USING THE MOTIVATED INFORMATION MANAGEMENT THEORY AND THE SOCIAL SUPPORT THEORY TO UNDERSTAND CAREGIVER PERSPECTIVES OF CURRENTLY AVAILABLE HEALTH COMMUNICATION REGARDING DEMENTIA: A QUALITATIVE STUDY

By

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Abstract

Dementia brings a cascade of changes into the life of not only the person facing it, but also the lives of the supporting family and caregivers. Dementia manifests with a gradual decline, or in some cases, a variably progressive decline in cognitive abilities. This decline requires the individual to rely more and more on caregivers. Caregiving necessitates the giving of oneself for another's sake and oftentimes results in negative physical and social-emotional side effects. To navigate through the changes that are happening to their loved ones, as well as to themselves, caregivers need educational and social support. The purpose of this communication research was to seek the perspectives of adults in the Ohio Valley who are caring for their parents with dementia, regarding their experiences with searches for dementia health communication. The theory of motivated information management and the social support theory were the guiding frameworks for understanding these perspectives. Qualitative methods included a social constructivist, phenomenological approach as the ontological lens through which the researcher looked for themes in data taken from semi-structured interviews. The findings of this study specifically pointed out that current health communication regarding dementia may not contain enough relatable information about dementia staging. Six themes emerged from this study including: 1. Brain changes motivate searches for more dementia health communication. 2. Perceived breakdowns happen in certain trajectories of health communication regarding dementia. 3. Avenues of in-person dementia support/resources are better one-on-one. 4. Avenues of online dementia support/resources are variable. 5. Caregiver perspectives of what they know about dementia align with the literature. 6. Communication changes with parents after dementia.

Keywords: dementia, caregiving, health communication, theory of motivated information management, social support theory, phenomenology, Global Deterioration Scale (GDS)

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Chapter One: Introduction

Overview

The purpose of this qualitative, phenomenological research was to explore the lived experiences of adult caregivers in the Ohio Valley who are searching for health communication about their parents' dementia. The problem is that dementia-care practitioners in the Ohio Valley need more information about how caregivers search for and perceive health communication in order to implement best practices for meeting the needs of this growing population. This chapter introduces the research including a background of the topic, statement of the problem, statement of the purpose and significance of the study, research questions and sub-questions, definitions of terms that are relevant to this research, assumptions, and communication-centric theoretical constructs.

Background

Dementia is an epidemic that currently affects approximately 55 million people worldwide and is the "fastest growing clinical population, nationally and globally" (Bayles et al., 2020, p. 1). Alzheimer's is the most prevalent cause of dementia, which manifests with a gradual worsening of cognitive abilities. Cognition refers to a person's overall capacity to analyze any incoming sensory information and use the information to plan and execute actions in everyday life (Bayles et al., 2020). "Adults with dementia experience difficulty completing daily routines, solving problems, and orienting to time and place. They frequently misplace items, withdraw from social engagements, and experience changes in personality" (Smallfield, 2017, p. 1). Dementia is a syndrome disorder that results in neurodegeneration (Weiner & Lipton, 2009). Cells in the brain, called neurons, slowly die causing the disruption of communication between the central nervous system and other systems in the body. Because dementia is considered a problem to contend with later in life, this epidemic may not be a time-pressing issue for most individuals. However, for those who are providing care to loved ones experiencing the effects of cognitive decline, this epidemic is a consuming thought that becomes overwhelming and difficult to bear.

This study seeks to understand the perspectives of adults in the Ohio Valley who are caring for their parents with dementia, regarding their experiences with searches for dementia health communication. It is time to take a closer look at the familial caregiver perspectives in the Ohio Valley region of the United States regarding what is missing from current health educational support systems; more specifically how to effectively care for a parent with dementia. The results of this study may add to the evidence-based tools in professional practice by revealing to dementia care professionals how adult children communicate about and search for interventions that will improve the quality of life for their parents living with dementia. Because this study aimed to explore the lived experiences of individuals caring for parents with dementia, it is a phenomenological study of how caregivers perceive currently available health communication, social support, and/or formal support regarding Alzheimer’s and dementia care.

In one scenario, a daughter was faced with the responsibility of caring for her aging father, who began demonstrating short-term memory problems over time. The physician determined that the father had dementia and required 24-hour supervision due to his increasing levels of confusion. The father was able to walk without assistance and perform self-care tasks with only a minimal amount of prompting. The daughter decided that between her and her siblings, they could provide 24-hour supervision. The daughter began to feel energized and privileged to take on the task of caring for the man who cared for her most of his life. Then, two to three weeks after her father moved in, she became overwhelmed and exhausted. Her father got out of bed at 4:00 a.m. and walked around the house, even leaving the house at times. She had to call the neighbors to be on the lookout for him, only to find him wandering down the street. He usually communicated his wants and needs at a basic level, but he could not seem to explain why he kept leaving the house. This new routine had taken a toll on the daughter’s body, mind, and spirit. She contemplated placing him in a nursing home, but her siblings pleaded with her to keep him at home a little longer. She felt lost, wondering if there was an easier way to do all of this. She was faced with a decision on how and where to look for resources that would give her the information she needed.

She made the decision to search the internet to find out more about dementia and more about how to be an effective caregiver. She came across social media groups, consisting of other caregivers, and found she was not alone. She combed through websites, blogs, and online organizations that specialize in Alzheimer’s and dementia. She was overwhelmed by the different avenues and was unsure of how to make sense of it all. She was lucky enough to join a social media group that pointed her in the right direction for her caregiver needs. Through the group, she found a local speech-language pathologist and occupational therapist who specialized in dementia cases (Swan et al., 2018; Smallfield, 2017). She also found a neuropsychologist who gave more insight into the nature of the behavioral aspects of cognitive decline. The professionals were able to formally assess her father’s stage of dementia and were able to educate her on using strategies to better understand her father’s behaviors (Allwood et al., 2017).

The daughter learned that her father’s dementia was causing him to be living in his past. Her father used to work in the coal mine and his shift would start before the sun came up. The reason he began getting up at 4:00 a.m. was because he believed he was living in the days when he was working in the coal mine. The speech pathologist and occupational therapist were able to give the daughter strategies, such as changing the lighting in her father's living space, so that he stopped perceiving the dark as a time to get ready for work (Urrestarazu & Iriarte, 2016). Other strategies included engagement in meaningful tasks, appropriate for her father's level of cognition according to his dementia stage. The daughter and her siblings were able to assist him in completing these tasks to keep him engaged, help him tire at appropriate times of the day, and give him a sense of purpose (Mansbach et al., 2016, 2017). The information gained from her online searches became so valuable that she was not only able to keep her father out of a nursing facility a little longer, but she began discovering new ways to communicate with him.

Evolving Approach to Dementia Caregiving

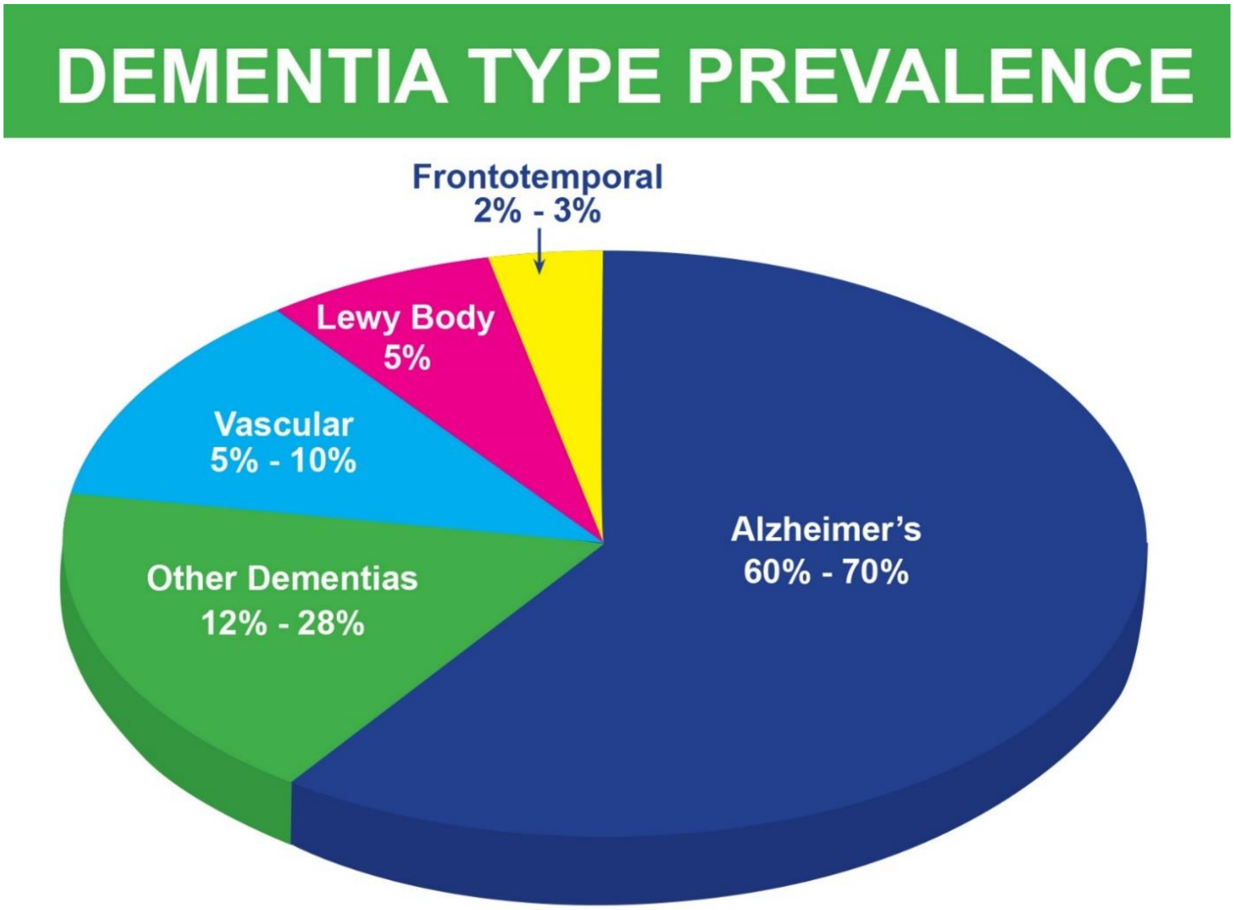
Unfortunately, a successful scenario such as the one described above is rare. In fact, prior to the 1950s people who were considered to have dementia were mainly placed in psychiatric hospitals, or asylums (Weiner & Lipton, 2009). That trend changed and continues to change as the research contributes to evidence-based knowledge on how to care for individuals with neurodegenerative decline. A revolution is happening in the way society is now viewing Alzheimer's and dementia. Legislation, such as the Omnibus Budget Reconciliation Act of 1987 (OBRA), has played a big part in the perception of how to care (Landes & Lillaney, 2019). OBRA, sometimes called the Nursing Home Reform Act, implemented legislation that mandates expectations in standards of nursing care.

The *Diagnostic and statistical manual of mental disorders* (DSM-1 through DSM-5) is a professional guide that describes the diagnostic criteria for mental disorders. As it has evolved through the years, the differentiation between psychoses and dementia-related cognitive decline has become more distinct (Weiner & Lipton, 2009). OBRA and diagnostic specifications in the DSM have allowed for caregiving in the realm of dementia to eventually land in nursing and memory care facilities. Now more than ever though, many families are trying to care for their loved ones at home for as long as possible before placing them in a nursing care facility. According to Williams et al. (2018), the Alzheimer’s Association reported that “there are currently 15.9 million in-home dementia caregivers in the United States, saving the healthcare system an estimated $230 million annually by providing an estimated 18.2 billion hours of unpaid care” (p. 220). Research around this topic has boomed in the last 50-60 years, and the medical field has taken a more thorough approach to training healthcare teams to better care for individuals with Alzheimer’s disease and other dementias. Unpaid caregivers are benefiting from this research as more in-person and online educational resources are becoming available. Health communication and caregiver education are essential components of successful dementia care.

One important aspect of caregiver education exists in learning about the nature of dementia. Because it is a progressive disease, Alzheimer’s can be mistaken for age-related memory loss during its early stages. A more recently recognized pre-clinical risk factor for Alzheimer’s disease is called Mild Cognitive Impairment (MCI). MCI causes changes that are noticeable to the person going through them; however, those changes do not interfere with everyday functional living (Alzheimer’s Association, 2022). Therefore, many individuals do not seek health information regarding Alzheimer’s and dementia until their MCI has progressed into a clinically recognizable cognitive loss. “The global prevalence of MCI among community dwellers is over 15% and is affected by age, gender, education level, and region of study sites” (Bai et al., 2022, p. 1). Thaipisuttikul et al. (2022) studied conversion rates from MCI to dementia and found that 18.4% of their participants with MCI converted to dementia after about a year.

Dementia Diagnostics

Alzheimer’s and other dementias are diagnosed using careful clinical evaluation tools such as neuropsychiatric examinations, cognitive assessments, and neuroimaging studies. Many healthcare professionals help in the diagnostic process. General practitioners/gerontologists conduct baseline testing at yearly examinations as well as rule out any medical reasons for cognitive change. Speech-language pathologists conduct language and cognitive-communication assessments. Neuropsychologists differentiate psychoses/mental disorders from dementing illnesses. Neurologists conduct neuroimaging studies and look at biomarkers. While Alzheimer’s is the most prevalently diagnosed type of dementia, there are other less frequently diagnosed dementias which include vascular, Lewy body, frontotemporal, and more.



Alzheimer's Dementia. Among other pathologies, neuroimaging for Alzheimer's dementia reveals atrophy in the hippocampal region of the brain that helps convert memories from short-term to long-term. When short-term memories, also known as working memories, become long-term memories, they can be declarative in nature. A subcategory of declarative memory, known as episodic memory, is the recall of experiences and events. Episodic memories are usually the first area of cognition to become affected in Alzheimer's dementia, secondary to atrophy in the hippocampus (Kovács, 2021, 2022). Alzheimer's makes up about 60-70% of dementia diagnoses worldwide (WHO, 2022).

Vascular Dementia. Vascular dementia has diagnostic criteria that include a cognitive decline in conjunction with cerebrovascular pathologies, such as stroke (Sachdev et al., 2014). There must also be an absence of any delirium or psychosis. When compared to Alzheimer's dementia, vascular dementia presents with more deficits in attention and speed of information processing than deficits in episodic memory (Bayles et al., 2020). "About 5% to 10% of people with dementia have vascular dementia alone. It is more common as a part of mixed dementia" (Alzheimer's Association, 2023f, para. 5).

Lewy Body Dementia. Lewy body dementia is indicative of aggregates in a-synuclein proteins throughout the outer portion of the brain, more commonly called Lewy bodies. This type of dementia presents with "fluctuating cognition, recurrent well-formed hallucinations, and spontaneous parkinsonism" (Weiner & Lipton, 2009, p. 197). Lewy bodies and dopamine reduction are the main pathologies in Parkinson's disease. Parkinson's-related dementias have similar cognitive deficits to Lewy body dementia, except that the temporal sequence of decline is more variable in Lewy body dementia than in Parkinson's (Bayles et al., 2020).

Lewy body dementia is almost as prevalent as vascular dementia as it accounts for 5% of cases (Medline Plus, 2021).

Frontotemporal Dementia. Frontotemporal dementia typically affects the frontal and temporal lobes of the brain and can be further divided into behavioral, language, and motor variants (Bayles et al., 2020). Frontotemporal dementias have an earlier onset than other dementias and are often misdiagnosed as a psychiatric disorder as opposed to neurodegeneration (Yay Pençe et al., 2022). Compared to Alzheimer's, frontotemporal dementia has a shorter survival duration (Weiner & Lipton, 2009). In a study by Leroy et al. (2021), frontotemporal dementia made up 2.6% of all-cause dementia cases in the research.

Other Dementias. As mentioned previously, Parkinson's disease can often cause brain changes that lead to dementia. Other comorbidities that can lead to dementia include normal pressure hydrocephalus, encephalitis, chronic traumatic head injury, alcoholism, and toxin exposure. Genetically related diseases such as Huntington's, Down syndrome, and William Syndrome all may result in neurodegeneration causing dementia (Bayles et al., 2020; Weiner & Lipton, 2009).

When an individual has the diagnostic criteria for more than one dementia, they are typically given a mixed dementia diagnosis. (Custodio et al., 2017). Mixed dementias make it difficult to distinguish where one type begins and another type ends. Learning about brain changes associated with the different types of dementia may give caregivers insight into strategies that can decrease caregiver burden. These brain changes lead to loss of cognitive function, or cognitive decline. Unpaid familial caregivers may not be fully aware of the different types of cognitive decline associated with Alzheimer's and other dementias. The fact that normal aging comes along with a small degree of brain change, which is not necessarily a result of dementia, makes differential diagnostics even more difficult in the early stages (Torres-Quesada et al., 2022). Possible dementias are most often noticed when cognitive dysfunction is interfering with the individual's functional independence. At this point, the progression of dementia has already begun. Cognitive dysfunction is typically the catalyst for someone to seek professional help, and it can be categorized into five domains.

Five Cognitive Domains

When a loved one is diagnosed with Alzheimer's disease or another type of dementia, issues with the loved one's cognitive function become evident in many forms. Issues such as deficits in attention, memory, language/communication, executive function, and/or visual perception, are at the top of the list and are mentioned throughout literature as the five cognitive domains (Bayles et al., 2020; Weiner & Lipton, 2009). These types of brain changes create a burden on the caregiver. Although there are health communication resources available to decrease the level of burden on those who care for individuals with dementia, many caregivers are overwhelmed in their searches for information about the nature of cognitive decline.

Attention. Without the ability to attend to a stimulus for a certain amount of time, an individual is not able to independently complete an intended task, communicate with others effectively, and/or overcome distractions and incongruencies in the environment. "Within the cognitive domain, attention involves the mental states and operations needed to detect stimuli, select stimuli over 'noise', and manage resources for the detection and processing of competing stimuli" (Kolanowski et al., 2012, p. 24). The term attention is subdivided into sustained, selective, and divided (Bayles et al., 2020). Sustained attention happens when a person can orient to and focus on the task at hand. Selective attention happens when a person can continue focusing on the task at hand, despite any distractions in the environment. Divided attention happens when a person can “share attention resources across competing stimuli” (Kolanowski et al., 2021, p. 24).

Attention is closely tied with working memory and declines in normal aging to a certain degree. In Alzheimer’s disease, attention and memory begin to decline early. In contrast to normal aging, the decline becomes more significant as Alzheimer’s progresses. Dementia with Lewy Bodies causes “rapidly fluctuating attentional deficits and memory loss” (Weiner & Lipton, 2009, p. 197).

An example of deficits in attention may manifest in a situation where the individual is cooking or doing dishes but walks away to answer the telephone. A person with normal aging decline may momentarily forget that the first task still needs attention but will eventually remember to return to the task and complete it. A person with Alzheimer’s dementia will not only forget that the first task still needs attention but may also blame the inattention and forgetfulness on someone else.

Memory. Just like attention, the cognitive domain of memory can be subdivided into different types. Episodic memory impairment, or difficulty remembering day-to-day happenings, is a telltale symptom in the early stages of Alzheimer’s disease but is affected in other dementias as well (Economou et al., 2016). The ability to recall facts about oneself that occurred in the prime of one’s life is spared longer than recent episodic memory. Patterns of memory deficits in the subdivisions, such as semantic memory, lexical memory, and procedural memory are also present in other dementias. A language variant of frontotemporal dementia, called primary progressive aphasia, manifests in the decline of semantic memory, which allows a person to produce the right words from a memory bank of categories (Weiner & Lipton, 2009). Similarly, lexical memory is tied to language through the recall of word forms and their meanings.

Procedural memory, or the ability to perform familiar tasks from motor conditioning, is typically spared until dementia has progressed into later stages (Better Help Editorial Team, 2022). Examples of procedural memory tasks are brushing one's teeth, making the bed, tying one's shoes, and so on. Many dementia care professionals choose to build upon the strength of procedural memory, which is present well into the progression of dementia because it relies on motor recall rather than language and verbal communication.

Language and Communication. As dementias progress, the ability to effectively communicate declines because communication is directly affected by the decline in cognition. In most types of dementia, the individual can still communicate throughout the progression of neurodegeneration. However, effective communication depends on language performance, and the ability to recall and execute rules of language performance requires intact memory systems. In other words, communication may be present, but it does not always result in effective comprehension or expression of intended messages. Bayles et al. (2020) described this with the following:

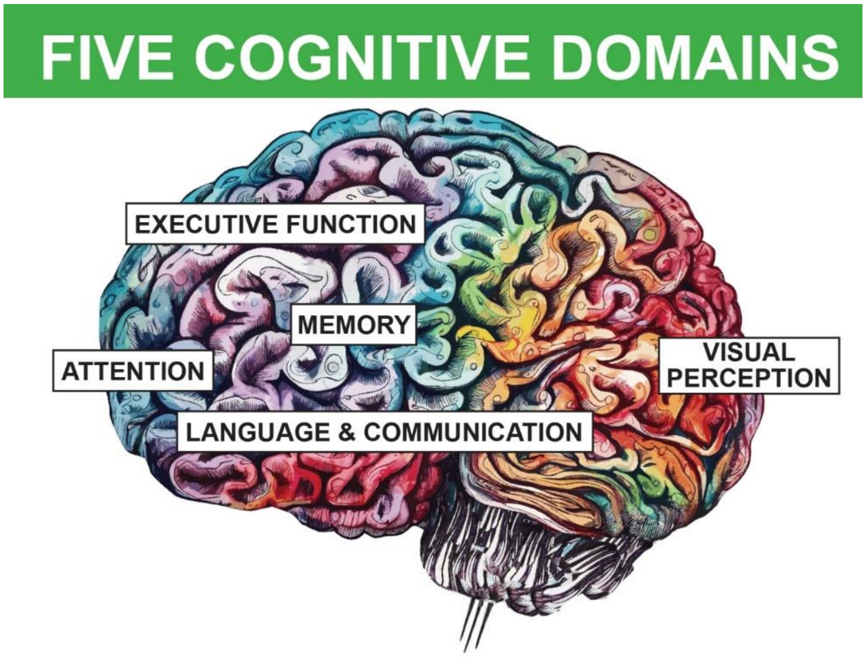
> To ensure that what we say is what we intended to say, we monitor our utterances and make judgments about them; thus, the production of linguistically expressed information uses semantic memory, lexical memory, working memory, motor procedural memory, and the central executive system. (p. 20)

Executive Function. "Executive functioning refers to the ability to plan, initiate, and monitor goal-directed behavior, with the flexibility to update goals when presented with new information" (McKinlay, 2010, pp. 268-269). Tasks that are considered to use high-level executive functions may include driving, meal planning, paying bills, scheduling an itinerary, and managing medication. Executive functioning begins its evolution from childhood to adulthood as individuals learn to be more and more independent in their environments. Some standardized tests that assess the cognitive domain of executive functioning may ask clients to sort cards into categories, draw a clock, or complete a trail-making task that involves drawing lines to connect numbers chronologically and letters alphabetically while alternating between the two. Many individuals with MCI and even early stages of dementia may still be working jobs but find that job performance has slowed or has become more difficult. For some, this decline in the high-level executive functioning tasks needed for job performance is the first sign of trouble.

Visual Perception. Visual perception may be the most overlooked domain as an actual function of cognition because it is mistaken for other pathological visual changes associated with normal aging (Daffner et al., 2013, pp. 11-12). However, subtle changes in the perception of visual information can be one of the earliest signs of dementia. Visual perception deficit is a defining characteristic of Lewy body dementia but may be present in other types as well. Visual hallucinations tend to be more prevalent in Lewy body and Parkinson's type dementias. "Poor visuoperception in dementia has been associated with reduced quality of life, increased fall risk, and earlier admission to nursing home care. A recent study found that visuoperceptual abilities start to decline 3 years prior to diagnosis of dementia" (Wood et al., 2013, pp. 501-502).

Early visual changes may manifest as inaccurate depth perception, mistakes in reading and writing, difficulty with figure-ground, and difficulty with color contrasting. Depth perception directly affects balance and ambulation. Mistakes in reading and writing directly affect independence with executive functions. Difficulty with figure-ground directly affects recognition of objects that are in an environment with competing visual stimuli. Difficulty with color contrasts directly affects the recognition of food on the plate. White mashed potatoes on a white plate may not be seen at all.

In Alzheimer’s dementia, visual deficits may include loss of peripheral vision with eventual changes into monocular vision (Feurich, 2022). When a person sees with monocular vision, he/she only sees approximately six feet of distance directly in front of him/her. This can cause the person to startle easily when approached from the side. It can also cause the person to have trouble recognizing familiar people and to lose things in plain sight (Snow, 2020). A caregiver would benefit from understanding the process of how neurodegenerative brain changes not only affect visual perception but also the other four cognitive domains.



Caregiving and Health Communication

Statistics reveal that the need for knowledgeable and willing caregivers is increasing (Resciniti et al., 2020). They also reveal that being a caregiver is not easy. Alzheimer’s disease and dementia-related cognitive disorders are on the rise, and approximately one in 45 Americans may be afflicted by the year 2050 (Robillard et al., 2013, p. 1). In 2011, an estimated 25-30% of adults in the United States were reported to have taken on a caregiver role for family or friends (Stacey et al., 2016, p. 2). According to Weiner and Lipton (2009), in longitudinal studies during the early 2000s in the United States "the number of informal caregiving hours provided to each person with dementia increased from 8.5 per week in mild cases to 17.4 per week in moderate cases to 41.5 per week in severe cases" (p. 28). In a Swedish study of the health aspects of caregiving, "more than 79% of high-burden caregivers reported general fatigue, and over half of the high-burden caregivers experience depressive mood" (Ekstrom et al., 2020, p. 1).

"Health literacy is essential for optimal caregiving and for better health outcomes of care recipients" (Mullins et al., 2016, p. 539). Caregivers who tend to people with dementia may be required to provide extensive hands-on assistance and to use strategic redirection cues during daily activities. According to Mullins et al. (2016):

> Lower health literacy has been reported among racial and ethnic minority groups and approximately 15% of informal caregivers are black, Hispanic, or Asian… Informal caregivers have different experiences, care abilities, and resources based on their role in the relationship with their care recipient (i.e. wife vs daughter vs friend), gender, or age, which could influence their level of health literacy. Communication with healthcare providers is one of the main ways to improve health literacy. (pp. 539-540).

Familial caregivers need to learn about the nature of dementia types to understand how certain interventions may be beneficial throughout the progression of cognitive decline. With dementia-related cognitive decline, comes a decrease in the capacity to make medical and financial decisions for oneself. Caregivers eventually take over the role of decision-making, and access to health communication allows caregivers to be well-informed decision-makers. Online health communities have been a valuable resource for many caregivers in search of social support for caregiving (Hajili et al., 2015, p.7).

Recent research has studied the effect of social support and formal support, in the form of access to dementia-care professionals, on the perception of caregiver burden. One study by Ekstrom et al. (2020) concluded that "formal support should be offered to all informal caregivers in need of assistance, especially to high burden and female caregivers, as these groups might be at risk for poor mental and somatic health" (p. 8). Another study by Piraino et al. (2017) stated that "finding ways for caregivers and service providers to collaborate to optimize outcomes for families and older adult home-care clients is critical" (p. 85). Roman et al. (2020) stated, "studies have reported that healthcare practitioners who provide spiritual care to their patients contribute significantly to improve their patients' overall well-being. Spiritual care is regarded as a life-enhancing factor and a coping resource" (p. 2). Research demonstrates the need for easier access to professionals who can provide formal support to caregivers of individuals with dementia. While many organizations have a distinct online presence for supportive information, direct access to formal support is a growing need that warrants more research into caregiver perspectives of how best to approach this need.

Caregiving in the Ohio Valley Region of the US

The Ohio Valley region of the United States is a particular geographic location worth studying familial caregiver perspectives of dementia-care health communication. The Ohio Valley is comprised of the states that surround the Ohio River. Many of the Ohio River's tributaries feed the rural states that make up the Ohio Valley with freshwater and provide it with rich and fertile soil for farming. It extends from western Pennsylvania (PA) through northern West Virginia (WV) and down into Ohio (OH), Indiana (IN), Illinois (IL), and Kentucky (KY). According to the United States Census of 2020, rural states have higher elderly populations, and West Virginia ranks third highest among the 50 states in the percentage of people who are 65 years and older. Pennsylvania ranks ninth and Ohio eighteenth (Kilduff, 2021). These high percentages indicate that the need for caregivers in this region is also high.

The Alzheimer’s Association provided statistical fact sheets for each state in the United States regarding the number of elderly residents and the number of unpaid familial caregivers for loved ones with Alzheimer’s disease in 2023. PA had 404,000 caregivers providing 646 million hours of care without pay. This would equal approximately $4.8 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023e). WV had 65,000 caregivers providing 116 million hours of care without pay. This would equal approximately $1.6 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023g). OH had 493,000 caregivers providing 736 million hours of care without pay. This would equal approximately $13.4 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023d). IN had 216,000 caregivers providing 321 million hours of care without pay. This would equal approximately $5.1 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023b). IL had 312,000 caregivers providing 481 million hours of care without pay. This would equal approximately $9.8 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023a). KY had 157,000 caregivers providing 302 million hours of care without pay. This would equal approximately $10.7 billion of paid care for family members with Alzheimer’s disease (Alzheimer’s Association, 2023c).

The phenomenological approach in this study aimed to learn more about the Ohio Valley’s familial caregiving experiences with attempts to receive support through specific dementia care resources/interventions. The results of this study may add to the evidence-based tools in professional practice by revealing to dementia care professionals what is most needed in health communication for this population that will improve the quality of life for both caregivers and their loved ones suffering from dementia. Disseminated results of the qualitative data may benefit professional practices that are looking to add to or enhance in-person or telehealth options for health communication. A standard of care for allied health interventions may be influenced by the results of this study.

To stay within the realm of health communication research, only adult caregivers tending to parents with dementia that seek information and/or social support about dementia care were included as participants in this study. Semi-structured 1:1 interviews were used to collect textual data for analysis. Purposeful sampling was used to gather caregiver participants in and around the Ohio Valley. In accordance with the necessary ethical considerations for research involving human subjects, all participants were educated on the purpose and procedures of this study. The Institutional Review Board reviewed and approved the research procedures. All participants agreed to all aspects of the study with written consent. Interviews were conducted either in person or via remote connection response methods, one time a month for three months.

Problem Statement

The aging population continues to grow, and with it, the global population of people with Alzheimer’s and other dementias (Bayles et al., 2020). According to the World Health Organization (2022), there are approximately 55 million people around the world living with dementia-related brain changes. An increased number of family members are “filling the gaps in the healthcare system” by caring for their loved ones at home, and it is taking a toll on them physically and psychologically (Park et al., 2021, p. 2). Some caregivers do not reach out for help that could ease the caregiver burden until they are already too overwhelmed. Most caregivers are underprepared for how to support someone with Alzheimer’s or dementia. According to Byers et al. (2022), some caregivers are searching for answers about the stages of the disease, available resources, and strategies for dealing with cognitive decline.

Continually advancing technology has provided a real-time avenue of potential support that healthcare professionals can provide. While some recent mixed methods research exists in the realm of caregiver needs for online dementia training, a gap remains in qualitative methods research regarding caregiver perception of currently available interventions (Teles et al., 2020). The problem to be explored is that dementia-care practitioners in the Ohio Valley need more information, about how caregivers search for and perceive health communication, in order to implement best practices for meeting the needs of this growing population.

Purpose and Significance

The purpose of this qualitative study is to explore how caregivers in the Ohio Valley search for and perceive health communication regarding Alzheimer's and dementia. If dementia care practitioners understand how caregivers perceive the effectiveness of dementia-related health communication, they can determine what is currently missing and how best to communicate strategic information through supportive interventions. At this stage in the research, health communication generally refers to dementia care health promotions**,** interactions between patient/family and dementia care practitioners, dementia care interventions, and overall health communication technologies for dementia care (Littlejohn et al., 2017). One theory guiding this study is Afifi and Weiner's (2004) motivated information management theory, which serves as a framework for dementia care practitioners to learn how positive reputations are built, so that caregivers will not experience anxiety when making decisions to seek information from the healthcare professional. A second theory was originated by Drennon-Gala and Cullen (1994) who both posited that perceived social support may improve overall outcomes where physiological and social-emotional issues are embedded in life experiences. The social support theory also provides a beneficial framework to guide the analysis of caregiver perception in the effectiveness of support through health communication.

Qualitative Study General Research Questions

RQ1: How can dementia-care practitioners provide health communication and interventions to unpaid familial caregivers struggling with negative physical and psychological outcomes?

RQ2: Using the motivated information management theory as a framework, what motivates caregivers who have parents with dementia-related cognitive decline to seek health communication through avenues of support?

Qualitative Study Research Sub-Questions

- What questions are caregivers of parents with Alzheimer's/dementia asking when searching for information about dementia-related cognitive impairment?
- From the perspective of unpaid familial caregivers, what is missing from current health communication avenues regarding how to care for someone with dementia?
- If using Reisberg's seven-stage Global Deterioration Scale (GDS) as a reference, at what stage are unpaid familial caregivers seeking information about how to care for their loved one with dementia?
- From the perspective of individuals caring for a parent with Alzheimer's/dementia, what organizations/practitioners are currently providing the best avenue of support and why?

Definition of Terms

The following terms have been defined based on the context of this research.

Caregiver- a person who provides care, paid or unpaid, for another person who cannot meet needs on his/her own

Care recipient- a person who receives care from a caregiver

Cognition- a person's ability to independently think for himself to complete everyday functional tasks

Dementia- a debilitating neurogenic syndrome disorder that causes a decline in cognitive skills, resulting in the eventual need for 24-hour care

Dementia Care Practitioner- a health care professional who is trained to facilitate some aspect of care for individuals with dementia; aspects may include but are not limited to diagnostics, therapeutic interventions, direct care, and educational support for individuals and their caregivers

Dementia Progression Prediction Model- general representation of the possible forecasted symptoms an individual may experience during cognitive decline associated with dementia; useful in dementia staging

Dementia Staging- assessment of a person's progression of dementia using informal and standardized testing measures

Neuropsychologist- a healthcare specialist who is qualified to conduct in-depth assessments to differentially diagnose underlying causes of behavioral and cognitive changes

Occupational Therapist- a healthcare professional who evaluates and treats individuals who need assistance with activities of daily living

Physical Therapist- a healthcare professional who evaluates and treats individuals who need assistance with functional mobility in the whole body

Social Support Theory (SST)- a communication theory based on the premise that individuals may benefit from decreased stress or anxiety related to a health disparity, due to the perception of feeling supported by other individuals

Speech-Language Pathologist- a healthcare professional who evaluates and treats individuals who need assistance with functional communication of wants and needs

Theory of Motivated Information Management (TMIM)- a communication theory used to predict strategies that individuals use when seeking information about an uncertainty

Assumptions

Prior to this research, it was assumed that adults caring for their parents with dementia were seeking health information from the medical community and/or others who were also caregiving in order to connect with people who could provide them with support. According to the National Alliance for Caregiving, AARP (2020), most adults caring for parents with dementia are of the Generation X population and are between the ages of 39-54 years old. Recent Pew Research data indicated that 90% of Generation Xers reported owning a smartphone and 91% reported daily internet use (Vogels, 2019). It was assumed that many potential participants were seeking health communication regarding dementia mostly through online resources. It was also assumed that at least 12 adults in the Ohio Valley, who were currently caring for parents with dementia, would be willing to share information with the researcher about their decisions to search for and their perceptions of health communication avenues regarding dementia caregiving.

Communication-Centric Theoretical Constructs

Walid Afifi and Judith Weiner (2004) presented the theory of motivated information management (TMIM) as a predictive tool for learning strategies used by people making decisions to seek information from specific resources when they have uncertainties. This theory has been applied in many health information studies and has proven itself effective in learning more about the way individuals make decisions to get their questions answered. Afifi and Weiner used

TMIM to predict the strategic process college students go through when deciding to ask their sexual partners about their sexual health (Afifi, 2016). TMIM was also applied “to predict decisions by older adults to seek information from their parents about eldercare wishes across a three-week period” (Afifi, 2016, para. 15).

TMIM was a valuable theoretical framework to use when exploring how caregivers reconcile the stress of caregiving with the necessity of caregiving. Adults caring for their parents with dementia likely go through the phases of TMIM when dealing with each new symptom as their parents experience the effects of brain change. This predictive model may be proven useful for dementia care professionals in helping familial caregivers through this process. According to Kokorelias and Ashcroft (2020), qualitative research is limited regarding how adults, caring for parents with dementia, seek information and make decisions about the process. Qualitative data regarding this crucial decision-making process has the potential to give dementia care practitioners a deeper understanding of how to support adults caring for their parents with dementia.

Cullen and Drennon-Gala’s (1994) social support theory has been researched in health contexts to study the effects of support groups on decreasing the negative effects of caregiving. The research suggests that when caregivers perceive that they are getting help from others, they feel less stressed and better equipped for caregiving (Del-Pino-Casado, 2018). The recent COVID-19 pandemic opened a door for using social support theory concepts to look at how spirituality can provide a bridge of hope during medical crises. According to Roman et al. (2020), “spirituality is significant in healthcare because it promotes coping strategies for stress, promotes recovery and resilience and prevents burnout” (pp. 3-4). Throughout the first year of the COVID-19 pandemic, patients were faced with a medical crisis including many unknowns, fear of death, and isolation from family support. When a family fits into an ethnography of customs that involves social support through prayer and community fellowship, those customs live on throughout generations. Roman et al. (2020) documented that trends in past research have shown positive effects on the immune systems of patients who were recipients of some sort of spiritual care, including reflection, empathy, and promotion of compassion. While a COVID-19 diagnosis is notably different from an Alzheimer's diagnosis, the social support theory framework in health contexts plays a significant role in understanding how support, spiritual or otherwise, affects the physiological and psychological well-being of caregivers. This theory can be used to guide the understanding of what caregivers perceive to be adequate support.

Summary of the Introduction

This study explored the perspectives of Ohio Valley adults who have parents with dementia regarding their searches for health communication. The problem is that dementia care practitioners in the Ohio Valley could learn from how caregivers search for and perceive health communication, in order to implement best practices for meeting the needs of this growing population. This chapter presented the Background, Problem Statement, Purpose and Significance of the Study, Research Questions and Sub-questions, Definitions, Assumptions, and Communication-Centric Theoretical Constructs.

Chapter Two: Literature Review

Overview

The job of a parent is to raise the child through love, support, and promotion of healthy habits and behaviors. When children become adults, their parents typically remain in the parenting role continuing to provide love and support to their adult children. However, in a situation where Alzheimer's begins causing brain changes in the parents, adult children must take on the caregiving role and the relationship is never the same. The purpose of this research is to seek caregiver perspectives on currently available health communication regarding dementia. This chapter includes an overview, the literature search strategy and purpose, a description of theoretical frameworks, and the themes in the related literature.

The Family Caregiver Alliance (2014) defines caregiving as assuming the responsibility of ensuring that another person's needs are met because he/she cannot meet those needs without assistance. The person who receives care is referred to as the care recipient. When the care recipient is someone's parent who has Alzheimer's or another type of dementia, the burden on the caregiver becomes progressively more demanding as the disease takes over.

There are different types of dementia, but regardless of the type, caregivers mainly express the burden in similar ways. Alzheimer's disease is the most prevalent type of neurodegenerative dementia, which results in memory loss and cognitive decline, such as impaired attention, judgment, problem-solving, and reasoning (Yang et al., 2019). Cognitive decline, also known as cognitive impairment, causes the care recipient to rely more and more on the caregiver. The progressive decline puts a strain on the caregiver (Thordardottir et al., 2019). Spouses of those with dementia often describe increased loneliness, due to the change in the balance of the relationship, worsened by fatigue and bankruptcy of personal time. Adult caregivers of parents with dementia also describe increased frustration, sadness, and anger at times (Fauth et al., 2012). “Caregiving is a career comprised of hard work, isolation, lack of time for self and family, and a financial drain” (Gilliand & Bush, 2001, p. 53).

The number of unpaid caregivers and the cost of caregiving continue to rise. According to Coe et al. (2018), who conducted a case study of one daughter’s unpaid caregiving situation, an estimated “median cost to the daughter’s well-being of providing care to an elderly mother ranged from $144,302 to $201,896 over 2 years, depending on the mother’s functional status” (p. 2004). The unpaid caregiver does not benefit from an extrinsically rewarding paycheck as the paid caregiver does. The unpaid caregiver also does not benefit from employer-provided training in understanding how to meet a care recipient’s needs. Instead, the unpaid caregiver is typically a close friend or family member who has stepped into the caregiving role as an unplanned necessity. Unpaid caregiving may provide an intrinsic feeling of pride when helping someone in need, but the research represents overwhelming evidence that “caregivers are at risk for negative health outcomes, both physically and psychologically” (Piraino et al., 2017, p. 85).

Purpose of Literature Review

The purpose of this thematic literature review was to gain an understanding of the most up-to-date research that exists in the realm of caregiving for a parent experiencing brain changes that are associated with Alzheimer’s disease or other dementias as well as the need for support from dementia care practitioners. The theory of motivated information management (TMIM) added value to this review by providing a framework on which to study how caregivers seek health information regarding dementia. The social support theory (SST) also added value by providing a framework on which to study how caregivers perceive the educational support they are seeking. The TMIM and SST support a social constructionist, phenomenological approach for the research because they provided a map for qualitative data collection and a deeper, holistic perspective of dementia care health communication.

Literature Search Strategy

Multiple library databases were searched to gather current peer-reviewed articles and other publications using keywords specific to the dementia caregiving topic. Topic phrases such as, 'theory of motivated information management and caregiving,' 'social support theory,' 'familial caregiving for dementia,' 'health communication in dementia caregiving,' and 'dementia care practitioners,' gave way to the saturation of themes and subthemes represented in this review of the literature. Additional sources were reviewed regarding qualitative methods, phenomenology, and social constructivism in the context of health communication and specifically in dementia caregiver perspectives.

Communication Tradition

Of Robert Craig's seven traditions in communication research, the phenomenological tradition was chosen for this study (Craig, 1999). A phenomenological study aligns with TMIM and SST in that, "authentic human relationships are sustained, and common ground is established through the direct experience of others" (Maguire, 2006, p. 90). The way adult caregivers make decisions about searching for health information and social support is guided by their direct lived experiences with a parent's dementia-related decline as well as the relationships encountered in the process.

Another one of Craig's traditions that may have offered insights and perspectives for the questions being explored in this study is the socio-cultural tradition in communication research. An ethnographic approach to this research was considered due to the potential for data collection methods using a deeply engaged and in-the-field experience with Ohio Valley caregivers. While this tradition and approach would be beneficial to further explore caregiver perspectives in the realm of dementia health communication, the phenomenological tradition was best suited at this time for this researcher. The researcher acknowledged the lack of experience with qualitative methodology. Semi-structured interviews were viewed to be a more reliable data collection method for an inexperienced researcher than observations and informal interviews with caregivers during on-site interactions with parents, the medical community, and online resources during health communication exchanges.

Social Constructionist, Phenomenological Approach

A phenomenological study, with a social constructionist approach, allowed the researcher to collect and interpret qualitative data regarding familial caregiving perspectives of what is missing from current health communication regarding dementia care. "The goal of a phenomenological research study is to better understand the subjective, lived experience of a particular phenomenon as it was experienced by a person or a group of people" (Terrell, 2016, p.156). Adult caregivers are not only living through the phenomenon of watching their parents gradually deteriorate because of Alzheimer's dementia but are also living through the experience of searching for information on how to cope with this deterioration. Founded by Edmund Husserl, phenomenology tasks the philosopher "to describe the structures of experience, in particular consciousness, the imagination, relations with other persons, and the situatedness of the human subject in society and history" (Armstrong, n.d., para. 1).

Phenomenological approaches to learning dementia caregiving perspectives are noted in recently published research (Mayo et al., 2020; Dovi et al., 2021; Champlin, 2020). A Kent State University graduate student named Penny Minor (2020) studied the unique lived experience of being an adult caring for a parent with dementia through a phenomenological approach. Minor's interview questions were geared toward her participants’ perspectives on what roles they had while caregiving for their parents during dementia-related cognitive decline. While her research was a major contributor to ongoing qualitative studies in the familial caregiver perspective, Minor did not take the research to the next level of gathering additional points of view about what may be missing from health communication regarding dementia.

Jurgens-Toepke et al. (2015) used the social constructionist perspective in studying problem-based learning methods, noting that humans construct knowledge through social interactions, preconceived notions, and any other variables in the learning environment. Adults caring for their parents with dementia are desperately searching for much-needed interventions and information through social constructs available via in-person and online learning environments (Birkenhäger-Gillesse et al., 2020). From a social constructionist point of view, it is understood that the caregiver’s perspective of health communication regarding dementia will be influenced by his/her social-emotional state, expectations of the informational source, pre-existing knowledge, learning needs, and more. “The social perceiver must fill in the gaps, and resolve the ambiguities, by making inferences about the stimulus given his knowledge, expectations, and beliefs” (Kihlstrom, 2017, p. 30).

Primary Theoretical Framework

The theory of motivated information management (TMIM) is a valuable theoretical framework to use when exploring how caregivers reconcile the stress of caregiving with the necessity of caregiving. The purpose of TMIM is to explain what motivates or does not motivate individuals to seek information and make decisions about health contexts. Walid Afifi, Judith Weiner, and their colleagues (2004) introduced TMIM to give insight into the three phases that individuals experience as they are reconciling changes in their mind, body, and/or spirit. These three phases are interpretation, evaluation, and decision (Afifi, 2016). According to Tian et al. (2016):

> At its core, the TMIM seeks to explain how individuals respond to uncertainty and the negative emotions that accompany it by assessing the potential outcomes of different information-management strategies, as well as whether or not individuals possess the efficacy to enact the strategies they choose. (pp. 281-282)

Adults caring for their parents with dementia likely go through these three phases when dealing with each new symptom as their parents experience the effects of brain change. A personality change, such as the use of profane language, may be out of character for a care recipient. The caregiver may be contemplating how to deal with a parent's increased use of profanity during outings, such as Sunday morning church. The caregiver must do an efficacy assessment about whether to avoid this topic or seek the information and deal with the outcomes that this information may bring.

Risk-benefit Analysis

The caregiver performs a risk-benefit analysis quite often during the progression of the care recipient's cognitive decline. One difficult aspect of deciding to seek information about brain change associated with dementia is that caregivers must divulge personal revelations about their loved ones in this process. Trusting that the source providing information is reputable and worthy of being privy to these personal revelations is a key motivator. Lillie and Venetis (2020) found that siblings who have trusting relationships are motivated, following a risk-benefit analysis, to share and seek interventions for their parents with dementia. This finding correlates with a feeling of trust that may be a motivator when caregivers seek information from outside sources. Caregivers perceive that the benefits outweigh the risks when they are motivated by trust.

During the risk-benefit analysis, the caregiver moves through the three phases, interpretive, evaluation, and decision. Dementia caregiving brings forth an incredible amount of uncertainty about what dementia does to a person, how to deal with it, and what the result of dealing with it will become. One aspect of the interpretative phase is uncertainty-discrepancy, where a discrepancy exists between how much the caregiver already knows about dealing with problematic behaviors and how much they want to know. The interpretive phase is where the caregiver begins to find that the amount of discrepancy between what is certain and what is uncertain is bringing forth an amount of internal or external emotions that are either bearable or unbearable (Droser, 2020). This leads to anxiety, which then leads to an internal evaluation phase that causes the caregiver to weigh the costs and benefits of whether or not to seek information about the uncertainties in dealing with the new behavior (Littlejohn et al., 2017).

The evaluation phase is where the caregiver evaluates what can be done about this discrepancy. Caregivers evaluate the pros and cons of learning more about the things that make them uncertain. Questions are asked about whether gaining the new information will be beneficial to the situation as a whole. This is called an efficacy assessment. Will this new information bring forth positive or negative outcomes and will the caregiver be able to cope with the changes brought forth because of the new information (Droser, 2020)? From there a decision is made based on the caregiver's perspective of efficacy in the choice to seek the information.

Kanter et al. (2018) used the TMIM to study how individuals seek information through online support groups. They summarized Afifi and Weiner's explanation of the final decision phase as when the caregiver chooses the information strategy that works best:

> These strategies include information seeking, or looking for relevant information about

> the issue, information avoidance, or eschewing relevant information about the issue, and cognitive reappraisal, which refers to cognitively altering the need for managing uncertainty. TMIM predicts that individuals are more likely to seek information when they expect positive outcomes and have high efficacy assessments. (pp. 103-104)

TMIM in the Dementia Caregiving Context

According to Kokorelias and Ashcroft (2020), qualitative research is limited regarding how adults, caring for parents with dementia, seek information and make decisions about the process. Kokorelias and Ashcroft specifically reported that the “process of which caregivers undergo when making health service decisions in relation to service use and the factors that influence use for persons with dementia is unclear…qualitative literature highlighting the health care decision-making processes of family caregivers is sparse” (p. 1). Chang et al. (2010) also noted that more qualitative studies would add to the literature in understanding familial caregiving decision-making and the need for support. They specifically studied the process that Chinese familial caregivers go through when seeking information and making decisions regarding nursing home placement. A Chinese cultural tradition, known as filial piety, places high regard on children who care for their parents at home. Chang et al. (2010) stated that even though this tradition is well known, “much less is known about how filial piety influences the context of adult children caregivers' decision-making processes and how their evaluation of postplacement care impacts their adjustment to the placement decision in today's Chinese society” (p. 108). Cultural norms will create differences in the way caregivers seek information, make decisions, and view support. More qualitative studies on this angle of caregiver perceptions would add to the literature base on cross-cultural phenomena.

After reviewing the literature regarding end-of-life decision-making by familial caregivers for loved ones with dementia, Xie et al. (2018) noted a few more gaps in the literature worthy of future study. There was sparse literature on studies of rural area caregiving needs and experiences with interventions and support. There was a need for more studies involving online and technological interventions for caregivers. There was a need for “tailoring of information to caregivers’ preferences for different types and amounts of information necessary to make decisions consistent with patients’ values” (Xie et al., 2018, p. 1). Gaps in the literature made room for more studies using TMIM as a framework reference to learn more about this topic.

Kokorelias and Ashcroft (2020) reported that applying TMIM in the context of healthcare decision-making could potentially give insight into how providers can improve services and support to caregivers. As the care recipient progresses into the later stages on Reisberg’s Global Deterioration Scale of Dementia, caregivers have an even tougher time with information management than in earlier stages because it requires making decisions about nursing home placement (Reisberg et al., 1982). At this point, certainty-uncertainty discrepancies are more present than ever, and anxiety is coupled with guilt, leaving the caregiver with more stress than not. Many times, this leads to a delay in information-seeking, due to information avoidance (Kokorelias & Ashcroft, 2020).

Uncertainty Reduction Theory

The uncertainty reduction theory can also guide this discrepancy. Charles Berger posited that predictions could be made when a person has uncertainty about approaching a communication situation, such as one with a health information provider (Knobloch & Knobloch, 2009). The theory predicts that a person’s uncertainties will be reduced when he/she anticipates incentives given by the other party, trusts that the other party will not deviate from unexpected behavior and looks forward to future interactions (Knobloch & Knobloch, 2009).

Additional qualitative data regarding this crucial decision-making process would give dementia care practitioners a deeper understanding of how to support adults caring for their parents with dementia through in-person and remote interventions.

Secondary Theoretical Framework

The social support theory (SST) was originally developed from the works of Don Drennon-Gala and Francis Cullen, which focused on the concept that a socially supportive society could reduce crime (Kort-Butler, 2017). Further research on social support has evolved the theory to encompass health-related outcomes, including an individual's perception of the social support, the quality and quantity of the social support, and the relationships involved in the support system (Hupcey, 1998, 2002). Adults who are caring for their parents with dementia are at risk for negative health outcomes; therefore, support for caregivers is an essential part of coping with the life changes that result from taking on this role (Piraino et al., 2017). In some studies, social interactions have been associated with decreasing physiological and mental health decline in the elderly (Tsai et al., 2017). Information about dementia progression provided by health care professionals, as well as by others who are going through the same process, should be an easily accessible form of social support. Results from a qualitative study by Davies et al. (2019) concluded that caregivers longed for this connection with other caregivers as well as reliable information and support from professionals and that resources should be established for caregiver support.

SST in Health Contexts

Many studies give insight into the buffering effects of social support (Del-Pino-Casado et al., 2018; Md Nawi et al., 2018; Gilliand & Bush, 2001). Social support in the health context "consists of action and information that lead individuals to perceive that they are cared for because of the receipt of aid, assistance, and comfort from others when they need it" (Littlejohn et al., 2017, p. 362). The fatigue and negative physiological effects that result from stressful situations may be buffered with the right social support system (Dam et al., 2017). The caregiver of an individual who suffers from dementia fits the criteria of someone who is experiencing a stressful situation. Caregivers seek out information about the stages of dementia, what to expect from each stage, and how to balance being an effective caregiver while maintaining a healthy lifestyle of their own. While healthcare professionals will provide informational support regarding the biological effects of dementia and generalizations about the progression of the disease, caregivers may benefit even more from the empathy received from social support groups made up of other caregivers in their shoes.

Cross Cultural Constructs with Strong Ties and Weak Ties

The social support theory can be further analyzed by learning the difference between strong ties and weak ties. A study by Kim et al. (2015) looked at the aspects of strong ties and weak ties in social support by asking Korean Americans about accessing relevant health information. Strong ties are social networks that include close relatives, while weak ties are networks that include outside organizations such as churches, neighbors, service providers, and so on (Wright & Bell, 2016). Participants in the study by Kim et al. (2015) reported finding relevant health information from weak ties in online social support systems, and that they primarily seek the perspective of individuals from strong ties due to the nature of the cultural similarities.

Wright and Bell (2016) studied an online forum for older adults, and the results revealed that many caregivers in the group felt closer to the members of the support network than they did to their own family members. "Participants mentioned that the people they turned to for online support understood their problems better than non-Internet supporters, despite the fact that they had never met members of their online support network in the face-to-face world.” (p. 47). When the social support system is made up of weak ties, it is important for the information to be accurate, especially when looking to obtain social support pertaining to coping with a dementia diagnosis. Social media and online support groups are weak ties that come with the added challenge of determining the validity of the information given (Iftikhar & Abaalkhail, 2017). This added challenge does not deter many caregivers from using social media as a source of information and social support. In fact, Robillard et al. (2013) indicated that the number of older adults who search the internet for information about health-related issues is steadily growing and that online options offer endless possibilities for communicating this information to a large audience.

A cross-cultural comparison adds an interesting element to the social support theoretical construct when looking at strong ties and weak ties. “In Western cultural contexts, the self is often considered independent and separate from other people, whereas, in Eastern cultural contexts, it is viewed as being interdependent and connected to other people” (Zheng et al., 2021, p. 2). The comfort level that the Western culture has in seeking support through weak ties, such as strangers on social media, is much different from the comfort level of the Eastern culture in seeking support. In general, Eastern natives are hesitant to ask for help through weak or strong ties but are very comfortable being supported by strong ties because the sense of community and interdependence already exists within. Support is expected in the interdependent culture; therefore, an individual who may need additional support may feel like they are overstepping if they ask for more. Eastern culture does not typically view people as siloed, but rather as pieces of the network with communicating parts. “In East Asian cultural contexts, the emphasis on social networks and accommodation to others can lead people to maintain harmony within the networks and avoid matters that disrupt this harmonious relationship" (Zheng et al., 2021, p. 3). Ishii et al. (2017) reported that Asian Americans benefit from the support they perceive from their social networks. They just feel that "support experienced without disclosing one's stressors and problems is more effective" (p. 444).

In comparison with their Eastern counterparts, Western natives are less networked with strong ties; thus, they feel more comfortable seeking support from other less networked individuals who are considered weak ties. Generally, Western natives feel less obligated to the harmony of a strong-tie social network, allowing them more freedom to deviate from social norms. Western natives put themselves above what may be perceived as a social rule violation, and do not mind disclosing personal circumstances in the name of receiving support from weak ties (Ishii et al., 2017).

Spiritual Constructs of Social Support

The book of Proverbs in the Holy Bible has been referred to as "a library of the wisdom of the Israelites" (Church of Jesus Christ of LDS, n.d., para. 2). Perhaps the Israelites are one of the first ethnographical descriptions in the Holy Bible with a rich set of shared beliefs, customs, and traditions. The Proverbs provide the reader with insight into the Israelite's cultural way of looking at mutual understanding and differences as well as strategies that will help one grow closer to the God of Moses. Proverbs 18:14 states, "The human spirit can endure in sickness, but a crushed spirit who can bear?" (Holy Bible, NIV). Approximately 3000 years before the social support theory was conceptualized, the framework behind it was already playing out. The Proverbs writer referred to feelings such as burnout, isolation, and hopelessness as components of a crushed spirit. Without proper strategies and support systems, caregivers may feel the effects of a crushed spirit as they give up self to take care of another.

Social support was recently further studied through a spiritual lens by several authors (Thunstrom & Noy, 2022; Bradshaw & Kent, 2018; Albatnuni & Kozycki, 2020; Keisari et al., 2022). All the studies included an element of spirituality and its effect on well-being. All agreed that when spiritual support was utilized, if support included mutual respect for a person’s set of spiritual beliefs in a particular higher power or way of worship, most participants reported positive correlations in some aspect of life.

All in all, most studies agree that perceived social support has a positive impact on health-related outcomes (Labrague, 2021; Moeini et al., 2019, 2020). These positive impacts are most likely a result of the caregiver’s perceptions and feelings that accompany social support, as opposed to a tangible remedy like medication. This perceptual positive impact on physiological health issues allows for a social constructivist approach to a phenomenological study of caregiver perceptions.

Dementia Caregiving

Themes in the literature regarding dementia caregiving include the topic of negative social-emotional and physiological outcomes that manifest in the caregiver as a care recipient experiences changes in cognition. To fully understand a caregiver’s experience in dealing with these changes, it is important to examine the process of the care recipient’s cognitive decline. Many dementia care educational resources are rooted in Barry Reisberg’s (1982) Global Deterioration Scale for Dementia (GDS), which is a seven-point description of cognitive decline. Dementia care practitioners typically use the GDS as a framework to assess and treat clients with dementia. They also use it to educate paid and unpaid caregivers on how to properly approach care recipients based on any preserved abilities in their current GDS stage. This cognitive decline, also known as brain change, brings forth a multi-dimensional need for health communication in dementia caregiving. The literature introduces many caregiver support interventions that provide this health communication, but caregivers are still feeling overwhelmed and still suffering through negative outcomes of caregiving. Adults caring for their parents must face multiple decisions throughout their unpaid familial caregiving journey.

Social-Emotional Outcomes of Caregiving

As the care recipient's dementia progresses, any intrinsic rewards of being a caregiver for a parent become overshadowed by necessary sacrifices. Numerous research studies dedicated to learning more about familial caregivers have all agreed that unpaid family members experience many negative outcomes associated with sacrifices in personal time, money, and their own mental stability (Chan et al., 2021; Zwingmann et al., 2017; Alves et al., 2019). These sacrifices lead to feelings of burnout, depression, de-prioritization, frustration, and guilt, placing the caregiver at higher risk for stress-related diseases.

Burnout. Caregiver burnout is a broad term that describes when the caregiver has reached a point of mental and physical exhaustion due to the stressors associated with providing increasing levels of care (Chan et al., 2021). This stress can lead to an increased risk for physiological and psychological problems such as cardiovascular disease, high blood pressure, mood disorders, and cognitive decline for the caregiver (Zwingmann et al., 2017). "Financial costs also leave caregivers struggling long after the death of a loved one, with annual out-of-pocket expenses for Medicare beneficiaries with dementia averaging nearly US$10,000 and care lasting up to 20 years" (Lewis, 2015, p. 488). Chronic stress associated with caregiving can cause a psychosocial disorder known as Burnout Syndrome, which leaves a person with mental and behavioral risk factors that lead to the inability to care for the care recipient (Alves et al., 2019).

Research that focuses on helping to decrease caregiver burden has revealed that social support and education regarding coping strategies have been successful in lessening the effects of burnout (Birkenhäger-Gillesse et al., 2020). A study by Dam et al. (2017) looked closely at caregiver burnout and the effects of a social media intervention designed to be a source of social support. The tested social media intervention was feasible for informal caregivers of individuals with dementia and the effectiveness of the intervention allowed for much-needed positive interactions geared toward decreasing burnout.

Depression. Depression is the most prevalent negative outcome reported in the literature about familial caregiving (Park et al., 2021). Adults caring for parents with dementia are typically juggling work schedules, parenting their own children, and maintaining spousal relations, putting them at a higher risk for negative experiences when compared to other types of caregivers (Lillie & Venetis, 2020). Without caregiving as the catalyst, depression is already an increasingly prevalent diagnosis that affects people worldwide. “The Korean Epidemiologic Catchment Area study, an epidemiological survey on mental health conducted every five years, has reported a gradual increase in the prevalence of depression [2001, 4.0%; 2006, 5.6%; 2011, 6.7%]” (Park et al., 2021, p. 1). This study went on to specifically say that adult females caring for a parent with dementia, in all the demographics represented, reported the most depressive symptoms than other represented populations. Pillemer et al. (2017, 2018) found that female caregivers experience more depressive symptoms than males, due to the type of care they provide and due to ineffective coping strategies.

One of the many factors that lead to depression when caring for people with dementia is sleep disruption. As Alzheimer’s Disease progresses, many patients experience disturbances in circadian rhythm, which regulates healthy sleep patterns. “The most frequent disturbances are excessive awakenings (23%), early morning awakening (11%), excessive daytime sleepiness (10%), and napping for more than 1 hour during the day (14%)” (Urrestarazu & Iriarte, 2016, p. 29). Loss of sleep that happens because of the care recipient’s disruptive behaviors has been associated with the caregiver’s depressive symptoms (Jiménez-Gonzalo, 2020). Stressors such as caregiving for multiple hours per week, increased neuropsychiatric behaviors exhibited by the care recipient, and losing sleep are all attributed to depression (Simpson & Carter, 2013).

De-Prioritization. Many caregivers feel that their own needs take a backseat to the care recipient’s needs, which becomes the main concern in all facets of life. Taking on the caregiving role can provide peace of mind as the adult child has more control over a parent’s medication management, medical decisions, overall safety, and financial checks and balances. However, this more active role brings on more time dedicated to the parent’s needs and less to one’s own needs (Li et al., 2020). The caregiver becomes deprioritized in many instances. Social events, mealtimes, and even conversations are centered around the care recipient. Caregivers tend to forget about their own physical and emotional health and put themselves at risk for medical conditions (Stacey et al., 2016). When falling into this deprioritized state, caregivers give up employment opportunities, time with friends and family, and time to themselves (Stacey et al., 2016).

Frustration. A care recipient’s changed personality, accompanied by problematic behaviors, causes frustration for the caregiver. To understand how families deal with different dimensions of frustration, Chen et al. (2017) studied the expression of emotion when the care recipient is a family member with a severe mental illness. “Greater levels of negative attitudes toward the patient have been correlated with escalating negative behavior in interpersonal interactions and less reciprocal positivity between caregiver and care recipient” (p. 90). For adult caregivers of parents with dementia, frustration causes increased criticism toward the parent and a decreased ability to tolerate even the mildest behaviors.

Cultural expectations in caregiving shed light on different angles of frustration for certain groups of people. For example, in Vietnamese culture, the eldest son and his wife take on the caregiving role for aged parents. In one qualitative study by Nguyen et al. (2021), a widowed daughter-in-law expressed increased frustration with her situation because she was left caring for her children as well as her in-laws who were experiencing cognitive decline.

Many research studies have been dedicated to understanding methods for helping caregivers work through their frustration. Education regarding the progression of dementia has been successful in helping adults who are caring for their parents to understand why problem behaviors manifest, allowing them to have more reasonable expectations of their parents (Chen et al., 2017). Support groups and psycho-educational programs help caregivers by giving them an outlet for expressing negative emotions and a place to be around others who are having similar experiences (Pihet & Kipfer, 2018).

Guilt. Caregiving for a parent with dementia ultimately ends with feelings of guilt. Sometimes guilt and grief coincide when caregivers begin trying to cope with the realization that the end of the care recipient’s life is near. Meichsner and Wilz (2018) conducted a study to learn if a cognitive-behavioral therapeutic intervention (CBT) for caregivers may positively affect coping efforts to deal with guilt during and after pre-death grief. This was an experimental study looking at a CBT intervention for a large sample of caregivers, compared to a control group, and collecting data in a follow-up assessment to understand latent changes. Results revealed that caregivers in the experimental group benefited from the CBT intervention and reported better coping skills for guilt and pre-death grief associated with dementia caregiving.

Some adult children feel guilty when they must place their parents in a memory care facility. Many adult children face the feeling of guilt when they wish for their parents' suffering to end as well as their own. In a study by Lewis (2015), one daughter stated, "Mom was pushing the limits of my energy, every muscle in my being screamed for release" (p. 490). This study introduced the substantive theory of rediscovering remaining (STRR) as a framework for caregiver coping techniques. The goal of this coping framework is to decrease feelings of burden and guilt by learning about remaining abilities in different stages of dementia as well as rediscovering oneself in the process. Caregivers go through a process of missing their own lives before caregiving and longing for the chance to have their own identity again (Lewis, 2015). Other coping strategies highly used to decrease feelings of guilt include "self-distraction, active coping, emotional/instrumental support, venting, positive reframing, planning, humor, acceptance, and religion" (Yuan et al., 2021, p. 684).

Li et al. (2020) discussed the feeling of guilt that occurs when caregivers choose to let their parents eat what they want, instead of what they should, in the face of avoiding negative behaviors as well as wishing to be agreeable as opposed to argumentative. They reported one informal caregiver's sentiments about mealtime as the following:

> Just try to pour love on like pouring water on a rock, thinking you can wear it down. And then you realize all that you did the day before has no carryover. You are starting with a new rock every day and you are pouring water again. But we do it anyhow, even if it starts to get a little heavy. We just carry the water. We just keep pouring it on. (p. 3322)

Reisberg's Seven-Stage Global Deterioration Scale for Dementia

Without knowing what the progression of Alzheimer's and other dementias looks like, it is difficult to comprehend why the caregiving role for a parent with dementia is unique when compared to other caregiving roles. Back in 1982, Barry Reisberg developed a seven-point scale to categorize the clinical stages of dementia-related decline, which is still relevant and widely used in the assessment of cognitive changes associated with dementia (Herndon, 2022). It is known as the Global Deterioration Scale (GDS). Reisberg et al. (1982) verified the accuracy of the clinically measured stages using comparisons with other standardized scales such as the Wechsler Adult Intelligence Scale, the Inventory of Psychic and Somatic Complaints in the Elderly, and the Mental Status Questionnaire. The GDS has been instrumental for dementia care practitioners in the development of care plans and maintenance plans for their patients. The seven clinical stages describe the progression of dementia-related decline and provide the client, family, and practitioner with a quick overview of the individual's cognitive abilities at each level. Knowing what to expect in the next stage allows caregivers to plan and feel confident in decision-making.

At times, some variability in inter-informant reliability exists in scoring the GDS. This is because, in many situations, the information gleaned from the GDS is provided subjectively by a caregiver. Mougias et al. (2018) studied "patient and caregiver-related features in order to identify the predictors that explain the variability of an informant-based GDS score in a large sample of Greek patients with dementia" (p. 2). Findings showed that demographic features, such as the caregiver's culture or personal background, did not significantly influence variability in results. However, some variations in results may be influenced by caregiver burnout, stress, and depression. Nonetheless, the GDS is an overall reliable subjective assessment, sensitive to the progression of Alzheimer's disease (Mougias et al., 2018).

Breakdown of GDS Stages. In Stage One, there is no detectable evidence or complaint of any cognitive impairment during an in-depth examination using standardized assessments and questionnaires (Alz Editorial Team, 2019). The individual functions independently. In essence, most people walk around in Stage One.

In Stage Two, the individual begins to feel like something is off. Most of the complaints are subjective in nature, "like misplacing objects or forgetting names. There is no evidence of memory issues during a clinical interview or problems with work or with social situations" (Herndon, 2022; Reisberg et al., 1982, p. 1136). Standardized assessments may detect mild executive function deficits if the test is normed for high-level cognitive skills (Gurarie, 2022).

In Stage Three, the individual begins to display cognitive deficits that are noticeable in social and work-related situations (Alz Editorial Team, 2019). Deficits may be present during tasks that require independence in executive functioning such as complex reading, divided attention, driving, planning meals, managing finances, and managing medications. In this stage, memory deficits are not the dominating symptom. However, a geriatric psychiatrist or a neuropsychiatrist may conduct an extensive assessment that can detect subtle memory impairments (Reisberg et al., 1982). "An individual might find it harder to keep up with a demanding job and start to have some denial about memory issues" (Herndon, 2022). Dementia care practitioners often refer to Stage Three as Mild Cognitive Impairment (MCI). MCI does not always become a dementia diagnosis. However, some longitudinal studies have indicated that MCI will lead to Stage Four, which indicates a clear-cut Alzheimer's or another dementia-related diagnosis during neuropsychiatric testing (Bayles et al., 2020).

In Stage Four, the individual may be in denial about previously recognized symptoms. The individual may be less inclined to engage in social opportunities because it becomes more difficult to keep up with conversational exchanges in group settings and to recall recent events (Gurarie, 2022). An individual in this stage may still be able to travel to familiar places without incident but will likely become lost when attempting to travel to unfamiliar locations. Stage Four is indicative of a moderate cognitive decline (Alz Editorial Team, 2019). While there are more clinically recognizable deficits in Stage Four than in Stages One through Three, there are still many preserved cognitive abilities (Reisberg et al., 1982). If provided with a routine and familiar environment, an individual in this stage may be able to function without supervision for several hours of the day. Many caregivers opt to allow their loved ones to remain living in their own homes, using memory aides that assist with medication management and other high-level activities of daily living.

In Stage Five, the individual “cannot survive without some kind of assistance” (Herndon, 2022). Stage Five is considered a moderately severe cognitive decline (Reisberg et al., 1982). During an assessment interview, the individual will have difficulty recalling current information, even about him/herself. The individual may be disoriented to time concepts as well as spatial concepts, especially if living in a nursing facility or assisted living (Alz Editorial Team, 2019). Long-term memory concepts are still intact, such as recalling the names of parents and siblings, but many times the individual will have difficulty recalling the names of children or grandchildren. The individual will typically only require set-up assistance with toileting and self-feeding, but moderate to maximal assistance with planning, problem-solving, and reasoning (Gurarie, 2022). When dressing, an individual in this stage will still don all the extras, such as glasses, hearing aids, dentures, makeup, and jewelry.

In Stage Six, the individual will present with a severe cognitive decline (Gurarie, 2022). Sensory and motor deficits are present, meaning the individual seeks to be comfortable and may begin to have trouble ambulating. The individual frequently sheds all the extras and engages in purposeless wandering to find something comfortable and familiar. At this stage, “personality and behavior changes start to happen, which can include delusions, hallucinations, anxiety, agitation, obsessive behaviors, and a loss of will” (Herndon, 2022). Individuals may talk to themselves in the mirror as if it is a whole other person, or they may see familiar faces as imposters (Reisberg et al., 1982). Sleep disturbances are most prevalent in Stage Six, which makes nighttime caregiving quite challenging. Individuals often become incontinent of bowel and bladder (Alz Editorial Team, 2019). Left-brain hemisphere deficits are more pronounced than right brain, meaning language expression and comprehension are severely impaired, but rhythm and social language are mostly spared. An individual in Stage Six will likely not be able to name five animals in a category but may be able to sing along with a caregiver for the song, ‘Happy Birthday to You.’

Stage Seven is the final clinical stage on the Global Deterioration Scale by Barry Reisberg. In this stage, verbalizations are limited to grunts and guttural sounds (Herndon, 2022; Reisberg et al., 1982). Total assistance is required for all care, such as feeding, toileting, bathing, and dressing. The individual may become contracted, where muscles begin to atrophy and stiffen. “The brain appears to no longer tell the body what to do. Generalized cortical and focal neurological signs and symptoms are frequently present” (Reisberg et al., 1982, p. 1138).

Application of the GDS. The GDS is not only used by dementia care practitioners to set practical goals for their patients, but also to study pharmacological and non-pharmacological interventions when it comes to the progression of dementia. One such study by Ellul et al. (2007) used the description of dementia symptoms as noted on the GDS to examine the effects of certain drugs on the progression of these symptoms in a sample of patients with Alzheimer’s disease. Ellul et al. were able to find that taking antipsychotics and sedatives was congruent with a faster progression on the GDS than not taking these drugs in their representative samples. They were also able to find that with “patients taking drugs licensed for dementia, drugs affecting the renin–angiotensin system and statins had a significantly lower risk of deterioration than those who were not taking any of these drugs” (Ellul et al., 2007, p. 233).

García-Martín et al. (2022) used the GDS as a standard of reference to study neuropsychiatric symptomology throughout the stages of dementia. “NPSs [Neuropsychological Symptoms] can occur in 50–98% of patients living in the community and include depression, anxiety, apathy, agitation, irritability, continuous complaints, delusions, hallucinations, disinhibition and sleep or appetite disturbances, among others” (p. 2). The symptoms can be present throughout the stages, but the specifics vary throughout the stages as well. The Garcia Martin et al. (2022) study was able to determine that there is a relationship between the NPSs and the stage of dementia, where the frequency and intensity of specific symptoms progress with the cognitive decline and according to stage. Apathy is most prevalent throughout. Specifically, in GDS Stage Three, patients began to lose previously solid circadian rhythms and became anxious, depressed, and/or irritable (p. 11). The NPS of agitation was more prevalent in GDS stages 4 and 5. Delusions, as well as hallucinations, were seen more in GDS stages 6 and 7.

Dementia Care Practitioners

For the purpose of this study, dementia care practitioners are anyone in a paid healthcare-based position who has a role in managing care for a person with dementia. These can be physicians, physician assistants, nurse practitioners, nurses, nursing assistants, physical therapists, occupational therapists, speech-language pathologists, social workers, activities/recreational directors, researchers, and other specialists. There are many healthcare professionals on this list of practitioners because dementia affects the whole person, including cognition, communication, ambulation, task initiation/completion, psychosocial demeanor, and more.

Zwingmann et al. (2017) acknowledged that researchers have found it difficult to effectively study dementia care management due to “multifaceted caregiver burden” and “high demands on intervention complexity” (p. 889). A multi-disciplinary approach to dementia care management is ideal. Yet, many times dementia care practitioners work on their area of expertise in silos. Multifaceted caregiver burden and intervention complexities make it difficult to standardize a multi-disciplinary dementia care procedure that works. In other words, to be able to agree on a standardized dementia care management procedure that would decrease the overall caregiver burden, numerous individual studies would need to be completed in order to learn about each facet that causes a burden on the caregiver. Overall, the Zwingmann et al. (2017) study resulted in the realization that dementia care management is mostly about concentrating on multimodal caregiver support programs that influence the care recipient’s quality of life.

Examples of how dementia care practitioners may work together to educate caregivers with a multi-disciplinary approach may be seen in skilled nursing facilities as physical therapists, occupational therapists, and speech-language pathologists collaborate. All these therapeutic interventions require a regimented plan of care with goals to target the rehabilitation or maintenance of functions within the individual profession’s scope of practice. The interventions must be evidence-based, meaning there must be proof that the interventions are appropriate and beneficial for the patient. According to Zorina et al. (2020), physical therapy has been shown to slow the progression of dementia-related cognitive decline as well as enhance certain aspects of quality of life. Occupational therapists play a big part in enhancing quality of life despite cognitive decline by working with caregivers and care recipients in compensation and coping techniques for functional, everyday tasks (Martinez-Campos et al., 2022; Smallfield, 2017). Speech-language pathologists provide rehabilitative therapies in the early stages of dementia while educating patients and their caregivers about preparations for later stages of cognitive decline. Speech-language pathologists can provide cognitive-communication techniques throughout all the stages of dementia (Swan et al., 2018). Speech-language pathologists "may also play a critical role in supporting diagnosticians to detect subtle changes in cognitive and functional impairments to help improve diagnostic accuracy and early diagnosis" (Lanzi et al., 2022, p. 1654).

Caregiver education is an ongoing process throughout the progression of cognitive decline. Physical therapists, occupational therapists, and speech-language pathologists in skilled nursing facilities work as a team to continually educate caregivers in the physical, behavioral, and cognitive-communicative manifestations that accompany each stage of dementia. An interprofessional approach in dementia caregiver support is beneficial for everyone involved in working toward the care recipient's best quality of life, while decreasing caregiver burden.

Current Caregiver Support Interventions

Numerous studies have been dedicated to learning effective interventions that involve the care recipient who is experiencing brain change as well as the caregiver. After reviewing the literature focusing on interventions involving caregiver-care recipient dyads, several subthemes emerged. Memory cafes, also known as dementia cafes, feature comfortable spaces to have difficult conversations. Online support programs allow caregivers and care recipients to experience social support. Several organizations have interventions that are specific to educating caregivers and care recipients in strategies that enhance quality of life, despite an Alzheimer's or dementia diagnosis. By looking closely at the current caregiver support options, additional insight may be gained regarding how familial caregivers search for and decide upon the most beneficial interventions.

Memory Cafes

A study by Fukui et al. (2019) specifically looking at the concept of dementia cafes, also known as memory cafes, began in the late 1990s in the Netherlands. Memory cafes were created to provide an accommodating environment for individuals with dementia and their caregivers. The environment allows for increased socialization and decreased isolation, which are sometimes associated with dementia as well as caregiving. Research questions in the Fukui et al. (2019) study aimed to learn more about the needs of caregivers who participated in dementia cafes, as well as the needs of individuals with dementia. The study concluded that persons with dementia need to share their own experiences about the changes in their brain, to feel like others may validate their feelings as these changes are happening, and to have comradery with others who may be experiencing the same changes by staying connected during the memory café time and after. The study also concluded that unpaid familial caregivers need to verbalize the emotional outcomes of being a caregiver, contribute to and learn from others who are experiencing similar feelings and difficulties, and have comradery with others by staying connected during the memory café time and after. The benefits of memory cafes carry over into life outside of the memory café environment; in that, caregivers feel the effects of social support with other caregivers, and care recipients feel the effects of cognitive stimulation from social interactions (Protoolis et al., 2022).

Masoud et al. (2021) conducted a qualitative study to learn about the effect of virtual memory cafes implemented during the height of the COVID-19 pandemic when in-person cafes were not possible. Caregivers and care recipients were interviewed, and themes were derived from the data about the perception of social interactions in the virtual memory café. Themes revealed that memory cafes offer a reprieve from the ongoing struggles associated with cognitive decline. Virtual memory cafes also offer insight into finding possibilities within abilities that remain intact throughout the stages of cognitive decline. The memory café provides a place of worth, connectedness, and inclusivity (Masoud et al., 2021).

Social interactions and social support systems have been associated with decreasing physiological and mental health decline in the elderly (Tsai et al., 2017; Del-Pino-Casado et al., 2018). Results from a qualitative study by Davies et al. (2019), concluded that caregivers longed for this connection with other caregivers as well as reliable information and support from professionals. Information about dementia progression provided by health care professionals, as well as by others who are going through the same process, should be an easily accessible form of social support. Online social media groups have been instrumental in increasing access to social support and dementia education.

Online Support Programs

Online support groups are a growing symposium for those wanting to discuss health information, especially regarding chronic illnesses. Since 2012, there has been an increase in internet users of the Baby Boomer and Generation X populations, who may be caring for parents with dementia (Vogels, 2019). This increase, coupled with a worldwide forum for real-time conversations with people from any location, has created a surge in the use of online social support. “Participating in an online support group has been linked to decreases in depression, pain, loneliness, and stress, as well as increases in self-efficacy when interacting with a health care provider" (Kanter et al., 2018, p. 103).

Ruggiano et al. (2021) created a small, local, and private social media group for a study. The social media group's administrator uploaded educational resources regarding dementia caregiving each week for 12 weeks. A sample of group participants were interviewed before and after the 12 weeks to answer questions about the social media support group experience. Results revealed that even though social media does not provide an in-person experience, it does have its benefits in other ways. Caregivers liked the easy accessibility and the asynchronous aspect as well as the low-cost element that online forums can provide.

Wright et al. (2003, 2016) reported the advantages of computer-mediated support forums as similar to the advantages noted in the Ruggiano et al. (2021) study, but Wright et al. reported the disadvantages as well. Weak ties give an online conversation the opening for skewed perceptions and possible misrepresentation of information. Zhao et al. (2021) took a sample of one online support community's messages and ran it through textual software analysis to begin developing a model for detecting misinformation in health-related content. The detection model included not only an analysis of linguistic features from the messages but also sentiment and behavioral features behind the message creators as well. The behavioral features, which reflected upon the message creator as opposed to the message itself, proved to be an effective dataset from which to detect the misrepresentation of health information in this study (Zhao et al., 2021).

The World Health Organization took note of the need for increased dementia caregiving social support and developed an online intervention called 'iSupport,' which is currently undergoing field testing (WHO, 2019). A Portuguese study was completed to evaluate the effectiveness of 'iSupport,' which featured a series of self-learning modules designed to take the caregiver through defining dementia, understanding how to care for individuals experiencing brain change, and understanding how to care for oneself in the process (Teles et al., 2020). Results revealed that while these self-guided modules contained extremely useful information, the intervention lacked the elements of emotional support and individualized programming that a real-time professional can provide (p. 2048). During the process of a neuro-degenerative decline, emotional social support is beneficial, not only for the caregiver, but also for the care recipient. Along with physical exercise and a healthy diet, social interaction with emotional support contributes to feelings of happiness and self-worth for care recipients experiencing cognitive decline (Tsai et al., 2017; Md Nawi et al., 2017).

Organizations that Support

Hopwood et al. (2018) reviewed the literature for online caregiver support interventions regarding Alzheimer’s and dementia. This review resulted in the identification of several themes that current health information sites target. These themes included “peer support, contact with a health or social care provider, provision of information, decision support, and psychological support” (p. 11). A couple of globally recognized organizations were dominant in the literature when it comes to caregiver-care recipient dyads in dementia education, specifically concerning the themes identified by Hopwood et al. (2018).

The Alzheimer’s Association is an organization with global outreach in Alzheimer’s/dementia research as well as caregiver and care recipient support (Alzheimer’s Association, n.d.; Farran & Keane-Hagerty, 1994; Benner et al., 2018). Part of their community support efforts are dedicated to the Alzheimer’s Association Helpline, designed to provide individuals with “master’s degree level consultants who offer confidential emotional support, valuable and actionable information, and referrals to additional resources in the community” (Hodgson et al., 2021, p. 896-897). This avenue of health information support is accessible around the clock. Hodgson et al. (2021) conducted a survey analysis to evaluate the effects of the helpline. It resulted in 80% of the participants, who used the helpline, reporting that the actionable steps to remedy a situation were most helpful in decreasing caregiver burden (pp. 901-902). The Alzheimer's Association features numerous avenues of support for anyone in need at a regional, national, and international level.

Another caregiver/care recipient support system comes from Teepa Snow's Positive Approach to Care, also referred to as PAC (Brown & Baylie et al., 2020; Brown & Reddy et al., 2020). Snow's organization focuses on training paid and unpaid caregivers, as well as anyone who wants to learn more about persons living with dementia, in "understanding the neurological changes associated with dementia" and "focusing on retained skills of those living with dementia as opposed to skills lost" (Ehlman et al., 2018, p. 191). The completion of the PAC educational courses results in certification statuses for individuals who want to implement strategies in their homes, workplaces, or other mentoring environments. A pilot study was completed to evaluate the efficacy of PAC dementia certifications in 12 skilled nursing facilities throughout southwest Indiana in the United States. "The pilot study provided empirical evidence to support that the novel certification program using a regional approach can improve dementia knowledge in general" (Ehlman et al., 2018, p. 194). The certification courses reinforce very specific strategies to help participants learn effective ways to approach people living with the brain changes associated with dementia. This organization offers a unique learning method in dementia training known as adult experiential learning cycle (AELC), which appears to be bridging the gap in transferring newly learned skills into the healthcare environment. According to one PAC coach/mentor/trainer, Snow's organizational PAC model is only a couple of research studies away from being considered an evidence-based practice.

Bridging the Gap for Dementia Education

As noted from Teepa Snow’s PAC certification model, dementia care practitioners need to understand the importance of transfer strategies in terms of health education. Asking the right questions about what is working and what is not working, when it comes to health communication regarding dementia, helps us get one step closer to efficiently learning how to help caregivers deal with this diagnosis. Van den Eertwegh et al. (2012, 2013) used a constructivist point of view to review the literature about identifying gaps in the effective transfer of health communication skills into clinical workplaces. These authors concluded that isolated studies of specific health communication skills for specific problems did not carry over into transferred skills for a multi-faceted diagnosis. In fact, these skills required in-context learning and even ongoing learning models. This conclusion aligns with Snow’s PAC adult experiential learning cycle method.

As mentioned before, there are increasing numbers of caregivers looking to the internet for health communication, information, and social support. Hajili et al. (2015) looked at internet-based technologies as a potential hub for health professionals, like dementia care practitioners, to integrate health communication and intervention, while mitigating a portion of medical cost. Caregivers, who are already struggling with loss of income and rising costs of medical care, rely on online health communication avenues to get them through the challenges they face. Hajili et al. (2015) concluded that the healthcare sector should continue studying ways to support health communication efforts in all contexts and cultures.

Summary of the Literature Review

The literature review included the theoretical frameworks and related studies regarding general aspects of dementia caregiving, dementia staging, and current organizations that provide support. Caregiving for family members with dementia is not an easy journey, especially for those who are caring for a parent. Familial caregivers do their best with the tools that they have but are at risk for negative health outcomes because of feeling frustrated, overwhelmed, and fatigued. Care recipients with dementia typically progress through seven stages of brain change, as described in Barry Reisberg's Global Deterioration Scale (1982). When adult caregivers are trying to balance their own lives with the needs of their parents who are progressing through the stages of dementia, they go through many decision-making moments, which require support from peers and experts. This decision-making process can be studied using the framework provided in the TMIM and the perception of feeling support can be studied using the framework provided in the SST.

TMIM contributes to the discipline of communication studies by providing a reference for communication scholars and healthcare professionals to understand how to improve rapport with people seeking trusted environments of information. Knowing that the evaluation phase entails assessments of efficacy, scholars and professionals might have an advantage when planning effective programs for potential information seekers. Dementia care practitioners, for example, may use the theory to understand how to build a positive reputation in each type of efficacy assessment, so that caregivers will feel that their anxiety may decrease if they decide to seek information from the practitioner. Because online health information is spread into numerous avenues and driven by numerous caregiver support options, a caregiver may find this to be overwhelming and frustrating. It would be beneficial to expand the research on caregiver perception of currently available online dementia health information/support interventions.

Basing caregiver support interventions inside the theoretical framework provided by SST, also gives dementia care practitioners the knowledge that social-emotional support needs to be a priority in the intervention. Caregivers, as well as care recipients, need to feel that they are not alone, that their needs matter, and that they have a community of people who understand what they are experiencing. The current literature suggests that in-person and online health communication avenues may be most beneficial when intertwined with social-emotional support options. A phenomenological study of familial caregivers' experiences with current dementia-related online health communication will give additional insight into what is working and what is not working. Dementia care practitioners may take this feedback and learn how to connect with caregivers and care recipients efficiently and effectively in ways that decrease negative health outcomes and improve quality of life.

Chapter Three: Methodology

Overview

The nature of this communication research study was based on caregiver perceptions and descriptions of experiences in the realm of dementia health communication, making it a qualitative research design. Caregivers, who are working through all the unknowns about a loved one's neurological decline, quickly find that they need help and support. Caregivers want to know how to give their loved ones dignity and comfort, despite the fears that accompany brain changes associated with Alzheimer's or dementia. According to Byers et al. (2022), some caregivers are searching for answers about the stages of the disease, available resources, and strategies for dealing with cognitive decline. Understanding what caregivers are experiencing throughout this journey will help healthcare professionals learn how to provide specific supportive interventions. The purpose of this qualitative study was to explore how adults caring for their parents in the Ohio Valley search for and perceive online health communication regarding Alzheimer's and dementia.

This chapter reiterates the research questions and describes the research paradigm. Qualitative methods and a phenomenological approach align with the nature of the study as it seeks to understand social experiences through the perspectives of a specific lived phenomenon. The researcher's role in the study is mentioned in this chapter, as well as carefully planned procedures to allow for ease in future replication of this study.

Research Questions

RQ1: How can dementia-care practitioners provide health communication and interventions to unpaid family caregivers struggling with physical and psychological burnout?

RQ2: Using the motivated information management theory as a framework, what motivates caregivers who have parents with dementia-related cognitive decline to seek health communication through avenues of in-person and online support?

Qualitative Study Research Sub-Questions

- What questions are caregivers of parents with Alzheimer's/dementia asking when searching for information about dementia-related cognitive impairment?
- From the perspective of unpaid family caregivers, what is missing from current health communication avenues regarding how to care for someone with dementia?
- If using Reisberg's seven-stage Global Deterioration Scale (GDS) as a reference, at what stage are unpaid family caregivers seeking information about how to care for their loved one with dementia?
- From the perspective of individuals caring for a parent with Alzheimer's/dementia, what online organizations/practitioners are currently providing the best avenue of support and why?

Qualitative Method Research

This research followed a qualitative design. Qualitative research methods are not a new concept, but they "have continued to grow in influence within the Communication discipline" (Lindlof & Taylor, 2017, p. 21). It is important to describe the basic characteristics of a qualitative design when using this method to study health communication on the topic of dementia care. The basic characteristics of qualitative design include a very active role by the researcher in data collection and analysis, a holistic view of textual data in multiple forms "such as interviews, observations, documents, and audiovisual information," and a goal of learning more "about the problem or issue from participants" (Creswell & Creswell, 2018, p. 182).

Researching caregiver perspectives of health communication regarding dementia requires close communication between the researcher and the participants. This researcher did not simply want to learn what information is missing from dementia-care communication and interventions; rather, what caregivers perceive is missing or still needed when they seek health communication and interventions that will help them be better at caregiving. In-depth, rich qualitative data gleaned from participant responses regarding their behaviors when seeking dementia care information contributes to the insight gained during this research process. For the purpose of this study, House (2018) best explained the reason for qualitative research versus quantitative research with the following statement:

> The basic function of qualitative research is to Understand Human Behaviour, which is rooted in the philosophical strand of Hermeneutics, whereas the basic function of quantitative research is to Explain Human Behaviour. Understanding implies empathy with human participants. The rich context provided in qualitative research provides a lot of personal information, with hypotheses evolving gradually through interpretive findings of repeated patterns. (p. 7)

Phenomenological Approach, Strategy of Inquiry

For this proposed study, a phenomenological approach allowed the researcher to collect and interpret qualitative data regarding caregiver perspectives on what is missing from current health communication and interventions. Founded by Edmund Husserl, phenomenology tasks the philosopher “to describe the structures of experience, in particular consciousness, the imagination, relations with other persons, and the situatedness of the human subject in society and history.” (Armstrong, n.d., para. 1). “The goal of a phenomenological research study is to better understand the subjective, lived experience of a particular phenomenon as it was experienced by a person or a group of people" (Terrell, 2016, p.156).

This researcher sought to understand the perspectives of caregivers who are living through the phenomenon of watching their loved ones gradually deteriorate and how they may be desperately searching in-person or online for much-needed interventions. Punch (2014) explained that by using open-ended data collection strategies, such as interviews, the researcher could tap into lived experiences on a much deeper level than with close-ended strategies. "Most analysis is done with words. Words can be assembled, subclustered, broken into semiotic segments. They can be organized to permit the researcher to contrast, compare, analyze and bestow patterns upon them" (Punch, 2014, p. 199). Interviews allow the researcher to gain a rich set of contextual data regarding the caregivers' decision-making processes and the experiences they have gone through as they respond to questions about their perspectives of dementia care health communication.

Researcher's Role in the Study

It is important to note the researcher's reflexivity in this communication study to counterbalance any perceived biases in the interpretation of the results. The researcher in this study is a speech-language pathologist who has worked with the dementia population for 20 years. The researcher has worked in nursing care facilities as well as outpatient settings, home health settings, and acute hospital settings where caregivers have benefitted from in-person health education and interventions concerning dementia. Regarding researcher reflexivity, Creswell and Creswell (2018) stated, "Be explicit, then, about how these experiences may potentially shape the interpretations the researchers make during the study" (p. 184). The researcher in this study leaned toward coding the data into themes that reflected a cognitive-linguistic communication perspective. Under their scope of practice, the speech-language pathologists' roles in dementia care include diagnosing and enhancing communication abilities while educating caregivers in following through with techniques to improve quality of life throughout the progression of the disease (Swan et al., 2018). When studying caregiver perspectives of health information about dementia, cognitive-communication themes were more amplified with a speech-language pathologist researcher.

Procedures

A recruitment letter was sent to potential participants and purposeful sampling narrowed down interviewees appropriate for this research study to represent the Ohio Valley caregivers. Semi-structured interviews allowed for a rich dataset. Themes were derived from the data using appropriate coding techniques.

Sampling Strategy

This study necessitated approval from the specified institutional review board because human participants were needed. Following this approval, purposeful sampling was employed by requesting volunteers who met the criteria of adults who are caring for their parents with dementia and who are seeking health information through in-person or online resources. "Purposeful sampling requires access to key informants in the field who can help in identifying information-rich cases" (Suri, 2011, p. 66). The researcher requested assistance from regional Ohio Valley organizations and teams that provide caregiver support in the realm of dementia. These agencies agreed to work with the researcher in communicating with potential participants who were recruited for this study.

The researcher was transparent in the intent of the study, which was to improve dementia care providers' communication with caregivers by learning what they perceive is missing from current health communication avenues. Participant criteria was slightly revised to include caregivers with parents who may not have been formally diagnosed with dementia but have been medically labeled with cognitive decline indicating possible or probable dementia. After gathering demographic data and ruling out caregivers who did not meet the participant criteria, a sample of 12 participants was used to represent the population of adults caring for their parents with dementia in the Ohio Valley who seek or have already sought health information on this topic. The final participant was from outside of the Ohio Valley, but located within one state's proximity from the other states that make up the Ohio Valley. Following consent, a pre-interview was conducted with this participant to determine if this caregiver's perspectives would invalidate the results of the study. While this participant had to share an outside perspective of cultural influences in the Ohio Valley, all other responses did not result in any conflicting codes during post-interview memo-ing. The researcher determined that this participant's perspectives were relevant to this study. See Appendix 1 for a participant recruitment form.

Instruments Used in Data Collection and Rationale

Semi-structured interviews were used to collect textual data for analysis. DeJonckheere and Vaughn (2019) described semi-structured interviews as a very effective data collection method for a phenomenological study because they allow participants to share experiences and personal thoughts as well as researchers to adapt to questions as the unfolding of contextual data takes shape. Given the nature of how demanding caregiving can be, it was noted that face-to-face interviews were likely too difficult for the participants in this study (Vechia et al., 2019). Interviews were offered face-to-face or via remote connection. One participant did permit the researcher to conduct the interview in her home. All other participants were interviewed using a private link via Zoom® behind a locked door to protect privacy and anonymity.

Interview Protocol

The participant signed an informed consent document prior to enrolling in the study. Verbal consent was also obtained from each participant at the beginning of each scheduled interview to ensure that the participant did not have any reservations or change of mind. “Informed consent (IC) to participate in research is one of the fundamental ethical principles considering respect for the persons, their dignity, and autonomy” (Al Demour et al., 2019, p. 3). See Appendix II for the informed consent form.

Protocols for the data collection procedure included those suggested by Creswell and Creswell (2018). The researcher asked interview questions in person or over an encrypted remote interview setting. Participants gave informed consent to the recording of the interview, but the interviewer also took handwritten notes as a backup in case of technical difficulty with saving a quality recording. The interviewer tried not to read the questions during the interview, but rather memorized them for a more naturalistic conversational atmosphere. According to Creswell and Creswell (2018), “the interview protocol consists of several important components. These are basic information about the interview, an introduction, the interview content questions with probes, and closing instructions” (p. 190).

The researcher practiced semi-structured interview skills beforehand to feel comfortable with facilitating the question-and-answer interactions, trying not to lead the conversation in a specific direction. An interview guide was created to give the researcher a format ensuring that participants were all asked the same questions and that they were asked to elaborate on topics that specifically filled gaps in the existing literature. See Appendix III for the interview guide.

When the participant arrived for the interview, the researcher established a rapport with the participant. The researcher reiterated the purpose of the semi-structured interview and once again obtained verbal permission to proceed. The researcher began the interview with a question to allow the participant to talk freely about his/her loved one. Questions then moved from the least complex to the most complex, maintaining the rapport with sensitivity toward any delicate topics in the questions. The interview was set to be no longer than one hour in duration, and the researcher recorded the session as well as took notes throughout. The researcher closed the interview by thanking the participant and asking if he/she would like to provide additional information or ask any questions to the researcher. An interview recording application called Otter.ai™ performed transcription of each interview.

Data Analysis Steps

The researcher utilized a qualitative computer software program, NVIVO™, to assist in data analysis, along with DOVETAIL™ for transcription summaries. All participants' responses were de-identified and uploaded to the software programs for coding and analysis. According to Creswell and Creswell (2018), the features of qualitative software programs include:

> the ability to incorporate both text and image data, the features of sorting and organizing data, the search capacity of locating all text associated with specific codes, interrelated codes for making queries of the relationship among codes, and the import and export of qualitative data to quantitative programs. (p. 192)

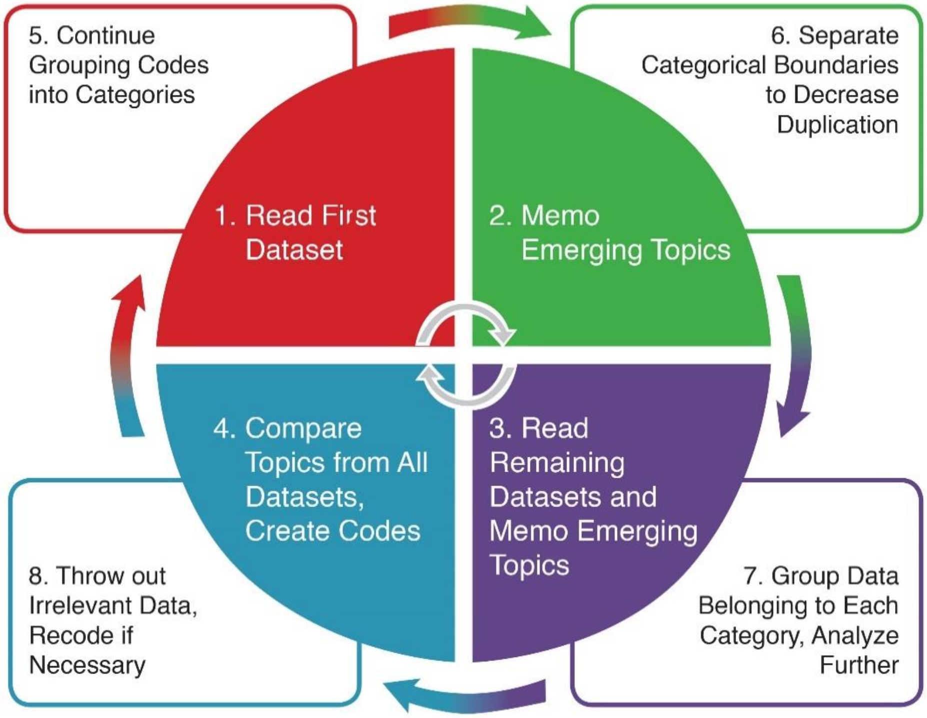
The five sequential steps identified by Creswell and Creswell (2018) were used in this process: 1). Organize and prepare the data. 2.) Read all of the data. 3.) Begin coding the data. 4.) Generate descriptions and themes in the data. 5.) "Advance how the description and themes will be represented in the qualitative narrative" (p. 195).

Organization of Data for Analysis

According to Punch (2014), one way to sort and see the progression of the themes and descriptions is to display the data in organized charts or visualizations. “Displays are used at all stages, since they enable data to be organized and summarized, they show what stage the analysis has reached, and they are the basis for further analysis” (p. 172). Terrell (2016) stated, “Starting analysis early allows the researcher to identify other topics to be covered … This iterative process allows you to develop a much deeper understanding or, as it is often called, a thicker view of your material” (p. 166). For this study, the researcher continually reviewed the data throughout the interview process, with an open mind in order to leave out any personal opinions and to accurately capture the participants’ perceptions of their experiences.

Coding Data

“Codes are tags, names or labels, and coding is therefore the process of putting tags, names or labels against pieces of the data” (Punch, 2014, p. 173). Creswell and Creswell (2018) suggested the use of Tesch’s (1990) Eight Steps in the coding process of textual data in qualitative design studies. By using this framework, the researcher was able to “assemble the data material belonging to each category in one place and perform a preliminary analysis” (p.196).



Descriptions and Themes

The researcher used primary and secondary coding levels to narrow the information into workable categorical themes. “These themes are the ones that appear as major findings in qualitative studies and are often used as headings in the findings section of the studies” (Creswell & Creswell, 2018, p. 194). Six themes about caregiver perspectives of current health communication information regarding dementia surfaced as these headings. 1. Brain Changes Motivate Caregivers to Seek More Information, 2. Perceived Breakdowns Happen in Certain Trajectories of Health Communication Regarding Dementia, 3. Avenues of In-Person Support or Resources are Better One-on-One, 4. Avenues of Online Support or Resources are Variable, 5. Caregiver Perspectives of What They Know Align with Literature, and 6. Communication Changes with Parents After Dementia.

Higher Level of Analysis

The goal was to explain the themes and descriptions of the caregiver perspectives in a narrative results section of the study. Chapter Four explains how themes are interrelated and why the themes provide important information for dementia care practitioners when it comes to health communication and caregiver education. Data is represented using charts and tables “to show the flow of ideas in the findings section” (Creswell & Creswell, 2018, p. 198).

Basis for Interpreting the Analysis

Due to the literature having indicated that caregivers go through a decision-making process when seeking health communication and social support, the interpretation of the results was closely tied to the theory of motivated information management and the social support theory. The use of these theories and interrelated themes from the data analysis generated an action agenda for further research as well as suggestions to improve health communication regarding dementia. Themes indicated that caregivers make decisions based on their parents' types of brain changes as well as the need for support in planning for external resources and transitions to the next level of care. Caregivers also seek support from both strong ties in one-on-one conversations and from professionals. Dementia care practitioners and support structures can be available to caregivers in a more effective health communication method than currently exists.

Trustworthiness for Valid Findings

The researcher reduced the chances of researcher or respondent bias by establishing a neutral rapport, carefully wording questions in the interview consistently across participants, and ensuring ethical considerations were not compromised. Triangulation strategies were used by carefully following evidence-based methods in hand-coding and data analysis, corroborating the hand-coding with transcription and coding software analysis tools, and asking participants to verify their responses in the data taken by the researcher. The researcher followed the procedures carefully to allow for future reduplication of this study.

Ethical considerations

Prior to the initiation of any participant recruitment or collection of data, the IRB was consulted to review and approve this study involving human subjects. Risk was deemed low, and the IRB provided an approved stamped consent document outlining all procedures for participants to sign. Participants in the study signed the informed consent prior to participating in the study, where the researcher advised them of their rights to privacy and their rights to leave the study at any time. The protection of health information was of utmost importance. Anonymity was upheld through the de-identification of participants and the use of pseudonyms. All recorded data has been stored in password-protected files. The researcher upheld ethical standards in beneficence and nonmaleficence for all participants.

Plans for Presenting the Results

The results of this research will be published as a dissertation study. Each participant in the study has been de-identified in the final publication and will receive the results if desired. The resource/referral agencies in the Ohio Valley who assisted with referring potential participants for the study will be given a copy of this publication. The research study may be submitted for educational purposes in caregiving for persons with dementia and decreasing caregiver burden.

Summary

This chapter described the qualitative, phenomenological method of research which was based on understanding the lived experiences of caregivers who are searching for answers that will help them meet the needs of persons suffering from dementia. This phenomenological approach opened the door for the collection of open-ended textual data through semi-structured interview questions. After identifying and recruiting a valid sample of participants made up of caregivers who met the criteria, interviews commenced. The data collected from the participants' responses were compiled and analyzed to give healthcare professionals a framework on which to build more effective strategies for caregiver support. This chapter also included the role of the researcher, participant recruitment, data collection and analysis procedures, and plans for validation and adherence to ethical considerations.

Chapter Four: Findings

Overview

Chapter Four describes the results of this qualitative, phenomenological study of caregiver perspectives regarding currently available dementia health communication. The caregivers who participated in this study are adults in the Ohio Valley region of the United States who have a parent with possible, probable, or definitively diagnosed dementia. Themes were developed using an inductive coding approach from the data collected through semi-structured interviews. The results of this study revealed that despite the numerous avenues of in-person and online health communication for caregivers of persons with dementia, the caregivers have been left with plenty of unanswered questions, which can lead to negative social-emotional outcomes.

Description of Participants

For this qualitative study seeking to understand the lived experiences of adults searching for health communication regarding dementia, a call for participants was given via social media platforms such as Facebook and Instagram. Recruitment requests were also made to Ohio Valley regional professionals who specialize in care for the aging. Purposeful sampling was initially used, describing participant criteria as people at least 18 years of age, living in the Ohio Valley, and caring for a parent with dementia (Creswell & Poth, 2018). This recruitment method resulted in approximately half of the desired number of 12 participants. Another call was elicited with amendments to the criteria in order to open up the participant pool. The new call described the need for participants at least 18 years of age, living in or near the Ohio Valley region, and actively involved in any aspect of care for a parent with brain changes that are possibly, probably, or definitively diagnosed with dementia. Snowball sampling methods recruited additional participants for this study. One participant was outside of the Ohio Valley but within one state's proximity to the region. One participant was the daughter-in-law of a person with dementia but was quite active in her mother-in-law’s care. Participants were given pseudonyms to protect the anonymity of their identities. The participant pool was made up of 75% females and 25% males, all identifying as white. All participants had at least a high school education, and 75% reported themselves to be college-educated. Additional participant demographics are represented in the table below.

Demographics Table

Participant	***Gender***	***Age Range (years)***	***Race/ Culture***	***Level of Education***	***Employ-ment Status***	***Marital Status***	***Parent’s Living Situation***
Amelia	Female	55-64	White	Bachelor’s Degree	Full Time	Married	Amelia’s home
Brandy	Female	45-54	White	Doctoral Degree	Full Time	Single, in a relationship	Home with spouse
Cameron	Male	55-64	White	Doctoral Degree	Full Time	Married	Home with spouse
Denise	Female	45-54	White	Associate degree	Full Time	Married	Long-term care facility
Emily	Female	55-64	White/ Lebanese	Master’s Degree	Full Time	Engaged	Assisted Living
Farrah	Female	55-64	White	High School	Retired; Business Owner	Married	Long-Term Care Facility
Gregory	Male	55-64	White Jewish-American	Master’s Degree	Full Time	Married	Long-Term Care Facility
Harrison	Male	55-64	White	Associate degree	Full Time	Single	Long-Term Care Facility
Isabelle	Female	45-54	White	Master’s Degree x 2	Full Time	Married	Isabelle’s home transitioned to Long-Term Care Facility
Jillian	Female	45-55	White	Unknown	Full Time	Married	Home with spouse

Kate	Female	45-54	White	Master’s Degree	Full Time	Married	Home with spouse
Lydia	Female	65-74	White	High School	Homemaker	Married	Long-Term Care Facility

Participant 1: Amelia

Amelia is a female in her mid-50s who works a full-time job while she and her spouse are the primary caregivers for her live-in mother. Amelia has two grown children and one recently born grandchild. Amelia’s mother was recently diagnosed with Lewy Body dementia, vascular dementia, and Alzheimer’s disease. Until about a year ago, Amelia’s mother worked in an office and cared for herself in her own home. During the study, Amelia recalled the challenges in adjusting to the new mother-daughter dyad, the new living situation, and the process of planning for the future. Amelia’s experience with navigating her mother’s sudden need for in-home care made her a uniquely appropriate participant for this research.

Participant 2: Brandy

Brandy is a female in her mid-50s who works 40+ hours a week. She has two grown children who are attending college. Brandy’s mother has been experiencing cognitive changes for the past couple of years. While Brandy’s mother does not have a formal diagnosis, informal screening measures have indicated that she has probable dementia. Brandy’s mother lives in her own home with her spouse, who has also been experiencing some mild decline in his memory. Brandy’s unique experience with reconciling the thought of her mother’s brain change has made her a relevant participant in this research.

Participant 3: Cameron

Cameron is a male in his mid-50s who works a full-time job. Cameron’s father has Lewy Body dementia and lives in his own home with Cameron’s mother. Cameron’s mother is his father’s primary caregiver, but Cameron stays actively involved and provides support as much as needed. Cameron’s perspective in this study is relevant because he is experiencing how to be a main branch of support for both of his parents to facilitate his father’s ability to maintain function for as long as possible.

Participant 4: Denise

Denise is a female in her early 50s who works full-time and looks forward to weekends with her grandchild. Denise is the mother of two sons, having lost one of them around the same time her father began experiencing cognitive decline. Denise’s father has been living in a nursing care facility for a few years, because of ongoing brain changes that accompany dementia.

Denise shared specific instances where her father’s dementia manifested as aggressive and paranoid behaviors that were completely out of character compared to his pre-dementia personality. Denise is a very involved family caregiver, visiting her father frequently and advocating for his wants and needs. As an adult caring for a father with dementia, Denise brings her unique experiences to this research study. When sharing her perspectives, Denise recounted the many emotions that have accompanied this journey so far.

Participant 5: Emily

Emily is a female in her early 60s who works a full-time job and has a mother with mild to moderate dementia. Emily is her mother’s medical power of attorney and primary family caregiver. Emily’s mother recently transitioned from her own home to an assisted living facility following a hospital stay. Emily’s mother experienced a mild stroke, and due to her vascular changes, requires 24-hour care. Emily’s perspective was beneficial to this research study as she recalled her experiences visiting her mother, taking her mother to her appointments, and trying to navigate the differences in her mother’s ability to remember conversations from day to day.

Participant 6: Farrah

Farrah is a female in her mid-50s who is a retired business owner. Farrah visits her mother-in-law, who has dementia and lives in a nursing care facility not far from Farrah's home. The responsibility of executing her mother-in-law's transition from home to the facility fell to Farrah and her husband. Farrah's mother-in-law thrives in the nursing care facility despite her cognitive deficits. Farrah's mother is also a recipient of Farrah's caregiving heart, but not for the reason of cognitive change. Farrah was able to bring her and her husband's unique experiences to this research study regarding how they continually support her mother-in-law in her daily routine.

Participant 7: Gregory

Gregory is a 55-year-old male who works full-time. He has been able to shift his work into a flexible hybrid structure because he primarily cares for his wife, who is in a rehabilitation center following a sudden neurological event. Gregory's mother lives in a nursing care facility a few hours away from him. Gregory and his sister are their mother's primary support system, working through the challenges of adjusting to their mother's brain change. Gregory's experience as an adult male working through not only his mother's sudden need for a memory care facility but also his wife's sudden need for rehabilitation made him a uniquely appropriate participant for this research.

Participant 8: Harrison

Harrison is a male in his early 60s who works full-time while remaining highly active as his mother's medical power of attorney and primary family caregiver. Harrison's mother lives in a nursing care facility, where Harrison finds that he needs to advocate for the adequacy of her care quite often. Harrison's mother has advanced dementia, but he reports that she continues to recognize him because of the frequency with which he visits. Harrison's distinctive experience as an adult male caregiver for his mother with dementia made him a relevant participant in this study.

Participant 9: Isabelle

Isabelle is a 52-year-old female who works full-time. Until halfway through the study, Isabelle's mother lived with her. Her mother's brain change is due to a possible dementia that accompanies Parkinsonism. Isabelle's perspectives were an integral part of the study because she was the only participant actively going through a parent's transition from home to a nursing facility. Isabelle recalled previous experiences caregiving for a parent with dementia when her mother-in-law was diagnosed with Alzheimer's, lived with Isabelle and her husband, and eventually passed away while living in a nursing facility. When it comes to caregiver perspectives, Isabelle had a lot to offer to this research study.

Participant 10: Jillian

Jillian is a female in her mid-50s who works full-time and has grown children. Jillian's father has Alzheimer's type of dementia, and he lives at home with Jillian's mother, who is her father's primary caregiver. Jillian has always had a very close connection with her father. She lives a couple of hours away from her parents, but she reported that she visits them biweekly and that she calls them frequently. Jillian's main concern throughout the series of interviews was that she wanted her parents to be able to stay together as long as possible, and she wanted to do all she could to make this happen. Jillian brought her unique perspective to this study regarding her efforts in providing support to not only her father with dementia but also her mother as a primary caregiver for her father.

Participant 11: Kate

Kate is a female in her mid-40s working full-time and also caring for a child with special needs. Kate's mother began experiencing brain change and was diagnosed with Alzheimer's type of dementia. Kate's mother recently qualified for an experimental drug trial but, at the time of the interview series, was awaiting the initiation of that trial. Kate reported that her mother lives at home with Kate's father and that her mother remains in a mild Alzheimer's stage of progression. Kate's perspective was essential to this study as she recalled the recent diagnostic process and the many questions that have presented themselves as she navigated this new dynamic in her life.

Participant 12: Lydia

Lydia is a 66-year-old female who was very close to her mother during her childhood. Lydia has always been a homemaker, caring for her six children and many grandchildren throughout her adult life. Lydia's mother began experiencing cognitive decline several years ago, manifesting at first with wandering off and becoming lost. Lydia has siblings who are involved in her mother's care. She worked hard to allow her mother to stay at home for as long as possible until it became safer for her mother to transition to a long-term care facility. According to Lydia, her mother currently resides at the long-term care facility and has been experiencing a steady but gradual cognitive decline. Lydia provided a very relevant perspective of what it is like to go through her mother's onset of brain change, transition to long-term care, and her mother's changes in communication.

Codes and Themes Development

Miles, Huberman, and Saldana's (2020) qualitative data analysis strategies guided the steps in this longitudinal look at adult caregivers' perspectives on their lived experiences of searching for dementia health communication. The 12 participants were interviewed three separate times, once a month for three months. Interviews were conducted over a remote connection software, Zoom™, with the capability of video and audio recording, permitted by each participant via informed consent documentation. A second audio recording tool, Otter.ai™, was also used which performed transcription of each interview for further analysis. Other software used in the data analysis process included DOVETAIL™ and NVIVO™ for transcription summaries and coding.

Interviews were semi-structured in nature, consisting of pre-determined questions without pre-established response categories. This allowed for open-ended replies and for the interviewer to probe for additional meaning in the data (Punch, 2014). Interview questions were carefully designed to seek answers to the research questions. Codes were assigned to participant responses following each round of interviews using a holistic method. Codes evoke a more in-depth thought organization on meanings derived from the data (Miles et al., 2020). Patterns were detected across participant responses from the first round of interviews. Those patterns were loosely condensed into possible themes. A theme is an extension of the coding process that follows thought-provoking reflection and results in a description of the data's interpretation (Miles et al., 2020). Because the participants were interviewed on three separate occasions over time, the researcher was able to generate new questions based on the themes that were not originally hypothesized in the interview construction (Creswell & Creswell, 2018). The themes were integrated into the questions for the second round of interviews to saturate and ensure the validity of the interpretation. The same process was used to saturate themes even further for the third and final round of interviews. Member checking was employed throughout the process. Interview transcripts were sent to participants using encrypted email correspondences. Participants were instructed to send the researcher any clarifications needed in the transcripts as another method to validate the interpretation of the data. Tables 1 and 2 provide an organized visualization of themes and codes.

Codes

Coding was guided by Tesch's (1990) eight steps in qualitative research. The researcher made notes and memos throughout the data taken from all interview transcripts. Then, the artificial intelligence software application, DOVETAIL™, was used to generate two different summaries of each interview. Additional notes were made in the summary margins (Creswell & Creswell, 2018). Topics emerged as the researcher identified similarities across original transcript memos and summary memos. "Memo writing often provides sharp, sunlit moments of clarity or insight—little conceptual epiphanies. They are one of the most useful and powerful sense-making tools at hand" (Miles et al., 2020, p. 88). NVIVO™ assisted in tagging the original interview transcripts for the frequency of codes. The researcher went back to the data and compared the software-assisted codes to the topics that emerged from hand-coding. Lines were drawn "between categories to show interrelationships" (Creswell & Creswell, 2018, p. 196). Re-coding was ongoing throughout the process as final decisions were made. As seen in Table 1, primary codes and secondary codes were recorded. Miles et al. (2020) described the reason for secondary coding. "It can be employed after an initial, yet general coding scheme has been applied and the researcher realizes that the classification scheme may have been too broad, or added to primary codes if particular qualities or interrelationships emerge" (p. 72).

Table 1

Codes and Themes from Interviews

THEMES	PRIMARY CODES	SECONDARY CODES	QUOTES
BRAIN CHANGES MOTIVATE CAREGIVERS TO SEEK MORE INFORMATION (TMIM)	Cognitive Decline Characteristics	Decreased orientation to time	*“He’s going further back in time since we last talked.”*
		Decreased ability to communicate in conversations	*“She had stuff to say, but she couldn’t find the words to say it.”*
		Difficulty initiating/completing familiar sequences	*“And then suddenly, she couldn’t initiate anything, she would sit there and be like, what do I do next?”*
		Loss of recognition of familiar people	*“She’s sat beside me on the couch and we’re watching television, and she reaches over and says, who are you?”*
		Hallucinations	*“Mom says, well those little kids were here today; and I’ll look at her and she goes, but they probably weren’t, were they?”*
	Physical Changes	Balance/Falls	*“She does say, you know, I’m having trouble with my balance.”*
		Weight changes	*“She went from probably a 200-pound person like me to a 120-pound person and she’s my height.”*
	Medical Changes	Hospital stays	*“Since then, he’s developed kidney problems and has been in and out of the hospital…”*
	Preserved Abilities	Communicates at a basic level	*“She comes to Sunday School with me and on certain days she’ll put her two cents in…”*
		Reminisces about the past and thinks about family	*“The last time I went to visit her I just talked about when I was like 3 or 4 [years old] and we were at the farm because that’s where she was at, talking about living there.”*
	Parent’s Perspective of Their Changes	Poor recognition and acceptance	*“She doesn’t want to accept that she has any brain change and she doesn’t want to be associated with those people [in a support group]”*
PERCEIVED BREAKDOWNS HAPPEN IN CERTAIN TRAJECTORIES OF HEALTH COMMUNICATION REGARDING DEMENTIA	Early Detection is Lacking	Early concerns were dismissed by the physician as normal aging	*“We went to his doctor and tried to explain things and my dad was able to say who the president of the United States was, so he gave answers like these to two or three questions, so the doctor wouldn’t help us.”*
	Too General of a Diagnosis	Not enough information about staging and predictive progression	*“What should I be looking for? What should I be prepared for? What is the marker for the next stage?”*
	Transitioning Out of the Home	Poor communication from facility care staff	*“Why don’t you communicate with the family when something [personal supplies] is getting low?”*

	Too Many Unanswered Questions	There is a diagnosis, what do I do now?	*"What about the stress? Who is going to be the caretaker? What if the person is gainfully employed? They cannot take off to take care of their loved one….so?"*
AVENUES OF IN-PERSON SUPPORT OR RESOURCES ARE BETTER ONE-ON-ONE (SST)	Siblings/Family	Siblings can make or break the perception of social support	*"There have been some things that we have not agreed about but thus far, knock on wood, we have been able to give and take and it's worked out. I am sure that will be an issue in the future though."*
		There are concerns about the other parent	*"We have been having trouble finding people to come into the home and help give mom a break."*
	Support Groups vs One-to One Conversational Support	Support groups are not ideal for working adults	*"We are such a stupid busy society that I don't know how we have time to do anything"*
		Conversations with others experiencing the same phenomena are ideal avenues of social support	*"I have a really close friend whose father went through something similar, and she passed on a book to me to read."*
	Professionals	Unless there is a personal connection, medical professionals lack in social support	*"Sometimes I feel in my heart, I could be wrong, that they don't listen to families because they think you're trying to come into their money or something."*
AVENUES OF ONLINE SUPPORT OR RESOURCES ARE VARIABLE (SST)	Professional Videos and Documentaries		*"Then there's stuff like TED talk."* *"I watched this documentary on Netflix about centenarians in the blue zones, people who live to be 100 years old and how they don't have as many problems as we do."*
	Podcasts	Regarding dementia/ brain change	*"One of the people I really like is Dr. Andrew Huberman, a neuroscientist at Stanford University who has a podcast."*
		Desire for a local podcast with regionally available resource information	*"I would listen to it [local podcast]. What would make me keep listening is the fact that it is local and talking about activities or facilities that are familiar, which makes it more real, I think."*
	Medical Journals Research Studies		*"There's an enormous amount of information on PubMed, if you look for can find abstract after abstract."*
	Websites/Blogs		*"There is a Lewy Body Dementia website and I've looked at that one. It is not the Michael J. Fox one, but I do look at that one a lot."*
CAREGIVER PERSPECTIVES OF WHAT THEY	Genetics	I may be at risk.	*"I still kind of get conflicting information as to whether there is a significant genetic*

KNOW ALIGN WITH THE LITERATURE			*component to Lewy Body disease."*
		Do I even want to know?	*"I would probably like to know more about it [my own risk], but it is hard to learn more about it without starting to obsess about it for me."*
	Lifestyle/Prevention	Diet is important	*"If we start her on that [psychotropic medication], one of the big deals with dementia is they go into failure to thrive, I did read that somewhere."*
		Exercise is important	*"Being mobile maintains your cognition, I get after my mother to get up and move around because this is part of your brain's function is to motivate."*
	Medical Intervention	Some medications slow the progression	*"She's on a medicated 24-hour extended-release patch that's supposed to aid in the cognitive."*
	Cultural Influence	Ohio Valley has strong family ties that influence how they care for their parents	*"I do think to a degree that Appalachia has strong family ties. There may be more personal communication than via phone as compared to bigger cities and depending on the timeline of Alzheimer's they [big city residents] may not be communicating at all."*
COMMUNICATION CHANGES WITH PARENTS AFTER DEMENTIA	Finances	Planning for external care resources is tough	*"Legal stuff, right now I am stuck. I need to sell the house"*
	End-of-Life Decisions	Advanced directives	*"My parents do not have their crap together. They do not have a living will. They don't have a power of attorney. So I started having those conversations with them."*
		Transition to memory care or nursing care	*"So, when I talk to Mom about assisted living [for Dad], she asks, well can your dad and I be together?"*
		Funeral planning	
	Communication Changes and Strategies	Validation orientation vs reality orientation	*"She is [mom] way different with me than them [memory care staff]. I make her attend [to reality] with me. I do not let her stay in La La Land like they do."*
		Role reversal	*"You had to treat her almost like a toddler, you know, give her two choices and she had to pick one."*
		Loss of the familiar connection	*"I kind of sit back and reflect and think how it used to be, it's so different, you know?"*

Table 2

Frequency of Codes and Themes Table

Theme	Primary Code	Secondary Code	Appearance Across Data Sets
1. Brain Changes Motivate Caregivers to Seek More Information	Cognitive Decline	Decreased orientation to time	14
		Decreased ability to communicate in conversations	15
		Difficulty initiating/completing familiar sequences	19
		Loss of recognition of familiar people	8
		Hallucinations	10
		Total	**66**
	Physical Changes	Balance/Falls	14
		Weight changes	4
		Total	**18**
	Medical Changes	Hospital stays	10
		Total	**10**
	Preserved Abilities	Communicates at a basic level	17
		Reminisces about the past and thinks about family	7
		Total	**24**
	Parent’s Perspective	Poor recognition and acceptance	11
		Total	**11**
2. Perceived Breakdowns Happen in Certain Trajectories of Health Communication Regarding Dementia	Early Detection is Lacking	Early concerns were dismissed by the physician as normal aging	9
		Total	**9**
	Too General of a Diagnosis	Not enough information about staging and predictive progression	26
		Total	**26**
	Transitioning Out of the Home	Poor communication from facility care staff	14
		Total	**14**
	Too Many Unanswered Questions	There is a diagnosis, what do I do now?	13
		Total	**13**
3. Avenues of In-Person Support or Resources are Better One-to-One	Siblings/Family	Siblings can make or break the perception of social support	29
		There are concerns about the other parent	13
		Total	**42**
	Support Groups vs One-to One Conversational Support	Support groups are not ideal for working adults	6
		Conversations with others experiencing the same phenomena are ideal avenues of social support	27
	Professionals	**Total**	**33**

		Unless there is a personal connection, medical professionals lack in providing social support	6
		Total	**6**
4. Avenues of Online Support or Resources are Variable	Professional Videos and Documentaries		7
		Total	**7**
	Podcasts	Regarding dementia/brain change	4
		A desire for a local podcast with regionally available resource information	9
		Total	**13**
	Medical Journals Research Studies		6
		Total	**6**
	Websites/Blogs		11
		Total	**11**
5. Caregiver Perspectives of What They Know Align with the Literature	Genetics	I may be at risk	12
		Do I even want to know?	7
		Total	**19**
	Lifestyle/Prevention	Diet is important	14
		Exercise is important	10
		Total	**24**
	Medical Intervention	Some medications slow progression	10
		Total	**10**
	Cultural Influence	Ohio Valley has strong family ties that influence how they care for their parents	11
		Total	**11**
6.Communication Changes with Parents After Dementia	Finances	Planning for external care resources is tough	19
		Total	**19**
	End-of-Life Decisions	Advanced directives	13
		Transition to memory/nursing care	13
		Funeral planning	2
		Total	**28**
	Communication Changes the Need Strategies	Validation orientation vs reality orientation	10
		Role reversal	7
		Loss of the familiar connection	8
		Total	**25**

Theme Development

Six themes emerged following careful reflection upon the primary and secondary codes derived throughout the data analysis process described above. Table 1 lists these codes and themes, along with examples of direct quotes taken from participant responses in the data. The themes are described in narrative form below.

Theme One: Brain Changes Motivate Caregivers to Seek More Information

It was evident throughout the data collection process that adults caring for a parent with dementia have been motivated to seek information from the healthcare community to cope with this phenomenological experience. Changes in cognitive-communicative skills dominated this theme. The literature supports the primary and secondary codes that were evident throughout the interviews.

Some participants reported that they were not the first to notice their parents' brain changes. The participant, Amelia, stated, *"People from mom's work called and said that she [mom] was starting to have dementia, and I'm like, what? No way! She's depressed..., but I would go to her house and the electricity was paid, the water was paid, the dog was fed, and I just didn't see it at first."* According to Amelia, not long after those reports from her mom's work, she began asking her friends and family members who work in healthcare if she should be concerned. Her mother's ability to initiate and carry out everyday tasks was changing to the point where she was stuck in a parking lot at a local grocery store because she could not remember how to put the car in park. Then, the hard reality of a definitively diagnosed mixed dementia, including Lewy Body, Alzheimer's, and vascular, was given through the West Virginia University Rockefeller Neuroscience Institute's Memory Health Clinic.

Another participant, Gregory, recalled a sudden onset of brain change that occurred when his mother had to move apartments due to a landlord circumstance. According to Gregory, after moving to a new environment, his mother *"suddenly couldn't initiate anything. She would sit there and ask, what do I do next?"*. This motivated him and his sister to seek information through urgent care and eventually through a neurology consult.

Loss of balance and dizziness were frequent secondary codes associated with this theme of brain change. Another participant, Cameron, recalled that since his father was diagnosed with Lewy Body disease, his father has had "*chronic problems with getting light-headed. If he stands up, he has chronic problems with dizziness,*" which has resulted in several falls. His father also had problems with his autonomic functions, where his body temperature would not always regulate. These brain changes that result in physical and medical changes, have been motivating factors for seeking additional information from the healthcare profession.

As indicated by the theory of motivated information management, the participants described how their uncertainties regarding their parents' brain changes motivated information-seeking behaviors. The participants also shared what strategies were used to resolve these uncertainties, as indicated by the uncertainty reduction theory. The next theme gives insight into the participants' perspectives on whether the uncertainties were resolved through the avenues they explored.

Theme Two: Perceived Breakdowns Happen in Certain Trajectories of Health Communication Regarding Dementia.

Of the 12 participants, nine reported that the parent, at the very least, had been formally given a dementia diagnosis. Of those nine participants, only three of them knew what type of dementia their parents had. Some participants recalled that they, or even the parents themselves, had reported early symptoms to a family physician who did not recommend or pursue any follow-up at that time. One participant, Denise, recalled how emotionally taxing it was when she tried to convince her father's primary care physician that her father was experiencing brain changes. Denise stated, *"My husband and I took off work to go to my dad's doctor and explain to him that there were things about his personality that were not normal. He was seeming very agitated, wanting to argue with people all the time. When we got to the doctor, my dad was able to say who the president of the United States was, so the doctor would not help us."* This coded theme brought forth a follow-up question regarding the participants' perspectives on whether an earlier diagnosis may have made any difference in the course of care that ensued thereafter. This particular participant replied yes. She thought an earlier diagnosis could have been a catalyst for medication that would have eased her father's agitated behaviors. Her father's agitated behaviors would eventually land him in jail before he received a definitive dementia diagnosis.

While there were participants who felt the diagnostic process was too burdensome, some were satisfied with their diagnostic experience as it resolved the uncertainty of the reason for their parents' brain change. Knowing that the brain change was the result of a neurological pathology gave way to the reconciliation that more decisions would need to be made. This is where the codes in Theme Two become more specific. Following the diagnosis, participants were left with more questions and more uncertainties.

While specialty clinics and diagnostic centers did a better job than primary care physician offices in giving more definitive information about follow-up after diagnostics, communication regarding resources and next steps was lacking. After receiving a diagnosis, uncertainties included questions like: 'How far along are we in this process?' and 'Where do we go from here?'. Two participants specifically stated that they did not know about dementia staging and progression until indirect interventions were provided by a speech-language pathologist who recognized that the parent's communication deficits were not so much due to a stroke, but rather more due to the stage of dementia. According to most participants, dementia staging information was rarely obtained from a physician or a neurologist. Given that Reisberg's seven-stage Global Deterioration Scale for Dementia originated in the early 1980s and has been used as a framework in many research studies (Ellul et al., 2007; García-Martín et al., 2022), it is surprising that health communication regarding dementia staging was perceived to be in short supply for this participant sample.

Here are a couple of examples of participant responses that were coded in this theme. When asked if anyone in the healthcare community had indicated how far her mother-in-law had progressed in her dementia, Farrah, responded*, "I do not believe I know that information, but if I had to guess, I would say she is in the middle."* Lydia, who requested the interview questions before the interview took place, responded to that same question with, *"I was just looking that up today because I had no information. I don't know, but kind of like middle stage, I guess. She [mom] has had problems for several years. When you look online, the charts are like a year and a half for this and two years for that. She is not following those online charts."*

Other participants experienced a surprising realization during their parents' transition to a memory/nursing care facility that not all caregiving staff were familiar with dementia stages. This made for awkward and sometimes unpleasant communication exchanges between staff and the participant's parent. These exchanges triggered adverse behaviors that may have otherwise been avoided if memory/nursing care staff had been educated on the characteristics that accompany dementia progression. Harrison's mother was placed in a nursing care facility following a hospital stay, and he was listed as her medical power of attorney. She was ordered skilled-care physical therapy, occupational therapy, and speech therapy from those in the field who would qualify as dementia care practitioners in the nursing care facility. During her therapy, caregiver education was provided to Harrison, which included dementia staging information and progression. Harrison reported that he was beginning to come to terms with the fact that his mom needed to stay at the facility for long-term care due to her level of progression. Out of the blue, he received a phone call from a nurse at the facility reporting that his sister was coming to take their mother home. Harrison did not have a good relationship with his sister, so this caused a great deal of unnecessary strife because the nurse was not familiar enough with dementia staging and did not read all the therapy notes regarding the mother's level of needed care. The nurse argued with Harrison, saying that his mother was able to make her own medical decisions because she was of sound mind. The therapy notes clearly indicated that his mother had progressed to a stage where she needed 24-hour care and that she could not make adequate and safe decisions for herself. Transitioning a parent from their home to a nursing care facility brings enough uncertainty without having to worry about breakdowns in health communication in the medical community.

Theme Three: Avenues of In-Person Support or Resources are Better One-on-One

Theme Three ties in with the characteristics of social support theory. As evidenced in the literature as well as in the data from this research, adults who have a parent with dementia need support throughout this phenomenological experience. All but one participant described at least one moment of sharing their lived experience with others who are living a similar experience. Brandy, reported, *"I'm thinking about my best friend who kind of went through this with her father and I sometimes will talk to her about my mom."* Isabelle stated, *"I think with people that I have talked about this with mainly it was for us just knowing that other people had been there and made it through, I guess. It has not been so much about advice on how to handle things as* *much as it's been about an ear to listen."*

Very few of the participants in this study were a part of any formal support group. Three participants reported that they were actively involved in a monthly in-person support group. All nine other participants reported that working a full-time job and making sure to be an arm of support for their parents, left little time to commit to joining a support group. Three of those nine participants reported that they did not think a caregiver support group would be beneficial to their needs. Emily reported that her perception of a support group was that it may not be made up of people who could identify with her situation. She also stated, *"I don't think people in this day are made to really support one another anymore. It's all about their world and how bad they feel, but when it comes time to listen to me, it's like where did everybody go? When I say they have to be of the same mindset, I mean someone who is really invested in listening to me."*

All the participants talked about family members at some point in their interviews. Some brought up concerns about the other parent. Concerns ranged from whether the other parent really understood what was happening, to whether or not the other parent was burning out from being the main care provider. The participants' siblings were discussed quite often throughout the interviews when talking about someone who could identify with their situations. Most participants recalled at least one instance where they did not see eye to eye with their siblings on how to manage their parent's dementia. Two participants are estranged from at least one sibling due to arguments that stemmed from miscommunications or arguments in this process. However, most participants admitted that they were grateful for their siblings in terms of social support. When talking about her mother's disorientation to other people and to time, Emily recalled that she, her brother, and her sister-in-law have tried to use a bit of humor to cope. Emily's mother mistakes one of her nurses for her daughter-in-law. Emily reported that she teases her sister-in-law saying, *“I wish I were as good of a visitor as you are. According to Mom, you care about her the most out of all of us.”* Emily stated, *“If we don’t laugh about it, we won’t get through the day sometimes.”*

As noted in the literature, unless there is a personal connection with a healthcare professional or the healthcare professional specializes in social support, most adults who have a parent with dementia do not perceive much social support from the healthcare team. Jillian stated, *“I think the doctors have trouble saying, well, here’s what’s gonna happen next because the pace of the whole thing is so different for everyone. Today might be fine, but tomorrow might be a mess, and then it’s back to fine the next day. It’s hard to always know what to ask the doctor [in terms of how do I get through this.]”* On the other hand, Isabelle attends church with her mother’s nurse practitioner and finds the nurse practitioner to be a wonderful avenue of social support.

Theme Four: Avenues of Online Support or Resources are Variable

When comparing the frequency of codes between Theme Three and Theme Four, the participants in this study talked about in-person support more often than online support. The discussions of online support were mostly informational resources, almost an extension of what the healthcare team provided. Only one participant, Kate, reported that she benefits from a Facebook support group called Alzheimer’s and Dementia Caregiver Support. She stated, *“It is a private group that has 59.3K members. I have been reading all their suggestions and what their doctors say, and that’s been helpful and enlightening.”* Kate’s description appeared to be more of informational support than social support, but Kate perceived it as an avenue of social support.

Other frequently mentioned avenues of online support by the participants in this study were professionally established websites and podcasts, such as Alzheimer’s Association or medical universities, and user-generated content (UGC), such as personally documented YouTube or TikTok videos. When asked about the effectiveness of health communication in these avenues, participant responses were not consistent. Farrah specifically recalled the names of the podcasts, websites, medical journals, and TED Talk videos that she found effective. Amelia specifically recalled finding the Lewy Body Dementia-related websites and blogs effective but felt the UGC YouTube videos were undignified to the parent featured in the video. Denise talked about a specific individual on the West Coast of the United States who uses the TikTok platform to post videos about being an in-home caregiver for his father. Denise follows this individual and thinks of him as an effective avenue of online support because she finds herself using some of his communication strategies with her father. Denise also reported that she critiques his methods at times, which gives her a look at what not to do in certain situations.

The researcher added a follow-up question to the third round of interviews as themes emerged around the lack of time for participants to attend social support groups. When Denise mentioned in the second round of interviews that she listened to podcasts in her car and would love to find a podcast that was specific to the Ohio Valley region, the researcher asked participants about this in the third round of interviews. Nine of the 12 participants were interested in listening to a local podcast about resources for caregivers in the Ohio Valley. Brandy reported that she listens to podcasts and that she would add a local podcast to her list if available. When asked what would keep her listening, Brandy responded, *“A good speaker who was engaging and who could share stories or experiences that pertained to my situation.”*

Theme Five: Caregiver Perspectives of What They Know Align with the Literature

Theme Five was developed from the primary and secondary codes that formed interrelationships around what caregivers have learned throughout their journeys until the last interview. The researcher considered that the experience of participating in this study was an added catalyst for motivated information management. This theme is a conglomeration of the patterns that emerged from what the participants perceived as knowledge taken from currently available dementia health communication.

The participants learned that experts have been studying genetics and lifestyle in terms of what causes brain changes that result in dementia. When asked what questions he was still exploring about Lewy Body disease, Cameron reported, *"One thing I keep searching about, is there a genetic link, [like in Alzheimer's]? Am I at risk?"* When it comes to lifestyle, Lydia reported learning about the effect that hearing loss has on social isolation and its link to risk for dementia. Farrah reported learning about diet changes and how trans fats affect the brain. Harrison reported about his mom's need for physical therapy in the nursing care facility. He knew how important it was for her overall health. He stated, *"If you think they need it [physical therapy] you gotta get it now, because if you don't it's not getting any better.*"

Most participants also reported on the medications that their parents were taking. Amelia attributed an improvement in her mother's cognition, from the point of diagnosis to the present, partially to one of her medications. The other reasons Amelia gave for her mother's improvement were reasons that she learned from the health communication she received regarding Lewy Body dementia. She stated, *"I think that's why we are seeing many good days, 1) because her medication kicked in, 2) because she's in a routine, and 3) because she's gonna have really good days sometimes because it's the Lewy Body type."* Kate reported that her mother qualified for an experimental study using anti-amyloid monoclonal antibodies, and reading about the potential for slowing her mother's brain change was uplifting.

Cultural influence questions were integrated into this study as the literature supported many instances of differences in health communication and social support throughout ethnographical research. When asked if being from the Ohio Valley had any influence on what they know about dementia and how they communicate and support their parents with dementia, the code was prevalent within Theme Five that Ohio Valley residents have close ties with their parents. These close ties influence where they live in proximity to their parents, how involved they become in their care, and how often they communicate with their parents. Jillian stated, "*I know a lot of people my age are trying to figure out how to move just a little closer to their parents if they can. I think the Ohio Valley is more like a 'we will come to you Mom and Dad' than it is a 'Mom and Dad you need to come to us' type of thing."*

Theme Six: Communication Changes with Parents After Dementia

Because this is a communication research study, Theme Six emerged and accentuated the important conversation topics and communication strategies that have taken place with parents since brain changes were first noticed. Participants talked about the crucial conversations around planning for an unknown future. Discussions were noted regarding financial planning for external care resources and at what point you know when it is time for transition to a memory care or nursing care facility. Kate stated, *"After talking to my parents, I now know I have to ask questions about what resources are available to us and when they start to go through the stages, what do people in this local area do, and where do they go."* When asked about end-of-life conversations, Isabelle stated, *"Those end-of-life things are not conversations that people just sit around and have while drinking coffee, you know. Luckily, my dad began planning for this before he died, and my mom was included in this. So, we knew pretty much what those decisions were gonna be before Mom began declining."*

Emily's mother had already transitioned to an assisted living facility before her interview series. Emily talked about the new communication strategies that have worked for her and her mother since her mother's dementia diagnosis. Emily reported noticing that when her mother was not oriented to people and time, the staff at the assisted living facility did not correct her (validation orientation technique). Emily reported she did correct her mother during disoriented communication exchanges and that her mother would eventually acknowledge her mistake (reality orientation). Denise reported the opposite about the communication between her and her father. She stated, *"It seems like he forgets the grandkids when I show him pictures, but I just go along with what he says, you know, whether he thinks they belong to him or not."* In another interview with Denise, she also commented on the loss of the familiar connection she once had with her father. "*I would like for somebody to tell me how I can communicate with him because this isn't the same dad I had growing up who was easy to talk to and who I was super close with."*

Results

The phenomenological approach to this research study allowed for the collection of a rich dataset as participants shared details about their lived experiences. The lived experience of being an adult with a parent who has dementia brings forth challenges that are unique to this population. The participants responded to specific research questions about their experiences navigating health communication regarding dementia. The research questions were guided by the constructs of the theory of motivated information management (Afifi, 2016) and the social support theory (Cullen, 1994). The first research question sought to learn how dementia-care practitioners can provide health communication and interventions to unpaid familial caregivers struggling with negative physical and psychological outcomes. The second research question sought to learn what motivates caregivers who have parents with dementia to seek health communication through avenues of in-person or online support. These two questions and sub-questions in this research study closely correlated with the scholarly researched evidence provided in Chapter Two: Literature Review.

Research Question Responses: RQ1

Research Question One asked, “How can dementia-care practitioners provide health communication and interventions to unpaid familial caregivers struggling with negative physical and psychological outcomes?” Participants reported the perception that earlier interventions may have been influential in helping their parents preserve some cognitive function in the earlier dementia stages, which would have made planning for the future a bit easier. Adults caring for parents with dementia were concerned that current screening methods in routine physician visits were not effective in diagnostics for early stages. This perception is supported by the literature, which states Mild Cognitive Impairment (MCI) can be mistaken for normal deficits that accompany aging, and without further testing by a neuro-psychiatrist, early signs for possible dementia can go undetected (Reisberg et al., 1982; Bayles et al., 2020). Theme One brought forth descriptions of cognitive changes that motivated caregivers to seek health communication. Many participants described situations where their parent was demonstrating disorientation to time, decreased ability to initiate and complete familiar sequences, and increased confusion in otherwise trivial situations. Participants discussed times when these concerns were brought to the attention of the primary care physician, who did not always refer for additional testing.

Adults caring for parents with dementia would also like to be given follow-up resources to assist them with a full understanding of staging and progression at the time of diagnosis. Only four of the twelve participants in this study were educated about what type of dementia their parents have, and all but two participants reported that they did not receive formal education about Reisberg's (1982) seven-stage GDS. While dementia staging is not an absolute prediction of the same characteristics for all individuals and all types of dementia, it can be used as a guide for planning throughout progression. Some participants perceived the feeling of being lost along the journey and perceived that if they had been given the right tools, it may have alleviated a portion of the stress involved in caregiving. The scholarly literature supports this in the study by Chen et al. (2017).

> Many caregiver interventions incorporate education regarding the anticipated symptoms, course, and nature of dementia. Such information may help daughters recognize aspects of the parents' behavior attributable to the disease and not under the care recipient's control. Making alternative attributions for problematic behaviors may translate into smoother interactions and less caregiver stress. (p. 93)

A final answer to Research Question One comes with a suggestion to improve the quality of dementia education provided to workers in nursing care facilities. Some of the participants whose parents were in nursing care facilities perceived that there was poor communication within the facilities during their parents' transition to this new environment. Those participants who perceived miscommunications reported that many of them were due to the nursing care facility's overgeneralizations of people with dementia. The staff was not fully educated on dementia stages, meaning they reacted to all communication exchanges without regard for individual needs. Other participants who were planning for future transitions expressed a bit of anxiety and guilt about the thought of their parents requiring this transition due to the fear that others would not care for their parents as they would. This feeling of guilt about transitioning to a nursing care facility is supported in the literature by Lewis (2015). Facilities that have a reputation for ongoing staff education may be an avenue of indirect health communication intervention for adults who have parents with dementia.

Research Question Responses: RQ2

Research Question Two asked, “Using the theory of motivated information management as a framework, what motivates caregivers who have parents with dementia to seek health communication through avenues of in-person or online support?” Adults who have parents with dementia are motivated to seek health communication when they fear that their parents’ cognitive changes, physical changes, and/or medical changes are indicators of brain pathology. The participants in this study discussed before-dementia and after-dementia comparisons when asked what motivated them to seek more information. Some participants discussed their parents’ preserved abilities as being the motivation, in hopes that if these abilities were still present, the other changes may not necessarily equal dementia. This is supported by the scholarly literature, which indicates that “TMIM predicts that individuals are more likely to seek information when they expect positive outcomes and have high efficacy assessments” (Kanter et al., 2018, p. 104).

The participants in this study most frequently mentioned a parent’s difficulty with initiating and/or completing familiar tasks as a motivator for seeking healthy communication regarding dementia. This finding closely correlates with the literature about characteristics noted in the early stages of dementia and/or MCI (Herndon, 2022; Gurarie, 2022). Another frequently mentioned motivator was the parents’ decreased ability to communicate in group conversations, yet the preserved ability to still make wants and needs known. The uncertainties that families face while noticing changes in their parents’ cognitive, physical, and medical health confront them with efficacy assessments of what it would mean to acknowledge a diagnosis. Sometimes, families and physicians do not pursue the next steps when subtle changes arise because there may be a subconscious level of denial that allows everyone to put off the need to reconcile the way they will affect the future.

Research Question Responses: Sub RQ1. The first sub-research question asks, “What questions are caregivers of parents with dementia asking when searching for information about dementia-related cognitive decline?” Similar to the response in Research Question One, caregivers of parents with dementia are mainly asking questions about the staging and the progression of dementia to know how to plan for the future. Just as models and theories provide frameworks for researchers to scaffold their research questions and build upon areas of inquiry, the staging scales or staging models can provide frameworks for caregivers to guide their search for health communication. This is supported by a grounded theory study from Kokorelias and Ashcroft (2020). “Understanding the processes caregivers undergo to make health service decisions can help inform service delivery that better supports decision-making for care partners facing the challenges of dementia” (p. 6). Caregivers want to know how to determine when their parents can no longer live alone. Perhaps more education about staging and progression would help caregivers evaluate their parents’ manifestations of overall decline and compare them with characteristics on the staging scale. Dementia-care practitioners who are adept at using the staging scales in caregiver education can assist caregivers with this comparison to help decrease the burden of guilt that may accompany this decision-making process.

Caregivers also want to know what memory care facilities or nursing facilities have the best-trained staff to deal with brain change. Evidence in the literature, based on activity theory, supports that facilities with meaningful recreational activities can keep older adults engaged and in better psychological health than facilities that lack in this area (Mansbach et al., 2015). As already mentioned, facilities that invest in ongoing staff education regarding dementia staging scales and predictive progression models may satisfy this caregiver’s desire to be at ease with placing a parent in a facility (Elman et al., 2018).

Caregivers want to know who can help them with financial planning and advanced directives. If conversations like these are not pre-emptively deliberated with parents before cognitive decline occurs, caregivers may end up feeling a sense of entrapment in this role, as supported by the literature (Zwingmann et al., 2018). Adult caregivers feel that if they do not follow through with meeting this need, then who else will?

Caregivers want to know how to best communicate with their parents in each stage of decline. Communication changes are prevalent throughout the stages in the Global Deterioration Scale (Reisberg, 1982). As the parent's communication deficits increase, the loss of a familiar connection with the parent also increases. Caregivers look for ways to engage their parents hoping to find a glimpse of the parent's old self. There is a misconception that Alzheimer's and dementia mean there is no intervention that will result in any kind of improvement (Bayles et al., 2020). The contrary is evident in the systematic review completed by Swan et al. (2018). "Overall, the included studies suggest positive evidence for direct treatment of communication in moderate-severe dementia but with different patterns of results for different approaches" (p. 847).

Research Question Responses: Sub RQ2. The second sub-research question asks, "From the perspective of unpaid familial caregivers, what is missing from current health communication avenues regarding how to care for someone with dementia?" Along with the dominant theme of staging scales and progression models, caregivers expressed concern that they could not always find definitive answers about respite care resources, meaningful activities, communication strategies, genetic links, and lifestyle strategies that promote prevention. All of these unanswered questions closely correlate with evidence in the literature behind the reasons for some of the social-emotional outcomes of caregiving. Burnout, (Chan et al., 2021), stress (Zwingmann et al., 2017), depression (Park et al., 2021), de-prioritization (Stacey et al., 2016), frustration (Nguyen et al., 2021), and guilt (Lewis, 2015) were noted in the literature as sentiments and/or physiological manifestations resulting from the multitude of responsibilities and worries associated with caregiving. Adults helping with the care of a parent are still looking for answers to questions. Where are the reputable resources in planning for the next level of care? What meaningful activities can I incorporate into my parent's daily routine, which is now limited by cognitive decline and decreased communication skills? Am I at risk for the same type of dementia due to genetics, or can I prevent this from happening to me? These are all great questions that may need answers provided through personalized interventions.

Research Question Responses: Sub RQ3. The third sub-research question asks, "If using Reisberg's seven-stage Global Deterioration Scale (GDS) as a reference, at what stage are unpaid familial caregivers seeking information about how to care for their loved one with dementia?" In general, caregivers are not familiar with staging models and scales. This researcher compared participants' descriptions of their parents' brain changes that motivated health communication searches with Reisberg's seven-stage GDS (1982). The researcher assumed that most participants were seeking health communication between stages three and four on the GDS. Recall that stages three to four on the GDS are considered mild-moderate in severity. Characteristics of Stage Three are indicative of deficits noted in high-level executive functioning tasks, such as money management and medication management (Reisberg, 1982; Herndon, 2022). Many of the participants in this study described their parents' out-of-character mishandling of finances and medications, which triggered a search for health communication regarding cognitive changes. Stage Four is indicative of withdrawing from group conversations and denial of symptoms (Reisberg, 1982). These characteristics were coded in this research and evolved into Theme One, brain changes that motivate searches for health communication.

Research Question Responses: Sub RQ4. The fourth sub-research question asks, “From the perspective of individuals caring for a parent with Alzheimer’s/dementia, what organizations/practitioners are currently providing the best avenue of support and why?”. There was no definitive answer to this particular question in this dataset. The individuals in this study mostly reported that finding one-on-one conversation opportunities with someone who has lived the same experience has been the best avenue of support for them. Davies et al. (2019) reinforced this concept in their evidence-based study of online support for family caregivers of people with dementia at the end of life. Also supported by the literature (Lillie & Venetis, 2020), this study revealed that individuals caring for a parent with Alzheimer’s or other dementias might also eventually find their siblings to be the next best avenue of support.

While participants were honest and forthcoming with responses to this question, no themes emerged from a high frequency of codes. Support came from a variety of resources. Three participants in this study were involved in support groups that provided a great deal of informational and social support in person. Three other participants found their online research to be enough support in that they were satisfying uncertainties about their futures by learning what others have found to be viable lifestyle changes in the prevention of dementia for themselves. One participant found support in social media groups, while three participants found support in church or work friends. Two participants found support in just about anyone who would listen. No specific organization or practitioner was mentioned more than once or twice in the 36 interviews as being the best avenue of support.

Summary of the Findings

This chapter analyzed and developed the overall findings of this qualitative research. A Description of Participants opened the chapter revealing the recruitment and sampling procedures. Participant narratives were provided to allow the reader an inside look at why each of the 12 participants’ perspectives were relevant to this study. The Codes and Themes Development section described each layer of the data analysis and how hand-coding and electronic coding paved the way for six themes to emerge from the data. Finally, the Results section described the answers to the two primary research questions as well as the four sub-questions. It was evident throughout this section that adults who are directly involved in caring for a parent with dementia are not finding enough support from the healthcare community in learning and understanding dementia staging scales that may act as a framework for navigating through this phenomenological experience.

Chapter Five: Discussion

Overview

The purpose of this qualitative, phenomenological research was to explore the lived experiences of adult caregivers who are searching for health communication about their parents' dementia. Semi-structured interviews were conducted with 12 adults from the Ohio Valley who are actively involved in the care of a parent with possible, probable, or definitively diagnosed dementia. The interview questions were designed to inquire about the caregiver's perspective of currently available avenues of health communication. This chapter presents a discussion of the findings, implications, limitations, and recommendations for future research.

Discussion

This study sought to learn how adult caregivers in the Ohio Valley perceive currently available health communication regarding the care of a parent with dementia. To gain the answers to the research questions, it was important to get the perspectives of individuals who are searching for dementia health communication. The phenomenological approach was used because it allowed the researcher to learn about the participants' unique experiences with managing information on how to navigate the care of a parent with dementia.

Six themes were identified as data was analyzed throughout the data collection process. These themes were used to answer the two primary research questions and the four sub-questions. The primary research questions were the main avenue of focus to solving the problem stated in this study. Dementia care practitioners in the Ohio Valley need more information about how caregivers search for and perceive health communication to implement best practices for meeting the needs of this growing population. The sub-questions were included to further explore specific aspects of the primary research questions. TMIM was foundational in understanding how caregivers dealt with times of cognitive dissonance as a factor in deciding whether to explore a dementia diagnosis for their parents. SST aided in understanding how caregivers perceived different kinds of support in the three months of this study, and how social support could be perceived if given an even more longitudinal look in future studies.

Communication Trajectories within this Research

Trajectories of communication, or paths of communication, have been examined through different eras of time in different ways. Marshall McLuhan (1964) talked about how the medium can affect the nature of communication trajectories. Walter Ong’s works (1977, 1982) discussed communication trajectories in the context of communication modes, such as oral versus written. It is important in communication research to acknowledge these paths that emerged throughout the exploration of the collected data. The research questions in this qualitative study gave way to a unique look at communication trajectories throughout the participants’ perspectives of their caregiving journeys.

Examples of communication trajectories in this research involved both interpersonal and intrapersonal dialogues. Interpersonal, or person-to-person, trajectories noted from the data in this study included caregiver-to-parent, caregiver-to-physician, caregiver-to-dementia care practitioner, caregiver-to-caregiver, caregiver-to-sibling, and parent-to-spouse. Intrapersonal, or internal, trajectories noted from the data in this study included the caregivers’ and the parents’ internal dialogues.

Participants in this study talked freely about conversations with their parents (caregiver-to-parent). They specifically noted how communication changed as cognitive decline progressed and how this motivated their need to seek information from medical professionals (caregiver-to-physician) or others who have experienced the same phenomenon (caregiver-to-caregiver). The data revealed perspectives of support-related dialogue with siblings (caregiver-to-sibling). Participants also discussed different emotional responses in the communication trajectory that involved the spouse of the parent who has cognitive decline (parent-to-spouse).

In line with the two theoretical frameworks, TMIM and SST, the participants shared sentiments about their internal dialogues as well as their perspectives of their parents' internal dialogues throughout information management and support-seeking endeavors. It was evident throughout this study that many intrapersonal communication trajectories were accompanied by a struggle with facing the perspective of lost agency if cognitive decline was acknowledged. Without acknowledgment, motivation to seek information or support is not present. These interpersonal and intrapersonal communication trajectories have opened doors for more possibilities to further explore dialogues in the midst of dementia.

RQ 1

The first primary research question set out to identify ways that dementia care practitioners can improve their methods of health communication with individuals caring for a parent with dementia. Patterns emerged throughout the data analysis, which specifically answered this question. Caregivers reported that they were looking for a better understanding of dementia staging, earlier dementia detection, and more peace of mind when transitioning a parent to nursing/memory care facilities.

Dementia Staging. Many of the participants in this study were honest in reporting that they had little knowledge of dementia staging. While they could get a basic sense of their parents' progression through comparisons of then and now, they were still unsure of how much more change to anticipate and what it meant for planning and preparation. Having a working knowledge of how their parents would be changing may give caregivers new insights into strategies that may reduce negative physiological and social-emotional effects of caregiving (Steenfeldt et al., 2021). Based on this research, dementia care practitioners can improve dementia health communication by explaining dementia staging and progression prediction models in detail while individually relating this information to the person with dementia.

Early Detection. Another pattern that emerged within these constructs is that dementia care practitioners may not detect cognitive decline in the early stages. According to the perceptions of the participants in the Ohio Valley, physicians are performing cognitive screening measures during yearly check-ups, but when the family expresses concern, those concerns do not always prompt any further referrals. Bradford et al. (2009) studied reasons for missed or delayed dementia diagnoses and found that physicians reported several factors, but the most prevalent reason was the fear of misdiagnosing and causing more harm. Many physicians admitted that they waited until concerns or symptoms were more obvious before referring for additional testing or making a diagnosis of dementia. In the time since the Bradford et al. (2009) article, the medical community has made more efforts to work toward early detection (Rasmussen & Langerman, 2019). Therefore, the finding in this research that early concerns brought forth by caregivers in the Ohio Valley were sometimes dismissed by primary care physicians illustrates that these efforts are still in progress. Considering the decision-making factors that go into searches for health communication, if concerns are important enough for patients and/or their families to mention to the physician, they should be important enough to warrant further investigation. Dementia care practitioners can improve health communication by not dismissing concerns brought forth by patients and/or family members regarding suspected brain changes, even if further investigation merely confirms a false alarm.

Peace of Mind in Nursing Care Transitions. A final answer to this question emerged from the participants who had already transitioned their parents into a nursing care or memory care facility. Perceptions were noted that employees in nursing care facilities did not collectively have a working knowledge of different types of dementia or staging prediction models. This was evident when communication breakdowns occurred between the nursing care worker and the care recipient or between the nursing care worker and the study participant. This gap in knowledge for practice made transitions even more difficult than they already were, due to compounded caregiver guilt about leaving a parent behind (Gallego-Alberto et al., 2022). Dementia care practitioners can improve health communication by enhancing inter-professional collaboration efforts with nursing/memory care staff who need the right tools to adequately care for patients with dementia.

RQ 2

Using the theory of motivated information management as a framework, the second primary research question sought to identify motivating factors that play a role in the caregiver’s desire to search for health communication regarding dementia. According to the participants in this study, adults with parents who have dementia are seeking health communication avenues when cognitive or physical changes are interfering with daily routines. More specifically, when the parent demonstrates a moment of forgetting how to initiate or complete a task, caregivers are motivated to learn whether this is cause for concern.

Some participants reported hindsight regarding factors that should have motivated them to seek health communication sooner. If the other parent or another family member dismissed the concerns as a form of denial, they did not seek information. While this study did not include perceptions from the other parent, or spouse of the care recipient, many of the participants in this study talked about concerns they had for them. The concerns were variable in nature but ranged from too much spousal caregiver burden to recognition that spouses may be making excuses for the parent experiencing the changes. When the brain changes appeared to negatively affect the other parent, or the spouse of the care recipient, the participants in this study were motivated to seek health communication regarding dementia. In essence, if the other parent dismissed concerns, the study participant dismissed concerns, but if the other parent began to noticeably take on too much caregiver burden, the study participant was motivated to seek health communication/support.

Sub-RQ 1

The first sub-research question set out to learn what specific questions caregivers with parents who have dementia are asking when searching for information about cognitive-related decline. According to the participants in this research, caregivers are most prevalently asking how to plan for the inevitable effects of continued cognitive decline. Caregivers in the Ohio Valley frequently asked four main questions: What are the indicators that give insight into making an informed decision about transitioning to another level of care? What is the most seamless avenue of assistance in making decisions about financial planning? What local nursing care/memory care facilities are appropriate, affordable, and reputable? How do I effectively communicate with my parent as the cognitive decline progresses? “As the number of people with moderate-to-severe dementia increases, researchers, family members, and healthcare workers need methods and approaches to facilitate meaningful communication with this population to enable their involvement in research and service development” (Collins et al., 2022, p. 1137). Seeking answers to this research sub-question allowed the researcher to learn specific ways that dementia care practitioners can structure health communication models. A health communication model that includes insight into what type of dementia, how fast the type progresses, what progression looks like, and how progression affects function, may pose a resolution for more informed planning and decision-making as a parent's cognition declines. An ideal model would find a way to include the care recipient in the planning and decision-making process.

Sub-RQ 2

The second sub-research question sought to learn what is missing from current health communication avenues regarding how to care for someone with dementia. By seeking the answer to this question, the researcher was able to learn more about the lived experiences of this population. During this line of questioning, participants were honest about some of the social-emotional aspects that accompany their unique experiences with searching for health communication regarding dementia, specifically when help was hard to find and when they were worried about their own risk.

Help is Hard to Find. The participants in this study felt that health communication avenues only gave a surface level of information regarding recommendations for external resources and strategies for maintaining function. Participants were left with more questions than answers when motivated to seek information about the right time to ask for more help. They felt that health communication regarding dementia should be streamlined to provide better pathways for caregivers to find a temporary respite from caregiving. They reported feeling frustrated when realizing that their geographic location did not have respite options such as adult daycares or senior centers with dementia-knowledgeable staff. They reported that when uncertainties arose about their ability to adequately care for their parents in the home, they wished they could find more information about strategies to help their parents be less dependent, to possibly allow their parents to stay out of a facility a bit longer.

Familial Risk of Developing Dementia. The participants in this study were not able to find definitive answers to some questions simply because those questions are still being researched by the medical community. Most caregivers in this study were curious about their own risk of developing dementia. Participants perceived that health communication is available about genetic links as well as lifestyle prevention techniques, but they were not able to find anything specific in health communication avenues that spoke to their population about planning for themselves. They felt that evidence-based lifestyle strategies should be something that takes center stage in health communication forums regarding the prevention of dementia. They did admit that they realized the research is ongoing regarding genetic information and familial risk of developing dementia. The caregiver perspectives on this part of sub-question 2 align with the literature. Lourida et al. (2019) stated, “Genetic factors increase risk of dementia, but the extent to which this can be offset by lifestyle factors is unknown” (p. 430).

Sub-RQ 3

The third sub-question in this research aimed to learn if using Reisberg’s seven-stage GDS as a reference, at what stage are unpaid familial caregivers seeking information about how to care for their loved one with dementia. Once again, this sub-question’s purpose was to build upon the information from answers to RQ1 and RQ2. One theme that emerged from this study encompassed a few patterns of brain changes the participants reported. Most participants were not familiar with Reisberg’s seven-stage GDS, so the researcher used the patterns of reported brain changes in the data to hypothesize an answer to this research question. The participants in this study reported concerns when parents began having trouble initiating and completing familiar tasks, initiating and following conversations, keeping track of time, and walking without losing their balance. According to Reisberg (1982), clinical characteristics of Stage Three of the

GDS can involve difficulty with high-level executive function tasks such as driving, paying bills, and managing medications. As individuals move into Stage Four on the GDS, there can be noticeable changes in communication during conversations as well as occasional disorientation to time and place. Heape (2020) noted that Stage Four on the GDS is sometimes accompanied by posterior cortical atrophy, or changes near the visual processing part of the brain, which may indirectly affect overall balance. The results of this study indicate that adults caring for a parent with dementia are likely seeking health information around Stages Three and Four on Reisberg's seven-stage GDS. According to Dementia Care Central (2023), most patients are diagnosed in Stage Four on the GDS.

Sub-RQ 4

The fourth sub-question sought to learn from the perspective of individuals caring for a parent with Alzheimer's/dementia, what organizations/practitioners are currently providing the best avenue of support, and why. According to this study, no specific organization or practitioner was named with high frequency across all participants as providing the best support. However, themes in the data did point to certain characteristics of support that were perceived as better than others.

One-on-One Support is Ideal. The adult caregivers of parents with dementia in the Ohio Valley indicated they felt the most supported when having one-on-one conversations with trusted communication partners, especially those who were going through the same phenomenon. The participants also frequently talked about siblings throughout the series of interviews. When sibling relationships were harmonious, participants were grateful for having this avenue of perceived social support. When sibling relationships were strained, participants were quick to acknowledge how much harder this living experience has been without having that avenue of support. A theme of strong ties, such as siblings and others who can empathize, is supported by Steenfeldt et al. (2021) regarding the needs of family caregivers.

Support Groups are Not Ideal. The idea of a formal support group did not intrigue most participants in this study. While three participants regularly attended a support group for caregivers, the other nine participants shared the sentiment that being in a support group would not be helpful to their situations. They felt that they would not perceive social support from an unfamiliar group of people made up of weak ties, but more from people within their social network made up of strong ties. Perhaps this is why no specific organization or dementia-care practitioner stood out as an answer to sub-question four. The results of this study indicated that adult caregivers in the Ohio Valley are not looking for social support from weak ties throughout this journey. Given that the participants in this study felt that being from the Ohio Valley has a cultural influence of many strong ties, this is a logical indication. Interestingly, the preference for strong ties over weak ties in social support expressed by the participants in the Ohio Valley aligns closer with Eastern cultural preferences than Western cultural preferences, due to the interdependence that accompanies a close-knit community (Zheng et al., 2021).

Implications

The implications of this research stem from the two primary research questions and the four research sub-questions, which were answered using the six themes derived from the findings in the data. Phenomenological studies end by interpreting the meaning of the findings. The researcher must draw conclusions about the significance those findings bring to the chosen professional field (Claxton & Mallory, 2024). Sutton & Austin (2015, p. 230) stated, “Do not be afraid to draw assumptions from the participants’ narratives, as this is necessary to give an in-depth account of the phenomena in question.” This section culminates the research by giving an account of the drawn conclusions and assumptions, calling them implications. Theoretical implications are given based on the theory of motivated information management (TMIM) and the social support theory (SST). Empirical implications are presented to align the conclusions with the supporting literature. Practical implications are given to explain how the conclusions add to the field of study.

Theoretical Implications

The theoretical frameworks that have provided a basis for this study were chosen because they gave insight into the motivating factors that lead to the search for, and perception of, health communication. The theory of motivated information management (Afifi & Weiner, 2004) suggests that people search for information when they have uncertainty about a subject and then decide how much uncertainty they wish to have about it. A second theory was originated by Drennon-Gala and Cullen (1994) who both posited that perceived social support may be a motivator for reduced juvenile delinquency. This paved the way for further research to integrate social support theory within health constructs (Kiecolt-Glaser et al., 2002; Uchino, 2006; Kort-Butler, 2017). The social support theory postulates that feeling socially supported can lead to improved physiological and social-emotional health outcomes. These theoretical frameworks gave the researcher a lens through which to interpret the participants' perceptions concerning information management and social support taken from dementia health communication. Using both TMIM and SST to understand this phenomenon allowed this research to explore participants' experiences with the interwoven intricacies of decision-making outcomes and social-emotional outcomes in searches for health communication.

TMIM. The theoretical analysis of the findings suggested a connection between motivating factors that led to health communication searches and health communication that could have been conveyed before there was even a need for the search. Nine of the 12 participants reported early symptoms that were dismissed as normal aging which they felt may have been reasons for a more in-depth look at the uncertainties in the situation. This research extends Afifi and Weiner's theory of motivated information management in that while some participants were disappointed in the physician for dismissing the early concerns, many admitted that they, or the care recipient's spouse, were guilty of the same. TMIM is differentiated from Berger and Calabrese's uncertainty reduction theory (1975) by this very phenomenon. Adults caring for parents with dementia did not convey information when they had uncertainty about a symptom because, at that moment, they decided that uncertainty was better than the possibility of dementia. This same theoretical correlation integrates into the literature-supported reason that physicians explained away the early symptoms as well (Bradford et al., 2009). The explanation is easier to digest than the reality that there are difficulties on the horizon.

Many participants in this study verified that their decisions to seek health communication about a possible dementia diagnosis were compounded by several pre-existing factors that created cognitive dissonance. Initial denial of indistinct cognitive changes, the presence of many preserved abilities, and the acknowledgment that a dementia diagnosis is accompanied by the loss of agency, created a disharmony in motivation to investigate further. Further, not all cognitive decline is associated with dementia. Perhaps another implication of this research could suggest possible integration of TMIM and Leon Festinger's (1957) cognitive dissonance theory in health contexts. Cognitive dissonance theory posits "that we have an inner drive to hold all our attitudes and behavior in harmony and avoid disharmony" (Mcleod, 2023, para. 4). It was only when distinct brain changes tipped the scales in the direction that parents could no longer independently care for themselves, did participants feel disharmony in not being motivated to investigate further.

SST. Additional theoretical analysis of the findings suggested a connection between social-emotional factors that motivated specific health communication searches and the perception of adequate social support. Participants felt that when health communication avenues included directly applicable connections to their situations, they were perceived as viable avenues of social support. Adults experiencing negative physiological and social-emotional effects of caring for a parent would benefit from health communication avenues that provide not only the informational support they are searching for but also directly applicable social support. Participants in this study defined this as support that came from one-on-one conversations with someone who can empathize with them because they are experiencing the same phenomenon.

The social support theory focuses on the significance of communication in relationships and its effect on well-being. As noted in Theme Four of this study, directly applicable informational and social support can come from a variety of resources. Social support theory could be investigated further in a specific context of learning about all the communication trajectories that caregivers explore in the different stages of dementia and their effect on caregiver well-being.

Initial interpersonal communication exchanges with the parent about their cognitive decline may lay a foundation for a caregiver’s positive or negative intrapersonal communication about future decision-making, depending on how that conversation unfolds. A caregiver may feel positively supported by the parent throughout the different stages if they have constructively communicated his/her wishes in the initial stages. As staging progresses, social support may come from outside sources through other interpersonal communication trajectories such as caregiver-to-church family or caregiver-to-allied health professionals. Even though participants in this study more prevalently reported the importance of strong ties through one-on-one conversations, online informational angles of support were also perceived to be relevant in the form of weak ties throughout some stages of a parent’s cognitive decline. This could be the reason for the emergence of Theme Four in this study; avenues of online support or resources are variable.

Variable resources indicate that informational support can be perceived as beneficial to different caregivers at different times. Even though no online resource was named with high frequency, online social support and/or resources were still named. The variability may just indicate that the currently available support resources are looking to meet different needs for different times and different scopes within the dementia health communication framework.

Empirical Implications

To this researcher’s knowledge, there have been no studies conducted using the dual theoretical structure of TMIM and SST to understand caregiver perspectives on dementia health communication. There have been studies using qualitative design to research decision-making for caregiving in this population (Kokorelias & Ashcroft, 2020). Specific studies included decision-making for nursing home placement, (Chang & Schneider, 2010), decision-making for end-of-life (Xie et al., 2018), and the buffering effects of social support (Del-Pino-Casado et al., 2018; Md Nawi et al., 2018; Gilliand & Bush, 2001). Other studies sought to learn about factors that motivate individuals to seek social support through strong ties versus weak ties (Kim et al., 2015; Wright & Bell, 2016). Studies have also explored ways to bridge the gap in dementia education (Van den Eertwegh et al., 2012, 2013; Hajili et al., 2015). Minor (2020) studied the unique lived experience of being an adult caring for a parent with dementia through a phenomenological approach. However, Minor’s interview questions were geared toward her participants' perspectives on what roles they had while caregiving for their parents during dementia-related cognitive decline. None of the existing research fully addressed the caregiver perspectives of what may be missing from health communication regarding dementia and how the missing pieces affect decision-making and the feeling of having social support. More research was needed to address this gap in the literature (Kokorelias & Ashcroft, 2020).

The problem addressed in this study is that dementia-care practitioners in the Ohio Valley need more information about how caregivers search for and perceive health communication, in order to implement best practices for meeting the needs of this growing population. The answer to addressing the problem was taken from specific factors that were associated with the six themes in this study. Those themes are 1. Brain Changes Motivate Caregivers to Seek More Information, 2. Perceived Breakdowns Happen in Certain Trajectories of Health Communication Regarding Dementia, 3. Avenues of In-Person Support or Resources are Better One-on-One, 4. Avenues of Online Support or Resources are Variable, 5. Caregiver Perspectives of What They Know Align with Literature, and 6. Communication Changes with Parents After Dementia.

Facilitating Caregiver Decision-Making and Social Support. This research revealed that when it comes to improving dementia health communication, participants perceived they would have benefited from early interventions when symptoms/concerns were first discovered. They felt they may have been able to plan for possible dementia if this information had been communicated at the time of noticing early symptoms/concerns as opposed to assuming that concerns were unwarranted. Participants in this study also perceived that current dementia health communication avenues were not effective in the description of dementia staging models that would have allowed them to fully understand their parents' progression. Participants who were going through transitions to nursing/memory care facilities with their parents were surprised at the limited knowledge displayed by nursing/memory care staff, regarding dementia staging and communication strategies. All these concerns led to increased feelings of frustration and guilt throughout the health communication journey. On a positive note, participants perceived effective social support in health communication avenues that included someone else's testimony of experiencing the same phenomenon.

Motivating Factors and Timing in Decision-Making. When it comes to identifying motivating factors that prompted caregivers to seek dementia health communication, the existing empirical studies regarding decision-making and social support paved the way for understanding perspectives. Most participants in this study were not motivated to seek dementia health communication or support until a parent displayed difficulty with initiating and/or completing familiar tasks. This characteristic of cognitive decline is typically manifested in the middle stages of dementia progression indicating that early symptoms may have been overlooked or dismissed. Current literature by García-Martín (2023) revealed that staging scales and models can be important guideposts in dementia health communication.

Most participants in this study did not have a working understanding of dementia staging. This made it difficult to learn from caregivers at what stage in their parents' dementia progression they were deciding to ask questions. The codes associated with Theme One in this research, regarding brain changes that motivate caregivers to seek health communication, allowed the researcher to infer that most caregivers seek health communication when a parent is in Stages Three to Four on the GDS. This research also revealed that adults caring for parents with dementia were asking questions in health communication avenues that may have been answered, to the level of perceived satisfaction, if given a forum to understand scales or models of dementia staging progression.

A Multi-Faceted Undertaking for Inter-Professional Communication. The current base of literature, as reviewed in Chapter Two, addresses the specific areas of social-emotional effects of caregiving (Chan et al., 2021; Zwingmann et al., 2017; Alves et al., 2019), dementia staging using the Global Deterioration Scale (Reisberg et al., 1982; Herndon, 2022; Mougias et al., 2018), professionals who are considered dementia care practitioners (Zorina et al., 2020; Smallfield, 2017; Lanzi et al., 2022), caregiver support interventions (Fukui et al., 2019; Kanter et al., 2018; Teles et al., 2020), and bridging the gap in dementia education (Hajili et al., 2015; Van den Eertwegh et al., 2012, 2013). The prominent perspectives taken from this research study regarding how dementia-care practitioners can improve dementia health communication were that allied and non-allied health professions in the Ohio Valley must work better together to achieve earlier detection and better communication of dementia staging progression prediction models. Results from the current research substantiate the empirical evidence demonstrated in the literature review, but the current study furthers the knowledge base to specifically include Ohio Valley caregiver perspectives across time in relation to how dementia health communication can be improved to decrease the burden associated with decision-making and social support.

The caregiver perspectives taken from this study corroborate information from current literature regarding strategies that have been shown to slow the progression of dementia-related cognitive decline through physical, occupational, and speech therapies (Zorina et al., 2020; Martinez-Campos et al., 2022; Smallfield, 2017; Swan et al., 2018). Two of the participants in this study reported that most of what they knew about dementia staging was conveyed to them through a speech-language pathologist who assessed and treated their parents for cognitive-communication interventions. The recent study by Lanzi et al. (2022) reported the benefits of speech-language pathologists in the early detection of indistinct cognitive changes if and when physicians make referrals. The medical community and dementia-care practitioners need to fill in the gaps by improving inter-professional collaboration in dementia health communication for caregivers.

Findings from this research confirm that while there are multiple avenues of health communication regarding dementia, caregivers are still left with many unanswered questions which have the potential to be answered with the right structure. Whether searches for health communication were conducted via in-person or online resources, adults caring for parents with dementia perceived communication breakdowns from the medical community regarding the specific topic of dementia staging and early detection. This aligns with the current base of literature, specifically, Zwingmann et al. (2017), which revealed that an effective caregiver support program would be a multi-faceted undertaking.

Practical Implications

The practical results of this study may affect dementia care practitioners the most because the results reveal factors that contribute to health communication in relation to dementia management and social support. Dementia management strategies and the perception of social support both impact caregiver well-being. The result of this research provides a new point of view through which dementia health communication, according to the caregiver perspective, could be better delivered to promote earlier detection, understanding of dementia staging prediction models, understanding of lifestyle prevention strategies to decrease caregiver risk of dementia, inclusion of one-on-one conversations that promote social support, and strategies to improve communication with loved ones who have dementia.

For caregivers, the information revealed in all six themes of this study is important for improving dementia health communication. Understanding caregiver perspectives, as well as how a carefully structured health education model may impact the perception of support, is of value to dementia care practitioners. Better awareness of how dementia progression impacts cognitive decline may influence the decisions caregivers make regarding their loved ones with dementia. Earlier detection may influence decision-making for planning, which could result in less negative social-emotional effects of caregiving. Prevention strategies may introduce a feeling of hope for caregivers when burdened with the thought of genetic risk. One-on-one conversations that facilitate the perception of support could be tied into caregiver education sessions that focus on communication strategies that maximize a parent's preserved strengths.

Williams et al. (2018) noted that the number of unpaid familial caregivers continues to rise, and as a result, the need for caregiver support continues to rise. The information in this study revealed that adults in the Ohio Valley who are caring for a parent with dementia believe there is not enough ongoing support from the medical community as their parent's cognitive function declines. This dilemma may cause caregivers to experience negative social-emotional outcomes associated with caregiving such as frustration, burnout, and guilt (Chen et al., 2017; Alves et al., 2019; Yuan et al., 2021). While a vast amount of knowledge exists about dementia and caregiver support (Zwingmann et al., 2018), this study narrows the gap in the literature revealing caregivers' perspectives regarding how health communication avenues are not always leading to descriptive enough resources that help them with ongoing planning and coping. The practical implication of this study is that dementia care practitioners need to work toward an interprofessional health education model for caregivers that includes earlier detection and ongoing resources following a diagnosis. Practical implications are further explained in this study in that Ohio Valley caregivers specifically search for insight into characteristics that accompany dementia staging and how the stages relate to their parent’s current and future abilities. A final practical implication of this study is that dementia care practitioners should consider facilitating one-on-one connections with others who are going through, or have already gone through, the same phenomenon as the adult caring for a parent with dementia.

Limitations

According to Ross and Bibler-Zaidi (2019), “limitations represent weaknesses within the study that may influence outcomes and conclusions of the research” (p. 261). It is important to list and describe the limitations of this study. It is also important to describe ways the limitations may be mitigated in future research or replication of this research.

Phenomenological research focuses on the rich set of personalized data that is collected from participants regarding their unique experiences. Because the researcher wanted a specific look at caregiver perspectives in the Ohio Valley region of the United States, this limited the ability to recruit participants with multifarious demographics. A demographic limitation is the lack of diverse ethnic representation among the participants in this study. Recruitment strategies did not yield participants identifying outside of the white race/ethnic group, making it a small and concentrated sample size. The overall ethnic representation of the states that make up the Ohio Valley region averages 74% white, 11% Black, 10% Hispanic, 3.2% Asian, .5% Indigenous, and 2.5% multi-racial (US Facts, 2022). More ethnically diverse participation would have better represented the demographic makeup of perspectives coming from the Ohio Valley region.

A second limitation noted in this study lies within the researcher herself. This researcher recognizes reflexivity regarding bias as a speech-language pathologist and a dementia care practitioner. While a researcher outside of the dementia care community would have had different influences on data analysis, it is important to note that this researcher's connection to the dementia care community allowed for an empathetic dimension while examining data in relation to social-emotional aspects of caregiving. Olmos-Vega et al. (2023) said it best: "Rather than reporting reflexivity via a discreet paragraph or as an apology for the researcher's influence on the data, we suggest that effective reporting should embrace researcher subjectivity and address the nuances of decisions throughout the research process" (p. 247). A final aspect of reflexivity to be noted as a limitation of this research is the researcher's minimal experience with qualitative methods. There was a learning curve in all areas of the research, specifically in effective interviewing using semi-structured questions and textual data analysis, as a student researcher.

Delimitations

Theofanidis and Fountouki (2019) described delimitations as purposeful limitations consciously determined by the researcher to set specific boundaries for the aim of the study. This study of caregiver perspectives was delimited by data collection methods, population, and scope. Interviews were the purposefully selected method of data collection because of the rich quality of information able to be gleaned from the participants. This single method of data collection is a delimitation in the research because additional data collection methods, such as surveys or even observations of participant/parent interactions, could have provided a set of findings outside of the scope of this study. The delimitation of recruiting only residents in and around the Ohio Valley kept the research relevant to this population. The scope of this research was delimited to caregiver perspectives only, leaving out care recipient perspectives as well as dementia care practitioner perspectives, although both care recipients and dementia care practitioners benefit from the implications of this research.

Recommendations for Future Research

The current research study opened possibilities for future research. Caregivers in the Ohio Valley perceived that dementia staging was not well communicated in their quest for dementia health education. This study focused on Reisberg’s (1982) Global Deterioration Scale for dementia as a widely recognized dementia progression prediction model. Perhaps future research could include a systematic review of the literature or a qualitative interpretive meta-synthesis of all dementia progression prediction models and their effectiveness in health communication for caregivers.

Another recommendation that would build upon this research is to learn from dementia care practitioners in the Ohio Valley what they perceive of their effectiveness in dementia health communication. Interviews could focus on research questions that explore how they structure their dementia-care health communication and education methods. Other research questions could glean from dementia care practitioners how they approach the negative social-emotional effects of caregiving in their caregiver education plans. A specific study using qualitative methods to learn how physicians in the Ohio Valley work toward early detection of dementia is highly recommended. There is also the possibility of performing a comparison study exploring a different geographic location’s approach to caregiver support and dementia-health communications, such as an established retirement district like The Villages in Florida, USA (The Villages, Inc., 2024).

As previously mentioned, the communication trajectories that manifested throughout the data collection of this research have provided opportunities for possible future studies on this topic. The specific intrapersonal dialogues and emotional responses to cognitive dissonance in the early dementia stages are areas to probe further in communication research. Looking closer at interpersonal communication trajectories through different mediums, such as in-person or over remote connections, could be explored further in a longitudinal study regarding the perception of support throughout the different stages of cognitive decline.

The limitations of this study provided a path to explore more caregiver perspectives through an ethnographic approach. Future research of caregivers in the Ohio Valley could be more intentional in recruitment strategies and participant sampling methods to accurately represent the diversity in the demographics. If considering an ethnographic approach, different data collection methods could include a more immersive experience with participants as they interact in different communication trajectories, such as within family structures during health communication exchanges.

Summary of the Study

The purpose of this health communication research was to explore the experiences of adult caregivers in the Ohio Valley who are involved in caring for a parent with dementia as they seek health education and support. The research design took a phenomenological approach with the collection of qualitative data. It began with a background description and an introduction to the study. The study then reviewed current scholarly literature on the notions of caregiver burden, dementia staging, dementia care practitioners, caregiver support, and bridging the gap in dementia education. Then, data was taken from a total of 36 interviews conducted with 12 adult caregivers over the course of three months. After data was thoroughly analyzed, six themes emerged including: 1. Brain Changes Motivate Caregivers to Seek More Information, 2. Perceived Breakdowns Happen in Certain Trajectories of Health Communication Regarding Dementia, 3. Avenues of In-Person Support or Resources are Better One-on-One, 4. Avenues of Online Support or Resources are Variable, 5. Caregiver Perspectives of What They Know Align with Literature, and 6. Communication Changes with Parents After Dementia. An analysis of those themes offers theoretical implications that support Afifi and Weiner's (2004) theory of motivated information management and Drennon-Gala and Cullen's (1994) social support theory, while the practical implications indicate that caregivers provide valuable insight into how the medical community can improve dementia health communication and dementia support frameworks. The empirical implications contribute to gaps in the research through a discussion of facilitating caregiver decision-making through a multi-faceted approach in inter-professional dementia health education models. Empirical implications also indicate that ideal dementia health education models should strive for earlier detection, follow-up resources about dementia staging, lifestyle dementia-prevention strategies, and strong ties for social support. Recommendations for future research were provided based on the limitations of this study, including a small participant pool and a limited geographic area for participants. Ultimately, this study answered the research questions by determining that while caregivers are making decisions to search for dementia health communication from the medical community, there are specific factors in these searches that are essential to the perception of support and future planning as the parent's cognition declines.

References

Afifi, W. A. (2016). Theory of motivated information management. In C. R. Berger, M. E. Roloff, & J. P. Caughlin (Eds.), *International encyclopedia of interpersonal communication*. Wiley.

Afifi, W. & Weiner, J. (2004). Toward a theory of motivated information management. *International Communication Associations. 14*(2), 167-190. doi:10.1093/ct/14.2.167

Al Demour, S., Alzoubi, K. H., Alabsi, A., Al Abdallat, S., & Alzayed, A. (2019). Knowledge, awareness, and attitudes about research ethics committees and informed consent among resident doctors. *International Journal of General Medicine, 12*, 141-145. https://doi.org/10.2147/IJGM.S197511

Albatnuni, M., & Koszycki, D. (2020). Prayer and well-being in Muslim Canadians: Exploring the mediating role of spirituality, mindfulness, optimism, and social support. *Mental Health, Religion & Culture, 23*(10), 912-927. https://doi.org/10.1080/13674676.2020.1844175

Allwood, R., Pilnick, A., O'Brien, R., Goldberg, S., Harwood, R. H., & Beeke, S. (2017). Should I stay or should I go? How healthcare professionals close encounters with people with dementia in the acute hospital setting. *Social Science & Medicine, 2017*(191), 212-225. doi:10.1016/j.socscimed. 2017.09.014

Alves, L. C, Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. C, & Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. *Dementia & Neuropsychologia, 13*(4), 415-421. https://doi.org/10.1590/1980-57642018dn13-040008

Alz Editorial Team. (2019, April; 2023, February). The global deterioration scale: the Reisberg

Alzheimer’s stages. *Reviewed by the Health Union Medical Review Board*. https://alzheimersdisease.net/reisbergs-stages

Alzheimer’s Association. (n.d.). *About.* https://www.alz.org/about

Alzheimer’s Association. (2022). *Alzheimer’s disease facts and figures; Special report more than normal aging: understanding mild cognitive impairment*. https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Alzheimer’s Association (2023a). *Illinois 2023 Alzheimer’s Statistics.* https://www.alz.org/media/Documents/illinois-alzheimers-facts-figures-2023.pdf

Alzheimer’s Association (2023b). *Indiana 2023 Alzheimer's Statistics.* https://www.alz.org/media/Documents/indiana-alzheimers-facts-figures-2023.pdf

Alzheimer’s Association (2023c). *Kentucky 2023 Alzheimer’s Statistics.* https://www.alz.org/media/Documents/kentucky-alzheimers-facts-figures-2023.pdf

Alzheimer’s Association (2023d). *Ohio 2023 Alzheimer’s Statistics.* https://www.alz.org/media/Documents/ohio-alzheimers-facts-figures-2023.pdf

Alzheimer’s Association. (2023e). *Pennsylvania 2023 Alzheimer’s Statistics.* https://www.alz.org/media/Documents/pennsylvania-alzheimers-facts-figures-2023.pdf

Alzheimer’s Association. (2023f). *Vascular dementia*. https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/vascular-dementia

Alzheimer’s Association. (2023g). *West Virginia 2023 Alzheimer’s Statistics*. https://www.alz.org/media/Documents/westvirginia-alzheimers-facts-figures-2023.pdf

Andriuta, D., Anthony, P., Auriacombe, S., Balageas, A., Ballan, G., Boutoleau Bretonnière, C., Carlier, J., Cassagnaud, P., Castelnovo, G., Champion, C., Chaussenot, A., Ceccaldi, M., Chen, Y., Cognat, E., Contegal-Callier, F., Courtemanche, H., Cretin, B., Crinquette, C., Croisille, B., . . . Alzheimer's Disease Neuroimaging Initiative (ADNI. (2022). Penetrance estimation of Alzheimer disease in SORL1 loss-of-function variant carriers using a family-based strategy and stratification by APOE genotypes. *Genome Medicine, 14*(1), 1-69. https://doi.org/10.1186/s13073-022-01070-6

Armstrong, P. B. (n.d.). *Architecture body and performance; Phenomenology.* Brown University. https://www.brown.edu/Departments/Joukowsky_Institute/courses/architecturebodyperformance/1065.html

Bai, W., Chen, P., Ca,i H., Zhang, Q., Su. Z., Cheung, T., Jackson, T., Sha, S., Xiang, Y. (2022). Worldwide prevalence of mild cognitive impairment among community dwellers aged 50 years and older: A meta-analysis and systematic review of epidemiology studies. *Age and Ageing*, *51*(8), 173. https://doi.org/10.1093/ageing/afac173

Bayles, K., McCullough, K., & Tomoeda, C. (2020). *Cognitive-communication disorders of MCI and dementia: Definition, assessment, and clinical management* (3rded.). Plural Publishing.

Benner, M., Steiner, V., & Pierce, L. L. (2018). Family caregivers' reports of hospitalizations and emergency department visits in community-dwelling individuals with dementia. *Dementia (London, England), 17*(5), 585-595. https://doi.org/10.1177/1471301216653537

Berger, C. R. & Calabrese, R. J. (1975). Some explorations in initial interaction and beyond: Toward a developmental theory of interpersonal communication. *Human Communication Research*, *1*(2), 99–112. doi:10.1111/j.1468-2958.1975.tb00258.x

Better Help Editorial Team. (2022, December 29). *Procedural memory: Its definition and importance*. https://www.betterhelp.com/advice/memory/what-procedural-memory-isandwhy-its-important/

Birkenhäger-Gillesse, E. G., Achterberg, W. P., Janus, S. I. M., Kollen, B. J., & Zuidema, S. U. (2020). Effects of caregiver dementia training in caregiver-patient dyads: A randomized controlled study. *International Journal of Geriatric Psychiatry, 35*(11), 1376-1384. https://doi.org/10.1002/gps.5378

Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer disease and associated disorders*, *23*(4), 306–314. https://doi.org/10.1097/WAD.0b013e3181a6bebc

Bradshaw, M., & Kent, B. V. (2018). Prayer, attachment to God, and changes in psychological well-being in later life. *Journal of Aging and Health, 30*(5), 667-691. https://doi.org/10.1177/0898264316688116

Brown, J., Baylie, P., Nwakasi, C., Reddy, P., Ehlman, K., Nolan, B., & Snow, T. (2020). Beta test of a PAC dementia knowledge training module included in a nursing home orientation curriculum. *Innovation in Aging*, *4*(Supplement_1), 88. https://doi.org/10.1093/geroni/igaa057.290

Brown, J., Reddy, P., Nwakasi, C., Nolan, B., Snow, T., & Ehlman, K. (2020). Dementia knowledge and caregiving skills improvement from using the PAC model: A pilot comparative evaluation. *Innovation in Aging*, *4*(Supplement_1), 89. https://doi.org/10.1093/geroni/igaa057.293

Byers, M. D., Resciniti, N. V., Ureña, S., Leith, K., Brown, M. J., Lampe, N. M., & Friedman, D. B. (2022). An evaluation of dementia dialogues®: A program for informal and formal caregivers in North and South Carolina. *Journal of Applied Gerontology, 41*(1), 82-91.

https://doi.org/10.1177/0733464820986671

Champlin, B. E. (2020). The informal caregiver's lived experience of being present with a patient who receives a diagnosis of dementia: A phenomenological inquiry. *Dementia (London, England), 19*(2), 375-396. https://doi.org/10.1177/1471301218776780

Chan, C. Y., Cheung, G., Martinez-Ruiz, A., Chau, P. Y. K., Wang, K., Yeoh, E. K., & Wong, E. L. Y. (2021). Caregiving burnout of community-dwelling people with dementia in Hong Kong and New Zealand: A cross-sectional study. *BMC Geriatrics, 21*(1), 261-261. https://doi.org/10.1186/s12877-021-02153-6

Chang, Y. P., & Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in psychiatric care, 46*(2), 108–118. https://doi.org/10.1111/j.1744-6163.2010.00246.x

Chen, C. K., Clayton, K., & Chodosh, J. (2017). The relationship between "what we believe" and "how we care" among daughters caring for a parent with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 32*(2), 90-95. https://doi.org/10.1177/1533317517689875

Church of Jesus Christ of Latter-day Saints. (n.d.). *Introduction to the book of Proverbs*. https://www.churchofjesuschrist.org/study/manual/old-testament-seminary-teachermanual/introduction-to-the-book-of-proverbs?lang=eng&id=p2#p2

Coe, N. B., Skira, M. M., & Larson, E. B. (2018). A comprehensive measure of the costs of caring for a parent: Differences according to functional status. *Journal of the American Geriatrics Society (JAGS), 66*(10), 2003-2008. https://doi.org/10.1111/jgs.15552

Collins, R., Hunt, A., Quinn, C., Martyr, A., Pentecost, C., & Clare, L. (2022). Methods and approaches for enhancing communication with people with moderate-to-severe dementia that can facilitate their inclusion in research and service evaluation: Findings from the IDEAL programme. *Dementia, 21*(4), 1135-1153. doi:10.1177/14713012211069449

Craig, R. T. (1999). Communication theory as a field. *Communication Theory, 9*(2), 119-161. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1468-2885.1999.tb00355.x

Creswell, J. W. & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approaches* (5th ed.). Sage

Creswell, J. W. & Poth, C. N. (2018). *Qualitative inquiry & research design: choosing among the five approaches* (4th ed.). Sage

Cullen, F. T. (1994.) Social support as an organizing concept for criminology: Presidential address to the academy of criminal justice sciences, *Justice Quarterly, 11*(4), 527- 559, DOI: 10.1080/07418829400092421

Custodio, N., Montesinos, R., Lira, D., Herrera-Pérez, E., Bardales, Y., & Valeriano-Lorenzo, L. (2017). Mixed dementia: A review of the evidence. *Dementia & Neuropsychologia*, *11*(4), 364–370. https://doi.org/10.1590/1980-57642016dn11-040005

Daffner, K. R., Haring, A. E., Alperin, B. R., Zhuravleva, T. Y., Mott, K. K., & Holcomb, P. J. (2013). The impact of visual acuity on age-related differences in neural markers of early visual processing. *NeuroImage, 67*, 127–136. https://doi.org/10.1016/j.neuroimage.2012.10.089

Dam, A. E. H., van Boxtel, Martin P. J, Rozendaal, N., Verhey, F. R. J., & de Vugt, M. E. (2017). Development and feasibility of inlife: A pilot study of an online social support intervention for informal caregivers of people with dementia. *PloS One, 12*(9), e0183386e0183386. https://doi.org/10.1371/journal.pone.0183386

Davies, N., Hopwood, J., Walker, N., Ross, J., lliffe, S., Walters, K., & Rait, G. (2019).

Designing and developing a co-produced theoretical and evidence-based online support for family caregivers of people with dementia at the end of life. *BMC Palliative Care*, *18*(1), 71-76. doi:1186/s12904-019-0455-0

DeJonckheere M, Vaughn L. M. (2019). Semistructured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health, 7*(2). doi: 10.1136/fmch-2018-000057

Del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & RamosMorcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PloS one*, *13*(1), e0189874. https://doi.org/10.1371/journal.pone.0189874

Dementia Care Central. (2023, January 26). *Stages of alzheimer's & dementia: durations & scales used to measure progression (GDS, FAST & CDR).* https://www.dementiacarecentral.com/aboutdementia/facts/stages/

Dovi, E., Bier, J., & Fantini-Hauwel, C. (2021). Evolution of lived experience of dementia caregivers after a psycho-educational group: An interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences, 35*(4), 1134-1142. https://doi.org/10.1111/scs.12929

Drennon-Gala, D. (1994). *The effects of social support and inner containment on the propensity toward delinquent behavior and disengagement in education* (Publication No. 942562) [Doctoral dissertation]. Retrieved from ProQuest Dissertations Publishing.

Droser, V. A. (2020). Information seeking and grief in bereaved emerging adults: A test of the theory of motivated information management. *The Southern Communication Journal*, *85*(1), 28-42. https://doi.org/10.1080/1041794X.2019.1678194

Economou, A., Routsis, C. & Papageorgiou, S. G. (2016). Episodic memory in Alzheimer disease, frontotemporal dementia, and dementia with lewy bodies/parkinson disease dementia. *Alzheimer Disease & Associated Disorders, 30*(1), 47-52. doi: 10.1097/WAD.0000000000000089.

Ehlman, M. C., Nimkar, S., Nolan, B. A. D., Thomas, P., Caballero, C. E., & Snow, T. (2018). Health workers' knowledge and perceptions on dementia in skilled nursing homes: A pilot implementation of Teepa Snow's positive approach to care certification course. *The Journal of Continuing Education in the Health Professions, 38*(3), 190-197. https://doi.org/10.1097/CEH.0000000000000216

Ekstrom, H., Auoja, N. L., Elmstahl, S., & Sandin Wranker, L. (2020). High burden among older family caregivers is associated with high prevalence of symptoms: Data from the Swedish study “Good aging in skane (GAS)”. *Journal of Aging Research*, 2020, 1-9. doi:10.1155/2020/5272130

Ellul, J., Archer, N., Foy, C. M. L., Poppe, M., Boothby, H., Nicholas, H., Brown, R. G., & Lovestone, S. (2007; 2006). The effects of commonly prescribed drugs in patients with Alzheimer’s disease on the rate of deterioration. *Journal of Neurology, Neurosurgery and Psychiatry, 78*(3), 233-239. https://doi.org/10.1136/jnnp.2006.104034

Family Caregiver Alliance Writers. (2009). *Caregiving*. FCA, National Center on Caregiving. https://www.caregiver.org/caregiving

Farran, C. J., & Keane-Hagerty, E. (1994). Interventions for caregivers of persons with dementia: Educational support groups and Alzheimer’s association support groups. *Applied Nursing Research, 7*(3), 112-117. https://doi.org/10.1016/0897-1897(94)90002-7

Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., …Tschanz, J. (2012).

Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging and Mental Health*, *16*(6), 699-711. doi:10.108013607863.2012.678482

Feurich, V. (2022, November 29). *Why a person with later stage dementia startles so easily.* Positive Approach to Care. https://teepasnow.com/blog/why-a-person-living-with-later-stage-dementia-startles-soeasily/

Fukui, C., Fujisaki-Sueda-Sakai, M., Yokouchi, N., Sumikawa, Y., Horinuki, F., Baba, A., Suto, M., Okada, H., Ogino, R., Park, H., & Okata, J. (2019). Needs of persons with dementia and their family caregivers in dementia cafés. *Aging Clinical and Experimental Research*, *31*(12), 1807-1816. https://doi.org/10.1007/s40520-019-01129-2

Gallego-Alberto, L., Smaling, H. J., Francke, A. L., van de Brug, T., van der Steen, J. T., Joling, K. J. (2022). The relationship between guilt feelings, conflicts with staff and satisfaction with care in relatives of nursing home residents with dementia: A longitudinal analysis. *Dementia*, *21*(1), 5-20. doi:10.1177/14713012211024015

García-Martín, V., de Hoyos-Alonso, M.C., Delgado-Puebla, R., Ariza-Cardiel, G. & del Cura-Gonzalez, I. (2023) Burden in caregivers of primary care patients with dementia: influence of neuropsychiatric symptoms according to disease stage (NeDEM project). *BMC Geriatrics*, *23*(525), 1-12. https://doi.org/10.1186/s12877-023-04234-0

Gilliand, M. P., & Bush, H. A. (2001). Social support for family caregivers: Toward a situation specific theory. *Journal of Theory Construction & Testing*, *5*(2), 53.

Gurarie, M. (2022, August 22). How Alzheimer's disease progresses: From diagnosis through 7 stages. *Health*. https://www.health.com/condition/alzheimers/how-alzheimers-diseaseprogresses

Hajli, M. N., Shanmugam, M., Hajli, A., Khani, A. H., & Wang, Y. (2015). Health care development: Integrating transaction cost theory with social support theory. *Informatics for Health & Social Care, 40*(4), 334-344. https://doi.org/10.3109/17538157.2014.924950

Heape, A. B. (2020). *Dementia diaries part 2: Staging on the severity continuum.* Speech Pathology. https://www.speechpathology.com/articles/dementia-diaries-part-2-staging-20402

Herndon, J. R. (2022). *The global deterioration scale; the Reisberg Alzheimer stages*. Alzheimers Disease. https://alzheimersdisease.net/reisbergs-stages

Hodgson, N. A., Petrovsky, D. V., Finegan, K., Kallmyer, B. A., Pike, J., & Fazio, S. (2021). One call makes a difference: An evaluation of the Alzheimer's association national helpline on dementia caregiver outcomes. *Patient Education and Counseling, 104*(4), 896-902. https://doi.org/10.1016/j.pec.2020.09.026

Hopwood, J., Walker, N., McDonagh, L., Rait, G., Walters, K., Iliffe, S., Ross, J., & Davies, N. (2018). Internet-based interventions aimed at supporting family caregivers of people with dementia: Systematic review. *Journal of Medical Internet Research, 20*(6), e216e216. https://doi.org/10.2196/jmir.9548

House, J. (2018). Authentic vs elicited data and qualitative vs quantitative research methods in pragmatics: Overcoming two non-fruitful dichotomies. *System (Linköping), 75*, 4-12. https://doi.org/10.1016/j.system.2018.03.014

Hupcey, J. E. (2002, 1998). Clarifying the social support theory-research linkage. *Journal of Advanced Nursing*, *27*(6), 1231-1241. doi:10.1046/j.1365-2648.1998.01231.x

Iftikhar, R., & Abaalkhail, B. (2017). Health-seeking influence reflected by online health-related messages received on social media: Cross-sectional survey. *Journal of Medical Internet Research*, *19*(11), 382. doi:10.2196/jmir.5989

Jiménez-Gonzalo, L., Romero-Moreno, R., Pedroso-Chaparro, M. D. S., Fernandes-Pires, J. A., Barrera-Caballero, S., Olazarán, J., & Losada-Baltar, A. (2020). The role of caregivers' sleep problems in the association between behavioral symptoms of dementia and caregiving depression and anxiety. *Behavioral Sleep Medicine*, *19*(5),1. DOI: 10.1080/15402002.2020.1835662

Jurgens-Toepke, P., Doubleday, A. F., Koerber, A., Briggs, C., Haley, C., Patston, P. A., Strotman, M. D., Knight, G. W., & Brown, B. (2015). Social constructivism and casewriting for an integrated curriculum. *Interdisciplinary Journal of Problem-Based Learning*, *9*(1), 44. https://doi.org/10.7771/1541-5015.1502

Kanter, E., Bevan, J. L., & Dorros, S. M. (2019). The use of online support groups to seek information about chronic illness: Applying the theory of motivated information management. *Communication Quarterly*, *67*(1), 100-121. https://doi.org/10.1080/01463373.2018.1539406

Keisari, S., Biancalani, G., Tavelli, E., Fassina, S., & Testoni, I. (2022). Spirituality during COVID-19 in northern Italy: The experience of participating in an online prayer group. *Pastoral Psychology*, *71*(2), 201-215. https://doi.org/10.1007/s11089-022-00998-1

Kiecolt-Glaser, J. K., McGuire, L., Robles, T. F., Glaser, R. (2002). Emotions, morbidity, and mortality: New perspectives from psychoneuroimmunology. *Annual Review of Psychology*, *53*, 83–107. doi:10.1146/annurev.psych.53.100901.135217

Kihlstrom, J. F. (2017). Realism and constructivism in social perception. *Behavioral and Brain Sciences*, *40*, 65. https://doi.org/10.1017/S0140525X15002344

Kilduff, L. (2021, December 22). *Which US states have the oldest populations?* PBR. https://www.prb.org/resources/which-us-states-are-the-oldest/

Kim, W., Kreps, G. L., & Shin, C. (2015). The role of social support and social networks in health information-seeking behavior among Korean Americans: A qualitative study. *International Journal for Equity in Health*, *14*(1), 40. doi:10.1186/s12939-015-0169-8

Kokorelias, K. M., & Ashcroft, R. (2020). How dementia caregivers make health service decisions: A scoping review and implications for grounded theory studies. *SAGE Open, 10*(1), 1-9. https://doi.org/10.1177/2158244020914396

Kolanowski, A. M., Fick, D. M., Yevchak, A. M., Hill, N. L., Mulhall, P. M., & McDowell, J. A. (2012). Pay attention!: The critical importance of assessing attention in older adults with dementia. *Journal of Gerontological Nursing, 38*(11), 23. https://doi.org/10.3928/00989134-20121003-05

Kort-Butler, L. A. (2017). Social support theory. *The Encyclopedia of Juvenile Delinquency and Justice.* https://doi.org/10.1002/9781118524275.ejdj0066

Kovács, K. A. (2021, 2022;). Relevance of a novel circuit-level model of episodic memories to alzheimer's disease. *International Journal of Molecular Sciences*, *23*(1), 462. https://doi.org/10.3390/ijms23010462

Labrague, L. J. (2021). Psychological resilience, coping behaviours and social support among health care workers during the COVID-19 pandemic: A systematic review of quantitative studies. *Journal of Nursing Management*, *29*(7), 1893-1905. https://doi.org/10.1111/jonm.13336

Landes, S. D., & Lillaney, N. (2019). Trend change in the intellectual disability nursing home census from 1977 to 2004. *American Journal on Intellectual and Developmental*

Disabilities, 124(5), 427-437. https://doi.org/10.1352/1944-7558-124.5.427

Lanzi, A. M., Saylor, A. K., & Cohen, M. L. (2022). Survey results of speech-language pathologists working with cognitive-communication disorders: Improving practices for mild cognitive impairment and early-stage dementia from Alzheimer's disease. *American Journal of Speech-Language Pathology, 31*(4), 1-1671. https://doi.org/10.1044/2022_AJSLP-21-00266

Leroy, M., Bertoux, M., Skrobala, E. Mode, E., Adnet-Bonte, C., LeBer, I., Bombois, S., Cassagnud, P., Chen, Y., Deramecourt, V., Lebert, F., Mackowiak, M. A., Sillaire, A R., Wathelet, M., Pasquier, F., Lebouvier, T. (2021). Characteristics and progression of patients with frontotemporal dementia in a regional memory clinic network. *Alzheimer Research & Therapy*, *13*(19), 1-11. https://doi.org/10.1186/s13195-020-00753-9

Lewis, L. F. (2015). Caregiving for a loved one with dementia at the end of life: An emergent theory of rediscovering. *American Journal of Alzheimer's Disease and Other Dementias, 30*(5), 488-496. https://doi.org/10.1177/1533317514559829

Li, Y., Sun, D., Zhang, X., Li, H., Zhao, Y., Ma, D., Li, Z., & Sun, J. (2020). Informal dementia caregivers' experiences and perceptions about mealtime care: A qualitative evidence synthesis. *Journal of Advanced Nursing, 76*(12), 3317-3328. https://doi.org/10.1111/jan.14550

Lillie, H., & Venetis, M. K. (2020). Topic avoidance as a privacy management strategy: Outcomes and predictors of parent well-being and sibling caregiving topic avoidance. *Journal of Family Communication, 20*(4), 313-326. https://doi.org/10.1080/15267431.2020.1823395

Lindlof, T. R. & Taylor, B. C. (2017). *Qualitative communication research methods (4th ed.).*

Sage

Littlejohn, S. W., Foss, K. A., & Oetzel, J. G. (2016). *Theories of human communication,* (11th ed.). Waveland Press, Inc.

Lourida, I., Hannon, E., Littlejohns, T. J., Langa, K. M., Hypponen, E., Kuzma, E. & Llewellyn, D. J. (2019). Association of lifestyle and genetic risk with incidence of dementia. *JAMA, 322*(5), 430–437. doi:10.1001/jama.2019.9879

Maguire, K. C. (2006). Making sense of the seven communication traditions. *Communication Teacher, 20*(4), 89-92. https://doi.org/10.1080/17404620601014708

Mansbach, W. E., Mace, R. A., Clark, K. M. & Firth, I. M. (2017). Meaningful activity for long-term care residents with dementia: A comparison of activities and raters. *The Gerontologist*, *57*(3), 461. doi:10:1093/geront/gnv694

Martínez-Campos, A., Compañ-Gabucio, L., Torres-Collado, L., & Garcia-de la Hera, M. (2022). Occupational therapy interventions for dementia caregivers: Scoping review. *Healthcare (Basel), 10*(9), 1764. https://doi.org/10.3390/healthcare10091764

Masoud, S. S., Meyer, K. N., Martin Sweet, L., Prado, P. J., & White, C. L. (2021). We don't feel so alone: A qualitative study of virtual memory cafés to support social connectedness among individuals living with dementia and care partners during COVID-19. *Frontiers in Public Health, 9*, 1-10. https://doi.org/10.3389/fpubh.2021.660144

Mayo, A. M., Siegle, K., Savell, E., Bullock, B., Preston, G. J., & Peavy, G. M. (2020). Lay caregivers' experiences with caring for persons with dementia: A phenomenological study. *Journal of Gerontological Nursing, 46*(8), 1727. https://doi.org/10.3928/00989134-20200527-02

Mckinlay, A., Grace, R. C., Dalrymple-Alford, J. C., & Roger, D. (2010). Characteristics of executive function impairment in Parkinson’s disease patients without dementia. *Journal of the International Neuropsychological Society*, *16*(2), 268-277. https://doi.org/10.1017/S1355617709991299

McLuhan, M. (1964). *Understanding media; the extensions of man.* McGraw Hill.

Mcleod, S. (2023, October 24). *What is cognitive dissonance theory*. Simply Psychology. https://www.simplypsychology.org/cognitive-dissonance.html

Md Nawi, N. H., Megat Ahmad, P. H., Malek, D. A., Cosmas, G., Ibrahim, H., Voo, P., & Mohd Suki, N. (2017). Structural relationship between emotional and social support for young adult carers towards intergenerational care of the multi-ethnic elderly. *Quality in Ageing*, *18*(3), 188. https://doi.org/10.1108/QAOA-05-2017-0015

Medline Plus. (2021, November). *Dementia with Lewy bodies*. https://medlineplus.gov/genetics/condition/dementia-with-lewy-bodies

Meichsner, F., & Wilz, G. (2018). Dementia caregivers' coping with pre-death grief: Effects of a CBT-based intervention. *Aging & Mental Health*, *22*(2), 218-225. https://doi.org/10.1080/13607863.2016.1247428

Miles, M.B., Huberman, A.M., & Saldana, J. (2020). *Qualitative data analysis, a methods sourcebook* (4th ed.). Sage

Minor, P. S. (2020). *The caregiving experiences of adult children who were primary caregivers to a parent with dementia: A phenomenological study* [Doctoral dissertation, Kent State University]. OhioLINK. *http://rave.ohiolink.edu/etdc/view?acc_num=kent1595184216344991*

Moeini, B., Barati, M., Farhadian, M., Heydari ara, M. (2020). The effectiveness of an educational intervention to enhance happiness in Iranian older people: Applying social support theory. *Australian Journal on Ageing*, *39*(1), e86-e93. Doi:10.1111/ajag.12702

Mougias, A. A., Christidi, F., Kontogianni, E., Skaltsounaki, E., Politis, A., & Politis, A. (2018). Patient- and caregiver-related factors associated with caregiver assessed global deterioration scale scoring in demented patients. *Current Gerontology and Geriatrics Research, 2018*, 9396160-7. https://doi.org/10.1155/2018/9396160

Mullins, J., Bliss, D. Z., Rolnick, S., Henre, C. A., & Jackson, J. (2016). Barriers to communication with a healthcare provider and health literacy about incontinence among informal caregivers of individuals with dementia. *Journal of Wound, Ostomy, and Continence Nursing, 43*(5), 539-544. https://doi.org/10.1097/WON.0000000000000263

National Alliance for Caregiving & AARP. (2020, May). *Fact sheet; the typical genx caregiver*. https://www.caregiving.org/wpcontent/uploads/2020/05/AARP1316_CGProfile_GenX_May7v8.pdf

Nguyen, H., Nguyen, T., Tran, D., & Hinton, L. (2021). “It's extremely hard but it's not a burden": A qualitative study of family caregiving for people living with dementia in Vietnam. *PloS One, 16*(11), e0259788e0259788. https://doi.org/10.1371/journal.pone.0259788

Olmos-Vega, F., Stalmeijer, R.E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, *45*(3), 241-251, DOI: 10.1080/0142159X.2022.2057287

Ong, W. J. (1977). *Interfaces of the world; studies of the evolution of consciousness and culture.* Cornell University Press

Ong, W. J. & Hartley, J. (1982). *Oral and literacy; the technologizing of the world.* Routledge.

Park, M., Nari, F., Kang, S. H., Jang, S., & Park, E. (2021). Association between living with patients with dementia and family caregivers' depressive symptoms-living with dementia patients and family caregivers' depressive symptoms. *International Journal of Environmental Research and Public Health*, *18*(8), 4372. https://doi.org/10.3390/ijerph18084372

Pihet, S., & Kipfer, S. (2018). Coping with dementia caregiving: A mixed-methods study on feasibility and benefits of a psycho-educative group program. *BMC Geriatrics*, *18*(1), 209-209. https://doi.org/10.1186/s12877-018-0896-y

Pillemer, S., Davis, J., & Tremont, G. (2018; 2017). Gender effects on components of burden and depression among dementia caregivers. *Aging & Mental Health*, *22*(9), 1162-1167. https://doi.org/10.1080/13607863.2017.1337718

Piraino, E., Byrne, K., Heckman, G. A., & Stolee, P. (2017). Caring in the information age: Personal online networks to improve caregiver support. *Canadian Geriatrics Journal CGJ*, *20*(2), 85-93. doi:10.5770/cgj.20.271

Protoolis, H. A., Burton, J., Riley, L., & Jancey, J. (2022). More than memory: A qualitative analysis of carer-reported psychosocial benefits of memory cafés. *Health Promotion Journal of Australia*, *33*(S1),358-366. https://doi.org/10.1002/hpja.573

Punch, K. F. (2014). *Introduction to social research; Quantitative and qualitative approaches* (3rd ed.). Sage

Rasmussen, J., & Langerman, H. (2019). Alzheimer's disease - Why we need early diagnosis. *Degenerative Neurological and Neuromuscular Disease*, *9*, 123–130. https://doi.org/10.2147/DNND.S228939

Reisberg, B., Ferris, S. H., De Leon, M. J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *The American Journal of*

Psychiatry, 139(9), 1136-1139. https://doi.org/10.1176/ajp.139.9.1136

Resciniti, N. V., Tang, W., Tabassum, M., Pearson, J. L., Spencer, S. M., Lohman, M. C., Ehlers, D. K., Al-Hasan, D., Miller, M. C., Teixeira, A., & Friedman, D. B. (2020). Knowledge evaluation instruments for dementia caregiver education programs: A scoping review. *Geriatrics & Gerontology International*, *20*(5), 397–413. https://doi.org/10.1111/ggi.13901

Robillard, J. M., Johnson, T. W., Hennessey, C., Beattie, B. L., & llles, J. (2013). Aging 2.0: Health information about dementia on twitter. *PloS One*, *8*(7), e69861. doi:10.137/journal.pone.00069861

Roman, N. V., Mthembu, T. G., & Hoosen, M. (2020). Spiritual care – 'a deeper immunity' – a response to COVID-19 pandemic. *African Journal of Primary Health Care & Family Medicine, 12*(1), 1-3. https://doi.org/10.4102/phcfm.v12i1.2456

Ross, P. T., & Bibler Zaidi, N. L. (2019). Limited by our limitations. *Perspectives On Medical Education*, *8*(4), 261–264. https://doi.org/10.1007/s40037-019-00530-x

Ruggiano, N., Washington, K. T., Luo, Y., Noh, H., & Brown, E. L. (2021). Feasibility of using private Facebook groups for community-based dementia caregiver support. *Best Practices in Mental Health, 17*(1), 44-55. https://www.thefreelibrary.com/Feasibility of Using Private Facebook Groups for Community-Based...-a0683998958

Sachdev, P., Kalaria, R., O'Brien, J., Skoog, I., Alladi, S., Black, S. E., Blacker, D., Blazer, D. G., Chen, C., Chui, H., Ganguli, M., Jellinger, K., Jeste, D. V., Pasquier, F., Paulsen, J., Prins, N., Rockwood, K., Roman, G. & Scheltens, P. (2014). Diagnostic criteria for vascular cognitive disorders: A VASCOG statement. *Alzheimer Disease and Associated Disorders, 28*(3), 206-218. https://doi.org/10.1097/WAD.0000000000000034

Simpson, C., & Carter, P. (2013). Short-term changes in sleep, mastery & stress: Impacts on depression and health in dementia caregivers. *Geriatric Nursing (New York), 34*(6), 509-516. https://doi.org/10.1016/j.gerinurse.2013.07.002

Smallfield, S. (2017). Supporting adults with Alzheimer's disease and related major neurocognitive disorders and their caregivers: Effective occupational therapy interventions. *The American Journal of Occupational Therapy*, *71*(5), 1-4. http://dx.doi.org.ezproxy.liberty.edu/10.5014/ajot.2017.715002

Snow, T. (2020, June 25). *5 challenging dementia behaviors explained!*. Positive Approach to Care. https://teepasnow.com/blog/5-challenging-dementia-behaviors-explained/

Stacey, A. F., Gill, T. K., Price, K., Warmington, R., & Taylor, A. W. (2016). Unpaid informal caregivers in South Australia: Population characteristics, prevalence and age-period-cohort effects 1994–2014. *PLoS One, 11*(9). http://dx.doi.org.ezproxy.liberty.edu/10.1371/journal.pone.0161994

Steenfeldt, V. Ø., Aagerup, L. C., Jacobsen A. H., & Skjødt U. (2021). Becoming a family caregiver to a person with dementia: A literature review on the needs of family caregivers. *SAGE Open Nursing*. doi:10.1177/23779608211029073

Suri, H. (2011). Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal*, *11*(2), 63-75. https://doi.org/10.3316/QRJ1102063

Sutton, J., & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *The Canadian Journal of Hospital Pharmacy*, *68*(3), 226–231. https://doi.org/10.4212/cjhp.v68i3.1456

Swan, K., Hopper, M., Wenke, R., Jackson, C., Till, T., & Conway, E. (2018). Speech-language pathologist interventions for communication in moderate–severe dementia: A systematic review. *American Journal of Speech-Language Pathology (Online), 27*(2), 836-852. http://dx.doi.org.ezproxy.liberty.edu/10.1044/2017_AJSLP-17-0043

Teles, S., Paúl, C., Sosa Napolskij, M., & Ferreira, A. (2020). Dementia caregivers training needs and preferences for online interventions: A mixed-methods study. *Journal of Clinical Nursing, 31*(13-14), 2036-2054. https://doi.org/10.1111/jocn.15445

Terrell, S. R. (2016). *Writing a proposal for your dissertation: guidelines and examples.* The Guilford Press.

Tesch, R. (1990). *Qualitative research: Analysis types and software tools.* Falmer

Thaipisuttikul, P., Jaikla, K., Satthong, S., & Wisajun, P. (2022). Rate of conversion from mild cognitive impairment to dementia in a Thai hospital-based population: A retrospective cohort. *Alzheimer's & Dementia : Translational Research & Clinical Interventions, 8*(1). https://doi.org/10.1002/trc2.12272

The Villages, Inc. (2024, April 7). *It's a pretty special place.* https://www.thevillages.com/about-us

Theofanidis, D. & Fountouki, A. (2019). Limitations and delimitations in the research process. *Perioperative Nursing*, *7*(3), 155–162. http://doi.org/10.5281/zenodo.2552022

Thordardottir, B., Malmgren Fänge, A., Lethin, C., Rodriguez Gatta, D., & Chiatti, C. (2019). Acceptance and use of innovative assistive technologies among people with cognitive impairment and their caregivers: A systematic review. *BioMed Research International, 2019*. https://doi.org/10.1155/2019/9196729

Thunström, L., & Noy, S. (2022). What we think prayers do: Americans' expectations and valuation of intercessory prayer. *PloS One, 17*(3), e0265836e0265836. https://doi.org/10.1371/journal.pone.0265836

Tian, X., Schrodt, P., & Carr, K. (2016). The theory of motivated information management and posttraumatic growth: Emerging adults' uncertainty management in response to an adverse life experience. *Communication Studies*, *67*(3), 280-301. https://doi.org/10.1080/10510974.2016.1164207

Torres-Quesada, M., Leiva, A., Lupiáñez, J., Humphreys, G., & Funes, M. J. (2022). A process specific approach in the study of normal aging deficits in cognitive control: What deteriorates with age? *Acta Psychologica*, *227*, 103625-103625. https://doi.org/10.1016/j.actpsy.2022.103625

Trinity College Dublin. (n.d.). Participant consent form template. Retrieved from https://www.tcd.ie/swsp/assets/pdf/Participant%20consent%20form%20template.pdf

Tsai, T., Chang, H., Chen, Y., & Chang, Y. (2017). Determinants of user acceptance of a specific social platform for older adults: An empirical examination of user interface characteristics and behavioral intention. *PloS One*, *12*(8), e0180102. doi:10.1371/journal.pone.0180102

Uchino, B. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*, *29(4)*, 377-387 doi:10.1007/s10865-006-9056-5

Urrestarazu, E., & Iriarte, J. (2016). Clinical management of sleep disturbances in Alzheimer's disease: Current and emerging strategies. *Nature and Science of Sleep*, *8*, 21-33. http://dx.doi.org.ezproxy.liberty.edu/10.2147/NSS.S76706

US Facts. (2022). *Our changing population: the United States*. https://usafacts.org/data/topics/people-society/population-and-demographics/our-changing-population van den Eertwegh, V., van Dulman, S., van Dalen, J., Scherpbier, A.J.J.A., & van der Vleuten, Cees P.M. (2013). Learning in context: Identifying gaps in research on the transfer of medical communication skills to the clinical workplace. *Patient Education and Counseling, 90(2)*, 184-192. https://doi.org/10.1016/j.pec.2012.06.008

Vechia, Akeisa Dieli Ribeiro Dalla, Mamani, A. R. N., Azevedo, Rosemeiry Capriata de Souza, Reiners, A. A. O., Pauletto, T. T., & Segri, N. J. (2019). Caregiver role strain in informal caregivers for the elderly. *Texto & Contexto Enfermagem, 28*. doi:10.1590/1980-265x-tce-2018-0197

Vogels, E. A. (2019, September 9). *Millennials stand out for their technology use, but older generations also embrace digital life*. Pew Research Center. https://www.pewresearch.org/facttank/2019/09/09/us-generations-technology-use

Weiner, M. F and Lipton, A. M. (2009). *The textbook of Alzheimer disease and other dementias.* American Psychiatric Publishing

Williams, K., Blyler, D., Vidoni, E. D., Shaw, C., Wurth, J., Seabold, D., Perkhounkova, Y., & Van Sciver, A. (2018). A randomized trial using telehealth technology to link caregivers with dementia care experts for in-home caregiving support: FamTechCare protocol. *Research in Nursing & Health, 41*(3), 219-227. https://doi.org/10.1002/nur.21869

Wood, J. S., B.Sc, Firbank, M. J., Ph.D, Mosimann, Urs P., M.D., Ph.D, Watson, R., F.R.A.C.P, Barber, R., M.D, Blamire, A. M., Ph.D, & O'Brien, J. T., D.M. (2013). Testing visual perception in dementia with Lewy bodies and Alzheimer disease. *The American Journal of Geriatric Psychiatry, 21*(6), 501-508. https://doi.org/10.1016/j.jagp.2012.11.015

World Health Organization (2022, September 20). *Dementia*.

https://www.who.int/newsroom/fact-sheets/detail/dementia

World Health Organization. (2019, May 9). *iSupport for dementia.* https://www.who.int/publications/i/item/9789241515863

Wright, K. B., & Bell, S. B. (2003). Health-related support groups on the internet: Linking empirical findings to social support and computer mediated communication theory. *Journal of Health Psychology, 8*(1), 39-54. doi:10.1177/1259105303008001429

Xie, B., Berkley, A. S., Kwak, J., Fleischmann, K. R., Champion, J. D., & Koltai, K. S. (2018). End-of-life decision making by family caregivers of persons with advanced dementia: A literature review of decision aids. *SAGE open medicine, 6*, 2050312118777517. https://doi.org/10.1177/2050312118777517

Yang, T., Zhu Z., Yin, E., Wang, Y., Zhang, C., Yuan, H., … Wang, X. (2019). Alleviation of symptoms of Alzheimer's disease by diminishing AB neurotoxicity and neuroinflammation. *Chemical Science (Cambridge*), *10*(43), 10149-10158. doi:10.1039/c9sc03042e

Yay Pençe, A., Ekmekçi Ertek, İ., & Coşar, B. (2022). Psychiatric misdiagnosis in frontotemporal dementia. *European Psychiatry*, *65*(S1), S870-S871. https://doi.org/10.1192/j.eurpsy.2022.2257

Yuan, Q., Wang, P., Tan, T. H., Devi, F., Poremski, D., Magadi, H., Goveas, R., Ng, L. L., Chong, S. A., & Subramaniam, M. (2021). Coping patterns among primary informal dementia caregivers in Singapore and its impact on caregivers - implications of a latent class analysis. *The Gerontologist*, *61*(5), 680-692. https://doi.org/10.1093/geront/gnaa080

Zhao, Y., Da, J., & Yan, J. (2021). Detecting health misinformation in online health communities: Incorporating behavioral features into machine learning based approaches. *Information Processing & Management*, *58*(1).

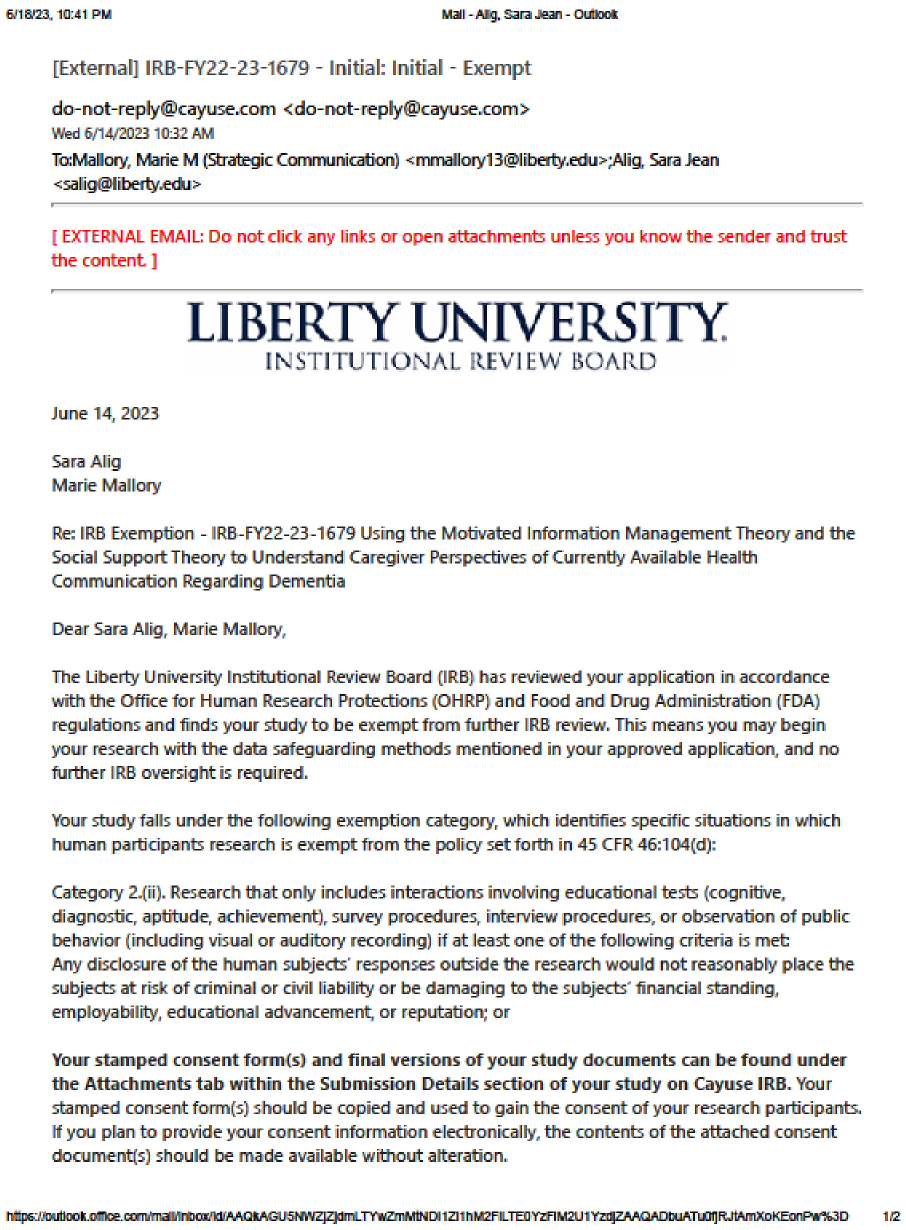
https://doi.org/10.1016/j.ipm.2020.102390

Zorina, S. A., Silviu, D. A., Daniel, D. A., Cristian, P., & Any, D. A. (2020). Physical therapy intervention in the perspective of dementia patients with neuropsychiatry symptoms. *Ovidius University Annals, Series Physical Education and Sport/Science, Movement and Health*, *20*, 348.

Zwingmann, I., Hoffmann, W., Michalowsky, B., Dreier-Wolfgramm, A., Hertel, J., Wucherer, D., Eichler, T., Kilimann, I., Thiel, F., Teipel, S., & Thyrian, J. R. (2018). Supporting family dementia caregivers: Testing the efficacy of dementia care management on multifaceted caregivers' burden. *Aging & Mental Health*, *22*(7), 889896. https://doi.org/10.1080/13607863.2017.1399341

Appendices A-F

Appendix A: IRB Approval Letter



6/18/23, 10:41 PM Mail - Alig, Sara Jean - Outlook

[External] IRB-FY22-23-1679 - Initial: Initial - Exempt

do-not-reply@cayuse.com <do-not-reply@cayuse.com>
Wed 6/14/2023 10:32 AM
To:Mallory, Marie M (Strategic Communication) <mmallory13@liberty.edu>;Alig, Sara Jean <salig@liberty.edu>

[EXTERNAL EMAIL: Do not click any links or open attachments unless you know the sender and trust the content.]

LIBERTY UNIVERSITY
INSTITUTIONAL REVIEW BOARD

June 14, 2023

Sara Alig
Marie Mallory

Re: IRB Exemption - IRB-FY22-23-1679 Using the Motivated Information Management Theory and the Social Support Theory to Understand Caregiver Perspectives of Currently Available Health Communication Regarding Dementia

Dear Sara Alig, Marie Mallory,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:
Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

Your stamped consent form(s) and final versions of your study documents can be found under the Attachments tab within the Submission Details section of your study on Cayuse IRB. Your stamped consent form(s) should be copied and used to gain the consent of your research participants. If you plan to provide your consent information electronically, the contents of the attached consent document(s) should be made available without alteration.

https://outlook.office.com/mail/inbox/id/AAQkAGU5NWZjZjdmLTYwZmMtNDI1ZI1hM2FILTE0YzFIM2U1YzdjZAAQADbuATu0fjRJtAmXoKEonPw%3D 1/2

Appendix B: Participant Recruitment Flyer

Research Participants Needed

Using the Motivated Information Management Theory and the Social Support Theory to Understand Caregiver Perspectives of Health Communication Regarding Dementia

- **Are you 18 years of age or older?**
- **Do you live in the Ohio Valley?**
- **Are you caring for a parent with Alzheimer's or dementia?**

If you answered **yes** to each of the questions listed above, you may be eligible to participate in a research study.

The purpose of the study is to:

Explore how caregivers in the Ohio Valley search for and perceive health communication regarding dementia. Dementia-care practitioners need to better understand the caregiver's perception so that they can determine what is missing from currently available dementia-care health communication and how best to communicate strategic information through supportive interventions.

Participants will be asked to:

1. Participate in three (3) remote (Zoom) video and audio-recorded interviews that will take no more than one (1) hour each. The interviews will be one (1) month apart, taking place over a three (3)-month timeframe.
2. Review interview transcripts to check them for accuracy and confirm that responses to the interview questions are accurately represented in the transcripts.

Participants will receive a $25 Amazon gift card!

If you would like to participate, please contact the researcher at the phone number or email address provided below.

A consent document will be sent to you before the time of the interview.

Sara Alig, a doctoral candidate in the School of Communication and The Arts at Liberty University, is conducting this study.

Please contact Sara Alig at [redacted] for more information.

Appendix C: Verbal Script: Participant Recruitment

Hello Potential Participant,

As a graduate student in the School of Communication and the Arts at Liberty University, I am conducting research as part of the requirements for a Doctor of Philosophy degree. The purpose of my research is to explore how caregivers in the Ohio Valley search for and perceive health communication regarding dementia, and if you meet my participant criteria and are interested, I would like to invite you to join my study.

Participants must be 18 years of age or older, live in the Ohio Valley, and currently care for a parent with Alzheimer’s or any other form of dementia. Participants, if willing, will be asked to take part in three (3) remote (Zoom) video and audio-recorded interviews that will take no more than one (1) hour each. The interviews will be one (1) month apart, taking place over a three (3)-month timeframe. Participants will also be asked to review their interview transcripts to check them for accuracy and confirm that their responses to the interview questions are accurately represented in the transcripts. The transcripts will be sent through an encrypted and secure email no later than one (1) week following each interview and will be asked to return any responses within one (1) week following the receipt of the transcript. Names and other identifying information will be requested as part of this study, but the information will remain confidential.

Would you like to participate? [Yes] Great, could I get your email address and can we set up a time for an interview? [No] I understand. Thank you for your time.

A consent document will be emailed to you 1-2 weeks before the initial interview. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document, scan it into a digital file, and return it to me by the time of the interview.

Participants will receive a $25 Amazon gift card following the third and final interview.

Thank you for your time. Do you have any questions?

Appendix D: Consent to Participate in Research Study

Consent

Title of the Project: Using the Motivated Information Management Theory and the Social Support Theory to Understand Caregiver Perspectives of Currently Available Health Communication Regarding Dementia
Principal Investigator: Sara Alig, Doctoral Candidate, School of Communication and the Arts, Liberty University

Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be 18 years of age or older, live in the Ohio Valley, and currently care for a parent with Alzheimer's or any other form of dementia. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about and why is it being done?

The purpose of the study is to explore how caregivers in the Ohio Valley search for and perceive health communication regarding dementia. Dementia-care practitioners need to better understand the caregiver's perception so that they can determine what is missing from currently available dementia-care health communication and how best to communicate strategic information through supportive interventions.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

3. Participate in three (3) remote (Zoom) video and audio-recorded interviews that will take no more than one (1) hour each. The interviews will be one (1) month apart, taking place over a three (3)-month timeframe.
4. Review your interview transcripts to check them for accuracy and confirm that your responses to the interview questions are accurately represented in the transcripts. The transcripts will be sent to you through an encrypted and secure email no later than one (1) week following each interview and you will be asked to return any responses within one (1) week following the receipt of the transcript.

How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

Benefits to society include improved methods of communicating health information regarding dementia to caregivers seeking support and interventions that decrease caregiver burden.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life. The risks involved in this study include the possibility of psychological stress from being asked to recall and discuss difficult content. To reduce risk, I will discontinue the interview if needed and provide referral information for counseling services.

I am a mandatory reporter. During this study, if I receive information about child abuse, child neglect, elder abuse, or intent to harm self or others, I will be required to report it to the appropriate authorities.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records.

- Interviews will be conducted in a location where others will not easily overhear the conversation.
- Data collected from you may be used in future research studies and/or shared with other researchers. If data collected from you is reused or shared, any information that could identify you, if applicable, will be removed beforehand.
- Data will be stored on a password-locked computer and in a locked file cabinet. After five/seven years, all electronic records will be deleted and all hardcopy records will be shredded.
- Recordings will be stored on a password-locked computer until participants have reviewed and confirmed the accuracy of the transcripts and then deleted. The researcher and members of her doctoral committee will have access to these recordings.

How will you be compensated for being part of the study?

Participants will be compensated for participating in this study. At the conclusion of the third and final interview participants will receive a $25 Amazon gift card.

Is study participation voluntary?

Participation in this study is voluntary. Your decision on whether to participate will not affect your current or future relations with Liberty University. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Sara Alig. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at [redacted] [redacted] You may also contact the researcher's faculty sponsor, Dr. Marie Mallory, at [redacted]

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to audio-record/video-record me as part of my participation in this study.

____
Printed Subject Name

____
Signature & Date

Appendix E: Interview Guide

Month One Guide

Topic	Guiding Questions	Possible Follow-Up Questions
Life before dementia	Tell me about your mom/dad before dementia.	How would you describe their personality? What are some things that were/are important to them?
Life after dementia	Tell me about your mom/dad now.	How have they changed?
Current knowledge about dementia	What do you currently know about your mom/dad's dementia?	Do you know what type of dementia? Do you know how far their dementia has progressed? Do you know what to expect in future progression?
Search for health information	How are you learning the things you want to know about your mom/dad's dementia?	What online searches are you conducting? What support groups do you attend, if any? At what point in this process did you decide to seek information from in-person or online options of support- what was the deciding factor? Was there a certain symptom or behavior that prompted you to seek information from in-person or online resources?
Specific resources	Tell me what specific in-person or online resources have been the most beneficial to you in this journey.	Are there specific resources (support groups, organizations, websites, blogs, social media groups, podcasts, or even real-time remote interventions) that you frequent to gain information about dementia or support in caregiving? If so, tell me about them and why you frequent them.
What is missing from in-person or online resources?	I want to know what is missing from current in-person or online content when adults caring for parents with dementia are searching for information and support throughout their situation. How would you finish this sentence: I wish I could just search online or find someone who helps with _________.	What questions do you still have about your mom/dad's dementia? How could dementia-care practitioners create an ideal in-person or online structure for caregivers searching for support, information, or even interventions? What features would be ideal in an in-person or online option of support for a caregiver to feel more confident and less anxious about their situation?

Summary: Thank you for your willingness to spend this time telling me about your caregiving journey and about your mom/dad. Is there anything else you would like to add or that you think I should know?

Do you have any questions for me?

Month Two

Topic	**Guiding Questions**	**Possible Follow-Up Questions**
Life after dementia	Last month we briefly compared your mom/dad before dementia and how he/she had changed. Tell me about your mom/dad now.	How have they changed since we talked last month?
Current knowledge about dementia	Have you learned anything new about your mom/dad’s dementia since we last talked? Themes that are emerging from these interviews are as follows: • Many adults have not ever actually been told that their parent has dementia- despite the brain changes that are happening. • Most adults who have parents with dementia, do not have insight into what type of dementia it is or how far it has progressed. • Many adults only have a base knowledge that the dementia will get worse, but do not know what specific symptoms to expect.	Do you know what type of dementia? Do you know how far their dementia has progressed? Do you know what to expect; in future progression?
Search for health information	Since our last conversation, you did have some questions that you were exploring. How are you learning the things you want to know about your mom/dad’s dementia? Themes that are emerging from these interviews are as follows: • Support groups are not ideal for adults caring for parents in their own home because they would need to bring their parent with them or they would have to leave their parent at home. Would a support group that included both the caregiver and the parent (where each would go to a separate meeting) be beneficial? • Men do not like to share their stories in support group settings, so they tend to find support through talking with a friend, family member, or co-worker.	What online searches are you conducting? What support groups do you attend, if any? At what point in this process did you decide to seek information from in-person or online options of support- what was the deciding factor? Was there a certain symptom or behavior that prompted you to seek information from in-person or online resources?

	• Most people look to the physician when seeking information about their parent's dementia. Is the information you are getting from the physician's office satisfying for information and for support?	
Specific resources	Since our last conversation, tell me about specific in-person or online resources that have been the most beneficial to you. Have there been any major revelations from these resources?	Are there specific resources (support groups, organizations, websites, blogs, social media groups, podcasts, or even real-time remote interventions) that you frequent to gain information about dementia or support in caregiving? If so, tell me about them and why you frequent them.
What is missing from in-person or online resources?	Since our last conversation, I asked what is missing from current in-person or online content when adults caring for parents with dementia are searching for information and support. Some of the themes emerging throughout these interviews have revealed the following: • conversations with parents about brain change are difficult to initiate and navigate • siblings do not always see eye to eye throughout the process • initial physician visits do not always detect the seriousness of the potential brain change soon enough • discussions about memory care facilities and end of life decisions are not always completed when the parent has the capacity to convey his/her preferences • does lifestyle or genetics play a bigger role in determining what the future holds for the me? Do any of those themes resonate with you? Has the completion of this sentence changed since last we talked? I wish I could just search online or find someone who helps with _________.	What questions do you still have about your mom/dad's dementia? How could dementia-care practitioners create an ideal in-person or online structure for caregivers searching for support, information, or even interventions? What features would be ideal in an in-person or online option of support for a caregiver to feel more confident and less anxious about their situation?

Summary: Thank you for your willingness to spend this time telling me about your caregiving journey and about your mom/dad. Is there anything else you would like to add or that you think I should know?

Do you have any questions for me?

Month Three

Topic	Guiding Questions	Possible Follow-Up Questions
Life after dementia	Last month we briefly discussed how your mom/dad had changed from the previous month. Tell me about your mom/dad now. • Reflect on how you think your communication with your parent during the past few months of brain change is different from your parent's other communication partners (such as spouse to spouse, friend to friend, grandparent to grandchild, etc).	How have they changed since we talked last month? • How do those changes affect the communication you have with your parent?
Current knowledge about dementia	Have you learned anything new about your mom/dad's dementia since we last talked? • Has this experience in general changed anything about your current knowledge regarding your parent's dementia?	Any advances in your knowledge about type of dementia? How far dementia has progressed? New insights about future progression?
Search for health information	Since our last conversation, how are you learning the things you want to know about your mom/dad's dementia? • Any new symptoms or behaviors that prompted you to seek information from in-person or online resources?	• If searching online, what keywords are you typing into the search bar? • If talking to others who are going through this same phenomenon, what topics come up the most? • If talking to healthcare practitioners, what questions are you asking?
Specific resources	Since we talked last, tell me what specific in-person or online resources have been the most beneficial to you. • One theme that has emerged in the data is that podcasts are beneficial for adults seeking information about a parent's dementia. There are current podcasts that are dedicated to this topic. Would a podcast dedicated to information in the Ohio Valley (or your own region) for caregivers/care partners be of benefit to you? What would keep you coming back for more?	Any new online searches? Any new support groups? Any new support organizations, websites, blogs, social media groups, podcasts, or even real-time remote interventions?

What is missing from in-person or online resources?	Has the completion of this sentence changed since last we talked? I wish I could just search online or find someone who helps with _________. • Themes- genetics?, navigating difficult conversations (with my parent; with my other family members)?, how do we catch this early if it is not detected during physician visits?, how do I stay connected with my parent as their communication abilities change?, how do I find the right memory care facility and know when that time is right for transition?, how do I get the care staff at memory care facilities to understand why my parent is the way they are?,	How could a dementia-care practitioner (such as me) create an ideal in-person or online structure for care partners (such as yourself) searching for the answers to these questions?
Cultural Aspect	Do you think region/culture makes a difference in how people communicate with parents with dementia? Do you think that being from the Ohio Valley has a specific cultural influence on our relationships with our parents?	

Summary: Thank you for your willingness to spend this time telling me about your caregiving journey and about your mom/dad. Is there anything else you would like to add or that you think I should know? Do you have any questions for me?

Appendix F: Member Check Email Request

Dear Participant,

As a doctoral candidate in the School of Communication and the Arts at Liberty University, I am sending you correspondence following your recent interview as a part of the study to explore how caregivers in the Ohio Valley search for and perceive health communication regarding dementia. You may recall that this research is a part of the requirements for a Doctor of Philosophy degree. One week ago, you participated in an interview as a part of this research and your responses were recorded. This email is being sent to allow you to review your interview transcript. Please review the entire attached transcript and reply using this securely encrypted link with any changes or clarifications that are needed in order to ensure that you are being accurately represented in this study. Your prompt reply within one week from the date of this email is greatly appreciated.

Recall that participants' names and other identifying information will be available to the researcher as part of this study, but participant identities will not be disclosed in the publication of the study.

Recall that participants will receive a $25 Amazon gift card following the third and final interview.

Sincerely,

Sara J. Alig
Doctoral Candidate at Liberty University
[redacted]