the general experience of living in the early-stage was the challenges faced by the participants. In a qualitative study of 12 individuals, Parsons-Suhl et al. (2008) found that living with AD can be frightening and life-changing, however, the disease is not just about memory loss but a daily experience for persons with the illness. Similar to the individuals in Parsons-Suhl et al.’s study, participants in this research shared about the impact of the disease on their life. The participants in this study expressed emotional struggles that come with the disease- frustrations with not remembering, loneliness due to lack of support, and fears of being a burden to the family. Despite the challenges, even more surprising was what the participants did that was opposite of the individuals in Parsons-Suhl et al.’s study. The findings were clear that there was a range of emotions but an emphasis on acceptance, a sense of empowerment over the disease, and the focus on the welfare of others. The participants in this study spoke of a sense of time, acceptance of the illness, and adaptation to the changes of living with Alzheimer’s. The majority of the participants
focus on the present and living in the moment. One participant shared, “it is what it is,” and another added that she does not dwell on the future. Also consistent with the individuals in this study was acceptance of having Alzheimer’s and not giving the disease power as P1 shared his motto, “I have Alzheimer’s, but it doesn’t have me.” P3 acknowledged it is a tough diagnosis and one can allow external sources to impact one’s mindset, however, she chooses to live in the moment and welcomes new adventures.

Gratitude and support. Despite their frustrations, fears, and challenges the individuals in this research expressed gratitude. Within this realm of appreciation, there was a sense of selflessness. Participants shared stories of people who were experiencing greater struggles in life than living in early-stage Alzheimer’s, compassion for individuals who were in later stages of the disease, and concern for the impact of the illness on individuals who support the participants. Although the research has shown that stigma has contributed to excluding and ‘othering’ individuals with AD (Swaffer, 2014) this study’s conclusion is people living with the disease want to embrace inclusion and focus on the well-being of others.

Another form of support this research discovered were coping strategies. Gorska, Forsyth, and Maciver (2018) looked at the lived experiences of individuals with dementia by evaluating qualitative research on the phenomenon. What the researchers found were themes such as adapting to changes and coping strategies. In alignment with the theme of coping strategy, two of the participants spoke to their use of technology to cope with changes because of the disease. Participants P1 and P5 use a device called Alexa, a voice service created by Amazon, to assist them during the day. The emphasis on this is
consistent with the capabilities individuals in the early-stage have to not only live with the disease but choose to assimilate techniques to cope with the changes and face the challenges the disease presents.

Research Question Two

Research question two asked the participants to share their experiences with perceptions of family, friends, and others because of living with AD.

Perceptions of family. Underlying all the sentiments, the participants expressed regarding Alzheimer’s disease and their family, the findings of this study emphasized individuals feelings of concern, burden, and their family’s journey surrounding acceptance of the diagnosis. Of note, researchers have indicated that the well-being and adjustment of the caregiver directly impact the welfare of the person with the disease (Charlesworth et al., 2011; Granello & Fleming, 2008; Martin-Carrasco et al., 2009). This research question asked how the participants felt their families perceive them. However, the recounting of their lived experience brought forth a sense of powerlessness in terms of wanting their family to be okay in light of the negative experience that the literature often refers to (Clyburn et al., 2000). Brodaty and Donkin (2009) further validated the sense of burden and responsibility the participants feel for the caregivers’ well-being.

The most common emotion that surfaces for caregivers are depression (Cuijpers, 2005; Clyburn et al., 2000; Etters, Goodall, & Harrison, 2008). P4 related to this emotion when she shared that both her husband and son experienced depression because of her diagnosis. Two participants expressed their struggle with depression, however, the
findings indicated that this emotion did not last for an extended period, instead, the individuals moved to acceptance of their Alzheimer’s.

Karner and Bobbitt-Zeher (2006) performed a qualitative study with 20 family caregivers about their reflections on the disease. In the study, one participant shared about accepting the illness when he/she shared, “…that is just the way it is…” P5 expressed a different experience with her own family. This participant explained how her husband is slowly accepting the disease, but her daughters and her mom are having a harder time. P5 described how her mom was the primary caregiver for her father who had Alzheimer’s and how this is impacting her ability to come to terms with P5’s diagnosis.

Unlike P5’s experience of her family coming to accept her diagnosis, P1 shared about the limited contact he has with his family. His brothers think he is faking the disease. P1 feels that his Alzheimer’s creates fear for his brothers who may see the possibility of them having the disease. Behuniak (2011) noted the fear and hatred associated with the disease. This author shared that individuals with AD are considered to be like zombies and the idea that living with Alzheimer’s separates one from the general population. In Sweeting and Gilhooly’s (1997) study caregivers indicated that they believed the individual they were caring for was socially dead and how they wish the person were physically dead.

Another feeling that caregivers experience is grief specific to ambiguous loss (Karner & Bobbitt-Zeher, 2006). Boss (2009) described ambiguous loss as the physical presence individual combined with the psychological absence of an individual. In Karner and Bobbitt-Zeher’s study, the findings indicated that the emotional toll is higher than the
physical experience on the caregiver due to the gradual cognitive absence of the individual with the disease. P4 related to her husband’s experience with the caregivers in the researcher’s study as she shared that her husband has also noticed her increasing psychological distance.

Perceptions of friends. The participants discussed three themes regarding the perception of friends due to the impact of Alzheimer’s disease: loss with a subtheme of depersonalization, support, and connection.

Connection and support. Brodaty et al. (1997) performed a study where individuals with dementia and their care partners were involved in a 10-day caregiver training program. Through this program, caregivers found a connection and support with other caregivers. The participants discovered a common bond through the shared experience of caring for someone with dementia. Although this dissertation focused on the experience of individuals with the disease, participants similar to the caregivers in Brodaty et al.’s study expressed a sense of comradery with others who live with Alzheimer’s. The individuals shared that the disease allowed them to meet new people living with AD who shared in their experiences. Toseland and Rossiter (1989) also expanded on the hope and awareness of the shared experience among caregivers. Two participants also used the word ‘shared’ to describe the commonality they have found with other people living with the illness. Yalom (2005) defined this desire to relate and common bond as universality.

Loss. When the participants spoke of loss concerning friends they spoke of the absence of friendships. The individuals also discussed the perception that friends thought
they were no longer capable of performing activities. Unfortunately, throughout the literature depersonalization is a common theme that speaks to the view that an individual is the illness and has deficits (Fazio et al., 1999; Snyder, 2009; Swaffer, 2014). For example, P1 became angry when he explained that stigma is the reason he has lost friends. P3 had to prove she was capable of performing activities, so she started a blog related to her journey with dementia. P4 was frustrated when she shared how a friend wanted to pick out clothes for her and how others try to speak on her behalf when she is in the room. P5 shared that his friends would take him to lunch, however, he had a perception that his friends did not want to bother him. The feelings of anger and frustration that two participants expressed, the action P3 took to prove her abilities, and the feelings that others wanted to leave P5 alone indicate that individuals with the disease are paying the price and being impacted by what the literature commonly addressed in regard to the separation of individuals with Alzheimer’s disease from the remainder of society (Behuniak, 2011).

Perceptions of others. In conjunction with loss regarding friends, the same theme of depersonalization surfaced when speaking about others perceptions of the participants due to Alzheimer’s. The overall theme of depersonalization for the individuals encompasses feelings from people that they do not matter and can no longer do anything. The individuals spoke to a loss of personhood, stigma, fear, and being treated differently. Mitchell, Dupuis, and Kontos (2013) validate the experiences of individuals in this study. These authors related the words and images of depersonalizing individuals with AD to a “suffering of personhood.” P4 described the image as if she had a big ‘A’ on her
forehead. This participant’s description may mean there is a sense of persons with Alzheimer’s disease living with a plague and needing to be isolated.

Along with these images, there is a theme throughout the literature where individuals with Alzheimer’s are referred to as zombies (Behuniak, 2011) and considered ‘the living dead’ (Dementia Action Alliance, 2016; Mitchell, Dupuis, & Kontos, 2013). Through exploring his journey with the perception of others P1 captured the essence of his experience of a social death commonly found throughout the research (Batsch & Wortmann, 2017). This participant’s words, “still alive inside,” emphasize the contradiction to what others, who are not living with the disease believe that the person with Alzheimer’s is no longer living. He explained he might no longer be the same person, but he is capable and still a human being.

Swaffer (2014) pointed out that stigma is a dominant theme throughout the literature about individuals living with the illness. This stigma comes in two forms—external and internal. As mentioned before, P3 shared that the external stigma can impact an individual internally. However, she chooses not to allow the stigma to impact her life. Despite the stigma, the participants expressed a level of acceptance of living with Alzheimer’s. These findings may suggest that individuals with the disease are underestimated and have a greater resolve and resilience to living with the illness than initially thought.

Research Question Three

This research question asked the participants to reflect on their experience of living in the early-stage of Alzheimer’s with the medical community. To date and the
knowledge of this researcher, this is the first study that asked individuals specifically in
the early-stage of Alzheimer’s disease to share their interactions with the healthcare
community. The medical perspective of the illness has dominated the research rather than
seeking the viewpoint of the person living with the illness about their treatment by
healthcare professionals (Bahro, Silber & Sunderland, 1995; Cotrell & Schulz, 1993).

This study’s findings similarly captured what Robinson et al. expressed in 2012, the
needs as experienced by those who are living through the early stages of the
disease is still poorly understood, and the care they receive is far from being well
developed. These patients are only beginning to receive recognition outside the
field of medical research and it is only recently that the care they receive has
become an issue of concern in society. (p. 217)

The participants in this research highlighted issues with the medical community that
included a focus on medication, being misunderstood and discounted as an individual,
feeling a sense of sterility rather than support, and lack of communication about the
diagnosis rather than next steps in living with Alzheimer’s disease. Individuals in this
study also reiterated what Gitlin and Hodgson (2018) described as the cycle of despair
that continues throughout the healthcare profession. According to these researchers,
within this cycle, medical professionals offer no solutions to living with the disease
because they are unable to provide a cure. This approach ultimately leads to a lack of
relationship, support, and care between the individual with the disease and their doctor.
The findings of this study may indicate an overall issue of the connection between the
medical profession and the individuals that are seeking guidance and support after
receiving a diagnosis of Alzheimer’s disease. Ultimately this may mean the medical
profession is relating to individuals with the disease on a scientific level and are focused
on the research aspect of the disease and finding a cure and the individual with AD remains objectified and unseen.

The majority of participants in this study spoke to this level of disconnection. P3 spoke to the significance of the medical community needing to understand the disease from a social rather than a medical perspective. P1 and P3 shared similar experiences of their doctors wanting to give them medications and see them again in six to eight weeks. As P1 described his experience, he dusted his hands off as if to represent his doctor no longer needing to spend time with him after giving him the diagnosis and that there was not anything else he could do for the participant but provide him with medication. P5 described not having met her current doctor and only having communication with the physician’s assistant (PA). P4 described how she attempts to discuss the latest research with her doctor who only discounts the information the participant shares. This participant also admitted people she knows feeling more confused about the disease after receiving a diagnosis because the medical community does not provide information and support.

P3 also mentioned what Zeilig (2013) noted about the language of the medical community surrounding the illness. Zeilig emphasized that the language of the medical community brings a sense of dread and fear. P3 expressed that the words the healthcare profession use to describe the disease are negative and not hopeful. This participant also observed the first understanding the medical profession has about the disease comes from textbooks contributing to a disconnect of the reality of living with the disease. This study concludes that the missing piece of understanding the disease is the one area that has
been overshadowed by the medical community (Johannessen & Moller, 2011)-
knowledge of Alzheimer’s disease from the person with the illness. Noted in Parsons-
Suhl et al.’s (2008) research is that persons living with AD have a lot to teach the world
about forgetting.

Robinson et al. (2012) noted how the medical profession’s misunderstanding of
the person with Alzheimer’s could impact how the individual ultimately adjusts to the
disease. Although the research points to a negative impact on the person with the disease,
it appears the participants in this study are adjusting to life despite the medical
community’s misunderstanding of how to communicate with individuals with AD. The
participants in this study expressed proactively attempting to educate the medical
community on their experiences and reaching out for support and information.

Implications for Practice

The findings of this study have implications that are far-reaching and begin with
the individual living with Alzheimer’s disease, to persons who provide care and support
to persons with the illness and ultimately to society at large. The primary focus of this
research was to understand Alzheimer’s disease from the perspective of the individual
living with the illness. The study assessed the overall experiences of living with AD, the
participants’ thoughts regarding family, friends, and others perceptions of them due to the
disease, and experiences with the medical community.

Foremost, this study highlight’s a paramount social change from ‘othering’
individuals with AD towards the inclusion of the person living with the disease. The
participants in this research validated the ongoing stigma that individuals with the disease
are inhuman or capable of participating in their own lives and the world at large. Although the belief exists that Alzheimer’s robs a person’s ability to share his or her story, the individuals in this study defied this belief by articulating their experiences with all three questions. Not only were the participants able to share their overall experiences, but they expressed specifics to challenges faced due to the disease, coping skills, the impact of Alzheimer’s on relationships, as well as interactions with the medical community. This study presents the findings that despite previous beliefs, individuals in the early-stage of Alzheimer’s disease can share their lived experiences. These findings indicate that individuals with AD are an important piece in understanding the multidimensional aspects of the illness. Therefore, assisting individuals in sharing their story may not mean speaking in their place but providing an opportunity to share and be heard. If an individual with the disease wants to share his/her experience and they are unheard the reasons for the person’s narrative being untold need to be explored to overcome these barriers. Allowing more individuals with Alzheimer’s disease to share their journey may begin to normalize the experience for others to discuss their experiences with the illness, as well as the world at large to start to view persons not as the disease but as individuals living with AD.

Another implication of this study is the steep learning curve that exists in understanding what life is like when living with Alzheimer’s disease. The current knowledge has come from research, textbooks, and caregivers’ experiences. Although the knowledge from those perspectives is important in understanding AD, only a person with the disease can truly describe how the disease is impacting his/her life biologically,
psychologically, and sociologically. Sharing his/her unique perspective may help aid medical professionals and caregivers to understand how the disease is different for each person. This first-hand knowledge would be significant in designing an individualized treatment and support plans that focus on the individual’s strengths and capabilities rather than deficits. The experience of individuals in this study finds that they are just as capable of communicating about the multidimensional aspects of Alzheimer’s as the medical community and caregivers. This ability for individuals to communicate implies that persons living with the disease can speak to their unique needs in treatment, care, and support. If a person with AD wants to participate in his/her treatment plan and is left out, the reasons for this exclusion should be investigated to eradicate the cycle of despair.

Participants in this research discussed their abilities to live life, however, they reinforced that the world remains focused on inabilities. Due to the increasing number of individuals with the disease, this is a crucial time for caregivers, medical professionals, and society to shift the cycle of despair and change in perception of the capabilities of individuals living with the illness. Through this study speaks to the need for the world for the focus to shift from inabilities to the strengths of persons in the early-stage. What this means is that even though the person is changing due to the disease they will communicate their needs.

The findings of this study found that caregivers are not the only individuals experiencing burden due to the impact of the disease. The majority of the participants in this study expressed concern in how the disease is impacting others. The individuals expressed a sense of responsibility for how the disease ultimately plays a role or is
playing a role in the welfare of their family. Unfortunately, the participants have experiences where medical professionals stressed that ultimately the disease only impacts the caregiver. Again, this approach emphasizes how the experiences of individuals with the disease are depersonalized. Therefore increased awareness and empathy of the thoughts, feelings, and experiences of the account of living with Alzheimer’s would play an essential part in valuing the life and personhood of an individual with the illness.

The narratives in this study also bring to light a profession that is often not recognized in providing empathy and support to individuals with Alzheimer’s disease-the counseling profession. As more individuals are diagnosed with the disease (Alzheimer’s Disease International, 2017) counselors will begin to have clients that are impacted by the disease. Due to the essential nature of individuals needing support in sharing their journey, this calls into question the knowledge, skills, and qualifications of individuals in the mental health profession to work with someone with Alzheimer’s disease. To provide mental health support to a person living with AD, a counselor should consider the following:

1) Do I have a basic understanding of the medical aspects of Alzheimer’s disease-symptoms, behaviors, process of receiving a diagnosis?

2) Do I have a holistic viewpoint of the person with this diagnosis- who they are, likes, dislikes, a psychosocial history, his/her perceptions of life as well as being diagnosed with AD?

3) Have I reflected on my own biases, stereotypes, and stigma regarding persons living with Alzheimer’s?
4) Am I aware of counseling techniques that are effective when working with individuals with the disease?

5) Am I aware of resources- medical professionals i.e. neurologists, support- i.e. groups, literature?

The timeliness of learning about the lived experiences of living in early-stage Alzheimer’s disease speaks to the current gravity of the illness in that it is considered to be a world public health crisis, the burden is tremendous, and the impact of AD is significant (Gitlin, 2019). The significance of this study is the narrative, the voice, the experiences of persons living with the disease no longer needs to be in the shadows. The implications rest on the inclusion of individuals with the disease- not as disease entities but as humans experiencing a disease who need the same support, resources, and consideration as persons living with other diseases.

These findings mean that a shift needs to occur in the perception of the abilities of persons living with Alzheimer’s. These individuals provide value in not only sharing the experiences in living with a complex multidimensional disease but also remain productive members of society. There is a need for increased understanding that caregivers are not the only individuals feeling the impact of the disease. Individuals in the early-stage are highly sensitive to how the diagnosis is affecting others.

This study concludes that awareness is needed among medical professionals and caregivers to include individuals with the illness in the treatment process. Also, to focus on the human aspect of AD to break the cycle of despair. Lastly, there is a call to the
mental health professionals to evaluate the effectiveness of counselors and future clinicians working with individuals with Alzheimer’s disease.

Recommendations for Future Research

There are several areas of future research that is needed to bring the experiences and voices of the individual with Alzheimer’s into the spotlight. Also needed are additional qualitative studies from the perspective of individuals in the early-stage including topics such as speaking about their diagnosis and the impact of sharing their story. Another area is an individual’s use of coping skills. This study would seek participants use of techniques to face the challenges with the disease. Another experimental study would include the implementation of technology, such as a speech generating device from Amazon, like Alexa, in the life of individuals in early-stage Alzheimer’s disease. Findings from this research could result in adding another technique to assist in the daily life of persons with AD. Another area of study from a qualitative perspective would be focusing on the strengths of the individual with the disease.

One area of future research is individuals in the early-stage use of mental health services. A study of this kind would explore what persons with the disease need from counselors in supporting them. This study would align with research evaluating the effectiveness of counselors in working with individuals in the early-stage of AD. The significance of these two studies would identify any barriers in individuals with the disease seeking counseling and assess the readiness of counselors in working with persons in the early-stage of the disease.
Another qualitative study would explore medical professionals understanding of Alzheimer’s disease from the social rather than the biological perspective of the disease. This research would entail discussing healthcare professionals interactions with individuals with the disease, struggles they face with sharing a diagnosis, assisting individuals with support and resources, and any challenges faced with connecting with persons in the early-stage of AD. The implications of this study could bridge the gap in the relationship between medical professionals and individuals with the disease.

Conclusion

After many years of the focus on Alzheimer’s disease from the medical and caregiver perspectives (Bahro, Silber & Sunderland, 1995; Cotrell & Schulz, 1993), and researchers calling for studies from the perspectives of individual’s with Alzheimer’s disease (Cotrell & Schulz, 1993), this research answered the call for learning about the illness from the first-hand accounts of persons living in the early-stage of AD. This study is one of the few that explored the phenomenon of living in early-stage AD from the perspective of the person with the disease from a qualitative approach. This research may be the first of its kind investigating individuals interactions with the medical community.

Findings from this research contradict the stigma that exists within the medical community, caregivers, and society and finds that individuals in the early-stage of the disease are able and willing to articulate their experiences and educate others despite the common theme of negativity and fear that surrounds the disease. Persons with the illness are capable of applying coping skills to deal with the challenges because of Alzheimer’s. Individuals in the early-stage are sensitive to how the disease impacts others and are
concerned regarding the future implications of AD. This study also found that there is a disconnect in the medical community regarding the human aspect of living with the disease. This study attempted to fill a gap in the literature of the narrative of persons with the illness. However, the research is still in the beginning stages of understanding what living with the disease means from the perspective of the individual living in early-stage Alzheimer’s disease.
REFERENCES


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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL
Wednesday, July 25, 2018

Ms. Jenny Heuer
Mercer University
Other
2930 Flowers Road South
Atlanta, GA 30341

RE: The Lived Experiences of Individuals in Early Stage Alzheimer’s Disease: A Qualitative Study (H1807180)

Dear Ms. Heuer:

On behalf of Mercer University’s Institutional Review Board for Human Subjects Research, your application submitted on 23-Jul-2018 for the above referenced protocol was reviewed in accordance with Federal Regulations 21 CFR 56.100(a) and 55 CFR 46.110(b) (for expedited review) and was approved under category(s) 06, 07 per 61 FR 66364.

Your application was approved for one year of study on 25-Jul-2018. The protocol expires on 24-Jul-2019. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

Item(s) Approved:
A new student application for qualitative research study design using semi-structured interviews to gain greater insight into the experiences, feelings, and preferences of persons living in the early-stage of Alzheimer’s disease.

NOTE. You MUST report to the committee when the protocol is initiated. Report to the Committee immediately any changes in the protocol or consent form and ALL accidents, injuries, and serious or unexpected adverse events that occur to your subjects as a result of this study.

We at the IRB and the Office of Research Compliance are dedicated to providing the best service to our research community. As one of our investigators, we value your feedback and ask that you please take a moment to complete our Satisfaction Survey and help us to improve the quality of our service.

It has been a pleasure working with you and we wish you much success with your project! If you need any further assistance, please feel free to contact our office.

Respectfully,

[Signature]

Ava Chambers-Richardson, Ph.D., CIP, CCM.
Director of Research Compliance
Member
Institutional Review Board

“Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice.”

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Mercer University IRB & Office of Research Compliance

Phone: 478-301-4101 | Email: ORC_Mercer@Mercer.edu | Fax: 478-301-2329
1301 Mercer University Drive, Macon, Georgia 31207-0001
APPENDIX B

MINI-MENTAL STATE EXAMINATION
# Mini-Mental State Examination (MMSE)

**Instructions:** Score one point for each correct response within each question or activity.

<table>
<thead>
<tr>
<th>Maximum Score</th>
<th>Patient’s Score</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td></td>
<td>“What is the year? Season? Date? Day? Month?”</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>“Where are we now? State? County? Town/city? Hospital? Floor?”</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient’s response is used for scoring. The examiner repeats them until patient learns all of them, if possible.</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>“I would like you to count backward from 100 by sevens.” (93, 86, 79, 72, 65, …) Alternative: “Spell WORLD backwards.” (D-L-R-O-W)</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>“Earlier I told you the names of three things. Can you tell me what those were?”</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>“Repeat the phrase: ‘No ifs, ands, or buts.’”</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>“Take the paper in your right hand, fold it in half, and put it on the floor.” (The examiner gives the patient a piece of blank paper.)</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>“Please read this and do what it says.” (Written instruction is “Close your eyes.”)</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>“Make up and write a sentence about anything.” (This sentence must contain a noun and a verb.)</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>“Please copy this picture.” (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)</td>
</tr>
<tr>
<td>30</td>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX C

MINI-MENTAL STATE EXAMINATION SCORING
**Interpretation of the MMSE:**

<table>
<thead>
<tr>
<th>Method</th>
<th>Score</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single Cutoff</td>
<td>&lt;24</td>
<td>Abnormal</td>
</tr>
<tr>
<td>Range</td>
<td>&lt;21</td>
<td>Increased odds of dementia</td>
</tr>
<tr>
<td></td>
<td>&gt;25</td>
<td>Decreased odds of dementia</td>
</tr>
<tr>
<td>Education</td>
<td>&lt;21</td>
<td>Abnormal for 8th grade education</td>
</tr>
<tr>
<td></td>
<td>&lt;23</td>
<td>Abnormal for high school education</td>
</tr>
<tr>
<td></td>
<td>&lt;24</td>
<td>Abnormal for college education</td>
</tr>
<tr>
<td>Severity</td>
<td>0-17</td>
<td>Severe cognitive impairment</td>
</tr>
<tr>
<td></td>
<td>18-23</td>
<td>Mild cognitive impairment</td>
</tr>
<tr>
<td></td>
<td>24-30</td>
<td>No cognitive impairment</td>
</tr>
</tbody>
</table>

**Interpretation of MMSE Scores:**

<table>
<thead>
<tr>
<th>Score</th>
<th>Degree of Impairment</th>
<th>Formal Psychometric Assessment</th>
<th>Day-to-Day Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-30</td>
<td>Questionably significant</td>
<td>If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.</td>
<td>May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.</td>
</tr>
<tr>
<td>20-25</td>
<td>Mild</td>
<td>Formal assessment may be helpful to better determine pattern and extent of deficits.</td>
<td>Significant effect. May require some supervision, support and assistance.</td>
</tr>
<tr>
<td>10-20</td>
<td>Moderate</td>
<td>Formal assessment may be helpful if there are specific clinical indications.</td>
<td>Clear impairment. May require 24-hour supervision.</td>
</tr>
<tr>
<td>0-10</td>
<td>Severe</td>
<td>Patient not likely to be testable.</td>
<td>Marked impairment. Likely to require 24-hour supervision and assistance with ADL.</td>
</tr>
</tbody>
</table>

**Source:**  
APPENDIX D

INFORMED CONSENT
The Lived Experiences of Individuals in Early-Stage Alzheimer’s Disease: A Qualitative Study

Informed Consent

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigator
Jennifer Anne Heuer, MS, LPC, NCC Penfield College, Counseling
3001 Mercer University Drive, Atlanta, GA 30341, 770-655-6282
W. David Lane, Ph.D., LPC, NCC, LMFT, AAMFT, CPCS, Mercer University, Counseling Department, 3001 Mercer University Drive, Atlanta, GA 30341, 678-547-6301

Purpose of the Research
This research study is designed to gain greater insight into the experiences, feelings, and preferences of persons living the early-stage of Alzheimer’s.

This research aims to answer the call to conduct qualitative research and bridge the gap in the literature regarding individuals living in early-stage Alzheimer’s disease. This research also aims to help foster knowledge of the sense of living with the disease, enhance empathy, and improve the support and care when interacting with individuals with the disease.

Procedures
If you volunteer to participate in this study, you will first be asked to take the Mini Mental State Exam (MMSE) which will be administered by the Primary Investigator, Jenny Heuer. The MMSE measures cognitive status in adults. Participants who score 18 to 30 will be asked to participate in the second step of this study which includes an interview to discuss the experience of living in the early-stage of Alzheimer’s disease.

Your participation in the interview will take approximately 45 minutes to 1 hour. Participants may be contacted after the interview to ensure accuracy of data.

Potential Risks or Discomforts
There are no foreseeable risks in taking part in this study.

Potential Benefits of the Research
There are no benefits to the participant taking part in this study.

The potential benefits to science and society that may result from this research is a greater understanding, empathy, and decreased stigma regarding individuals with Alzheimer’s disease.

Confidentiality and Data Storage

Mercer IRB
Approval Date 09/28/2018
Protocol
Expiration Date 07/24/2019

Rev. January 2017
In order to ensure confidentiality pseudonyms will be assigned to participants. Hard copies of the data will be stored in a locked filing cabinet. Data will be stored on a computer that is password protected. Access to data will only be available to the researcher and members of the team.

An audio recording device will be used to record information to record semi-structured interviews. Access to these recordings will only be available to the researcher and members of the team. The recordings will be stored throughout the duration of the project and will then be destroyed.

**Participation and Withdrawal**
Your participation in this research study is voluntary. As a participant, you may refuse to participate at any time. To withdraw from the study please contact Jenny Heuer at 770-655-6282 if you wish to withdraw. If the data is anonymous, subjects cannot withdraw after data collection has taken place.

**Questions about the Research**
If you have any questions about the research, please speak with Jenny Heuer at 770-655-6282 or W. David Lane at 678-547-6301.

**[In Case of Injury]**
It is unlikely that participation in this project will result in harm to subjects. If an injury to a subject does occur, he or she may be seen at a hospital or physician of his or her choice. All expenses associated with care will be the responsibility of the participant and his/her insurance.

**[Incentives to Participate]**
There are no incentives in participating in this research.

**[Audio or Video Taping]**
Audio taping will be used for the purposes of recording the participants’ interviews. Pseudonyms will be assigned to participants to establish and maintain confidentiality.

**[Reasons for Exclusion from this Study]**
Subjects will be excluded from this study if they do not have early-stage Alzheimer’s disease. If the subjects do indicate they have early-stage Alzheimer’s disease and score 17 points or less on the Mini Mental State Exam, they will be excluded from the study.

This project has been reviewed and approved by Mercer University’s IRB. If you believe there is any infringement upon your rights as a research subject, you may contact the IRB Chair, at (478) 301-4101.

You have been given the opportunity to ask questions and these have been answered to your satisfaction. Your signature below indicates your voluntary agreement to participate in this research study.

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<tr>
<th>Research Participant Name (Print)</th>
<th>Name of Person Obtaining Consent (Print)</th>
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<td>Research Participant Signature</td>
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