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Family Decision Making in Dementia Care Transitions: A Qualitative Case Study

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This is to certify that the doctoral dissertation by

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Walden University
2023

Abstract

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MSW, Rutgers University, 2015

BS, Radford University, 2013

Dissertation Submitted in Partial Fulfillment

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Abstract

Dementia is a debilitating disease that can affect more than just the person with the diagnosis. The family member(s) who are caregivers are put under a significant amount of stress as they previously had to identify symptoms and manage them on their own. Now, there are care communities that are available to take care of patients with dementia at different stages of their disease progression; however, many families are resistant to transitioning their loved ones with dementia to these facilities after moving them into their homes as they progress through the disease. This research study reviewed the experiences of family members with loved ones who have dementia, specifically those who have been given a recommendation to move to a higher level of care and are resistant putting that measure into place. Interviews with 10 participants that were caregivers to family members with dementia were used to gain understanding of their decision-making and their reasons for being resistant to moving their loved one into a higher level of care within their care communities. This qualitative study used the Health Belief Model (HBM) as a theoretical framework. Qualitative coding 6 stage process was used to pull codes, categories and themes of the data analysis. The results showed that family member caregivers to loved ones with dementia struggled with understanding dementia, finding resources and having enough emotional support during the caregiving process; proof that more is needed to better support this population. The implications for positive social change with this study are to give a deeper understanding to geriatric practitioners, healthcare providers, policy developers, political entities, and other families that are going through the same process.

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Dedication

I want to dedicate this dissertation to the people in my personal life who supported me the most throughout the process while I was on the emotional roller coaster when researching and writing. Monique Butcher and Archie Robinson, my mother and father, Ike and Maslow, my cats, and John Reid, my Godfather, have been my foundational rocks throughout this process. I want to make a special dedication to my grandmother, Eartha Butcher, (God rest her soul) who always knew I was smart and has watched over me from heaven since I was 15 years old. Dr. John Saindon is the real MVP who stuck by me with all the crazy changes and went above and beyond to keep me motivated when I was ready to just cry and give up, or when I had a long week (many weeks were long).

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To my friends, Shukura Abbott, Kristin Staten-Hall, Bonnie Lytle, and everyone whose names I have forgotten to write who dragged me out to dinner, happy hour, and dancing: you are my motivation and the reason I smile! Without you, my moments of writer's block and frustrations overall would have gotten the better of me. Thank you to my wonderful church family at Bethany Lutheran Church, who prayed for me and supported me throughout this whole process!

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Chapter 1: Introduction to the Study

Introduction

Dementia is a neurological disease that affects one’s cognition over time, causing a person to lose their memory, recall, speech, word association and selection, and reasoning and judgment skills (National Institute on Aging, 2021b, The Alzheimer’s Association, 2020). The stages of dementia include early, middle, and late/end of life stage (National Institute on Aging, 2021b). The early stage is where one forgets smaller details, such as someone’s name or forgets tasks that they were supposed to do; this stage often mirrors normative age cognitive decline (The Alzheimer’s Association, 2021). The middle stage is where the person starts forgetting other loved one’s names, lifetime milestones and dates, along with wandering and getting lost and behavior/personality changes (The Alzheimer’s Association, 2021). The late or end-of-life stage is where the diagnosed person now needs around-the-clock care for activities to support daily living, supervision, and assistance with appointments; they may show extreme behavior changes, loss of executive functioning, and has now forgotten who they are, as well as loved ones (The Alzheimer’s Association, 2021). When a person reaches the end stages of dementia, the individual has usually lost most of their cognitive functions and moves into the end-of-life stage (Alzheimer’s Association, 2021). Care that can be provided includes companionship and supervision, escorting and assisting at various appointments, meal preparation and feeding, hygiene and grooming, getting dressed, emotional support, and help with decision making for life management (power of attorney, guardianship, or conservatorship; National Institute on Aging, 2021b).

In the end-stage, many patients may need higher levels of care, as well as a targeted health education curriculum to guide families on those different levels and supportive resources (Brandao et al., 2016). Yet, family members in the D.C. metropolitan (Washington D.C., Maryland, and northern Virginia) area with loved ones with dementia ages 65 years old and older residing in a care community often lack appropriate health education (Macleod et al., 2017; O'Shea et al., 2017). Current health education materials that exist for family members are the Alzheimer's Association website and the association's hotline, a small number of phone and tablet applications, and information on the National Institutes of Aging website (Lee et al., 2017; National Institutes of Aging, 2019b; The Alzheimer's Association, 2018,). This study may assist in the expansion of health education resources to help with care and transitions in the community for families of loved ones with dementia. This study may also expand the knowledge gap for geriatric healthcare professionals and practitioners to help develop better understandings and fulfill the health literacy needs of their patients and patients' families.

Chapter 1 examines the overall background information of the study, the problem to be examined, the scope, assumptions, and the framework used in the study, the Health Belief Model (HBM). Chapter 2 is the literature review, where the literature surrounding the health belief model, the methodology as it relates to the study topic and population, and the synthesis of that information are presented to identify and articulate the gap in the literature and justify the need for this study. Chapter 3 includes the research design and case study methodology, along with participant selection, data collection instruments to be used and the analysis process. Chapter 3 closes with a discussion of the ethical protocols for the research project by reviewing the reliability and validity of the study, the interview protocol, and the IRB process. Chapter 4 will discuss the process for data collection and the results of the data collected (themes, categories and quotes) to dive deep into the analysis of the data. Chapter 5 reviews the implications that would come from data analysis and the possible social change that could be brought from this as well.

Background of the Study

Dementia care is a taxing job that oftentimes most family members take on at the expense of their own needs and self-care (Webb & Dening, 2016). In the Washington D.C. metro area, 299 people ages 65 years and older have been diagnosed with Alzheimer's (The Alzheimer's Association, 2021). The prevalence for other dementia's such as Lewy Body, Vascular, and unspecified/other specified dementia is at 1000 people over the age of 65 (The Alzheimer's Association, 2021). In 2019, per the Alzheimer's Association (2021), the number of deaths from dementia was 3,724, and the mortality rate is 11.5 per 100,000 people in Washington D.C., 16.7 per 100,000 people in Maryland, and 30.8 per 100,000 people in Virginia. The incidence rates for dementia increase with age due to various symptoms showing and movement for possible diagnosis with a healthcare professional. The incidence rate for dementia diagnosis in ages 65-74 is 4 out of every 1000 people (The Alzheimer's Association, 2021). For ages 75-84, the incidence rate is 32 out of every 1000 people. For age 85 and older, 76 out of every 1000 people (The Alzheimer's Association, 2021).

Alzheimer’s is the most common form of dementia, and it consists of cognitive decline due to the loss of grey matter in the brain (National Institute on Aging, 2021b; The Alzheimer’s Association, 2021). As a result, dementia affects executive function (decision making), language skills and communication abilities, emotional regulation, and memory (National Institute on Aging, 2021b; The Alzheimer’s Association, 2021).

Each dementia can only be specifically diagnosed during an autopsy, but certain pre-existing conditions and/or symptoms can aid in correct diagnosis (National Institute on Aging, 2021b; The Alzheimer’s Association, 2021). Lewy Body Dementia and Alzheimer’s Dementia have similar symptoms, but Lewy Body has neurons in the shape of Lewy bodies that trigger the loss of grey matter in the brain, and therefore, the cognitive decline (National Institute on Aging, 2021b; The Alzheimer’s Association, 2021). When assessing for Lewy Body, a distinguishing factor is that the visuospatial cognition, the ability to see an object and identify it, describe it, and draw it accurately is damaged (National Institute on Aging, 2021b; The Alzheimer’s Association, 2021). Vascular dementia is triggered by damage to the blood vessels that carry oxygenated blood to the brain, such as from Cerebral Vascular Accidents (CVA) or stroke, vascular damage caused by mismanaged diabetes, or vascular damage from heart attacks (The National Institutes of Health, 2020). For example, if a patient with a history of a stroke or poorly managed diabetes has shown symptoms of cognitive decline, this may suggest a diagnosis of vascular dementia (The Alzheimer’s Association, 2021). Continued research efforts are being done to improve the accuracy and speed of diagnosis of dementia so that earlier treatment planning and recommendations can be established (The Alzheimer's Association, 2021).

Making appropriate, ethical decisions on care needs while still being aware of the loved one that they knew before this diagnosis often causes emotional distress (Oliveira et al., 2019; Webb & Dening, 2016). Care communities were created to improve the quality of life of aging or disabled adults while receiving the necessary care (Webb & Dening, 2016). In a case study on a family of caregivers of a loved one with dementia, Webb and Dening (2016) discovered that the family struggled to make decisions regarding proper care for the family member with dementia, the family member had difficulty allowing autonomy of the loved one with dementia, and they could not balance their own needs. The study concluded that familial caregivers need more support, and that treatment teams develop better ways to educate and connect families to the needed higher levels of care for their loved ones with dementia (Webb & Dening, 2016). Similarly, in a study examining family member caregivers of those with dementia, Oliveira et al. (2019) identified a gap in research on family member caregivers of loved ones with dementia and that further research is needed on care transitions. The family member caregiver's ability to balance self-care with providing the care needs to a loved one can be difficult to manage (Oliveira et al., 2019). An implication of this study may be additional resources for family member caregivers and the connection that can be made between their self-care and the right level of care for their loved one with dementia as the disease progresses (Oliveira et al., 2019).

Current support measures for familial caregivers are mostly centralized with The Alzheimer’s Association. Their website has information on dementia that they produce and sell in print, as well as their information hotline that is available 24 hours a day, seven days a week (The Alzheimer’s Association, 2018). The Alzheimer’s Association hotline has counselors that work to provide general information to family members and other callers about dementia (The Alzheimer’s Association, 2018). Funding for the Alzheimer’s Association and its resources are gathered from donations from the general public, government contracts for research and advocacy, and grant funding for the Alzheimer’s hotline (The Alzheimer’s Association, 2020). The majority of the funding is from government contracts, and while it has been well funded in the past, shortfalls can happen should funding be cut from the government or from the grants that are given (The Alzheimer’s Association, 2020). While the resources are meant for general purposes, the information does not offer a thorough education on dementia, the disease process, and the management of it (The Alzheimer’s Association, 2018).

There are also a limited number of smartphone applications created to help others read and learn about dementia (Alzheimer’s Association, 2018). In a recent study, Andrews et al. (2017) noted that participating family members were not aware that resources on the signs and symptoms of dementia existed prior to study participation. Andrews et al. (2017) also found that while some family members knew these resources existed, they did not realize how these resources could be applied to a loved one, nor how to navigate what the information was telling them. Knowledge of dementia was limited to understanding how it affected a person’s memory, but the study showed that family member caregivers did not realize what cognition was regarding dementia (Andrews et al., 2017). Many caregivers also described the experience of being the primary care provider as intense, which led to depression symptoms intensifying (Guerrero & Mendez-Luck, 2019). Despite having these feelings and noticing the decline of their mental wellbeing, the caregivers reported that they still felt obligated to provide care to their loved one with dementia. Because of this feeling of obligation, families reported not recognizing the need for a transition to a higher level of care (Andrews et al., 2017). Combined, this suggests gaps in health education and literacy for family member caregivers regarding what dementia is as a disease and navigating the resources that are available to them (Andrews et al., 2017; Goeman, et al., 2016; Morgan et al., 2014).

The U.S. Centers for Disease Control and Prevention (CDC) define health literacy as one's ability to obtain, process, and communicate basic health information and health services to make appropriate informed health decisions (U.S. Centers for Disease Control and Prevention, 2019). The health literacy rate for the United States is low at 12% of adults having an ability to understand basic health information (U.S. Centers for Disease Control and Prevention, 2019). The rate also shifts based on age; people aged 65- 75 having a health literacy rate of "below basic" at 23%, and those over the age of 75, are 30% below basic (U.S. Centers for Disease Control and Prevention, 2019).-The lack of health education resources for family member caregivers of a loved one with dementia shows a need to increase the number of health educators in the community to provide these resources (Brandao et al., 2016; Macleod et al., 2017; Zhao et al., 2016).

Problem Statement

The incidence rate of dementia is expected to continue to rise as the aging population, largely consisting of the “Baby Boomers” group, continues to grow (Lee et al., 2017). However, previous studies have shown that for family members, a lack of education and understanding of the disease, as well as access to sufficient resources led to late or insufficient use of higher levels of care (Andrews et al., 2017; Goeman et al., 2016). Andrews et al. (2017) and Goeman et al. (2016) also mentioned that there was a need to identify factors that promote and impede the willingness of family members of those with dementia in residential care facilities to transition to higher levels of care. The need for more education of caregivers, older adults, and current patients early in the dementia journey can help with awareness of the need for acceptance of the disease, as well as an understanding of the demands that come along with it as the disease progresses (Goeman et al., 2016). Increased health education can also help promote supports for family caregivers, ensuring that they utilize them properly. There are many care communities with residents that have dementia, and many family members move them there to have better care as they age (O’Shea et al., 2017). While many family members are aware that their loved ones have dementia-focused needs, they are not always aware of what the causes are for those needs, how to remedy them, or how to promote a good quality of life (Toye et al., 2014).

Current research gaps include the need for materials that address health literacy and can help family member caregivers navigate the education and supportive resources available to them (Goeman et al., 2016). Many care communities do not have a social worker, geriatric care manager, or health educator that exists to help with that education and understanding process, and there is little to no health education that is appropriate for those with lower health literacy (Goeman et al., 2016). Although there is a multitude of research that speaks to the available levels of care and dementia as a disease (Brandao et al., 2016; Macleod et al., 2017; O'Shea et al., 2017), there is little known about what promotes or impedes a family's decisions with regards to transitioning their loved ones with dementia into higher levels of care such as in-home caregiving, assisted living, nursing care and/or memory support care (Brandao et al., 2016). Additionally, little is known about barriers to transitions needed in metropolitan areas, where there is a multitude of service options (O'Shea et al. 2017).

In response to these gaps, this qualitative case study used the health belief model (HBM) framework and examined biopsychosocial, environmental, and socioeconomic factors that promote and impede the openness of family members to transition loved ones in care facilities with dementia to a higher level of care. A qualitative case study further examines what health education promotion efforts are needed to support this population to understand dementia better and understand all available options of higher levels of care for their loved ones with dementia (O'Shea et al., 2017). For care community staff in metropolitan areas, this information could them understand how to provide and adjust health education content to address family member concerns and barriers and ultimately, improve the quality of life of those living with dementia.

Purpose of the Study

The purpose of this qualitative case study backed by the HBM is to examine which health education promotion factors promote or impede the decision of family members to transition loved ones with dementia in care facilities to a higher level of care. The study explores what content is needed to include in the health education curriculum to improve the navigation of family caregiver decision-making and enhance the quality of life of family members with dementia. To address the gap in research, this study is a qualitative case study using the HBM and semi structured interviews, observation memos, and brief survey screenings to identify catalysts and barriers to dementia care and care transitions. There are six constructs of the HBM that offer guidelines for how researchers can apply it to various situations and studies (Creswell, 2017). These constructs are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Creswell, 2017). This study examined the family member caregivers and their perceived severity, barriers, and benefits to moving to a higher level of care for their loved one with dementia, specifically connecting them to the research study objectives. I also work with participants to understand the factors that promote and impede timely dementia care for their loved ones with dementia. The results of this study aids future health education and policy development that improves the quality of life of those with dementia and their family member caregivers.

Research Questions

RQ1 – Health Education: How do the family member caregivers describe what their needs are for health education to help with making informed decisions about higher levels of care for their loved one with dementia within their care communities in the DC metro area?

RQ2 – Perceived Barriers: How do the family member caregivers describe the barriers of pursuing a higher level of care for their loved one with dementia who live in a care community in the D.C. metro area?

RQ3 – Perceived Benefits: How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to the quality of life/care within their loved one's current care community in the D.C. metro area?

RQ4 – Perceived Severity: How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?

Theoretical Foundation

The theoretical framework is the health belief model (HBM). The end goal is to view a problem and identify the barriers and facilitators of the population studied (University of Southern California, 2019). The HBM was created in the 1950s by social researchers in a federal public health agency (Boston University School of Public Health, 2019) out of the need to understand why people were reluctant to adopt various disease prevention strategies, as well as what the beliefs were behind those understandings (Boston University School of Public Health, 2019). This theory was later applied to understanding why patients may have issues with complying to various chronic and acute medical condition treatments (Boston University School of Public Health, 2019). Overall, this model looks at the desire to avoid getting an illness or get-well once sick and the belief that a specific action taken by the patient can prevent or cure their ailment (Boston University School of Public Health, 2019). Using flu season as an example, the health belief model would examine how people feel about getting the flu shot or not, the number of people who get the flu with and without the shot, and how many of those people who get the flu seek out treatment (antibiotics, Tamiflu, etc.). This model is appropriate for this study because it examine the understanding/comprehension of resources for family member caregivers of the older adult with dementia and their care as the disease progresses. The HBM supports this study in understanding why some may utilize resources to care for their loved ones while others may not.

The HBM connects to the research study because the project examines the family member caregiver's understanding of why a recommended higher level of care is needed. The literature review in Chapter 2 dives into the gaps in the literature regarding the lack of information on the caregiver's understanding of the benefits of a higher level of care. Some literature explains the barriers to pursuing a higher level of care with the understanding that some of it involves a lack of health education on the resources that are available as options; however, this does help families who already live in care communities (Brandao et al., 2016). Chapter 2 includes a critical examination of the literature found for dementia and caregiving, a lack of health education resources for caregivers, and the HBM theoretical model, connecting it to other studies that utilize the model to understand others' perceived benefits, barriers, and severity of the diseases or conditions that they focus on.

Nature of the Study

The nature of the study is a qualitative instrumental explanatory case study using the HBM to understand what factors promote and impede the decision of familial caregivers of those with dementia in multiple residential care facilities in the D.C. metro area to transition to a higher level of care. The bounded case is the family member caregivers that are participants in the research study whose loved ones are in a care community in the D.C. metro area. The care communities in the D.C. metro area included in the area that I will sample participants from are senior independent living communities, assisted living communities (with and without dementia care units), nursing facilities (with and without dementia care units) and continuing care retirement communities (CCRCs). Family member caregivers will be recruited to participate in the study for their perspectives on this topic and to gain a deeper understanding. Staff members that are involved with the care, treatment, and overall quality of life will also interviewed at each facility to gain their perspective and understanding.

An explanatory case study is defined as how or why a certain condition came to be or how, or why a sequence of events did or did not happen (Yin, 2018). An instrumental case study focuses on a person, specific group, or organization to provide insight into a particular issue (Yin, 2018). The purpose of a qualitative approach is to answer open-ended questions without placing the inquiry within any specific theoretical, philosophical, or even ontological tradition (Ravitch & Carl, 2016). A qualitative case study is an intensive holistic research review and analysis for a single instance or bounded phenomenon such as a program, an institution a process, a person, or even a social unit (Merriam & Tisdell, 2009). A case study aims to understand the world of the research population by reviewing how they view dementia and the higher level of available care resources. For this study, I will actively work with the participants to understand a real problem within various communities.

Glanz and Bishop (2010) note the importance of theory in health education intervention development and research, noting that there must be a general foundation for the framework to support a research study. It also supports the study of caregiver educational needs to understand catalysts and barriers to dementia care decision-making, as well as how to better support this population as dementia caregivers (Ravitch & Carl, 2016).

I will contribute memos or notes taken during the interviews to ask questions about the data. To analyze data, constant comparative analysis will be conducted at multiple levels of coding (Ravitch & Carl, 2016). The data analysis coding process happens in three steps, open coding, axial coding, and selective coding (Ravitch & Carl, 2016). With open coding, the researcher works with participants to review transcripts of interviews and identify initial categories by conducting a constant comparative analysis; the researcher then writes memos of themes that emerge along the way (Ravitch & Carl, 2016). Axial coding is the next step and, in this process, codes and memos are used to show those categorical relationships and form the foundations for the theory that is being created (Ravitch & Carl, 2016). A logic diagram is created as the visual model to explain the process found through the interviews and fieldwork (Charmaz, 2006). The final step is selective coding, which consists of writing a story about how the theory explains the core process (Charmaz, 2006).

This study is an instrumental explanatory qualitative case study combined with the HBM that reviews what family member caregivers understand about dementia, along with the catalysts and barriers that impact their decisions to transition their loved ones to a higher level of care. The study will employ a sample of 10-12 adult family member caregiver participants from the Washington D.C. metro area (Taverner et al., 2016). In the bounded case, the family member caregivers of loved ones with dementia will undergo an initial phone screening to ensure that they meet the criteria to participate in the study. Those criteria are:

- That the family member caregivers have to have a loved one that is:
- At least 65 or older
- The loved one that they care for has to have been diagnosed with dementia. Not a traumatic brain injury (TBI), anoxic brain injury (ABI), or chronic traumatic encephalopathy (CTE)
- This is the family member caregiver's first experience of caring for a loved one with dementia.
- The loved one that they care for needs to be alive at the time that they participate in the interview.
- The loved one they care for with dementia needs to be currently living in a care community within the D.C. metropolitan area and has reached a point where they require a higher level of care than they are currently receiving.

Family member caregivers in the study will have loved ones with dementia in different care communities. Thus, the study is not limited to one care community in the D.C. metro area. The bounded case is the group of family member caregivers with the viewpoint of being caregivers who are facing barriers to transitioning them, that participate in this study.

With data collection, Yin (2018) states that for case studies, multiple forms of data collection are important to allow for triangulation. With triangulation, Yin states that letting the multiple avenues of data collected be analyzed for the appropriate presentation of the needs for future research and health education development (Yin, 2018). The interview protocol contains open-ended questions to be asked during the interviews and to assist with appropriate data collection (see appendix A). Semi-structured interviews will be conducted individually via video, which allows each participant to identify and explore important themes with me. Each interview will also be recorded via an audio recording device or video recording to ensure the accuracy of the interview and the details shared. Participants will also be sent interview transcripts to check for accuracy following their interviews. Constant comparative analysis will be used to analyze data from participants to identify factors that promote and impede timely dementia transitions to higher levels of care. NVivo 11 Pro software will be used to organize coding efforts.

A short survey questionnaire will be conducted with the family member caregivers prior to the interview to preview their current understanding of the topic of dementia as a disease and the caregiving resources available to them (see Appendix F). This provides additional data on multiple perspectives on what the barriers are to transitioning. Triangulation is critical to case study research as having multiple sources of evidence can provide a clearer picture of what the respective themes are (Yin, 2018). For the short survey results the information was organized on Microsoft excel to align the information as well.

This data will further support the understanding of what familial caregivers of dementia patients do or do not know and continue to further help in identifying the needs for health education and health promotion among this group. I will also wrote memos to make observations during the interviews that are conducted with the family member caregivers and ask questions about the data to assist with the data analysis process. When the interviews are conducted, I'll make note of observations of the family member caregivers concerning their body language, emotional responses during their anecdotes, and their interactions with me.

Definitions

The below terms are used in this study to help with developing a better understanding of the research project:

Dementia: A chronic disorder that is caused by brain disease marked by loss of memory, language skills, and word find, problem-solving (executive functioning), and visuospatial skills (National Institute on Aging, 2021b; The Alzheimer's Association, 2020). There are multiple types of dementia, but it is a category of diseases, like cancer, and then there is a specific type with differing symptom combinations (National Institute on Aging, 2021b; The Alzheimer's Association, 2020). Some of the more common types of dementia are Alzheimer's, Vascular, and Lewy Body (National Institute on Aging, 2021b; The Alzheimer's Association, 2020). The types of dementia that will be included as a diagnosis for the study are Alzheimer's, Lewy Body, Vascular and Unspecified or Other specified dementia, as these are the most prevalent diagnosis in the Washington D.C. metro area currently per the Alzheimer's Association (2021).

Family Member Caregiver. In the context of this study, is defined as a loved one who is an immediate (blood-related or non-blood related) family member, extended (blood-related or non-blood related) family member, or family friend who has been chosen to be the decision-maker and/or physical caregiver of a person who has been diagnosed with dementia. Those excluded include anyone who is established as a guardian by the state or local government such as, an Adult Protective Services worker, a law office or lawyer, or other entity that is not established as one of the accepted definitions of a family member caregiver.

Health education. Defined by Kent State University (2021) as any combination of biological, psychological, environmental, physical, and medical sciences to promote one's health and prevent disease (the development and/or spread) through education-driven learning experiences that help to change behaviors concerning health management.

Health literacy. Defined by the Centers for Disease Control and Prevention (2020) and the National Institute on Aging (2021a) as the skills that people are able to use to realize their potential threat level in various health situations and understanding health information that is provided for services.

Health belief model (HBM): A model that is used to predict the likelihood of why people are going to take action to detect, treat or prevent an illness (Glanz et al., 2015).

Positive social change: Defined by Walden University (2020) as a process of developing and utilizing ideas, plans, and actions to promote the dignity and positive growth of individuals, populations, institutions, cultural groups, and societies.

Care community: A place where someone goes for treatment of an illness (mental, physical or both) while they reside there, having assistance with their activities of daily living, medication management, and treatment for acute and chronic illnesses (AARP, 2019). The types of care communities included in this study are as follows: Continuing Care Retirement Community (CCRC), Assisted Living Facility (ALF), Assisted Living Facility with Memory Support Unit (ALF w/MSU), Nursing Home (NH), and a Nursing Home with a Memory Support Unit (NH w/MSU). The staff members at the care communities are defined as any staff member who provides a level of direct care (nursing, medical, nutrition and dietetics, care aides, life enrichment, and social work and social services) or in-direct care (housekeeping and environmental services, dining services, admission coordinator, and the maintenance and security department staff) to the residents of the care facility to ensure a positive quality of life and care.

Higher level(s) of care: Defined by Stanford University (2020) as an increase and frequency of a specific treatment, higher rate of monitoring and supervision, and/or a treatment setting that has more rigidity and structure.

Phenomenon: Merriam-Webster dictionary (2020) defines phenomenon as a fact or event of scientific or researchable interest susceptible to description and explanation, a rare or significant fact or event.

Assumptions

In a qualitative case study, assumptions to consider with this research project are as follows:

- The participants will answer all the interview questions honestly.
- The criteria set for inclusion will assure that everyone selected for the project will have had the same or a reasonably similar experience with the phenomenon being examined.
- The participants are doing this for the reasons of moving the study and research forward and not for other motives.

It's important that as the researcher, Iunderstand the reasons for these assumptions and the meaningfulness of the information. Being able to work with the participants and understanding these assumptions early on can help them understand the potential of someone who may be participating in hopes of getting something out of the process, such as a monetary gift or a service of some sort with their participation. This can also help to ensure from the beginning the process is understood and participants know what their participation will contribute to the overall goal.

Scope and Delimitations

The scope of the study focuses on a group of 10-12 family member caregivers of someone who has been diagnosed with dementia (anyone of the types) that is at least 65 years old and living in a care community in the Washington D.C. metropolitan area. With the bounded case being this group of 10-12 family member caregivers, the focus is on what their experiences are with decision making on care and care transition needs for their loved one with dementia. The case is the family member caregivers being interviewed with the context of their loved ones with dementia living in a care community needing to transition to a higher level of care and the family member caregiver's resistance to that transition. Other qualifiers for the family member caregivers are that the loved one with dementia being cared for must have advancing symptoms and be in need of a higher level of care to manage these symptoms for safety purposes and increased quality of life. The delimitations for this study exist due to several environmental factors that are currently happening. Due to the COVID-19 pandemic, participants and methods for participation have drastically changed and interviews were conducted virtually.

It is less common for someone to be diagnosed with early onset dementia and therefore, those who are diagnosed with dementia are often 65 years of age and older (The Centers for Disease Control and Prevention, 2020). For this study, the research focuses on why family member caregivers of a loved one with dementia struggle to implement a higher level of care within the care community that their loved one resides in. Zhao et al. (2016) found that most healthcare professionals have a hard time getting family members to follow through on care recommendations to move someone with dementia into a care community. This study will shed light on what the barriers are for families who already have their loved one in a care community but are resisting a transition to a higher level of care after the care community.

Excluded Approaches

Approaches that were excluded from the study were grounded theory, participatory action research, and a phenomenological study. A phenomenological study was eliminated as an option because this project does not examine the experiences as the perspectives from their experiences are reviewed; therefore, it was not deemed appropriate for this project (Ravitch & Carl, 2016). A Participatory Action Research (PAR) project examines a current real-world problem and uses the research information obtained to formulate a new process that can be implemented in real time as a solution (Ravitch & Carl, 2016). Morgan et al. (2014) utilized a PAR research model to create a usable model for the very real work problem of understanding dementia resources and establishing more to fill the gaps for those who live in rural communities. While this research looks at a real-world problem, it focuses on educating readers and helping them understand the participants' perspective. Further, it allows for healthcare professionals to develop health education material to help them better educate their patients, residents, and their families earlier on to prevent the barriers identified from happening. This is why a case study was utilized and not a PAR or a phenomenological study.

Grounded theory is used to help formulate new theories for future researchers to follow and utilize when developing a new theory (Charmaz, 2006). This research project does not develop a new theory but focuses on providing information that can help develop health education and health literacy materials for future families, older adults, care communities, their staff, and healthcare professionals. Therefore, this framework is also not appropriate for this research study.

The DECIDE model was an option that was also not selected due to it being more appropriate for healthcare professionals and healthcare case managers/coordinators who are helping patients and families with appropriate guidance for decision making (Guo, 2008). The DECIDE model is a model that focuses on helping the health care manager to improve their decision-making skills to be more effective when helping to guide their patients or clients in care management (Guo, 2008). There are six areas of focus in the decision-making process per this model and DECIDE is an acronym for what defines it (Guo, 2008). The acronym is Define, Establish, Consider, Identify, Develop and Evaluate (Guo, 2008). Define the problem is the first step, and the health care manager will decide what the problem is that needs a solution, often it will be person-centered and include what the patient feels that the problem is (Guo, 2008). Establish the criteria for what the problem is, to better understand what the solution options could be (Guo, 2008).

The HBM helps professionals with understanding why patients and/or caregivers make the decisions that they do regarding healthcare treatment and management options (Glanz et al., 2008). The HBM still is most effective for this research study as this is laying the groundwork to understand the why behind their decision making, this research project does not examine how to help change that but could help lead other healthcare professionals in the future to provide enough education and understanding on dementia care to then utilize the DECIDE model when making appropriate treatment plans with their care management teams (Guo, 2008).

This research project also contributes to future research and policies that are developed at an organizational, local, state, and federal level that focuses on dementia education, support, and care needs as well. A case study with the HBM as the framework is the most appropriate as the participating population is experiencing various barriers that stem from the same issue of being a caregiver of a loved one with dementia. The caregivers may have similar or different interpretations of that experience that can help educate others on how to help them as well as future families that may have a need for dementia care services. The information can also help adjust laws, policies, or funding to be redirected toward helping to better support these patients and families with their needs for future care and understanding of dementia.

Limitations

For this study, several limitations and challenges may apply. A limitation is that the participants' loved one must have a confirmed diagnosis of dementia from a geriatric professional (doctor, nurse practitioner, physician's assistant, mental health professional). A "suspicion" of dementia does not suffice. The professionals that work in the care communities are able to filter through those who have dementia, and those who do not have a diagnosis to pass along the study information to eligible participants. A second limitation is that the population of people with dementia is limited to those who are 65 and older and those who live in a care community, limiting the participation of those with dementia in general communities who are younger or who have early onset dementia. Another limitation is the bias from the researcher due to there being only one interviewer who created the interview protocol and analyzed the data. The researcher had a colleague review the research data gathered and the analysis and give their understanding to help prevent implicit bias from one researcher and to ensure appropriate data interpretation.

With qualitative research projects, especially qualitative case studies, having the researcher conduct the collection and analysis of the data gathered, the subjectivity of the researcher can affect the overall data interpretation (Bloomberg & Volpe, 2019). Knowing that this is a possible limitation of the study, the data analysis included several checks and balances such as the coding to be conducted, but also by NVivo, a qualitative data analysis coding software. Comparison and scrutinization of the results of both, advisors on the dissertation committee, and a fellow professional in the field both via peer review. To further reduce the limitation of bias, all the participant data were deidentified, and the interview transcripts coded blindly to prevent any connection of the data to any one participant (Bloomberg & Volpe, 2019). I have prior experience with conducting interviews on topics that may be sensitive and therefore considered the participant reactivity to reflect and revise what may be influencing the participants. Knowing this, I will also make a conscious effort to make the atmosphere for the interviews one that is comfortable for open and honest dialog because a researcher's presence can also influence the participants' responses (Bloomberg & Volpe, 2019). While this is unavoidable, the setting of the environment can help address that and allow for the participant to feel comfortable enough to share (Anderson, 2010; Bloomberg & Volpe, 2019).

The volume of data that comes from a qualitative research study can be time consuming and overwhelming at times for any researcher, making it possible for important data to slip through and not be included in the interpretation properly (Bloomberg & Volpe, 2019). In qualitative research studies, rigor can be more difficult to assess and demonstrate, as well as to maintain throughout the research project, but this can be checked by having professionals in the same field and the advisors on my committee to assess the rigor from start to finish (Bloomberg & Volpe, 2019; Stanford University, 2021).

A final limitation is that the person's cognitive decline cannot have been caused by a traumatic or anoxic brain injury, also excluding chronic traumatic encephalopathy (CTE). Traumatic brain injuries, anoxic brain injury and chronic traumatic encephalopathy (CTE) are not a form of dementia. While they exhibit similar symptoms and are often found to need caregiving similar to those with dementia, it is ruled out due to not being a type of dementia. A possible challenge might be recruiting willing family members to participate in the study; however, based on the literature, there have been many family members who have engaged in similar research for the development of better programming (Andrews et al., 2017; Brandao et al., 2016; Burke et al., 2014; Macleod et al., 2017). The COVID-19 pandemic is another challenge that affected recruiting and participation. To help, this research project was conducted over another interview approach, video interviews.

Significance of the Study

Significance to the Discipline

This research study will address potential gaps by researching and assessing the barriers, needs, and perceptions of transitional dementia care among family members, who are working with their loved one to meet care needs. The findings of this research study will contribute to the body of knowledge by helping to determine what factors come into play in family member decision-making and what can promote or impede those care planning decisions. Having this understanding can give providers in all disciplines that work with the geriatric community more information to start more community-focused outreach programs spearheaded by family caregivers themselves (Andrews et al., 2017). The research will help to formulate future applications that could help teach the general population about dementia, as well as the people who provide care, regardless of the capacity in which they do it. A participant focused framework will help future health education programs become more tailored and focused on building the knowledge of this disease among those who live in these care communities and those who are interested in moving into care facilities.

Significance to Practice

As a result of study data, other health education programs could be established in the future to train health educators and geriatric professionals on how to work more effectively with this population and their family members. This research could also give geriatric providers more guidance if they have patients and/or families who have concerns in adding care and transitioning loved ones. It may also help provide more advanced care plans and community supports, as well as improved policies on multiple levels (organizational, local, state, and national). This study examines those with dementia ages 65 and older and how public health practitioners can use the information provided by family members to address barriers, educate family caregivers of adults in the early stages of dementia, and give more information to geriatric providers. The earlier that families and providers become educated, the easier it can be to enhance the quality of life of those living with dementia (The Alzheimer's Foundation of America, 2018).

Significance to Social Change

Social change is an essential aspect of this research study and plays a significant role in what the study examines. Geriatric practitioners among all disciplines struggle to proactively support families with decision making since family members face various barriers when making care-related decisions for loved ones with dementia (Zhao et al., 2016). Because practitioners often do not understand the families' reasons for saying no, this study identifies a few of these reasons and allows practitioners to provide better support to their residents and families. This study can also help agencies and communities on all levels focus on improving and developing health literacy education resources for dementia, as well as policy development to better support residents with dementia and their family members. Religious institutions and retirement community chaplains can also work together to inform those within their respective groups to allow for information to be shared.

Having culturally and religiously competent health education promotion will be an essential aspect of facilitating more informed decision making for families of those with a loved one with dementia. Providing health education based tailored to specific needs will help practitioners take a step back and not apply a general "noncompliant" label when residents and families resist or do not follow all recommendations given (Zhao et al., 2016). This study promotes social change by helping clinicians and practitioners better understand the health literacy that is currently available, the education gaps and needs that exist, and how to empower family members to identify and solve pressing issues so that their loved ones with dementia can experience a better quality of life and more timely care.

Summary and Transition

Dementia is a disease that affects one's cognition over time, leaving them vulnerable and needing more care and supervision as it progresses (Alzheimer's Association, 2018). This means that many dementia patients will inevitably need a higher level of care, and their family members will need education on the disease and those levels of care, as well as help getting connected to those resources in their communities overall (Brandao et al., 2016). Families of loved ones with dementia in the Washington D.C. metropolitan area currently lack appropriate health education and have lower health literacy levels for this illness (Macleod et al., 2017; O'Shea et al., 2017). This research project identifies these needs, assesses the overall need for health education material, and provides a better understanding of the health literacy rates for family member caregivers about dementia (Lee et al., 2017; National Institutes of Aging, 2019b; The Alzheimer's Association, 2018).

Chapter 2 includes a literature review on dementia disease, the population that this study samples (family member caregivers), the theoretical framework (HBM), and the research method (case study). The literature search strategy will be examined and discussed, specifying databases and search terms used when completing the literature review. Chapter 2 also discusses the theoretical model that guides the framework of the study.

Chapter 2: Literature Review

Introduction

Dementia is considered a neurocognitive disease that affects one's cognition over time, causing a person to lose memory, recall skills, speech, word association and selection, and reasoning and judgment skills (National Institute of Aging, 2021b; The Alzheimer's Association, 2018). There are over 100 types of dementia and for most, the causes are unknown. A definitive diagnosis can also be difficult to obtain depending on how symptoms manifest (National Institute of Aging, 2021b; The Alzheimer's Association, 2019). The progression of disease can leave many people in need for more care, and families in need of health education curriculum to guide them on what those different levels are and how to use other available resources (Brandao et al., 2016). Yet, family members in the D.C. metropolitan (Washington D.C., Maryland, and northern Virginia) area who have loved ones with dementia ages 65 years old or older that are residing in a care community lack appropriate health education (Macleod et al., 2017; O'Shea et al., 2017). Current health education materials that exist for family members are the Alzheimer's Association website, which provides education on 10+ forms of dementia (Alzheimer's Dementia, Lewy Body Dementia, etc.) and hotline, a small number of electronic applications, and information on the National Institute of Aging (NIA) website (Lee et al., 2017; National Institute of Aging, 2021b; The Alzheimer's Association, 2018).

In a recent study, Andrews et al. (2017) noted that participating family members were not aware that resources on signs and symptoms of dementia existed prior to study participation, and they did not realize how these resources may apply to a loved one, nor how to navigate what the information meant. Because of this knowledge gap, families reported not recognizing the need for a transition (Andrews et al., 2017). The gaps in health education for family caregivers include a lack of health literacy of dementia as a disease and navigating the resources that are available to them (Andrews et al., 2017; Goeman et al., 2016; Morgan et al., 2014). The lack of health education navigation and lower health literacy rates for family member caregivers of a loved one with dementia demonstrates a need for an increase in health educators to be in the community to provide those resources to families and residents. The incidence rate of dementia is expected to continue to rise as the aging population continues to grow (Lee et al., 2017). The need for more education of caregivers, older adults, and current patients early in the dementia disease process can help with building the need for acceptance of the disease, as well as an understanding of the needs for care that come along with it as the disease progresses (Goeman et al., 2016).

Although there is a multitude of research that speaks to the available levels of care and dementia as a disease (Brandao et al., 2016; Macleod et al., 2017; O’Shea et al., 2017), there is little known about what promotes and/or impedes a family’s decisions with regards to transitioning their loved ones with dementia into higher levels of care (home and community-based care, assisted living, nursing care and/or memory support care or hospice; Brandao et al., 2016). Little is known about barriers to transitions needed in metropolitan areas where there is a multitude of service options (O’Shea et al. 2017). A qualitative explanatory case study is most appropriate to be paired with the health belief model for this research project. In this chapter, I will go over into the literature review and possible themes for the focus of the study, along with the search terms used to find the literature reviewed. A detailed discussion of the theoretical foundation (HBM), of qualitative research, and case study research will be explored further in this chapter.

Literature Search Strategy

The literature review was conducted by looking at articles from the last six years, with some older articles for historical reference. Primary and secondary sources came from the following electronic databases: MEDLINE, CINAHL, SAGE, EBSCO, PROQUEST, and PsycINFO. The keywords that were used to search in the electronic were *older adults, seniors, geriatric, elderly AND dementia, Alzheimer's AND family support, family resistance, caregiver resistance, caregivers, caregiver support* AND *higher levels of care, health education and promotion* AND *qualitative case study,* and *qualitative research, case study,* AND *health belief model*. The research was conducted initially using information from 2010-2013 but was quickly outdated by more recent information found in the above databases, and the research and scholarly articles found and used were between the years of 2015- 2021.

Initially, the research process started with only a few of the above keywords. However, additional search terms were found and utilized after reading the peer-reviewed articles, which greatly expanded the peer-reviewed articles available. The abstracts were reviewed for each article, as well as the discussion and conclusion sections and the research that was applicable was reviewed and annotated. There were non-scholarly journal sources used to obtain history on the subject, as well as relevant information to use for this study. Those sources were National Institute of Aging, National Institute of Health, The Alzheimer’s Association, and the Centers for Disease Control and Prevention. During this literature and research review, a gap was found in understanding what the family member caregivers knew about the disease and there was a gap in understanding what respite and care resources were available for their loved ones with dementia.

The selected articles relating to struggles from family members in adding higher levels of care for their loved ones with dementia are described here, as well as supporting articles for the research design. Macleod et al. (2017) and Brandao et al. (2016) provided an understanding of resistance from caregivers or preventions in transitioning to higher levels of care from families not living in care facilities and communities. They also examined the lack of use for resources that provide respite assistance to caregivers. Storti et al. (2016) provided an understanding of the qualitative methodology and data collection with the use of interviews of the family caregivers of those with dementia. Goeman et al. (2016) discussed the support needed for someone with dementia as well as the support needed for their caregivers.

The next group of articles discuss the health belief model and how it applies to the model being used with loved ones making decisions for others with a medical condition, to include dementia. Taverner et al. (2016) gave a deeper understanding of the use of the HBM overall and examples of how it will be used as the base model for understanding the responses loved ones may have with regard to getting more help or care resources to be put into place. Toye et al. (2014), Andrews et al. (2017), and Burke et al. (2014) identified the process of decision making by the family members for those with dementia.

Theoretical Foundation

HBM is a model that was developed in the early 1950s to understand the reasons that people did not want to adopt established disease prevention methods or screenings to help with early detection and treatment (Coreil, 2010; Glanz et al., 2015; Janz et al., 2002). Recently, researchers have used the HBM to examine patients' responses to compliance with medical treatments and/or chronic illness management (Coreil, 2010). There are two foundational concepts that are important to this model. First, does the person have a desire to avoid the illness that is being focused on? Second, if there is a belief that a health action will end up preventing or curing an illness (Coreil, 2010). This model focuses on the experiences, cultural beliefs or attitudes of individuals that is based on understanding that a person will seek health related help but only if they feel that the treatment will alleviate the symptoms (Glanz et al., 2015).

Public health researchers utilize this model to study people's motivations (or lack thereof) regarding seeking treatment and/or preventative services for a disease or disorder (Glanz et al., 2015). There are six levels of the beliefs associated with HBM: perceived barriers, perceived benefits, perceived susceptibility, perceived severity, cues to action, and self-efficacy (Glanz et al., 2015). Perceived susceptibility is an overall belief about getting a disease or disorder, and a perceived barrier is the belief about the potential negative aspect of a health action (Glanz et al. 2015). Perceived severity is the belief about the seriousness of a specific disease or disorder and the consequences of leaving it untreated, and perceived benefits are beliefs about the potential positive rewards of a health action/response (Glanz et al., 2015). Cues to action are the overall factors that lead someone to have an action (either positive or negative), and self-efficacy is the belief that one can achieve the needed behavior or action to get to the outcome (Glanz et al., 2015).

The literature states that help-seeking behaviors are associated with the perceived idea of their disease causation. That is, if they do not feel that the cause of the disease matches what healthcare providers are saying, the patient will not seek help (Chilale et al., 2017). Health beliefs influence health behaviors, and how the person decides to get help and the amount/extent of said help (outpatient, urgent care, or emergency care) (Chilale et al., 2017).

The HBM has been used in several studies focused on caregivers making decisions on behalf of a loved one, which influenced the decision to use this as the framework for this study. In a study published in December 2020, researchers reviewed how a caregiver's decision changed based on the COVID-19 pandemic, and how they managed their child's dental health appointments (Setiawan & Zubaedah, 2020). The study demonstrated that the HBM is applicable to understanding caregiver's decisions in keeping or postponing dental visits (Setiawan & Zubaedah, 2020). This connects to the study as it shows the use of the HBM to understand how a family member caregiver's knowledge or lack thereof changed the behavior toward the health management of the loved on that they were caring for. In another study, the HBM was used to assess caregiver's decision making around their children getting the vaccine for the human papillomavirus (HPV; Barboza & Dominguez, 2016). Using the HBM, the researchers were able to understand what choices were made and how the caregivers came to those conclusions, which allowed them to emphasize new health education and health communication needs that this population had (Barboza & Dominguez, 2016). This study made connections to decision making with regard to preventative care needs for their loved one and allowed for the emphasis on the need for new health education material and health communication material.

Finally, a study was done on caregivers regarding understanding and knowledge about surfaces that are unsafe for infants to sleep and how that could lead to death and focused on what the needs were for health education among soon-to-be and new parents for the prevention of death and increased mortality rates (Chu et al., 2015). Again, the HBM was used to help determine understanding the knowledge and practices that the parents had with regard to unsafe sleep surfaces and their beliefs on what they should and should not do (Chu et al., 2015). This study connects to this research study because it examines via the HBM, what the family member caregivers understood about the health issue and how that health issue can lead to death and higher mortality rates, as well as establishing where changes in health education for this issue is needed and why. Similarly, in this study, the researcher explores the knowledge that the family member caregivers have on dementia and the care transition needs for their loved ones, the decisions made not to transition to the higher level of care, and why and identify where the health education and health communication is needed within this population.

The HBM is a widely used model for various studies as it provides practitioners, clinicians, and public health officials a view on population health with regard to any recurring themes among their patients, or residents in a group that appear to be affected highly by a disease (Glanz et al., 2015). Sripad et al. (2019) utilized the HBM to view perceptions of pre-eclampsia and eclampsia among women in Nigeria. The study showed that those women who were older and/or married had more access to counseling for these health risks and were able to act on them early on. In contrast, those who were younger and/or single only had their family history experiences to go off of and did not always engage in health counseling as often to prevent this from happening or from understanding the symptoms in advance (Sripad et al., 2019). Similarly, this research study observes the perceptions of family member caregivers and the decision not to transition them to higher levels of care and gain a deeper understanding of why, as well as the needs for more health communication and health education.

Literature Review

Dementia

Dementia is a disease that causes a gradual deterioration of one's cognition, leading to memory loss, language skill deterioration, judgement deficits, confusion and disorientation, wandering behaviors, and verbally and physically aggressive behaviors (National Institute on Aging, 2021b; The Alzheimer's Association, 2021). There are many types of dementia, the most common ones being Alzheimer's, Vascular, Lewy Body, Huntington's, and Frontotemporal Dementia (National Institute on Aging, 2021b; The Alzheimer's Association, 2021). Dementia, and complications from it, account for one out of every three deaths among older adults aged 65 and up in the US (Lee et al., 2017). Alzheimer's is the most common form of dementia and as it progresses, causes memory loss, executive motor functioning, aphasia, difficulty in concentration, aggression, and possible wandering or elopement (National Institute on Aging, 2021b; Mayo Clinic, 2021a). Vascular dementia is caused by brain damage from impaired blood flow to the brain, often triggered by a stroke, poor circulation from damaged blood vessels (National Institute on Aging 2021; Mayo Clinic, 2021b). The damage to the blood vessels can come from a stroke, diabetes, and various cardiac illnesses (National Institute on Aging, 2021; Mayo Clinic, 2021a).

Lewy Body Dementia is the second most common form of dementia in the United States (National Institute on Aging, 2021b; Mayo Clinic, 2021b; The Alzheimer's Association, 2021). This form of dementia involves protein deposits (Lewy Bodies) developing in neurons and these negatively affect the regions of the brain that control thinking, memory, and gross motor control (National Institute on Aging, 2021b; Mayo Clinic, 2021b; The Alzheimer's Association, 2021). Frontotemporal dementia predominantly affects the frontal and temporal lobe functioning of the brain, which manage language, personality, and behavior (National Institute on Aging, 2021b; Mayo Clinic, 2021b; The Alzheimer's Association, 2021). As this form of dementia progresses, the frontal and temporal lobes of the brain shrink, causing dramatic personality changes, be inappropriate in social situations, impulsivity and possibly lose the ability to use language and speech functions (Mayo Clinic, 2021a). Huntington's disease often develops in someone's 30s and 40s and is a rare disease that causes a progressive breakdown of neurons in the brain (Mayo Clinic, 2021b; The Alzheimer's Association, 2021). This can affect a person's ability to control their movement, negatively affects their cognition, and depressive symptoms with their mood (Mayo Clinic, 2021a).

Several diseases often can have similar symptoms of dementia but are not classified as a neurocognitive disorder. The diagnoses that can have similar symptoms are traumatic brain injury, anoxic brain injury, and chronic traumatic encephalopathy (Mayo Clinic, 2021c; The Alzheimer's Association, 2021; The Shepherd Center, 2021). Chronic traumatic encephalopathy (CTE) is a progressive and fatal brain disease much like dementia is and is caused by repeated brain injuries and can be a cause of dementia, but is not dementia (Alzheimer's Association, 2021). A traumatic brain injury is an injury that happens due to blunt force striking the head and causing damage to the brain; this can be mild, moderate or severe (Mayo Clinic, 2021c). An anoxic brain injury, also known as a hypoxic brain injury, are caused by a lack of oxygen to the brain (Mayo Clinic, 2021c; The Shepherd Center, 2021). After four minutes without oxygen, the neurons in the brain begin to die and that is when the damage risks becoming permanent (Mayo Clinic, 2021c; The Shepherd Center, 2021). The person's recovery depends on how long the brain is deprived of oxygen, and whether there will be mild, moderate or severe impairment (Mayo Clinic, 2021c; The Shepherd Center, 2021).

Past and Current Treatments and Services

For dementia treatment, there are several options for treatment to manage symptoms and behaviors, but there is no cure (Szabo et al., 2018). There are several treatments used that are medication management that can be used at different stages of the disease to manage different behaviors; however, these are generally used with in person cognitive stimulation related activities and programs (Brandao et al., 2016). Cholinesterase inhibitors are a medication that works to boost levels of acetylcholine which is involved in memory and judgement (Brandao et al., 2016). Medications such as Aricept (donepezil), Exelon (rivastigmine), and Razadyne (galantamine) are used in the early stages to prevent poor judgement and to improve memory retention and cognitive function (Brandao et al., 2016).

Memantine (Namenda) is a medication that works by regulating the activity and use of glutamate, a neurotransmitter involved in how the brain learns and creates memory (Alzheimer’s Association, 2020). Memantine and cholinesterase inhibitors are prescribed together to help overall results with cognitive management (Alzheimer’s Association 2020). Psychiatric medications are also used in the treatment of dementia and mostly function to manage the behaviors that come with the advancement of the disease (Mayo Clinic, 2021b). Often, treatment teams try to work on non-medicinal treatment methods before adding medications because it can be a hazard for people with dementia if they forget they have already taken their medication (Brandao et al., 2016). With Cognitive Communication Therapy (CCT) that is done by speech and language pathologists, this along with memory centers in adult day programs that help to prevent agitation, wandering, and aggressive behaviors (Lach et al., 2017).

Nondrug approaches to managing symptoms and behaviors associated with dementia exist to help with managing different symptoms at different stages. However, these are alternatives to medication and can be effective in the early stages of the disease whereas they can become limited in their scope of effectiveness as the disease progresses;

(The Alzheimer's Association, 2021; Mayo Clinic, 2021b). Rehabilitation has a large role of improving and providing cognitive stimulation, specifically occupational therapy and speech and language pathology (Pimouguet et al., 2017; The Alzheimer's Association, 2021; Mayo Clinic, 2021b). Occupational therapists can help to make the home safer, identify the fine motor skills that may need assistance, and determine what level of care is appropriate to help with those at that time (Lach et al., 2017; Pimouguet, 2017). Speech and Language Pathologists work on swallowing skills and motor skills related to eating, which are important to all dementias but especially Parkinson's dementia (Lach et al., 2017). The importance of people with dementia participating in rehabilitation efforts is underappreciated. The goal is to keep them moving and prevent physical deterioration as well as they age; this helps to slow the progression of the disease or prevent how much it affects them and their independence (Lach et al., 2017).

For those with dementia, speech and language pathologists can also do a treatment known as cognitive communication therapy (CCT) or cognitive speech therapy (Arahata et al., 2017). This therapy focuses on eating habits and ability to eat and drink during cognitive loss and deficits. It also allows the patient and their family caregivers to modify their environment for safety (Arahata et al., 2017). An example is to evaluate and treat the eating abilities and then order the patient to have nectar thickened liquids for safety with swallowing drinks and with altering foods to maintain nutrition and overall health needs (Arahata et al., 2017). Speech and Language Pathologists are also able to complete cognitive assessments such as the Montreal Cognitive Assessment (MoCA), allowing them to help with assessing their abilities to consent to treatment and care, helping primary providers understand cognitive abilities and needs for swallowing treatment and care (Arahata et al., 2017).

While diet and exercise may improve the health, management, and cognitive abilities of dementia for a multitude of reasons, they are not cures (CITE). Many experts believe that eating a Mediterranean diet has a positive effect on cognition and memory (Mayo Clinic, 2021b; National Institute on Aging, 2021). However, research has not strongly linked this diet to prevention or slower progression of dementia once symptoms begin to show (Mayo Clinic, 2021; National Institute on Aging, 2021b). This diet plan is also heart healthy, which is suggestive of the correlation between health heart and vascular systems and how it can affect the brain and cognitive health as well (Mayo Clinic, 2021b; National Institute on Aging, 2021b). Vascular dementia is one of the most common forms of dementia and is triggered by poor vascular function and poor heart health (heart failure, vascular disease, hypertension, etc.). Thus, having a prescription diet that promotes a healthy heart may promote better overall health and prevent getting dementia (Mayo Clinic, 2021b; National Institute on Aging, 2021b). Holistic approaches include aromatherapy and reflexology to help with managing symptoms (CITE). Aromatherapy can help with relaxing someone who is aggressive, which is often a symptom of dementia patients when they are agitated or having an episode. Occupational therapy can provide training and help with working on the treatment plan to build of fine motor skills and some gross motor skills (Pimouguet, 2017; The American Occupational Therapy Association, 2021).

Health Education in Dementia

Health education in dementia currently consists of online resources such as the Alzheimer's Association website, reading material created by the National Institute on Aging (NIA), and National Institutes of Health (NIH). Often, care communities do not always have the resources to keep a staff member dedicated to the health education of residents and family members (Paque et al., 2018). The Alzheimer's Association (2018) works with communities, annually, to give presentations to members on dementia, however there is no reinforcement or follow-up on the information given after the presentation. Families who have loved ones with dementia do not understand the disease and therefore often do not understand the resources out there to help provide care as the disease progresses (Macleod et al., 2017). The different dementias can often show deficits in different areas of cognition and can progress differently for each person. This further impedes the ability of loved ones to identify the cause of abnormal behaviors on their own without any real understanding of the amount of care and supervision that is being taken on. As previously stated, current health education materials are the Alzheimer's Association website and the association's hotline, a limited number of mobile device applications, and information on the National Institutes of Aging website (Lee et al., 2017; National Institutes of Aging, 2021b; The Alzheimer's Association, 2018).

The practitioners that can provide appropriate dementia health education are also limited in those numbers of people in the US. The professions that can give health education on dementia are physicians, nurse practitioners, physician's assistants, geriatric nurses, geriatric social workers, geriatric case managers, mental health professionals that work in geriatrics, health educators, and nursing home administrators. However, the numbers of people in those professions in geriatrics are not enough to support the number of older adults. The American Geriatrics Society shows that there will be a 45% increase of need for geriatric providers (American Geriatrics Society, 2021).

In 2018, there were 49.2 million older adults but there were 6,796 certified geriatricians of which only 3,590 that were actively practicing full-time (American Geriatrics Society, 2021). The US Bureau of Labor Statistics showed that in 2020, there were over 700,000 jobs available for geriatric social workers and geriatric case managers, with a possible 13% predicted increase over the next 10 years (US Bureau of Labor Statistics, 2021). Due to there being a low number of practitioners and health educators for this population, families may have limited support with understanding this disease and its associated care needs. This leads to family members that fall through the cracks with care and are left to find their own methods of care coordination (Macleod et al., 2017). Care coordination and health education plays an important role in helping families with navigating the services and resources in the community that they can get to for their loved one with dementia.

Level of Care

Level of care is a term that refers to a specific amount of care given to one person by an informal (nonprofessional) or formal (professional) caregiver for physical, emotional, psychological, and/or cognitive needs (Brandao et al., 2016). With dementia care, the caregiving starts from the day of diagnosis and sometimes before if the diagnosis is delayed (Brandao et al., 2016, The Alzheimer's Association, 2020). There are several levels of care that those with dementia can access with many of them being underutilized for various reasons (Brandao et al., 2016). The first level of care is home and community-based care which consists of home care and adult day programs. Home care is defined as care provided by another person in one's personal home and can include companion care, home making and personal care (i.e. grooming, bathing, dressing and, medication reminders) (Macleod et al., 2017). Companion care helps to provide supervision for those who have cognitive decline and can also provide emotional support for those who are lonely, as this is a time where depression can set in for older adults (Brandao et al., 2016).

Home making or home caregiving is a service that can be utilized to help with providing supervision, and assistance with household chores, such as laundry, housekeeping, changing of linens in the bathroom and bedroom, and meal preparation (O'Shea et al., 2017). This option allows for the loved one with dementia to still have some level of autonomy as well as continue to live in their own home while receiving assistance. Often, the loved one with dementia has a hard time accepting this option because if they are not always aware of their diagnosis, they believe they do not need help and this response can agitate them more (O'Shea et al., 2017). Home caregiving can be the most palatable option than placement in a facility but it can be a very expensive option as the amount of help needed or the type of help needed becomes more complex (O'Shea et al., 2017). Adult men typically have a hard time accepting the help due to wanting to maintain their independence and ability to provide (O'Shea et al., 2017).

Adult day programs are another community-based option that allow for adults with cognitive decline, dementia, intellectual or developmental disability or a serious mental health diagnosis to have supervision and interaction that is stimulating to their specific needs. Adult day programs come in two forms, medical management and social management (Marquez-Gonzalez et al., 2014). The adult day programs allow for cognitive and psychological stimulation that can come with having interactions with others, the prevention of isolation, and safety for those with cognitive decline while giving the caregivers regular respite for part or most of the day (Marquez-Gonzalez et al., 2014). The adult day medical management programs are the same as the social programs with the exception that there is not medication or nurse oversight in the social day programs. Adult day programs offer evidence-based ways to stimulate cognition and social skills for those with neurocognitive disorders (dementia, traumatic and anoxic brain injuries, etc.) (Marquez-Gonzalez et al., 2014).

The next level of care is assisted living, and there are two types: with memory care or without a memory care unit. This is a level of care that allows for autonomy but has services such as medication management, overall supervision via nurse oversight and certified nursing assistants (for health and cognitive needs), minimal assistance with activities of daily living, and promotion of social interaction. This level of care is good when there is a need for more assistance and a more stimulating environment. Often, clients see home care as a form of babysitting, and this can feel degrading after so many years of being independent; hence the resistance (O’Shea et al., 2017). Assisted living is also an option utilized by families when it makes more financial sense to pay for the move into an assisted living and have the care incorporated into the lifestyle on a constant 24 hours a day, 7 day a week basis. In 2019, home care costs the average rate of $26 per hour, coming out to be about $18,000 per month plus cost of living (Senior Living, 2020).

According to Senior Living, (2020), the average assisted living facility costs are $4,300-$6,000 per month for Virginia and D.C., and the average cost for assisted living memory care is $5,824 per month. With assisted living, the cost includes all meals, the cost of the care, the programs, the socialization, and living expenses. After assisted living, the client would transition to long-term care in a nursing center; this can have memory care unit or be without one. The determination for whether the client should be placed within the memory unit or not depends on two major things: their ability to participate in the facility's programming and socialization and if they are likely to explore their environment unsupervised, also known as "wandering" (O'Shea et al., 2017).

This level of care involves total assistance with activities of daily living and need more or all help with bathing, dressing, grooming, eating, and transportation to and from places both short and long distances (O'Shea et al., 2017). Nursing centers, formerly known as nursing homes, have a negative history of being undesirable places where older adults are abused, neglected, and become senile (Paque et al., 2018). While there is a history of negative treatment, today's nursing centers are regulated and surveyed annually to ensure that proper care is being given to the residents that are there (Paque et al., 2018). With those regulations, assisted living facilities care have improved and are more likely to incorporate evidence-based care to allow for patients to have improved quality of life and better managed health (Paque et al., 2018). Care plans (also known as treatment plans) are now geared more toward being person-centered, taking all areas of life into consideration; physical, mental, emotional, life enrichment, social, and medical (Paque et al., 2018).

For dementia care, care plans are specifically written to ensure that there is the right level of involvement by staff and family members, that there is enough care, what that specific amount and duration of care is, and the right providers are in place and focuses on being person-centered (Paque et al., 2018). Family is involved in care planning as they want or is appropriate and contribute to the social history of the resident as well as new behavior management (Macleod et al., 2017). Dementia care plans can happen at all levels of care to include home care, adult day centers, assisted living facilities, nursing facilities and, palliative care & hospice (Paque et al., 2018). Those care plans are created from appropriate evidence-based treatment and based in the whole person and not just their diagnosis (Paque et al., 2018). When developing a care plan for a loved one with dementia, the treatment team will usually consist of the medical professionals (doctors and nurses), the rehab team (PT/OT/SLP), a case manager or social worker, and nursing assistants (Paque et al., 2018).

The final level of care is hospice, which means the patient is at an end-of-life stage for which the client is either actively dying or has a terminal diagnosis that would possibly require symptom management and/or pain management (Glass, 2016). Support services are given to the patient and their family in the form of a hospice trained social worker, nurse, chaplain, volunteers, and a bereavement counselor for support after the loved one is gone; allowing them to receive the needed support while they are in their final stages of life (Glass, 2016). Dementia is a diagnosis that in its advanced stages would allow for one to qualify for hospice and get education and support (Glass, 2016). The Centers for Medicare and Medicaid Services (2018) state that hospice services are covered by insurance and that the teams providing them need to be comprehensive to provide those services.

The difference between palliative medicine and hospice is often misunderstood (Glass, 2016). Palliative care or medicine supports the treatments that are already being given for a chronic illness so that the patient can continue to be comfortable and thrive (Glass, 2016). Palliative medicine is also critical in pain management for those who have chronic pain. It can offer multiple ways to help with pain while managing to prevent abuse of pain medication and ensure safety while on various treatments; palliative care for pain management is an important part of the treatment for those with dementia as they progress through the disease process (Glass, 2016).

Hospice care on the other hand, focuses on noncurative treatments and pain management and does not look to support symptom management while receiving curative treatments (Glass, 2016). For people with dementia, the earlier stages will be where they receive palliative and the end stage is where hospice will come in to help with lessening agitation, help with behavior management and help with pain needs as well (Glass, 2016). The family members are also given support by offering information on hospice, a social worker to help with end-of-life planning needs, and funeral planning as well, and then counseling services are offered often up to a year after the loved one with dementia has died (Glass, 2016). Hospice care is also generally a support program that can extend services past the end of life of the patient, which can often help with managing caregiver stress during hospice and after the loved one has passed.

Qualitative Research on dementia and caregivers

Qualitative research is a type of research that involves studying the narrative experiences of others instead of looking at the numbers overall of a population or a group collectively and interpreting that (Glanz et al., 2015). Murray & Butow (2016) reviewed what it was like for caregivers to complete advance care planning when they care for someone with a motor neuron disease. The main focus was on their ability to accept advance care planning and what that impact would be on them and their loved one who had the motor neuron disease (Murray et al., 2016). They found that they would be open to having the advance care planning and that it is helpful to give the patient and family a sense of control over the future, but that this needed to be presented sensitively and early on in the diagnosis (Murray et al., 2016).

In 2020, a qualitative study was conducted on Hepatitis C. Sherbuk et al., (2020), utilized the Health Belief Model to conduct a qualitative research study on what the barriers were for patients with Hepatitis C for their appointments. The researchers utilized semi-structured interviews with a group of 11 patients (7 men and 4 women) to understand their views surrounding their inconsistency with their follow up appointment and care plan needs (Sherbuk et al., 2020). This research connects to the study by showing the use of the HBM and semi-structured interviews to show what barriers existed for the consistency in the recommended healthcare treatment recommendations, similar to this research topic of identifying the barriers to transitioning to a higher level of care when that is the recommended treatment plan. Qualitative research with use of the HBM for other health issues helps to strengthen the established use of qualitative research and the Health Belief Model (HBM) with this current proposed study.

A case study is a record of research that shows the development and changes over a period of time of a person, a group or population or a situation (Glanz et al., 2016). Case studies can be utilized in qualitative, quantitative, and mixed method research studies as they move fluidly between either due to how the studies are designed (Glanz et al., 2016). Hoedemakers et al. (2018) did a case study looking at integrated care programs for the older adults who have high care needs. The review looked at the baseline at the beginning of the study, at 6 months, and at 12 months into the study to see what program was viewed as the most valuable and comprehensive for the older adults who needed care in their homes (Hoedemakers et al., 2018). This study concluded that the older adult population wanted to have their own autonomy and enjoy life as the focus for the needed support of integrated care in independent living settings, and how the family member caregivers make decisions that incorporate that more often (Hoedemakers et al., 2018). The research study described here assesses the barriers and reasons that family member caregivers chose not to transition their loved one with dementia to the recommended higher level of care.

Webb & Dening (2016), did a case study following one family who was caregiving for a loved one with dementia. The caregiver was taking care of his father who has dementia so that his father could stay in his home. However, despite feeling he is safe enough to stay there, the stress this caused to himself and his family had brought about tension (Webb & Dening, 2016). The case study that followed this family showed that family member caregivers of those with dementia need more support to be able to safely care for their loved one; this will prevent the hard decisions ethically that need to be made by themselves (Webb & Dening, 2016). By following one family, this case study identified the problem, connected it to a societal problem, and then dive into the issues/themes that arise with this problem and at the end, revealed the needs for positive social change for this problem (Webb & Dening, 2016).

Qualitative studies have also been conducted on caregiver burden and what those specific situations for caregivers of loved ones with dementia are. Caregiver burden is a term that is utilized for any person providing caregiving services that are a family member or loved one who has reached a point of which most the care and safety procedures falls on them, which can be a hard load to carry (Thomas et al., 2019). Most caregivers experience psychological and emotional distress, and physical health issues depending on the level of and type of care that they are providing others (Thomas et al., 2019). Dementia is one of the most emotionally and financially draining diseases in the US currently, because of the progressive nature of the disease for the person with the diagnosis (Thomas et al., 2019).

Another study looked at a group of women and their experiences around caring for their husbands with prostate cancer which identified several themes (O’Brien & Steele, 2017). This case study was a qualitative research study and they utilized open ended interviews to help with capturing their specific stories, feelings around the topic (O’Brien & Steele, 2017). Women who were older, married for longer, and educated felt less burdened by the caregiving tasks that were needed, but those who may not have been together as long or were younger had higher levels of stress (O’Brien & Steele, 2017). Caregiver burden is a theme that is present in many research studies for both dementia and other diseases (CITE).

Summary and Conclusions

In summary, chapter two main reviews the literature surrounding the research project, to justify the need for the research project via the gaps being identified and to understand the themes that have been found to help with understanding what will be focused on with the research project. This chapter explained dementia as a disease, its progression and the health literacy issues that exist among this population and their caregivers. Understanding dementia, it’s past and current treatments or services, health education in dementia, and the varying levels of care are important for the reader to understand the overall study and the goals of said study. This chapter also discussed the Health Belief Model (HBM) as the theoretical framework for the research project. This selected framework is the most appropriate for the study overall and will give a good foundation when the study is conducted.

Chapter 3: Research Method

Introduction

Chapter 2 discussed the literature that supports the need for the research, the gap in the literature and the current understandings of the topic that exist now. Chapter 3 describes the research method that is used, frameworks that do and do not apply, an explanation of the selected research method, the ethical framework with the project and IRB and other areas of the research aspect for the project. The rate of newly diagnosed dementia is expected to continue to rise as the aging population continues to grow (Lee et al., 2017). Previous studies have shown that for family members, there is a lack of education and understanding of the disease process (Andrews et al., 2017; Goeman et al., 2016). Additionally, this lack of access to sufficient resources can lead to late or insufficient uses of higher levels of care. The research also mentioned that there was a need to identify factors allowing and stopping the willingness of family members of those with dementia in residential care facilities to transition to higher levels of care (Andrews et al., 2017; Goeman et al., 2016). There is a clearly identified need for more education of caregivers and older adults, for acceptance of the disease, and an understanding of the demands and ongoing education that come along with it as the disease progresses through the stages (Goeman et al., 2016).

The population of this study was recruited from several local care communities (four within the DC metro area), and recruitment ceased once enough interviews were conducted. If enough participants were not able to be sampled at these initial facilities, then other facilities within the DC metro area were reached out to. I sent them a recruitment email and flier (see appendices H and I) alerting them to the research study and what is hoped to be gained from their help with recruiting family member caregivers and staff from their community. This process continued until enough research participants were interviewed to saturate the data and show a recurrence of themes through data analysis.

The selected participants received an email that explained the information on the study and the goal of the study that they participated in. The email alerted them that it is voluntary, and that at any point, they can leave the study should they choose. My contact information was included in the email to them so that they could follow up with me if they needed more information. In that email, a short survey questionnaire was provided to collect the first form of data from the participants. Data were collected until 10-12 participants were interviewed. All interviews were held in a neutral location that was not the care community in which their loved one lives. Each interview was approximately 1 hour long, and participants were informed verbally during the phone call for scheduling, in the email that contains the informed consent, and on the day of the interview. The interviews were recorded using Zoom and saved onto a secure drive and the computer, both of which were password protected. The drive was locked in a drawer with the written documentation, observation memos, and documents pertaining to the study (informed consent forms signed, survey questionnaires, validity feedback from the three experts, etc.).

The purpose of this explanatory case study structured around the HBM is to examine what health education promotion factors exist that promote and impede the decision of family member caregivers to transition loved ones with dementia already in geriatric care facilities (such as assisted living facilities and nursing centers) to a higher level of care. Geriatric care facilities are communities that offer round-the-clock care to older adults who need assistance with their daily living skills and help manage medical, psychological, and social needs. This study explores what additional content is needed to include in the health education curriculum to promote family caregiver decision-making and enhance the quality of life of family members with dementia and ease the burden of care on family member caregivers. To address the gap in research, the study is a qualitative case study via semi-structured interviews, brief surveys, and observation memo notes to identify catalysts and barriers to dementia care and transitions. I also worked with participants to identify the factors that promote or impede timely dementia care and develop an action plan with participants to address the needs identified during the study. The results of this study will aid future health education and policy development that improve the quality of life of those with dementia.

This chapter includes the methodology that was used to acquire an understanding of what barriers family member caregivers face to get their loved one with dementia in a care community/facility a higher level of care. Throughout this chapter, the methodology topics that will be discussed are participant selection, instrumentation chosen, methods used for recruitment, data collection processes, and the plan for data analysis. The next section of the chapter has a review of trustworthiness regarding credibility, transferability, dependability, conformability, and how those were addressed in the process. The end of this chapter addresses ethical issues and procedures that came up during the preparation for the study and how those are addressed.

Research Design and Rationale

RQ1 – Health Education: How do the family member caregivers describe what their needs are for health education to help with making informed decisions about higher levels of care for their loved one with dementia within their care communities in the DC metro area?

RQ2 – Perceived Barriers: How do the family member caregivers describe the barriers of pursuing a higher level of care for their loved one with dementia who live in a care community in the D.C. metro area?

RQ3 – Perceived Benefits: How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to the quality of life/care within their loved one's current care community in the D.C. metro area?

RQ4 – Perceived Severity: How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?

The main goal for the case study is to understand what the barriers are to family member caregivers regarding their choices for not transitioning their loved one with dementia to a higher level of care. Qualitative research was selected because it was the most appropriate research methodology for the social phenomenon selected. Qualitative research is the best way to specifically review the point of view of the population being examined and allow for future research. Further, qualitative studies are better able to capture the nuances and complexities of human behavior that may be overlooked in quantitative approaches. This case study allows me to focus on each person's phenomenon from an exploratory perspective, assess the themes that arise, and share the results for the case of the barriers to transition to higher levels of care in dementia management. For familial caregivers, this study expands the understanding of the meaning and nature of dementia and spread awareness the care resources that are available. With the results from this study, researchers can examine the needs for health education promotion around dementia and additional care resources for the population and various healthcare practitioners.

While several possible structured study types exist for qualitative research, the best approach was the study type that allows for open-ended questions that open the door for participants to share their rich, personal experiences related to the study topic. Grounded theory was considered; however, it is not compatible with this study because I am not trying to establish a new theory through the systematic gathering of data, and this study does not consist of participant observation. A phenomenological approach was considered but ultimately not selected. A phenomenological approach focuses on figuring out the "what is it" question rather than the frequency or level of impact of a social issue (University of Dallas, 2014). This specific research study would focus on the frequency and magnitude of the themes regarding the research questions to help better understand what the reasonings are and what the health education and health communication needs are for the population being examined.

Participatory Action Research (PAR) was the final framework considered; however, because I am not observing participation and then action, this was not an appropriate framework to use. For this research study, an explanatory qualitative case study utilizing HBM was the best option as it allows for multiple participants to share their experiences around a specific phenomenon (Creswell, 2017). Using a case study combined with the HBM allows the researcher to understand the experiences of the participants and analyze their understandings of the disease dementia, what they know about dementia, and what they believe are the best treatment and management options for dementia are.

The rationale behind choosing a case study for the research study was because it has the benefit of being able to focus on one phenomenon through the eyes of multiple people experiencing the same things. A qualitative case study is a record that shows the formation and changes over a specific period of a person, a group of people or population, or a situation (Glanz et al., 2016). This research study reviews a group of people (caregivers), and their experiences in caregiving of a loved one with dementia, along with why they do not opt to transition that loved one to a higher level of care when recommended (similar phenomenon shared).

Role of the Researcher

My role as the researcher on this research project is as a participant working with the subjects one-on-one conducting the semi-structured interviews. The researcher can be viewed as the main part of the project, the main instrument in any qualitative study. The researcher conducts the study but also looks at extemporaneous documents, observes body language and behaviors of the interviewees during the interview process, and analyzes the data once the collection is done (Creswell, 2017). When conducting a research study and to avoid one-sided bias from appearing, the researcher should utilize more than one data collection tool (Creswell, 2017). With this study, I utilized semi structured interviews, a short survey questionnaire, and researcher observation memos to collect the data from subjects. Then, fellow professionals and members of the dissertation committee reviewed data analysis to help prevent researcher bias from happening during the overall process. In qualitative case study research, there is generally only one researcher; thus, there is a higher chance for bias, having solid checks and balances system in place will allow for that limitation of this research method to be less of an issue when proving internal reliability and validity (Yin, 2019).

The participating family member caregivers were first provided a short survey questionnaire prior to the interview. After completion of the survey, semi structured interview questions were asked to the participants of the study, their answers were recorded via audio recordings, and observations witnessed during the interviews by me, the researcher, were documented. The healthcare team that worked with the participant(s) and their loved one(s) with dementia was also interviewed to gain a better understanding of the process of working with the family member caregiver, their health education protocols, and also what they believed to be the barriers to transition. After transcribing the interviews, each one was coded to find the common themes between all of them and interpret their experiences with their loved one with dementia and the needs for care that they may have. All documents, notes, and transcribed interviews were safely locked in a desk drawer in my home. Copies of the transcriptions were sent to each respective participant via email or mail for their review to ensure accurate documentation of the information provided. The researcher had no prior relationship with the participants.

Methodology

Participant Selection Logic

The bounded case for this research project is the selected decision-making family member caregivers with loved ones who have been diagnosed with dementia and that loved one lives in a care community, to focus on getting the most important information on the specific phenomenon needs to have this population involved. The context for this being the established case is that we wanted to focus on the decisions made of the family member caregivers when it comes to care transitions for loved ones with dementia in care communities. The family members themselves make the decisions as to what the care levels are for their loved ones and understanding what factors lead to their decisions and the possible barrier to transitions is the main context for what the study was focused on. Baxter and Jack (2008) do provide a deeper dive and context into understanding qualitative case studies, establishing the bounded case, establishing the research questions, and the overall steps of doing a qualitative case study as the research methodology. The family members were spouses, adult children, siblings, or other extended family members, but they cannot be guardians that are staff of the state, such as adult protective services social workers or court-appointed guardians at law firms. Family member caregivers need to be English speaking, their loved one needs a confirmed diagnosis of a type of dementia (not Traumatic Brain Injury-TBI, Anoxic Brain Injury-

ABI or Chronic Traumatic Encephalopathy-CTE) and also reside in a care community in the DC metropolitan area. Family member caregivers were screened via a short phone survey to determine that they meet the above criteria and then scheduled for the interview to be held via video.

Sampling

The sample is going to be family member caregivers of loved ones with dementia who live in care communities that have a recommendation for higher levels of care needs, but those caregivers are refusing to make that transition. The care community criteria are that they are licensed assisted living facilities (ALF), skilled nursing facilities (SNF), continuing care retirement communities (CCRC) that offer care to older adults ages 65 years and older that are located in the D.C. metropolitan area. The Washington D.C. metropolitan area consists of Washington D.C., Northern Virginia (Alexandria, Arlington, Fairfax County, Fairfax City, City of Falls Church, Prince William County, Loudoun County, the city of Manassas, Manassas Park City, Stafford County, Spotsylvania County, and Fauquier County), and the surrounding counties in Maryland (Montgomery County, Prince George's County, and Frederick).

The sample size was 10 participants of family member caregivers of loved ones with dementia that participated in a structured interview that will be conducted as video interviews due to the global pandemic COVID-19. Previous studies completed involving interviewing family member caregivers that have been completed utilized an average of 10 caregivers to 35 caregivers, and so it was determined to utilize a sample size in the middle of that of 10 to 12 people (Hovland & Kramer, 2019; Macleod et al., 2017; Murray et al., 2016; Sherbuk et al., 2020; Tang et al., 2015,).

The participants who are selected completed a short survey questionnaire and a face-to-face interview via in-person or video call. Data was collected via the survey questionnaire, the face-to-face interview, and the detailed observation memo notes for each interview. Having these three avenues for data collection is a distinguisher for this study as a case study, differentiating this from possibly being a general qualitative study. I used purposeful sampling to help with selecting the participants of the study based on the criteria that is listed above. Purposeful sampling is designed to help with allowing the researcher to recruit a group of people that fit the phenomenon being studied (Creswell, 2017). Purposeful sampling is good for qualitative research studies to help with identifying participants that were able to participate appropriately and provide needed information based on the established research questions (Creswell, 2017).

The selection criteria of participants included (a) the family member caregivers who do not have dementia diagnosis themselves, (b) can be spouses, adult children, siblings, and other extended family members, (c) are not assigned state employees (Adult Protective Services, Social Services, Court Appointed Guardian Lawyers, etc.). The categories of this criteria made the recruitment more specific and will involve a group of participants that can participate effectively in the study, sharing their experiences in navigating dementia and the systems for the various levels of care needed to provide a positive quality of life for their loved one with dementia. Participants were reached out to via the care community treatment team contacting them and allowing me to email or mail them with an invitation to participate in the study. A list was gathered by the community, they asked the family members if they would like to participate, once confirmed, then their information was passed along; the researcher was given a list of names and contact information that this researcher to followed up with. If they chose to participate in the study, the participants emailed me back and completed the brief screening survey and I answered any questions they had to better understand the study and introduce them to what they would be participating in. Once they have been informed and were aware of the overall research project and goal, I was able to schedule them for a Zoom interview to conduct a longer, deeper discussion on their personal experience.

Instrumentation

For this study, a semi-structured interview was conducted with each family member caregiver, and members of their respective loved one's treatment team at the care community individually. Developing a good interview protocol can help to organize the process and allow for the interview to be smooth. The interview protocol established a script that was used at the beginning and end of the interview with each participant, open-ended questions were asked to encourage the participant to give as much information as they feel is important and the questions moved from basic to more difficult or intimate (Jacob & Furgerson, 2012) (see appendix A). A digital recording device was utilized to record the interview from start to finish and notes were taken of the observations made of the participants during the interview as well. Interview questions were created to help with moving the interview along, but participants were also asked open-ended questions and were allowed to give complete thought responses to those questions during the interview. Additional research data collection methods that were utilized are observation sheet notes (see appendix G) that were taken of body language, behaviors, and responses during the interviews that were conducted to give insight and another form of data for this research study. The final method of data collection that was utilized is a short questionnaire that will be given to the family member caregivers electronically prior to meeting for the interview (see appendix F). This survey is a short survey questionnaire that utilized multiple choice and a Likert scale for response options, each participant had the same questions and options to allow for equal abilities for coding this data. The research questions aligned well with the established interview protocol, for further understanding of this correlation please see Table 1.1 in Appendix C. A second table (Table 1.2) that is located in Appendix C section also shows the alignment of the data collection methods and the research questions established.

This research study is utilizing researcher-developed instruments as I used a list of interview questions that were all open-ended and created by myself. This and the structure of the interviews allowed participants the ability to answer freely and with as much detail as they feel is appropriate (Castillo-Montoya, 2016). Before this study is conducted, 3 colleagues in the field reviewed the interview protocol and short survey questionnaire. A letter was created explaining the request as well as the need for their constructive feedback on the items to ensure that this is appropriate and holds face validity within the pending research project (Castillo-Montoya, 2016) (see appendix E). Their feedback was incorporated into the needed changes as well as into chapters 4 and 5 of this dissertation.

A checklist was provided with the instruments to be used to appropriately review the data collection tools. For further validity, the checklist was not created by the researcher, but one already established in the study by Castillo-Montoya (2016) will be utilized and provided to the experts at the same time (see appendix D). The reviewing of the instruments will measure the concept and whether they match and align properly, evaluating the face validity and appropriateness for the study, the population being studied and, the research questions being utilized (Castillo-Montoya, 2016). The feedback provided on the checklist and anecdotally was used to improve the interview protocol and introduction survey questionnaire, the checklist is listed in Appendix D.

This research project is also not considered a pilot study, there will only be the main study which consists of semi-structured interviews; each participant will only be interviewed once. However, regardless of this not being a pilot study, one practice interview was given with a professional or colleague to ensure that any possible issues with the presentation of the interview protocol were addressed prior to the interview protocol being conducted with the research participants.

With a pilot study, you would work with participants and then mimic the study again in the main study, this research project does not have those components and therefore this was not the selected methodology. Semi-structured interviews are not published data collection instruments, as the list of open-ended questions will be created by the researcher and asked at the time of meeting with the participant, and this will not become published as a standard guide of use for future research projects or analysis. Due to the COVID-19 pandemic that is currently happening, most participants opted for video conferencing as an option for safety precautions and prevention of the spread of the virus.

Data Sources

Short Survey Questionnaire

Prior to each interview being conducted, the family member caregivers were given a short survey questionnaire that reviewed their current knowledge of dementia, the care resources available, and the health education they have been given on care needs for dementia (see appendix F). This was sent as a Google Form survey via email to maintain electronic records. If Google Forms was not accessible, the survey was offered to them as a word document or PDF document that they could complete, or a paper version of the survey can be mailed to them to complete. The surveys were completed and returned before the interviews are conducted as reminders were given to the participants if their responses were not obtained prior to the commencement of interviews. The survey questionnaire utilized a Likert scale for responses, and contained a line for their initials to deidentify the data, and included three questions for demographic information on their gender, age range, and racial background.

Audio Recordings

The researcher recorded each interview with a digital recording device. Permission for this will be explained verbally and will also be a part of the informed consent form. Each interview was saved as a separate recording and uniquely coded to ensure the protection of the participant’s identity. The recordings were saved on my password protected laptop for security.

Observation Sheet

An observation sheet was used to take notes during the video interviews. (see Appendix G). Notes were taken during interviews because participants may have reactions via their body language while answering questions that can also be important information in understanding their experiences and their perceptions on the barriers to providing higher levels of care or transition to a higher level of care for their loved one with dementia. This observation sheet documented observed reactions that are not verbal responses, such as emotional responses like sobbing, notable frustration, aggressive responses, etc. that occurred during the interview.

As part of this research project, there are data collection instruments that will not be utilized. I will not be utilizing artifacts, archived data, or medical records because the focus of this study surrounds interviewing the family of loved ones with dementia and not the patients with the diagnosis of dementia. It is because of the above information that the only data collection instruments that are used are an interview protocol for the family member caregivers and the healthcare professional team at the care community, observations memo, and the short survey questionnaire given at the beginning of the process with family member caregivers.

Procedures for Recruitment, Participation, and Data Collection

The study participants were emailed for recruitment and provided with the information on the study in an email form and an attached informational flier (see appendix H and I). The study participants that agreed to participate were directed to review and complete the informed consent information (see appendix B). When written consent was obtained, their appointment for the interview was set for the study. Walden's IRB reviewed my consent form and approved it for use. Interviews were conducted using the following platforms: a face-to-face interview, video interview via Google Meet (which is a HIPAA compliant and secure), or a phone interview. Per Google Workspace Admin (2021), Google Meet is deemed a HIPAA compliant platform once the Google Workspace administrator reviews and accepts a business associate agreement, which elaborates each party's role in managing PHI while using this platform and assures the user that PHI meets all requirements for HIPAA.

After the interview, I first thanked them for participating in the research study and that their words are valued greatly. I also them of the process of storing the information collected to reassure them that it is secure and confidential. I alerted of the potential for positive social change that this study could create as well as how the data collected from this interview and the study overall can contribute to health education for geriatric providers as well as other family member caregivers who are taking care of a loved one with dementia. I left time for the participants to ask any follow up questions and bring up any concerns they have overall from the interview and the process of what their information will be used for moving forward. All participants were alerted and received an emailed or mail (based on their preference) copy of their interview transcribed. As part of my notes, I wrote down a summary of the interview from my perspective and what I understood the participant's statements to mean. This will help to show that my views on the participant's interviews are based without bias.

Data Analysis Plan

The semi-structured interviews were completed as part of the data collection process, the analysis started with transcribing the interviews and ensuring the accuracy of the recordings. Once each interview was transcribed, a copy of the transcript is sent to the participant of their interview via email or mail a paper copy to them. Once all the interviews have been transcribed, coding was done to identifying recurring themes that are coming through as well as reviewing observation notes that were taken and coding those with the associated interviews, this was initially done by the researcher. A coding software was selected to do a second analysis and see what recurring themes come out and compare them to the coding that was conducted by the researcher.

According to Saldana (2016), some of the key things to look for when coding are things happening in the same way, if there is a frequency to them (often or rarely), if they are happening in a similar order, if they are happening in relation to other events, and if there appears to be another cause to the issue being explored. Once the interviews have been coded, I will review the codes found and start creating categories that can summarize the coding, and if subcodes were needed those can be created as well. Concerning first cycle coding methods, the two that seem most appropriate for use are “in vivo” coding and “process” coding (Saldana, 2016). In vivo coding involves pulling actual words or short phrases from the transcribed interview and using those as the codes and process coding uses the recurring themes and combines that with the similar words or phrases from the interview and paraphrases them together (Saldana, 2016). NVivo software was initially proposed to be used in the data analysis process to code the data collected from the interviews, the short survey questionnaires, and the observation memos, but no software was used to do data analysis. For the analysis I did the coding by hand and I started with going through all the interviews and circling the answers to the research questions, then I used a color coding method to highlight the answers that matched with each research question The information mentioned and presented above will be discussed in chapters 4 and 5 in more detail that lays out the process of the data collection, analysis and outcomes found.

Issues of Trustworthiness

Credibility

Credibility can be defined as prolonged engagement, observation, appropriate triangulation and peer review, negative case analysis, and adequate member check of a research study from the initial literature review to data collection and data analysis, this is also known as internal validity (Morse, 2015). The first step in establishing this is to check the transcribed interviews to ensure they are accurate, and I kept a written and digital journal of the codes found while analyzing the data collected. Changes to the project as they happen and update needed parties (experts reviewing the interview protocol, research study participants, care teams at the communities, and dissertation committee members with Walden University) were documented to these changes, the interview protocol was consistent for all participants to ensure that outcomes could not be deemed inappropriate due to any inconsistencies. I will keep the interview sessions all at the same amount of time (1 hour) for each participant. I will transcribe all the data and email or mail the transcribed interviews to each of the appropriate participants to review for accuracy of the information listed, this allows for member (research participants) checking to allow for reliability (Creswell, 2017).

Triangulation will be performed to help with reviewing and justifying the codes; the themes that will be found in the data, and if it shows that there are consistent themes showing that will show consistency overall in the study. The Yinian understanding of case studies, multiple forms of data collection are important to allow for triangulation (Yin, 2018). With triangulation, Yin states that letting the multiple avenues of data collected to be analyzed are needed for proper research study validity (Yin, 2018). The first form of data collection will be semi-structured interviews conducted individually via video, which will allow each participant to identify and explore important themes with the researcher. A comparative analysis is then used to analyze data from participants of factors that promote and impede timely dementia transitions to higher levels of care. NVivo 11 Pro software will be used to organize coding efforts.

Triangulation is an important part of case study research and having multiple sources of evidence can help to give a clear picture of what the themes are respectively (Yin, 2018). The researcher offered the family member caregivers a short survey questionnaire prior to the interview to get a brief understanding of their understanding of the topic of dementia is as well as the caregiving resources available to them. This data further supports the understanding of what they do or do not know and continue to further help in identifying the needs for health education and health promotion among this group. The researcher also wrote memos to make observations during the interviews that are conducted with the family member caregivers and ask questions about the data to assist with the data analysis process. As the interviews are conducted, the researcher made notes of observations that are made of the family member caregivers with regard to their body language, emotional responses during their anecdotes, and their interactions with the research interviewer. The researcher conducted interviews of the caregiving team at the care communities that the family member caregivers are associated with for additional data to compare and contrast experiences with the interviews conducted with the family member caregivers.

Transferability

Transferability is an aspect that is important in qualitative research studies. This researcher ensures transferability by providing robust details on the interviews when making connections to various social contexts and cultural contexts that occur or are observed (Morse, 2015). For example, this researcher noted the time of year that the participants did their interviews and if there are major cultural or religious holidays, seasonal aspects, and other items that may have affected their participation (Statistics Solutions, 2021). This researcher also noted the time of day that the interview happened, before or after work, on a weekend or day off, as that may affect the level of energy or rest the participant has during the interview to contribute information (Statistics Solutions, 2021). Having this information provides a fuller understanding of the research settings, which can help future researchers understand the ways to replicate the study or improve the study when conducting it, thus allowing for proper transferability (Morse, 2015). Having this level of richness with the research environment included in the data collection and analysis can help with preventing or identifying issues of transferability within the research study (Morse, 2015).

Dependability

The process to ensure dependability and confirmability is included the process, in detail, participant selection and all procedures that I used as part of the interview protocol. If there were any changes to the original interview protocol, participants were made aware and the researcher ensured that the participants understood why they needed to be made. All participants were able to select the location or modality in which they had their interview session either by video conference, telephone, or face-to-face. Participants were able to review their transcribed interviews for accuracy. This detailed interview protocol will allow for future researchers to replicate the study for other topics and also for them to continue to expand the understanding of family member caregivers of those with dementia and their needs for support and education on higher levels of care and advancing dementia symptoms.

Confirmability

Confirmability in qualitative research helps with addressing the issues of researchers having their own bias during the project itself. In this study, a methodological input that allows the readers to better understand and determine the themes that have come through with the data collected from the research project was developed. This helps the readers to accept the themes that were discovered from the interviews. The data analysis helps the Walden University dissertation committee review the information and understand the analytical triangulation that helps with reducing bias. Confirmability ensures that the information presented as the study findings from the family member caregivers is truly reflective of their experience on the phenomenon and not the researcher's preferences or bias (Creswell, 2017).

Ethical Procedures

All the participants in the study were adult males and females who were able to freely consent to participate in the study or refuse at any time. They were given a consent form and the research project was explained to the participant. Per the Institutional Review Board (IRB) guidelines, the consent form explained the participants' right to privacy, how the data was stored and utilized in the study. The consent form was written in accessible language for the participant to understand and I offered further clarification if they had any questions. The consent form also explained how their participation will benefit the research community, stakeholders for this population, and geriatric healthcare professionals. Finally, the consent form informed them of the time commitment, which entailed a short phone screening and explanation of the study, the interview, and then the follow up in which they will receive the copy of their transcribed interviews.

Conflicts of interest were limited as I do not work at any of the places that the research participants will be recruited from. There are no prior relationships with any of the family members that will be participating in the study and there will be no monetary reward given for participating to prevent participants from joining the study in bad faith to only receive a monetary reward. There were minimal risks via a possible emotional response, to participating in this study and there will be a $10 gift card reward given for participating in this study, which is acceptable by IRB and can help recruit participants while also thanking them for their time. While there is no physical harm that will come to the participants, emotional reactions may happen when sharing their stories of caring for their loved ones with dementia, emotions like sadness, guilt, or even denial. The researcher connected them to information on local community resources for managing their emotional responses as needed and appropriate. This researcher did not judge the participants for their responses and will see this as a time to learn and collect data.

The IRB assessed that everything is in place to ensure that the research study was safe and ethical for all participants included in the study. Informed consent was reviewed and explained to each participant and all questions will be answered for clarification. Informed consent was obtained in writing and was collected for each participant (see appendix B). The digital material was stored on an external drive and the audio recording device, and all written material was in one notebook and folder, all of which will be in a locked drawer in my office which will only be accessed by me. To ensure privacy, all participants were deidentified by being given an identification code that is used to refer to them so that their personal information (name or other information) will not be listed on the documents collected. While general demographic information such as race, gender, and age ranges will be shared within the dissertation study; to protect participants, nothing that could pinpoint any one person specifically was not shared.

The care communities that participants are affiliated with by being a family member caregiver was coded to mask the location and name of the, ensuring further privacy of the participants in the research study. Confidentiality agreements were needed and utilized only with the three other transcribers that completed the transcription of the interviews. Names were not used in the recordings so there were no issues with confidentiality for the other transcribers and I was able to identify each person via a system of naming the file with a code of one letter and one number that was matched with the name of the participant that only I had access to. Participants and community stakeholders will be able to have access to the dissertation at the end of the process once approved and published. This will help to disseminate the understandings overall and give insight to those stakeholders as well as a sense of positive social change for the participants. Upon completion of the study, data collection materials will be maintained for 5 years per the recommendation time by IRB to keep the research material. After this time period, then research data will be shredded and destroyed.

The interviews could be emotionally triggering due to speaking about their loved one's care, diagnosis, and the stressors that can come from this, but this is considered a minimal psychological risk. However, all participants are provided resources and referrals for emotional stress relief in the consent form and was be reminded once more when transcribed interviews are sent to the participants. If during the interview the emotional or psychological distress is evident and severe enough, referrals for services will be made on the spot and if needed, a break will be given for the participant to calm down and collect themselves. If the participant found this difficult, the interview was ended, and the options of rescheduling or selecting a new participant were considered. None of the participants in the study are considered a vulnerable population as they are the family members of loved ones with dementia, they do not have dementia themselves. There are no potential relationship risks identified because the caregiver's responses were not shared with the facilities and the facility staff responses will not be shared with the caregivers, only the overall research project results. There are no potential legal risks here, so this would be considered a minimal risk due to the nature of the study reviewing resistance to a transition to a higher level of care within a care community and not outward neglect of care at all.

There are minimal professional or economic risks due to the caregivers not working for the facilities and the staff within the facilities will only be asked their point of view on what they feel the barriers are for the caregivers to make the transitions recommended, but as previously stated, no one team or caregiver will see the opposing parties' responses or identified overall as participants. This will prevent anyone from knowing who was in the study and lessen the ability for there to be retaliation against the staff team involved or the family member caregiver involved. Interviews conducted will be in a location that is off-site of the care community and interviews will be limited to one interview per day to prevent anyone from identifying another participant. This researcher will not be professionally affiliated with any of the participants, and this will help to prevent any type of conflict of interest or quid pro quo incentives between myself and the participants respectfully.

The care communities that will refer possible family member caregivers or healthcare team members should not need to grant permission for use of facility space or personnel time because all interviews will be done off-site and for staff members, all interviews will be done in their off-work hours. Participant recruitment will be conducted in a non-coercive manner. With the permission of the care communities, a flier will be posted in the community and the staff will be able to share it with all the families within the communities and they will be invited to reach out to me to participate in the study and be interviewed. There will be no exchange for services however, there will be a small monetary compensation for participation in the study in the form of a $10 gift card, and participants will be made aware of that verbally at the beginning, in writing in the informed consent, and then once more at the end of the interview.

There are family member caregivers who are not going to be eligible, and their exclusion is justified. The loved one has to have a dementia diagnosis while residing in the care community and not have a diagnosis of CTE, TBI, or ABI. Potential participants that reach out will be screened briefly to ensure that their loved one meets that criteria before being offered a chance to participate in the study. Prior to the study, during the informed consent and again at the beginning of the study, all participants were notified of this researcher being a mandated reporter and that if any elder abuse, neglect, or exploitation is reported during the interview, that I will need to report it to the local county or city adult protective services. The report will be documented as to when I called, who I spoke to with the Adult Protective Services (APS), and what the report was that was made, and the participant will be notified as well. The facility will be notified as well to ensure safety and effective safety planning for the loved one. Should there be a breach of confidential information with this report, the interview and data collected will not be included in the overall research study and data analysis and their research materials will be destroyed as well.

This researcher is appropriately qualified to conduct the interviews due to having professional experience as a licensed clinical social worker and interviewing clients/patients/consumers is a part of my professional role. As a clinical mental health professional, I will also be able to assess if the participant is becoming distressed and make the appropriate referrals for services if needed at the end of the interview. The research participants were sent the informed consent in an email to review and have time to ask any needed questions and obtain clarification. Once they have had questions answered and clarification provided, they will be directed to sign the informed consent and then we scheduled the interview for the research study. The consent form includes the inclusion criteria that are understandable in a way the participants can interpret, it explains the research purpose for this project, a description of data collection procedures, the time commitment needed for the research study in their role, and that their participation is voluntary. The participant was reminded in the informed consent, as well as verbally, that they can decline or stop participation at any time. The informed consent also alerts the participants how many participants will be recruited to participate in the study overall, the reasonably associated risks with the subject possibly being emotionally or psychologically triggering, and that resources to support them can and will be provided.

The consent form included the possible benefits of their participation in the research study and explain the positive social change that can come from this; this will also be stated verbally at the beginning and end of the interview. The consent form will describe how the data will be kept private throughout the time of the study and even after the research project has ended. No identified conflict of interest needs to be disclosed to the participants. My contact information will be added to the informed consent form so that if the participants want to follow up with this researcher for questions about the study. The participant advocate contact information to inform them of their rights or answer any further questions was also added to the informed consent form in the form of the phone number 612-312-1210 or the email address irb@mail.waldenu.edu. There was a statement in the informed consent form recommending that they keep a copy of their informed consent form, and once they have signed it, the signed copy will be emailed to them for their records. This study is not experimental and so that information was not included on the consent form as that is not needed.

When the research project has concluded and the dissertation has been approved and published, the participants will be notified and invited to review the research study results via being sent the dissertation. An email was sent to them to ask if they would like to see the results via reading the dissertation. If they choose to, they will be sent a finalized digital copy that will be approved and published by ProQuest.

Summary

Family member caregivers of loved ones with dementia in a care community can face a number of barriers and catalyst that influence their decisions around care and treatment planning needs. Chapter 3 explains the research design that was established, the conceptual and theoretical frameworks, and the methodology. This chapter explained in detail the participant criteria, how they were recruited, the rationale behind the selection. Reasonings were described and information was given for the data collection process, the choice of data analysis, and the way themes were pulled from the interview transcriptions via coding. This chapter described the potential issues of trustworthiness, understanding what could make this research project credible, dependable, and reliable as well as ethical concerns that could arise due to participation in the study. Chapter 4 will dive into the understanding of the overall research project after it has been conducted, after the semi-structured interviews are completed, and what the data looks at.

Chapter 4: Results

Results

The purpose of this qualitative study was to explore and further understand what supports and health education resources there are for family member caregivers of a loved one with dementia living in a care community in the DC metropolitan area. The four research study questions are:

RQ1 – Health Education: How do the family member caregivers describe what their needs are for health education to help with making informed decisions about higher levels of care for their loved one with dementia within their care communities in the DC metro area?

RQ2 – Perceived Barriers: How do the family member caregivers describe the barriers of pursuing a higher level of care for their loved one with dementia who live in a care community in the D.C. metro area?

RQ3 – Perceived Benefits: How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to the quality of life/care within their loved one’s current care community in the D.C. metro area?

RQ4 – Perceived Severity: How does the family member caregiver feel about the severity of their loved one’s dementia and care needs within their care community in the DC metro area?

Chapter 4 includes the comprehensive evaluation of the research study conducted, the interview setting, participant demographics, data collection and analysis, the evidence of trustworthiness, and the study’s results.

Research Setting

This topic came as something that was needed when I worked as a geriatric medical social worker in several health settings (a CCRC and a hospital) and encountered family member caregivers who struggled with the needs (safety, health and financial) of their loved one with dementia while also trying to abide by their wishes. Seeing their struggle with this inspired me to complete this research project to help establish more of an understanding and hopefully provide more resources to the families and professionals in the long run. As previously described in Chapter 3, the participants in this study are family member caregivers of a loved one with dementia who have lived in a care community. Participants were sent to the informed consent form electronically, and after consenting to participate in the interview, were scheduled for a video interview. Participants were given a Zoom appointment to log on and participate, and the interview was recorded on Zoom from start to finish. Because of the COVID-19 pandemic and to keep the safety of all in mind, the interviews were all conducted virtually via Zoom.

Demographics

The group that participated in this study was recruited through social media and through information shared with geriatric healthcare providers who referred family members of their patients with dementia. From there, participants also referred others that they knew to participate, via a method known as snowball sampling (Clarke & Braun, 2017). Family member caregivers who were interested in participating could reach out via telephone or email, and I discussed with them the basis for the study, the criteria, and the purpose and the informed consent form over email to review further. All participants were directly connected family members of a loved one with dementia and were either the adult children or the spouse of that loved one. All participants were between the ages of 45 and 70 years old.

Table 1

Participant Demographics

Participant	Gender	Primary or Secondary Caregiver	State of Residence	Race/Ethnicity
Participant 1	F	Primary (D)	Maryland	White
Participant 2	F	Primary (D)	Virginia	White
Participant 3	M	Secondary (S)	Maryland	White
Participant 4	F	Primary (GD)	Virginia	White
Participant 5	M	Secondary (S)	Virginia	White
Participant 6	F	Primary (D)	Maryland	White
Participant 7	M	Secondary (S)	Maryland	White
Participant 8	F	Secondary (W)	Maryland	White
Participant 9	M	Secondary (S)	Maryland	White
Participant 10	F	Primary (D)	Virginia	White

Note: Key: D= Daughter W= Wife S= Son GD= Granddaughter

Data Collection

Recruitment began after IRB approval (approval number: # 04-14-22-0415257) was obtained in April of 2022. The recruitment process began with my sending out a flier and description of the study to various social media groups on Facebook, senior care communities, and geriatric healthcare professionals. On the flyer, I requested that anyone interested in participating contact me directly for additional information. Anyone who reached out and obtained more information either met criteria, participated, and shared with others who participated, or did not meet criteria and knew of another who would and referred them to the study (e.g., snowball sampling). Two participants were recruited through a professional connection, and the other eight participants were referred through snowball referrals from other participants a few weeks after those first two interviews were conducted. The initial recruitment flyer received little response on social media and from local healthcare professionals working in geriatrics. One professional work connection was able to connect me to a geriatric care coordinator who participated in the study and connected me with others she knew. The other few came from other professional connections of mine and a snowball sampling to others that they also knew who could participate.

With all potential participants, I reviewed what criteria they met to be able to participate and went over the informed consent form. Upon reviewing the informed consent form, I determined that there were several recruits that did not meet the criteria and could not participate. The ones that did meet criteria signed the consent form via email and returned it. All 10 participants were sent links for Zoom to participate in secure sessions that were passcode accessible, and they were recorded on Zoom with the platform recording video and audio combined, as well as on audio-only files. There were no in-person interviews conducted. The interviews were scheduled for an hour, but ranged from 40 minutes to 75 minutes, which included me introducing myself and the research project, sharing next steps, and thanking the participants. After the interviews were all completed, I began working on the transcription process to get the interviews on paper. Along with three interns, I reviewed and transcribed all the interviews. Any interviews that were transcribed by the interns, I reviewed once more for accuracy to ensure everything was typed correctly. Interviews that were transcribed by me were done with the files obtained as either video with audio or audio and interviews that were transcribed by the intern transcribers were given files with a code name for the file, and no names were used in the interview recording to help continue to ensure the confidentiality of the participants. The three intern transcribers all signed confidentiality agreements that have been stored for record. After all interviews were transcribed, I reviewed them and took notes while analyzing the data and finding themes. My notes when analyzing included emotional responses during the interview and reflections relating to the participants' responses to interview questions and the overall topic. No out of the ordinary behavior or unusual circumstances occurred during the interviews with the participants.

When the participant interviews were completed, all Zoom interview recordings were stored on my password protected desktop computer. During the analysis process, I listened to the audios and transcribed from start to finish, and to ensure as much accuracy as possible, I listened to the audio once more and read through the completed transcription at the same time. The transcription files were saved on my password protected desktop on the cloud. Once the transcription was completed, and the analysis process had begun, the transcriptions were sent to the participants to review for accuracy. I asked them to alert me to any information that was misinterpreted or inaccurate. No additional information was provided, and no adjustments to the transcribed interviews were requested or were needed. The proposed data collection did not deviate from the methods described in Chapter 3 of this dissertation and research study.

Data Analysis

This was a qualitative instrumental explanatory case study that used the HBM to identify themes in the experiences of family member caregivers of loved ones with dementia that live in the Washington DC metropolitan area (DC, Maryland and Virginia). The analysis process for the interviews and the short survey was conducted and utilized to understand the feelings and experiences of the family member caregivers of loved ones with dementia. The short survey had four questions with a Likert scale that had five options ranging from very unsatisfied, unsatisfied, neutral, satisfied and very satisfied. Each participant answered the four questions, and then went began interview. The first question of the short survey asked about their feelings on the health education that they received, and four of the participants responded either *very unsatisfied* (3) and *unsatisfied* (1); four responded with *neutral* and two selected *very satisfied*. The second question for the survey asked about their feelings about the perceived need for the higher level of care for their loved one's dementia care needs; there were four *satisfied* responses, two *neutral*, two *unsatisfied*, and one each for *very unsatisfied* and *very satisfied*. The third question explored their feelings on their perceived benefits of getting a higher level of care with the following responses: five *satisfied*, three *very satisfied*, and one response each for *unsatisfied* and *very unsatisfied*. The final question on the short survey explored the feelings on the perceived severity of their loved one's dementia and care with the responses as follows: six being *satisfied*, two *unsatisfied*, and one each *very satisfied* and *very unsatisfied*. After receiving their answers, I recorded the responses on an Excel spreadsheet and then calculated by the total number of a certain response that was given for each of the four questions. Once I had all the numbers for responses laid out with the other responses, I was able to review the numbers and analyze the responses, the similarities, and also compare them to the coding done on the interviews.

Table 2

Findings for Short Survey Questionnaire (n=10)

Research Questions	Very Unsatisfied	Unsatisfied	Neutral	Satisfied	Very Satisfied
RQ1: Your feelings about the education you received about dementia and the care resources in the DC area	3	1	4	0	2
RQ2: Your feelings when you pursued a higher level of care for your loved one with dementia in the DC area	1	2	2	4	1
RQ3: Your feelings about the perceived benefits of getting a higher level of care	1	1	0	5	3
RQ4: Your feelings about the severity of your loved one with dementia	1	2	0	6	1

For the process of analysis of the individual interviews, I used the six-phase thematic analysis process as created by Clarke and Braun (2017). This approach allows me to have a thorough careful approach to the participant experiences that were transcribed and find the codes and themes throughout the information provided (Clarke & Braun, 2017; Saldana, 2016). The phases consist of collecting the data, engagement and becoming familiar with the data, coding the data, generating code categories from the data, and conceptualizing the data into comprehensive understandings and meaningful relationships that represent the data (Clarke & Braun, 2017).

The data collection consisted of the interviews with the family member caregivers and utilized active listening and engaging with them. After the data were collected, I moved into phase two where I engage and become familiar with the data collected. Within this phase, I listened to the interview recordings and was able to review the transcripts for the interviews multiple times for accuracy and to gain a deeper connection and understanding of the information being shared. When reviewing the transcripts, I made connections to the research questions, the theoretical framework, and the nature of the study (Clarke & Braun, 2017). As the researcher, I was sure not to instill my personal views, values and biases on any of the participants when they were expressing their experiences and views.

The third phase involves generating codes from each individual transcript and then identifying patterns of those codes between all the different interviews. I was able to hand-code the transcripts in Microsoft Excel to organize the coded themes and the organization of where those codes were found in each of the interviews. The interviews were coded for each interview individually, and I noted what those codes were for each interview before finally comparing them all. Hand coding helped me to gain a deep understanding of the information and data because I read them several times, made notations on them, and found the codes that were applicable (Clarke & Braun, 2017). Coding was completed in what is called an “inductive manner.” This means that there were no preset or predetermined codes, and all codes generated came from analysis. I worked as a social worker professionally in this field with this population, and I had some general ideas of potential emergent themes, such as lack of education resources, emotional exhaustion, and severe stress; I allowed the participant interviews to be the guiding aspects with establishing the codes, themes, and categories as codes were developed at the appropriate level of the data.

When phase four began, I looked deeper into the themes that were presenting themselves and emerging from the research. The codes and themes most prevalent to the research data outcomes were used and narrowed down to four themes. The four themes primarily spoke to the things that these family member caregivers seemed to be lacking on their journey to caregiving for their loved one with dementia. I combined the themes: “a lack of health education from the diagnosing providers” and “lack of health education from healthcare team at the care community” into one, describing it as a lack of health education provided by healthcare professionals across settings. I continued to review and refine the themes that had come out, and after combining subthemes into one overarching theme, four comprehensive themes emerged from the data. The figure below lists the thematic map that shows the themes that emerged and how it led to the overall overarching themes in this analysis.

Figure 1

Thematic Map of Themes and Subthemes Emerged

1. Lack of health education provided at time of diagnosis.
   - No education from the doctors
   - Did not know what came after
2. Lack of health education and navigation of resources provided throughout the transition process.
   - Could not get information from heathcare team
   - hard to navigate the internet independently for information
3. Increase in stress during the caregiving process.
   - Reports of stress for the caregivers while supporting loved ones.
   - Lack of emotional support for those loved ones with dementia during transition.
4. Women caregivers show a higher rate of involvement than men.
   - Men reported their female spouses or other family members took most care.
   - Women were more descriptive in the interview; men did not have as much information.

As shown in Figure 1, when in the fourth phase, participants reported that were part of their experiences as family member caregivers to a loved one with dementia and here the subthemes and overarching themes were formed and created. Participants discussed not having enough support from healthcare providers and geriatric practitioners, not having any or very little health education on dementia and the care resources available to help them support their loved ones with dementia and the noticeable difference in how the primary caregivers were the women in the family (wives, sisters, daughters) for their loved ones with dementia. Several of the participants talked about the stressors that came from caregiving that they were not able to address for themselves or their loved ones with dementia. Several of those stressors came from not being able to navigate care resources or understanding dementia and care needs during their caregiving experience.

In phase five, the themes were reviewed and defined further to identify why they were highly applicable to this research study. The themes and subthemes were analyzed and each was defined and attached to the relationship that they had to the research project and data collected. Every experience was represented in the themes that were selected to ensure that they were heard and understood in a meaningful way. The themes were able to fit into categories of: lack of health education, lack of support, and the emotional toll it takes on the caregiver and the loved one. Each category is connected to a theme and there are at least two subthemes for every theme that emerged.

The final phase is the analysis written report, which will be laid out in a later section of this chapter and chapter 5. The categories, themes and subthemes in the written report are written out with excerpts from the transcribed interviews with the participants that would form the story that formed the central concepts for the categories, themes, and subthemes. The categories, themes, and subthemes represented the experiences of family member caregivers for their loved ones with dementia in the DC metropolitan areas, their transition process and their experiences with being educated.

Evidence of Trustworthiness

Credibility

The credibility of my research study was established by recruiting participants through established criterion, snowball sampling and use of professional connections in the field of geriatrics to link to the study. All the participants were provided with a detailed description to the study and either engaged in answering questions and screening over email, phone or a combination of both. The email or phone contact went over the purpose of the research study, the process to participating and that their participation was completely voluntary. Once they consented to participating and the interview was set, participants had their scheduled appointment. Participants were encouraged to answer each question as honestly as possible and that they could discuss and share the information that they felt comfortable with sharing. We discussed the informed consent, went over the informed consent document sent to them in an email, how I would store their information, dispose of their information and any limits in confidentiality. This helped them understand the process of how their information would be handled. I also discussed the $10 participation gift card that would be shared with them as well after the study was concluded and research analysis was done.

Participant checking was another way that I established credibility. All transcripts of the interviews were sent to the participants individually and I alerted them to review the transcript and provide any feedback that they have on the accuracy of the transcription. If they felt they found any misrepresentations in their interviews, they were then encouraged to follow up and clarify or provide other information. The process of allowing for member checks made sure that I, as the researcher, was encompassing the essence and heart of what the participants experienced and make sure to curb my own interpretations and/or beliefs about experiences were not influencing research, analysis and outcomes. All participants were sent their transcripts, and all were comfortable with the transcripts, and none sent feedback for any changes with their interviews.

Transferability

Transferability refers to the level that a research project can be utilized by other researchers in other settings and comes from reporting and outcomes from others in differing settings. Transferability can be seen as possible in this study as the focus was on older adult family member caregiver support and health education in a chronic illness, this study looked at dementia, but this can be used with other chronic illnesses in older adults and the caregiving process and health education needs for family member caregivers. I utilized a thematic analysis to give researchers and readers a very detailed and broken-down account of the information from the research participants with the research procedures, steps used in the data analysis process and what the categories, themes and subthemes were that emerged from the process. Having this detailed explanation of the research process gives readers the ability to identify the level of transferability of my study to their setting and how it can be applicable.

Dependability

When looking at dependability, this refers to how reliable the study and its results are. To establish dependability, I kept detailed notes of my process for starting the research project, recruiting, interviews, coding and analysis, emerging themes in the data and then final analysis of all data. The transcripts of the interviews, the notes for the questionnaire prior to starting the interview, my detailed descriptions of the coding and analysis process provide the audit trail (Shenton, 2004). All recruitment strategies were outlines in chapter 3, the data collection methods were consistent with all participants with pre-interview questionnaires, interviews, and utilized identical coding techniques for the data with all participant interviews. The semi-structured interview guide that I utilized was the same set of questions with all participants in the study and gave the same amount of time for every interview. No software for coding purposes were utilized, however Zoom software was utilized to have and record all interviews with participants.

Confirmability

When discussing confirmability, that would refer to if the research study is objective and at what level. This was established to prevent subjective experiences and other interpretations from influencing the research results and to ensure that the results produced were from the perspective of the family member caregivers of loved ones with dementia (Patton, 2015). The comprehensive audit trail that contained my notes of observations, the pre-interview questionnaire and the transcripts of the interviews that allowed for prevention of personal experiences and bias to interfere with the research project and the analysis process (Patton, 2015). Finally, the use of participants reviewing and checking their transcripts for accuracy helped to further solidify that their experiences were appropriately captured. As the researcher, I completed transcription of the interviews along with a transcription service that was used to help account for ensuring there was no bias and a third party was able to listen and transcribe for accuracy.

I listened to the interviews again and read through the transcriptions to ensure accuracy in what was given and said. This allowed for triangulation in use of my ability to have not only the researcher to listen in detail but a third party with no buy in listen and transcribe accurately as well. The safety of the participants' identities were kept as we did not use names in the recorded interviews themselves and the file names were saved as codes that were sent to the transcription service. Confidentiality agreements were signed as well and all files were handled with care when shared.

Study Results

Introduction

In the study results section, I will review in detail how the four research questions initially introduced to establish the research project align with the themes and subthemes pulled from the research data that was ascertained. Each participant provided information via a semi structured interview and a short 4 question survey.

Table 3

Short Survey Results

Short Survey Results	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Q1: Please tell me your feelings about the education you received about dementia and the care resources in the DC area at the time of diagnosis	5	5	3	3	1	3	3	1	2	1
Q2: Please tell me your feelings when you pursued a higher level of care for your loved one with dementia in the DC metro area	5	4	3	4	1	4	4	3	2	2
Q3: Please tell me your feelings about the perceived benefits of getting a higher level of care	4	4	1	2	4	4	5	4	5	5
Q4: Please tell me your feelings about the severity of your loved one with dementia's care needs are	4	5	2	2	1	4	4	4	4	4

Table 4

Themes

Research Questions	Alignment based on the research (Theme and Subtheme)
Research Question 1: How do the family member caregivers describe what their needs are for health education to help with making informed decisions about higher levels of care for their loved one with dementia within their care communities in the DC metro area?	Theme 1: lack of health education provided at the time of diagnosis Sub theme 1: No education from the diagnosing providers Sub theme 2: Did not know what to do after diagnosis was given
Research Question 2: How do the family member caregivers describe the barriers of pursuing a higher level of care for their loved one with dementia who live in a care community in the DC metro area?	Theme 2: lack of health education and navigation of resources during the transition process Sub theme 1: Felt they could not get information from the healthcare team Sub theme 2: Felt it was hard to navigate the internet independently for information
Research Question 3: How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to the quality of life/care within their loved one's current care community in the D.C. metro area?	Theme 3: female caregivers show higher rate of involvement than male caregivers and saw more of the perceived benefits of the higher level of care for their loved one with dementia Sub theme 1: no support emotionally for the family member caregivers while they were supporting their loved ones with dementia. Sub theme 2: no support emotionally for those loved ones with dementia during the transition
Research Question 4: How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?	Theme 4: An increase in stress during the caregiving process. Sub theme 1: the men in the study reported their female spouses or other female family took most care Sub theme 2: the women were more descriptive in the interview, the men did not have as much information on caregiving experiences for loved ones.

Theme 1: Lack of health education provided at time of diagnosis to family member caregivers.

When working with participants in their interviews, all of them explained that their knowledge of what dementia was prior to this experience was very little and that they thought upon the diagnosis, they would gain a wealth of knowledge, but that was not the experience. All of the participants said that they had some general knowledge of dementia in that they understood it happened at old age and that it caused memory loss. Five of the ten participants also reported that they did not know as much about the resources available for care outside of nursing homes and they felt negatively about that level of care because of previous stigmas they had heard of nursing homes and similar facilities. Seven out of ten of the participants also reported that it was a bit frustrating for them that they did not have a lot of education upon the diagnosis from their loved one's diagnosing provider as well as no real assistance with resource connections for care at all stages.

This is a thought shared during an interview by participant 2 about how there are not enough medical providers that are versed enough in dementia and their perceived need to get a formal diagnosis:

> Um, I feel very strongly that there's still too many physicians, especially family physicians that deal with older adults, that don't- that don't advise their patients to get a diagnosis. They- I think they think that dementia is a normal part of aging.

Subtheme 1: Little to no education from the diagnosing provider

The participants were asked a few questions on who they received their diagnosis from and what that was like overall for them. All 10 participants had different experiences with who provided them education. However, a common theme was that they felt like once their loved one was given the diagnosis, they were given a few facts on the diagnosis but nothing on the progression of the disease or the available resources in the community. Several of the participants (participants 1, 2, 3, 4, 6, 7, and 8) reported that they learned more about the disease after trying to research it themselves or after they had to urgently move their loved one into a care community, whereas participant 5 reported that they did learn about the disease from their provider or a geriatric care manager at the time of diagnosis or before they transitioned their loved one into a care community.

Participants 9 and 2 reported that the only reason they were able to navigate things for their loved ones are because they work in the field of geriatrics and care communities and resources, otherwise, they (participants 9 and 2) did not get any other resources or education until their loved one was in a care community. Participant 9 was a geriatric care professional but each of them (participant 9 and 2) had similar experiences with not receiving education from a provider at the time of their loved one's diagnosis. Participants 2 and 9 shared their thoughts on at what point, if at all, they received education on dementia as a disease from their providers. Participant 2 said, "I don't know that I can identify anytime anyone gave us information until he moved into memory care." Participant 9 added, "I'd have to say none. I think we had gone through it once before once before, and I don't think anybody really gave me any information."

Subtheme 2: Did not know "what now" after diagnosis

When this question was asked, the participants shared that several of them struggled with the what the next steps were after the new diagnosis and what needs their loved one would have now versus in the future. Participants reported that they did not feel they knew what to do once the diagnosis was given and that led to them having added stress over concerns that they had (Participants 4, 5, 6, 7, 8, 9, and 10). There are several quotes from participants who had both negative and positive experiences and what those were. Participant 5 stated "…he basically kind of gave us options as far as what we could do, but it didn't really cater to my mother's specific situation, so um kind of left out on our own a little bit my sister and I basically.". He felt that he did not have information that was helpful to what his mother was experiencing, and the doctor provided a generic answer and not a patient-centered answer to meet her needs.

Participant 3 had a more positive experiences with their navigation of the community resources upon the diagnosis of their loved one. They had support from a care navigator that they were matched with to help them understand the diagnosis and also to understand the options for care needs in the community. Below is a quote from participant 3 on their experiences working with a care navigator in finding their loved one's care needs and having them met.

> My sister was a legal admin for a law firm elder care law firm, and she had access to a person a woman that was an expert on care it's and nursing homes in the Washington DC area now we will go… my sister and I worked with this woman about everything. She advised is this on where to send her. On what to expect, I mean we spent a couple of hours one night with this lady and it was extremely helpful and based on her advice we- we selected the assisted living facility that we did and yeah, we kind of knew what to expect.

Theme 2: Lack of health education and navigation of care resources for people with dementia provided to family member caregivers during the transition process.

The participants in the study talked about how they felt that they did not have enough supportive resources in their journey to get their loved one with dementia the help and care that they needed. All the participants reported that upon diagnosis, they did not hear much about their loved one's dementia, what was needed, and what was available in their communities. They also reported that they did most of their own research to find out what was available in their community and any of the caregivers or the care communities they ended up with were primarily of their research. P10 and P9 reported that they only had an easier time with locating care resources to transition because they worked in the field of geriatrics. Participants P3, P4, P5, P7, P8, P2, and P1 reported that they did get some health education from their care communities once their loved one was there, but it was primarily about the changes in care that they were getting (toileting needs, going from 1 person assist to a two person assist, etc.) and not as much about dementia. Below is a quote from participant one that talked about their experiences with obtaining information on resources and the stressors.

> In DC it was not good. She did not qualify for the waiver; she makes too much money in Social Security. The only option was a nursing home and so that was a short stint, and she was rehabilitated enough to be eligible for assisted living and we relocated her to Florida at that point because they're able to establish residency down there and they have a much better healthcare system for people with limited resources.

Participant 3 talked about his experience with having to obtain the health education through the internet and what he was able to learn by having to search for it on his own.

> I learned a lot I suppose. I learned more after she was diagnosed, well, I know I did because I also did research on the Internet on what to expect and also mentally, I guess the biggest part was mentally how I should handle it. For instance, when she, when it was obvious she didn't know who I was or know my name, I needed to react a certain way to that so as not to upset her, you know,

> things like that. What was going to be my role and in this whole thing possibly. Like I said, I did I did internet research on dementia in general, it's the stages, and so forth and uh the longevity of and you know how many years she might live through this, things like that.

Subtheme 1: Could not get information (education) from healthcare team either outpatient or in the care community.

The participants were all able to report out what they felt their level of understanding of dementia and its care requirements were and how they gained that knowledge. All of the participants reported that they received little to no education from their loved one's healthcare providers, either their outpatient provider who made the diagnosis or the team in the care community. Participants felt that from the start they were having to navigate through things on their own mostly to find care and/or a care community to move them into. Participant 10 described having "little to none" regarding education, and Participant 1 noted the following. "None. I shouldn't say that I think I was given a pamphlet but there is really not a lot of discussion about what to expect, how to manage her day-to-day life, there are not really resources provided."

With the crisis situations, participants reported that they felt somewhat rushed into finding their loved one care and that it was more of a reaction and there was not much time, if any, to be proactive. Specifically, two participants had described their crisis situations as having a need to find their loved one a care community in a very short amount of time. Participants 2 and 1 were others were juggling full-time professions, their own family being pulled in emergently to help and having to find their loved one the proper care and getting them into a safe caring and affordable environment. Participant 2 shared this perspective:

> We did not have a choice. It was a crisis situation so I was not able to reach my mom I was out of town and I called non-emergency police departments to do a wellness check and she was not okay, but she was completely out of it, not aware of her surroundings, wasn't able to answer questions like this is the president, what day it was, and so she was brought to the hospital and we all agree that if it there was no other options, there was no other state discharged but to find a community setting for her.

Participant 1 shared their perspective as well, below are their thoughts:

> Yeah, I appreciate that. But my mom just, it's like she walked off a cliff. You know, fear was constant in her, you know what's going to happen to me? At that point, we were dealing with so much. And not only, burying my dad but trying to take care of my mom at the same, and dealing with all of the legal things, you know, she couldn't stay in the house by herself, so you know, trying to set her up at my sister's house and tag teaming and that kind of thing. It progressively just got worse very, very quickly. So, I would have to say to answer your question directly- we did find that when the home situation thing didn't work after a couple of months, it was just very um … not healthy, I guess is the best way to say it.

Subtheme 2: Hard to navigate the internet independently

When addressing the topics with the participants on health education, several areas were brought up in terms of their understanding of the diagnosis and what care tools are available to them. All 10 participants stated that they looked on the internet for dementia health education information and 4 participants reported that it was at times overwhelming for them to be able to find information or find the right information because they did not know what they were looking for in general. Participant 8 reports that they gained most of their understanding of dementia and care options from various places and all were things they had to search for on their own.

> None. I just started reading. I read… I read blogs, I read books, I read magazine articles, and journal articles, and I just started filling in the gaps on my end. There was no formal nothing formal.

Participant 6 also shared thoughts on this.

> …they would tell me what to expect, but most of it- most of it, I have to say, during the whole time, was my own research, and observing- observing other people. I didn't – I don't think I realized at the time, but that gave me a really good education, if you want to call it that, of the disease itself.

Participant 7 reported that they were told by their loved one's healthcare professional that they should go to a website and read from there. Nothing was provided directly to them from the healthcare professional making the diagnosis, which as previously stated, others also had to rely on the internet research that they did.

> Go to this website and do your own research is basically all we were given upfront… Maybe not one-on-one hand holding, but somebody helping you find the answers to your questions and just, instead of just saying, go to the Internet, which was basically what we got.

Theme 3: Women caregivers have shown a higher rate of involvement in caregiving of their loved one with dementia than men and reported seeing more of the perceived benefits to a higher level of care.

All the participants reported their level of involvement in their caregiving time for their loved one. Based on the reports given, many of the female caregivers were very involved in the caregiving and decision-making processes for their loved ones with dementia and the male caregivers reported that their female counterpart (wife, sister, or daughter) did most of the caregiving or decision making for that loved one over them. There were 4 participants that were family to each other, two were siblings and two were married (husband and wife) and they yielded similar outcomes showing that the female caregivers were very much involved in the process and their male counterparts were involved but relied heavily on their female family member making a majority of the decisions, gaining most of weight of the decisions and stresses that come with it. The subthemes below each show the differences in the interviews and viewpoints that the male caregivers had versus the female caregivers. Participants 3 and 5 reported that they had female family members that were more involved in their loved one with dementia's caregiving process than they were and that often times reported that their female family member counterpart knew more of the specifics on their care and care needs than they did. Participant 3 shared his thoughts on his sister's participation and being the predominant caregiver with the facility overall.

> My sister may have because she was the point of contact you know they all went through her the burden the burden of the daily care and planning fell on my sister.

> My sister would get the calls when my mother was sent to the hospital or whatever.

Participant 5 shared his thoughts and experience with his wife being the primary point of contact caregiver for his mother, while he helped.

> It got to the point where my- my wife was her main caregiver and she could not handle her physically, 'cause she wasn't able to stand as much and move around as much. That, I will say, is the worst decision I've ever made in my life. It had to be made, but I would- I would not- I would not do that again. Let me back up: it's probably the worst decision I made with regards to my mother.

Subtheme 1: Male participants reported their female spouses or other female family took on the majority of the caregiving duties

For this study there were 4 male participants. One of them had a sister participate in the study and another had his wife participate. Seeing their answers and how they reflected that their female counterparts took on more of the direct responsibilities showed more in these sets of interviews. P3 also stated that his sister took on a major role of caregiving for their mother while he looked for a care community and made other arrangements because their loved one with dementia had many special needs. Participant 3 stated specifically how his sister was in the major role in caregiving and also with the processes that the care community and care teams that were involved did with her as the primary family member caregiver.

> Well, I mean don't forget so my sister was the conduit right not me, so a lot of that information went to her directly or through her. Certainly, hospice for sure I

> was just a you know a visitor so to speak and then in terms of the health care um yeah the director and the nurses in the facility they would have to my sister as well so she got… I don't know I mean I didn't get I didn't have someone come up to me from that worked there and say OK this is what you're going to expect this is what's going to happen they would do that stuff with my sister if they did it all so I don't know.

Thus, they were either in crisis mode or they already had a lot going on in their family lives and were trying to navigate this. There were reports also of how very different an experience they had with getting into a care community and the care received there for their loved one with dementia. Participant 1 shared his experience with the care community his loved one with dementia got into was one that was welcoming, and he felt that the nurse and administrator was kind to his mother.

> Actually, the care community was very good. They had a head nurse/ administrator that kind of, um, not only with all the paperwork and all the other stuff, but just welcoming my mom the way they fussed over her, they made her feel real easy.

Participant 5 reported that the move was harder on him than it was for his loved one and even though he did not feel that he received any health education from either set of care resources, he felt that she was cared for by the treatment teams. Participant 5 shared his thoughts on his wife being heavily involved in the process of caregiving for his mother. He shares his experience in the quote below.

> I don’t think there was any problem getting her accepted. Um, moving her in was difficult for me, I don’t think it was difficult for her. And I’ll say that that discussion that I had with her is probably the- the first time that she was a- she was my mother again, telling me not to worry about it when I told her that’s what we’re going to do. But the- the getting her in, accepted, I don’t think was a really difficult thing. Picking a place, we spent some time doing that, but getting her in wasn’t problem. I think, again, leaving her there was probably more difficult on me. So, my wife probably read about it and told me about it before anybody else told me about it. So, what everybody would have told me about most of what I learned was probably from my wife… It got to the point where my wife was her main caregiver and she could not handle her physically, ‘cause she wasn’t able to stand as much and move around as much.

Subtheme 2: Women were more descriptive of their involvement in caregiving than men, men described more of their female family caregivers’ role and their assisting

There were 6 female caregivers and 4 male caregivers that participated in this research study. Of those interviews with the female caregivers, their answers to the questions and process started were generally more descriptive and involved whereas several of the male caregivers usually had short descriptions or referred to their female counterpart as the person who “did most things” and they were there to help but were most likely not primary contact/go-to person. Participant 4 talked about her experience with the caregivers initially working to support her in caregiving for her mother with dementia, how her mother's care needs evolved over time and the experience that she and her mother had in those changes between both home and also in the care community.

> I'd say her care – her personal caregivers – you know, being in there 5.5 years, I got to know everyone and . . . and her nurse. Usually, it was one nurse and then different caregivers throughout their shifts. They would've, for instance, my mom all of a sudden didn't want to take showers anymore. And when I mentioned that to the nurse, she said that was – that was normal, it happens a lot, but, you know, not to worry, she would – she would give her a shower. And she went through the whole procedure, how she would do that. And the reason, she said, your mom is not wanting to take a shower anymore, a lot of times, people with dementia – when they get to this stage – they're afraid of water. They get in the shower, because when you're in the shower, the water is hitting you. And a lot of them think that they're being hit. They don't understand that it's the water coming out of the shower anymore. They just can't understand that, or they don't grasp that anymore. They just think that someone is hitting them or hurting them. So that was one of the things that I learned. I also learned about her eating. She- before she went into Memory Care, when she was in assisted living there, she had to go into a special dining room because she didn't want to eat anymore. She was losing her appetite.

In seeing participant 4's experience, participant 6 talked about her experience juggling many of the things in her own personal life and family that she was trying to support while also caregiving for her loved one with dementia.

…I mean I was doing everything. I had a high schooler, I had a daughter in college, a high schooler and a younger child, four years younger, than high school. So, 5th grade, 5th grader, 9th grader, freshman in college… That's all I could do was she was very needy, so but and I had too, it was like physically needy, it wasn't like, "can you sit with me," although that too, you know. So, I had to get some in home care so that I could do other things as well, you know, I was running my home and so, Umm, so for the in-home care, I really just needed a little extra help and as time went by, it was more. At first it was a little bit, and then it got to be more and more. Finally at the end, and I went also, I had some people that I knew that did that and they helped and they were wonderful. The company, you know, it's only as good as the people who are hired. They're getting paid, you know, I don't even know not that much and they um they don't really love her the way I did. They have to kind of get to know our house and you know it's just it's a strange thing to have people come into your house to help. By the time she went into the care facility, like the all the time living there she was falling on caregivers. She was to the point, she, she tried to help to try to get her back up into her wheelchair but she what, she would do would work against us and she needed to be in the wheelchair all the time I couldn't lift her... and our house really wasn't designed like a place has you know, linoleum floors and wide doors and easy into the shower type of thing. So, so we had to go with a place because we could no longer physically do it.

Participant 8 talks about how overwhelming the caregiving was at times with all she had happening in her family at the time.

> We could not keep her safe we had I still continued to work. I'm a teacher and I was planning one of my daughter's weddings, my son was in a legal custody case for his child, there were a lot of things going on. We hired… first we hired visiting angels to come in but there was no consistency with the people who were coming and that was bothering my mom um… so then we hired independently people to come and take care of her and as she progressed trying to manage everything, you know to get her counseling for the brief which wasn't successful because of dementia.

Theme 4: An increase in stress during the caregiving process

For caregivers, there are various levels of work that goes into caregiving from supporting the loved one with dementia to get to doctor's appointments, shopping for needed things, taking there medications and even managing the cleanliness of their home and themselves. When interviewed, there were participants that stated there was an increase in their stress while trying to manage their loved ones needs as well as their own life needs. Those who did not state that they were outwardly stress showed it in their body language and emotional responses in the way they sounded when discussing it, listing the numerous things that they were managing. There were participants that were family (married or biological) and their male partner stated that their female caregiver counterpart provided a majority of the caregiving and decision-making over what they [male caregivers] did. Participant 5 talks about his wife's increasing struggle to care give for his mother with her dementia care needs overall and the stress involved, noting, “it got to the point where my- my wife was her main caregiver and she could not handle her physically, cause she wasn’t able to stand as much and move around as much.”

Participant 6 talked about all the things that she was managing and how that could had been overwhelming, and how much care her loved one needed once they finally transitioned into the care community, her quote is below.

> Yeah, so the first one the in-home care that we got the reason, I was doing everything. I had a high schooler, I had a daughter in college, a high schooler and a younger, four years younger, than high school… By the time she went into the care facility, like the all the time living there she was falling on caregivers. She was to the point, she, she tried to help to try to get her back up into her wheelchair but she what, she would do would work against us and she needed to be in the wheelchair all the time I couldn’t lift her...

Subtheme 1: Caregivers feeling overwhelmed when they were caregiving or finding care for loved ones with dementia

The participants were able to discuss their views on how things were going from an emotional perspective. When talking to the participants for many, even though these diagnoses and transitions were behind them, their body language still showed and emitted an emotional response that this experience was still affecting them emotionally. Three participants were tearful or verbalized feelings of regret for how they wished they could have handled things or what they wished could have been a less stressful process for both them and their loved ones with dementia. Participant 5 recounts his feelings of stress and experience with the transition, the stress behind caregiving he and his family experienced and his feelings after the transition.

> I maybe it was just a facility where we were, but I would never do that again with somebody that I had control over. I did have control over that decision. I think that, um, with- with a few exceptions, everybody was there doing a job and, um, didn't really care, um, too much personally about her. And my brother and I would go there every day and I told, at the end I told them, "My bar is low. You know we come at 5:00 o'clock. At 4:00 o'clock, somebody please just change her. You know we're coming." So that- that- my experience with that facility was, you know, I heard my- I walked upstairs, my wife was talking about it. My- I'm a little bit, I think, a little bit harsher than she was, um, about it. But that, you know, and- and having people come into the house is also challenging too because you've got now this stranger in your house kind of, uh, trying to blend in with your family. And some of them did it very well, some of them were great. But when it came down to it, they were employees of this company. And if they had problems with the company, they didn't- they didn't come to work here. They would, you know, not- not show up or- or one of them ended up quitting. She was, I think, the best one we had. She had a dispute with the company and left. Others would come in and not only try to take care of my mother but maybe take care of my boys, which, you know, kind of rubbed them the wrong way. It's just different- different having somebody in your house. It's- that- that's the best way I can put it.

Subtheme 2: Lack of emotional support for the loved one with dementia during the transition process

The Alzheimer's Association (2021) states that depression rates for someone with dementia is higher in the early and middle stages, because the person with dementia is likely still aware of what was happening, the changes in their cognition are something that they can notice, and it can trigger depression symptoms. Participant 9 reported that their loved one experienced a decline in their mental health and that it was not something she as the caregiver was prepared for seeing or dealing with.

> I also did not understand that depression could become a thing. My father had never shown any signs of depression and then that was just a really difficult thing to watch because he knew what was happening. In the beginning.

Summary

This chapter reviewed the process for and presented the results of this research study that examined the experiences of the family member caregivers of loved ones with dementia. The study looked at what health education they received if any, what resources they were provided if at all, and what they understood about dementia. The understandings that were provided were along the lines of there being a lack of health education that was provided at the time of the dementia diagnosis being given, and the family member caregivers felt that they did not know what to do next. The family member caregivers provided their experiences with finding education on dementia to be hard and also finding appropriate resources in the community for care needs was hard to find and link their loved one to. The participants shared their experiences with care needs at a care community and what they did to get them accepted into and cared for properly in a care community, many being emotional about that experience. There was an overwhelming sense of stress and dissatisfaction with their healthcare teams on education and understandings with dementia and care needs. Chapter 5 will go over the limitations and findings of the study, the recommendations for future studies, social change implications and the conclusion for the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore and understand on a deeper level what barriers, struggles, supports, and health education resources there are or are not for family member caregivers of a loved one with dementia in a care community in the DC metropolitan area. While reviewing the literature, the existing research predominantly focused on the needs of loved ones with dementia, while providing minimal insight into the available educational tools or addressing the caregiving requirements for those caring for a loved one with dementia. A qualitative study was selected to conduct semi structured interviews with the 10 participants who were able to provide their perspectives on the process to connect their loved one with care resources in the DC metropolitan area, as well as their experiences with health education, or the lack thereof, for dementia. Qualitative studies frequently allow researchers to discerningly construct the necessary parameters and requisites within a research study, facilitating a tailored approach to knowledge acquisition. I utilized it to gain and understand the participants' experiences, the emotions tied to them, what their experiences meant to them, and how they transformed their perspective on the topic and their actions. Since there was not a lot of research like this already, this was a large piece that was missing to support the family unit and not only the loved one with dementia.

Chapter 5 will provide the interpretations of the findings from Chapter 4, limitations of the study, recommendations for future research, implications of the study to the field, and summarize of the overall process and study. The qualitative approach was beneficial when exploring the topics and understandings and to expand on the research needed for the geriatric field. This chapter includes the interpretation of the findings, limitations of the study, recommendations for future research, implications for social change and then conclusions.

Interpretation of Findings

After reviewing the method by Clarke and Braun (2017), I was able to analyze the data via a six-phase coding and thematic analysis. I utilized this process to identify themes related to my research questions, with the primary question as the main foundation for the study: What are the health education barriers that family member caregivers of a loved one with dementia have? My analysis revealed four major themes and two subthemes for each major theme found. The themes and subthemes that were found help to further confirm what was seen in other research I reviewed.

Notably, there are gaps, deficiencies, or areas of inadequacy within the process being discussed for family member caregivers of loved ones with dementia in getting educated on the diagnosis, getting connected with appropriate resources for care needs, and also for support for the caregivers throughout their time with their loved one caring for them. The themes, subthemes and findings aligned with the HBM theoretical framework and health education upon analysis and are outlined in the Table 5.

Table 5

Alignment of Research Questions with Emergent Themes & Analytic Categories

Research Questions	Emergent Themes	HBM Analytic Categories
RQ1: How do the family member caregivers describe what their needs are for health education to help with making informed decisions about higher levels of care for their loved one with dementia within their care communities in the DC metro area?	Theme 1: lack of health education provided at the time of diagnosis Sub theme 1: No education from the diagnosing providers Sub theme 2: Did not know what to do after diagnosis was given	Health Education
RQ2: How do the family member caregivers describe the barriers of pursuing a higher level of care for their loved one with dementia who live in a care community in the DC metro area?	Theme 2: lack of health education and navigation of resources during the transition process Sub theme 1: Felt they could not get information from the healthcare team Sub theme 2: Felt it was hard to navigate the internet independently for information	Perceived Barriers
RQ3: How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to the quality of life/care within their loved one's current care community in the D.C. metro area?	Theme 3: female caregivers show higher rate of involvement than male caregivers Sub theme 1: no support emotionally for the family member caregivers while they were supporting their loved ones with dementia. Sub theme 2: no support emotionally for those loved ones with dementia during the transition	Perceived Benefits
RQ4: How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?	Theme 4: Theme 4: An increase in stress during the caregiving process. Sub theme 1: the men in the study reported their female spouses or other female family took most care Sub theme 2: the women were more descriptive in the interview; the men did not have as much information on caregiving experiences for loved ones.	Perceived Severity

Table 6

Alignment of Key Findings (Themes and Subthemes), Theoretical Framework and Previous Literature Studies

Theoretical Framework	Key Findings (Themes and Subthemes) & Theoretical Framework	Previous Literature Studies
Health Education	Theme 1: Lack of health education provided at time of diagnosis Subtheme 1: No education from the diagnosing provider Subtheme 2: Did not know "what now" after diagnosis	Paque et al., (2018): Living in a nursing home: a phenomenological study exploring residents loneliness and other feelings Lee et al., (2017): Usages of computers and smartphones to develop dementia care education program for Asian American family caregivers Szabo et al., (2018): Educational preparedness to provide care for older adults in alternative practice settings: Perceptions of dental hygiene practitioners Sripad et al., (2019): Exploring survivor perceptions or pre-eclampsia and eclampsia in Nigeria through the health belief model
Perceived barriers	Theme 2: Lack of health education and navigation of resources during the transition process Subtheme 1: Could not get information from healthcare team both outpatient and at the care community Subtheme 2: Hard to navigate the internet independently for information	Sherbuk et al., (2020): A qualitative study of perceived barriers to hepatitis c care among people who did not attend appointments in the non-urban US South Storti et al., (2016): Neuropsychiatric symptoms of the elderly with Alzheimer's disease and the family caregivers' distress Macleod et al., (2017): "There isn't an easy way of finding the help that's available." Barriers to facilitators of service use among dementia family caregivers: a qualitative study Hoedemakers et al., (2018): Evaluative an integrated care programme for frail elderly using multi-criteria decision analysis. The design of a case study in SELFIE
Perceived benefits	Theme 3: Female caregivers show higher rate of involvement than male caregivers and saw more of the perceived benefits of the higher level of care for their loved one with dementia Sub theme 1: no support emotionally for the family member caregivers while they were supporting their loved ones with dementia. Subtheme 1: Male participants reported their female spouses or other female family took on the majority of the caregiving duties Subtheme 2: Women were more descriptive of their involvement in caregiving than men, men described more of their female family caregiver's role and their assisting	Brandao et al., (2016): Underuse and unawareness of residential respite care services in dementia caregiving: Constraining the need for relief Chilale et al., (2017): Clients and carers perceptions of mental illness and factors that influence help-seeking: Where they go first and why Murray and Butow, (2016): Advanced care planning in motor neuron disease: a systemic review Tang et al., (2015): Perspectives on prevention of type-2 diabetes after gestational diabetes: a qualitative study of Hispanic, African-American and White women Webb and Dening, (2016): In whose best interest? A case study of a family affected by dementia Yeboah, C., (2015): Choosing to live in a nursing home: a culturally and linguistically diverse perspective

(table continues)

Table 6 cont.

Alignment of Key Findings (Themes and Subthemes), Theoretical Framework and Previous Literature Studies

Theoretical Framework	Key Findings (Themes and Subthemes) & Theoretical Framework	Previous Literature Studies
Perceived severity	Theme 4: An increase in stress during the caregiving process.	Andrews et al., (2017): Knowledge of dementia: Do family members understand dementia as a terminal condition?
	Subtheme 1: No support emotionally for the caregivers when they are caregiving for loved ones with dementia	Goeman et al., (2016): Evaluating the efficacy of the "support for life" program for people with dementia and their families and carers to enable them to live well: A protocol for a cluster stepped wedge randomized controlled trial.
	Subtheme 2: Lack of emotional support for the loved one with dementia during the transition process	Morgan et al., (2014): Evolution of a community-based participatory approach in a rural and remote dementia care research program
		Toye et al., (2014): Dementia knowledge assessment tool version two: Development of a tool to inform preparation for care planning and delivery in families and care staff
		Zhou et al., (2016): Delayed help seeking behavior in dementia care: Preliminary findings from the clinical pathway for Alzheimer's disease in China (CPAD) study

Many of the caregivers reported they had to navigate things on their own, which often led to their stress and emotional unwellness as well as the stress and emotional unwellness of the loved one with dementia, echoed by other family member caregivers of a loved one with a chronic illness in other literature reviewed. A case study completed by Webb and Dening (2016) showed that family member caregivers struggle with being able to provide adequate support on their own, and that it places heavy stress on the loved one needing care and the family member caregiver. Many individuals recounted their attempts to care for their loved ones in their original or personal homes, only to find it untenable due to diverse safety concerns and complex care needs. Consequently, they expedited the transition process to relocate their loved ones to a suitable care community.

The Webb and Denning (2016) case study walked through tension and stress brought to the home and personal lives, and this was a recurrent feeling noted in several of the caregiver's stories as they talked about their caregiving experiences and how that may have affected their decisions in what services they chose.

Caregiver burden is defined as any person that is providing services to help support a loved one's safety, health, and wellbeing; this can often be a lot of responsibility on a person in addition to them having to manage their own day-to-day life (Thomas et al., 2019). It was clear from the research study that all the caregivers had some level of caregiver burden when caring for their loved one with dementia, something that can affect their stress levels and has shown to cause situational and clinical depression. Through the literature review, caregivers reported that they experienced emotional and psychological distress that negatively impacted them, and others also experienced developing physical health conditions because of the type of caregiving they may have done or been involved in (Thomas et al., 2019).

Several of the research study participants talked about their experiences with caregiving, noting the struggle to get their loved ones into a comfortable setting for care when they felt that they could not care for them in their personal home or their loved one's homes anymore. Participants shared their accounts of encountering physical limitations while attempting to lift their loved ones, often finding themselves unable to do so. Additionally, caregivers expressed emotional defeat as they faced a dearth of viable options that they could discover independently. The participants presented a range of perspectives regarding their interactions with the facility staff. Some expressed positive sentiments, highlighting the exceptional care and genuine affection they perceived the staff to have for their loved ones. Conversely, others felt that the staff merely fulfilled their job responsibilities without the desired passion or level of warmth they wished for. Caregivers of a loved one with dementia are more likely to develop a mental health condition because of their caregiver duties. In 2022, a study in the World Journal of Psychiatry showed that one in three caregivers develop depression when caregiving for a loved one with dementia (World Journal of Psychiatry, 2022).

Limitations of the Study

When utilizing qualitative methodologies for the research method, it can involve several steps for sampling, data collection, and analysis. Qualitative research generally involves sampling a chosen population, collection and analysis of data from that population sample, and then interpreting or coding data that is not easily able to be reduced to numerical data (Palinkas et al., 2015). The data I collected focuses on the social and emotional world of the family member caregivers and their behaviors involving their experiences with those that they cared for (Palinkas et al., 2015). The 10 participants in my study were family member caregivers to loved ones with dementia living in the DC metropolitan area. The participants were asked to share their experiences and perspectives on caregiving for their loved one throughout various stages of dementia.

There are several limitations that can come up in qualitative research studies in general. Thus, the rigor of qualitative research can be harder to overall maintain and demonstrate whereas in quantitative research has the consistency or level of concreteness of numbers that can come out in data (Anderson, 2010). The amount of data to review and go through can be time consuming and no matter what is done, a researcher's bias and presence is among the data collection that can affect how the participants respond (Anderson, 2010).

As discussed in previous chapters, there are several limitations including participant selection, sample size, and the self-reporting perspectives of the family member caregivers. All participants were alerted that this process was voluntary, and that if there were experiences, they did not feel comfortable sharing, they were not required to. Participants were educated on the study and the purpose and encouraged to express their feelings honestly and as fully as they wanted to. I live and have worked in geriatrics in the DC metro area, as well as helped care for an older adult in my family with a chronic illness, all of which were experiences able to help bolster the trustworthiness of my study with the participants. To address potential concerns regarding objectivity, I took precautions by excluding participants who had loved ones residing in the care community where I previously worked. Instead, I focused solely on family member caregivers whose loved ones with dementia resided in care communities in DC, Maryland, and the Virginia areas that were unrelated to my professional experience or personal acquaintance.

All interviews were recorded on the Zoom platform that they were conducted on. Each participant was provided with verbal and written forms of the information on the research study and the informed consent. All participants were alerted to the nature and purpose of my study, what was being asked of the participants in the process, their rights and ability to withhold information they were not comfortable sharing, that they were able to withdraw at any point in the study, and that any information they shared would be deleted and removed from the study results. Based on their decision to consent and follow through with the interview and share what could be considered as very personal experiences, it can be reasonably assumed that all participants shared honest perspectives and experiences. To help with preventing bias, responses were limited to the perspectives of the individuals that were interviewed, and peer debriefing, triangulation of data, and member checking were used to help ensure that results were trustworthy in quality (Patton, 2015).

For this study, I utilized a snowball sample style to recruit participants. With the geriatric treatment community network being very connected, I was able to reach out to fellow professionals to help with initial recruiting. Snowball sampling is a nonprobability sampling technique that involves the existing subjects provide referrals to the researcher to recruit new participants to the study (Babbie, 2017). The primary data source essentially nominates other primary data sources. The type of snowball sampling that was used in this study was exponential non-discriminative snowball sampling. In this type of study, the initial primary data source participant provides multiple source referrals for future participants in the study, and then after that those new participants also provide research source referrals until all research study spots are filled (Babbie, 2017). While there are several positives to snowball sampling and what that looks like with getting new people into a study, it also has its limitations for a study. One limitation was that this study was leaning primarily on the word-of-mouth recruitment from the healthcare professionals I knew in the geriatric field, and then also the participants as they came into the study.

Because there was a network of professionals, I was able to reach out, get one to two participants and from there those participants were able to share others with me, sending others that they thought would meet criteria to my study and that continued until I reached 10 participants in total. The limitations of a larger study could be that I, the researcher wouldn’t be able to really connect, and the data can become repetitive in nature (Faber & Fonseca, 2014). The goal is to gain proper saturation in a study in qualitative research and so that means once you feel that there is enough data you should stop collecting data, this is to prevent the overly repetitive nature that could lead to oversaturation. On the other hand, a small sample size has a limitation as well that can also make it difficult for the researcher to really determine a specific finding and if it is a true outcome (Faber & Fonseca, 2014). They can produce a false-positive result or even over-estimate the level of importance of a result shown or found in a study (Faber & Fonseca, 2014). The participants were more connected because they knew others locally who were also caregivers to loved ones with dementia and their enthusiasm for the study allowed them to willingly connect me with others. These are the several limitations of this qualitative research that can be reviewed for the purposes of this research.

Recommendations

With there being so many types of dementia, there is not a lot known about many of them, the symptoms, how to manage them and what treatments are needed (Alzheimer’s Association, 2021). There is a scarcity of studies that specifically delve into the experiences of family member caregivers who are responsible for the care of loved ones with dementia (Macleod et al., 2017). Future studies need to explore crucial aspects such as the family member's education, their capacity to secure suitable care as the disease progresses, and the resulting implications of inadequate support and awareness. This research aims to enhance the understanding of healthcare professionals and community decision makers regarding the needs and consequences associated with dementia caregiving. For many families, the ability to support older adults is challenging as they may have children, spouses, and jobs that they are juggling on their own and cannot always provide the full care needs to those older adult loved ones. My study was limited in the findings that came from a qualitative methodology due to it only containing 10 participants in the DC metropolitan area. My recommendation is for there to be further research using qualitative methodology and aligned frameworks to better understand on a larger scale the perspectives and experiences of family member caregivers for loved ones with chronic illnesses but especially dementia. Future research studies should prioritize investigating the ways to assist family member caregivers in navigating the available care options, understanding the associated costs, comprehending the criteria for each option, and assessing the implications of choosing one option over another. This comprehensive exploration of caregiver support should form a significant component of future research endeavors.

Another theme of the research study was looking at what educational needs there are for dementia as a whole and being able to understand the disease and the implications behind the disease. Among the 10 participants, several individuals expressed similar sentiments regarding their lack of understanding about the diagnosis of their loved ones with dementia. They shared experiences of having to independently seek out educational materials and gain their own understanding of the condition. Additionally, they expressed a desire to receive information and knowledge directly from the healthcare professionals responsible for diagnosing their loved ones. Obtaining further information on these experiences would be advantageous for healthcare professionals and geriatric stakeholders. This knowledge can aid in the development of policies, securing additional funding, and creating avenues for diagnosing providers to offer comprehensive services. Whether provided by the diagnosing provider themselves, a nurse care coordinator, a case manager, or a health educator, there is a need to enhance the capability of healthcare professionals in delivering such services. Additional recommendations are to look at experiences for populations that live in suburban and rural areas in addition to urban areas and compare them to further understand the public health crisis that is dementia as a diagnosis and a lack of supports for dementia caregivers. By adopting a more global perspective on the subject, it becomes possible to identify potential similarities and differences in the themes observed across the provided information. This approach facilitates a clearer understanding of the specific support initiatives required by various populations and regions, enabling targeted efforts to better address their needs and create better support initiatives.

A final theme of the research study that was examined was what emotional supports are available to both the family member caregivers and also the loved one with dementia (and other chronic illnesses). Participants in the study were very open and honest about their experiences as caregivers and how it affected them emotionally and also took a toll on their loved one with dementia emotionally. There was an increase in depressed feelings, isolation and hopelessness that were described as having been experienced by both loved ones with dementia and the participants (the family member caregivers). Understanding mental and cognitive health can be difficult to navigate for anyone, no matter the level of support. One of the things that many caregivers do not always realize is that they are not only supporting their loved one with dementia but also with their mental health. The diagnosis of dementia can often lead people to develop depression and anxiety amid processing the diagnosis and what this could mean for their futures and care needs. According to Dr. James Ellison with the Bright Focus Foundation, one in six people diagnosed with dementia also suffer from major depression and that the incidence rates are even higher for those with dementia that are residents in a care community such as a nursing home (Ellison, 2021). Health educators can work with the family member caregivers and the loved ones with dementia to understand the implications of this diagnosis on everyone's mental health, what to look for, signs and symptoms, and resources to help with managing and/or treatment mental health needs. This is a huge need among this population that is a role that health educators are able to fill allowing for more supports to be present for those in these two populations.

Implications

The discoveries in this research study have the ability to positively impact social change with the population of caregivers in all areas. This study focuses on the barriers that family member caregivers have in taking care of their loved ones with dementia. It uncovered the lack of health education provided on the diagnosis of dementia, the lack of education on resources available to help with proper planning and also lack of emotional support for the loved ones with dementia and their family member caregivers. Dementia is a chronic illness and there are many other chronic illnesses that take family member caregivers to help offer support to their loved one. Not having enough health education, emotional support, and navigation in other resources is something that can cause burnout in many family member caregivers. Understanding the level of care and the amount of education and participation needed for other loved ones that care for other chronic illnesses is imperative to help the loved one and also the person with the chronic illness.

Positive Social Change

The study can help with changing organizational levels and policy by working to have a dedicated staff member (nurse, social worker, health educator, and/or geriatric case manager) that works with families who need education and need assistance with navigating what the care resources are and what the diagnosis is, the prognosis and be there to assist on a regular basis. Organizations that could benefit from having this resource available are geriatric doctors and providers, care communities, home care agencies, elder law firms and also hospitals. This research can serve as a valuable means of connecting patients and families to the necessary education concerning the diagnosis and the challenges they may encounter throughout the journey of a chronic illness. Providing up-to-date and readily available resources aimed at ensuring the safety and proper care of their loved ones with dementia, while also supporting family member caregivers help to mitigate the risk of burnout in the process.

Recommendations for practice consist of having a specific position that can provide education to patients and family member caregivers when their loved ones are diagnosed with dementia. A health educator can be a professional that is clinically licensed (a nurse, a social worker, and/or a psychologist) or that has an educational background in public health/health education. The topics that health educators can discuss with patients and family members dealing with new dementia diagnosis are teaching them about what dementia is, the progression that the disease can make and what to possibly expect, how to manage with treatment and proper follow up with their general practitioner or neurologist and also teach about the local resources in the communities that they work in that can help support and care for both the patient with dementia and the loved ones who care for them. The benefit can be that this person can establish a program that follows patients upon diagnosis and keeps in touch with the patient and their family member caregiver for needs on follow ups, facilitate referrals for community resources and provide ongoing education on relevant topics, both at the initial stage and as new challenges arise. Many offices have an advice nurse to help field clinical calls away from the doctors and allow for triage to happen; this would be similar but for the health education needs and resource connections as well.

Clinical practices could look at utilizing grant funding to help pay for this position and resources as well as research various billing codes that can be utilized to help with being able to afford the position as well. Mental health professionals are also able to be trained in working with neurocognitive disorders under geriatric social work and those who are clinically licensed can assess and support patients and family member caregivers and often depending on the needs, can bill insurance for that to help it be more affordable and obtainable. Professionals working in policy can utilize data obtained in public health settings to make social change by advocating for laws, funding, and policy changes on local, state, and federal levels.

Conclusion

The primary objective of the research study was to comprehend the experiences and needs of family member caregivers who are responsible for the care of a loved one with dementia. The study investigated how these caregivers navigate care in both home and care community settings, explore their existing knowledge and acquired understanding of dementia, identify available support systems, and determine the specific needs that remain unmet. Dementia is a disease that is chronic and degenerative with few treatments and no current cures available (The Alzheimer's Association, 2020). Many of those who are diagnosed often have a growing need for care over time as the illness progresses and those forms of care can be very costly on families and the person with the diagnosis. Home care, assisted living, and nursing center care can entail monthly costs amounting to thousands of dollars, which can pose a significant financial burden for many people for extended periods of time, considering many people lack such financial resources. With understanding these perspectives, policy changes can be made, funding can be allocated, and healthcare professionals can start implementing more health education within their facilities and offices for family members and patients needing guidance and better understanding. Having more research and understanding in topics related to chronic illnesses and family member caregiver experiences to help with understanding their needs for support to properly care for their loved one while not losing out on their quality of life.

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Appendix A: Interview Protocol

> This is going to be an interview conducted over 1 hour. Please take your time and share as much or as little as you wish, any input will be of great help to this research project.

RQ1: 1. Before your loved one was diagnosed, what was your understanding of Dementia?

RQ1: 2. Since your loved one has been diagnosed and living with dementia, what is your understanding of the disease now?

RQ4: 3. What was your initial reaction/response to finding out your loved one was diagnosed with dementia?

RQ1: 4. What health education were you given on dementia after your loved one was diagnosed?

RQ1: 5. What healthcare staff or healthcare professional provided you with the education on dementia?

RQ4: 6. What was your reason or final decision for moving your loved one into a care community?

RQ3: 7. What was that experience like with getting them accepted and moving into the care community?

RQ2: 8. When your loved one's treatment team stated they needed more care than they were getting, how long had they been living there and how did you respond to that?

RQ3: 9. What were the reasons to you making the decision to not getting the additional recommended care?

RQ1: 10. How did the treatment team work to meet your needs with health education toward understanding their point of view on your loved one's needs for increased care?

RQ1: 11. What do you feel like was needed to help you with making your decision?

Thank you for participating in this interview and overall, in the research study. Your participation will help to generate an understanding for future families going through similar events to you and will utilize the perspective you have given to help healthcare professionals and other stakeholders with understanding the needs of those in your shoes in the future.

Appendix B: Instrumentation Tables for Alignment of Research – 1.1

Research Question	***Interview Protocol Questions that align***
RQ1: ***Health Education*** How do the family member caregivers describe what their needs are for health education to help with making more informed decisions about higher levels of care within their care communities in the DC metro are for their loved one with dementia?	1. Before your loved one was diagnosed, what was your understanding of Dementia? 3. What health education were you given on dementia after your loved one was diagnosed? 8. How did the treatment team work to meet your needs with health education toward understanding their point of view on your loved one's needs for increased care? 9. What do you feel like was needed to help you with making your decision?
RQ2: ***Perceived Barriers*** How do the family member caregivers describe the barriers that have gotten in the way of pursing a higher level of care for their loved one with dementia who live in a care community in the D.C. metro area?	6. When your loved one's treatment team stated they needed more care than they were getting, how long had they been living there and how did you respond to that?
RQ3: ***Perceived Benefits*** How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to quality of life/care within their loved one's current care community in the D.C. metro area?	5. What was that experience like with getting them accepted and moving into the care community? 7. What were the reasons to you making the decision to not getting the additional recommended care?
RQ4: ***Perceived Severity*** How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?	2. What was your initial reaction/response to finding out your loved one was diagnosed with dementia? 4. What was your reason or final decision for moving your loved one into a care community?

Appendix C: Instrumentation Tables for Alignment of Research – 1.2

Research Questions	***Data Collection Methods that align***
RQ1: ***Health Education*** How do the family member caregivers describe what their needs are for health education to help with making more informed decisions about higher levels of care within their care communities in the DC metro are for their loved one with dementia?	Interview Protocol Observation memos Survey questionnaire
RQ2: ***Perceived Barriers*** How do the family member caregivers describe the barriers that have gotten in the way of pursing a higher level of care for their loved one with dementia who live in a care community in the D.C. metro area?	Interview Protocol Observation memos Survey questionnaire
RQ3: ***Perceived Benefits*** How does the family member caregiver describe their feelings about the perceived benefits of seeking a higher level of care, in reference to quality of life/care within their loved one's current care community in the D.C. metro area?	Interview protocol Observation memos
RQ4: ***Perceived Severity*** How does the family member caregiver feel about the severity of their loved one's dementia and care needs within their care community in the DC metro area?	Interview protocol Observation memos

Appendix D: Validity Tool for the Data Collection Table

Aspects of the Interview Protocol	**Yes**	**No**	**Feedback for Improvement**
Interview Protocol/Pre-Interview Survey/Observation Memo			
Beginning questions are factual in nature			
Key Questions are majority of the questions and are placed between beginning and ending questions			
Questions at the end of the interview protocol are reflective and provide participant an opportunity to share closing comments			
A brief script throughout the interview protocol provides smooth transitions between topic areas			
Interviewer closes with expressed gratitude and any intents to stay connected or follow up			
Overall, interview is organized to promote conversational flow			
Writing of Questions			
Questions are free from spelling error(s)			
Only one question is asked at a time			
Most questions ask participants to describe experiences and feelings			
Questions are mostly open-ended			
Questions are written in a non-judgmental manner			
Length of Data Collection Tools			
All questions are needed			
Questions are concise			
Comprehension			
Questions are devoid of academic language			
Questions are easy to understand			

Appendix E: Letter to Experts for Review of Interview Protocol

Dear _______________,

Thank you for agreeing to participate in reviewing my research study's interview protocol. An interview protocol is a series of interview questions that will be used with participants to gain data needed that is associated with research questions for the overall study. As an expert in the field of geriatric care, you will have a knowledge that others will not and can review these questions to assure that they appear to align and are not overly complex, hard to understand or hard to present to someone who is not an expert in the field and is a family member caregiver. Attached are the interview protocol, the overall study research questions, and the interview protocol review evaluation checklist. On this checklist are the items to consider when reading the interview protocol, a space to list if it does meet the criteria of the items listed and a space to provide feedback to improve the interview protocol. This information is an important part of the research project and will allow for me as the researcher to ensure that this is an appropriate data collection tool and that it is developed in the best way for the research study. Thank you for your time and consideration in this. You are helping to contribute to the goal of positive social change with this research study. Please email me your feedback and evaluation checklist to tanisha.robinson2@mail.waldenu.edu when you have completed it. Please return the feedback to be approximately 1 week from today.

Thank you,

Tanisha Nicole Robinson

PhD candidate at Walden University

Appendix F: Short Survey Pre-Interview Questionnaire

Short Survey Questionnaire (Likert Scale)

<u>RQ1: 1</u>. *On a scale from 1 to 5, please tell me your feelings about the education you received about dementia and the care resources in the DC area at the time of diagnosis.*

1: Very Unsatisfied 2: Unsatisfied 3: Neutral 4: Satisfied 5: Very Satisfied

<u>RQ2: 2.</u> *On a scale from 1 to 5, please tell me your feelings when you pursued a higher level of care for your loved one with dementia in the DC metro area.*

1: Very Unsatisfied 2: Unsatisfied 3: Neutral 4: Satisfied 5: Very Satisfied

<u>RQ3: 3.</u> *On a scale from 1 to 5, please tell me your feelings about the perceived benefits of getting a higher level of care.*

1: Very Unsatisfied 2: Unsatisfied 3: Neutral 4: Satisfied 5: Very Satisfied

<u>RQ4: 4</u>. *On a scale of 1 to 5, please tell me your feelings about the severity of your loved one with dementia's care need are.*

1: Very Unsatisfied 2: Unsatisfied 3: Neutral 4: Satisfied 5: Very Satisfied

Demographic questions:

Gender: Male Female Transgender Non-Binary

Age Range: 18-35 36-50 51-75 75+

Race: White/Caucasian Black/African-American Asian/Pacific Islander

Native American/Alaskan Middle Eastern

Hispanic/Latino Biracial/Multiracial

Appendix G. Observation Sheet

Appearance:

Neat Disheveled Unkept

Mood/Emotional State (Select as many that are appropriate):

Fearful Sad Happy Anxious

Curious Euthymic Angry Shame

Emotional Regulation:

Normal Over-controlled Not well controlled

Speech/Language:

Select 1: Loud Soft

Select 1: hypo talkative hyper talkative

Attention:

Easily distracted Poor focus hypervigilant normal

Judgement/Reason:

Normal Fair Poor

Anecdotal Comments (narrative format):

Appendix H: Recruitment Flyer

Who: *Family member caregivers of loved ones with Dementia within the greater D.C. metropolitan area*

What: *participate in a research study interview to gain a better understanding of one's experience with care transitions for their loved one with dementia and health education on care needs and options for higher levels of care transitions*

When: *Winter 2021/2022*

Where: *Virtually over a HIPAA compliant video platform such as Zoom or Google Meet*

Why: *The purpose of this study is to gain an understanding of what the health education needs are for family member caregivers of a loved one with Dementia with regard to levels of care, transitioning to a higher level of care and also to gain an understanding of the barriers to transitioning a loved one with Dementia to a higher level of care.*

How: *Contact Tanisha Robinson, MSW, PhD Candidate at* [redacted]

Appendix I: Recruitment Form

Hello,

Thank you for your time today. I am a PhD student at Walden University in the School of Health Sciences and I am conducting a research project in the greater D.C. Metropolitan area to gain a better understanding at your experiences with care transitions for your loved one with dementia. The purpose of this study is to gain an understanding of what the health education needs are for family member caregivers of a loved one with Dementia with regard to levels of care, transitioning to a higher level of care and also to gain an understanding of the barriers to transitioning a loved one with Dementia to a higher level of care. Your participation would require an interview that would last no more than an hour and have a conversation about your experiences thus far. I would appreciate your participation in this research study, please see the attached flier for further details. If you wish to participate, please respond to this email and we can begin the process.

Thank you,

Tanisha Robinson, MSW, PhD. Candidate

Walden University School of Health Sciences

[redacted]

Appendix J: Confidentiality Agreement

Confidentiality Agreement for Transcription Services

I, _________________________________, (transcriber) agree to maintain full confidentiality in regards to any and all materials (audio and video recordings, documentation, or other information regardless of medium) from [Tanisha Nicole Robinson] related to [Family Decision Making in Dementia Care Transitions: A Qualitative Case Study; IRB approval number: # 04-14-22-0415257]. I agree not to disclose the confidential information obtained from the discloser to anyone unless required to do so by law. Specifically, I agree:

1. To hold in strictest confidence any information received and the identification of any individual that may be inadvertently revealed in performing requested services.
2. To not make copies of any of the materials and transcriptions unless specifically requested to do so by [Tanisha Nicole Robinson];
3. To store all materials and transcriptions in a safe, secure location as long as they are in my possession;
4. To return all materials and transcriptions in a complete and timely manner to [Tanisha Nicole Robinson] upon request [or once all transcriptions are finished]; and
5. To delete all electronic files containing materials or transcriptions from any electronic device on which such files are stored.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, any for any harm incurred by individuals if I disclose identifiable information contained in the materials to which I will have access.

Transcriber's name (printed) ____

Transcriber's signature ____

Date: ______________________________________