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Community Perceptions on Access to and Communication Gaps Regarding Dementia-Specific Health Resources and Services

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COMMUNITY PERCEPTIONS ON ACCESS TO AND COMMUNICATION GAPS
REGARDING DEMENTIA-SPECIFIC HEALTH RESOURCES AND SERVICES

by

RANDI GINGER BASTIAN

(Under the Direction of Bettye Apenteng)

ABSTRACT

The people of Appalachia have less access to healthcare resources subsequently leading to deficits in healthcare, health education, and health research. There is a need to address the communication of healthcare resources among populations with low economic status such as the Appalachian communities in Northeast Tennessee. Alzheimer's disease and related dementias (ADRD) uniquely challenges the healthcare industry while further dividing communities already experiencing hardship in healthcare resources. The Baby Boomer generation is advancing into the age range frequently affected by ADRD, 65 and over. In preparation, healthcare continuum must acknowledge and set out to address dementia-specific care challenges. *"Keep something in the shadows, and people are not gonna even realize it is a problem."* This study uniquely supplements current research by exploring how communication influences acceptability, accessibility, affordability, availability (the 4A's) of dementia-specific health resources and services in Northeast Tennessee. The study is a qualitative study utilizing classic grounded theory (CGT). Together with cataloging the number and types of dementia-specific health resources and services existing in Northeast Tennessee, sixteen one-on-one interviews with organization leaders, caregivers, and healthcare providers took place between May 2018 and September 2018. The study revealed that the number of organizations offering dementia-specific resources and services in Northeast Tennessee is abundant. Nevertheless, they remain

unaccepted by some and unknown by many because PLWD and their caregivers experience multifaceted barriers, which constrains access to resources and services. Individual-level influences such as denial, control, and perceived stigma encumber on the likelihood of willingness to seek dementia-related assistance. Providers' and organizations' readiness to be the patient advocates enhances care delivery. Positive influencing factors and readiness among dementia care organizations and providers serve as the link for patients and their loved ones to the starting point of dementia care navigation, which is the secured point in time when a patient begins seeking resources and services and is guided by a knowledgeable professional to find the best available options to suit his or her individual needs. According to the findings from the study, refining access and improving communication requires awareness, knowing where to start, and working within and across disciplines and stakeholders. Accordingly, a two-pronged approach for addressing the communication gaps from both ends – provider and consumer – is needed. The suggested means of action to address these gaps include a peer health communication intervention and implementation of a patient navigation care coordination model designed explicitly for ADRD. Further, community organizations offering dementia-specific health resources and services must continue to market themselves to expand their visibility and to increase provider, patient and caregiver awareness about their services while strengthening their relationships with healthcare providers and other clinicians.

INDEX WORDS: Alzheimer's disease and related dementias; Gap analysis; Health communication; Care coordination; Northeast Tennessee; Patient navigators; Classic grounded theory

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DEDICATION

I dedicate my work to

God: for your sincere grace, guidance, love, and strength throughout this journey called life.

Mom and Dad: for supporting and loving me through life's adventures especially when I could not see the light shining within. I will never be able to thank you enough.

Papa: for having a servant's heart. You will forever live on in my life's work.

Grandma: for believing I was Dr. Bastian before I ever thought I could be.

My sisters and family: for pushing me to uphold our family namesake, "a Bastian never quits."

Bronson: my best friend and fur companion, for being by my side and loving me, always.

Lastly, I dedicate my dissertation to who I was, am, and will be. I have lived in the moment and championed my way through a long-awaited and the most challenging scholarly ride of my life. This journey showed new ways to accept life's joyous progressions as God's beautiful work of art.

"Welcome life's challenges and embrace the version of yourself that you'll meet when you make it to the other side—stronger, bolder, and a step closer to fulfilling your dreams or accomplishing your goals."

— Alexis Jones, *I Am That Girl*

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LIST OF ABBREVIATIONS

ADRD	Alzheimer's Disease and Related Dementias
CDC	Center for Disease Control and Prevention
IRB	Institutional Review Board
NIA	National Institute on Aging
NIH	National Institutes of Health
PLWD	People (s. person) living with dementia
QOL	Quality of Life
NETN	Northeast Tennessee
4A's	Acceptability, Accessibility, Affordability, and Availability

CHAPTER 1

INTRODUCTION

Statement of Problem

Dementia is one of the nation's major public health concerns, and according to the World Health Organization, it is a significant cause of disability and dependency of older adults across the globe (World Health Organization, 2017). Dementia is an umbrella term for a syndrome occurring when Alzheimer's disease or related dementias (ADRD) progress abnormally, affecting the brain's ability to function, therefore inhibiting one's ability to carry out daily activities (Alzheimer's Association, 2017a; Neitch, Meadows, Patton-Tackett, & Yingling, 2016; World Health Organization, 2017).

Alzheimer's disease (AD) is the sixth leading cause of death in the United States and is the most common form of dementia, accounting for 60-80% of cases (Alzheimer's Association, 2017a; National Center for Health Statistics, 2016; World Health Organization, 2017). Contrary to popular belief, AD is not a normal part of aging, worsens over time, and does not have a cure (Alzheimer's Association, 2019b; National Institute on Aging, n/d-b). In addition to the threat of AD, America faces one of the most significant aging concerns in history with the "baby boomer" generation, born between 1946-1964 (Center for Generational Kinetics, 2016; Colby & Ortman, 2014; Ortman, Velkoff, & Hogan, 2014). As this population ages, more adults will be at risk for AD. According to the Alzheimer's Association (2017a), one in 10 people over the age of 65 has AD, and more than five million Americans live with AD (Alzheimer's Association, 2017a).

Moreover, Tennessee's projected number of AD diagnosed residents is expected to increase from 120,000 in 2019 to 140,000 in 2025 (Alzheimer's Association, 2019a).

An increase in dependency is caused by the disease progression, which results in financial and emotional stress for the people living with dementia (PLWD), their loved ones, and the economy (Boustani, Peterson, Hanson, Harris, & Lohr, 2003; Galvin, Valois, & Zweig, 2014; Neitch et al., 2016; Stewart et al., 2014; Weiler, 1987). Severe disruptions occur when completing daily life tasks that were once easy, all while the progression rids individuals of the ability to communicate with others (Alzheimer's Association, 2019b; Robinson, Canavan, & Okeeffe, 2014; Sivananthan, Puyat, & McGrail, 2013). According to the Alzheimer's Association's calculations from BRFSS data (2019a), over 16 million unpaid caregivers assume the caregiving role for more than 5.8 million Americans with ADRD (Alzheimer's Association, 2019a).

The annual cost of care for ADRD in 2011 was estimated to be \$183 billion, mostly covered by Medicaid and Medicare (Alzheimer's Association, 2011). In 2004, Bynum and colleagues conducted a study of a sample of 1999 Medicare beneficiaries and after adjusting for age, sex, race, and comorbidity, they found the annual healthcare costs to be three times higher to care for dementia patients largely owed to frequent hospitalizations (Bynum et al., 2004). Deb and colleagues (2017) synthesized available studies reporting the overall care costs of managing ADRD and found that the resulting costs varied. However, their findings further support that the financial burden of healthcare costs when comparing ADRD and non-ADRD patients (Deb et al., 2017).

Advancements in technology, medicine, and public health have distinctly transitioned the quality and type of care related to chronic health conditions. Despite this, difficulties exist in developing effective interventions to reduce the burden of ADRD (Khachaturian, Hoffman, Frank, Petersen, & Khachaturian, 2017). Early diagnosis is often not achieved due to denial, failure to notice changes, or lack of awareness (Stewart et al., 2014). Less than half of diagnosed patients know of their diagnosis, and many go undiagnosed due to the absence of diagnosis during clinic appointments (Alzheimer's Association, 2017a; Boustani et al., 2003; Hunsaker et al., 2011). Providers can play a significant role in the coordination of care, yet they often spend little time with patients and may lack dementia relevant skills (Neitch et al., 2016; Reuben et al., 2013). Around 40 percent of providers caring for PLWD refer them for dementia-specific care, all while assuming responsibility for the entire continuum of care (Stewart et al., 2014). Contrastingly, providers that lead the dementia care coordination allow patients to receive individualized care to enhance their quality of life (Hoffman, 2014).

In recent years, rural health disparities associated with ADRD drew attention (Thorpe, Van Houtven, Sleath, & Thorpe, 2010; Wiese, 2013). For example, impoverished individuals living in rural areas are less likely to seek out services due to the inability to pay (Dautovich, Shoji, Stripling, & Dzierzewski, 2014). A provider's genuine concern for patients can create trust and increase the likelihood of follow-up for chronic health issues (Bushy, 2008; Presley, 2014). Also, healthcare provider's ability to connect with community resources would create relationships while reducing the burden due to dementia (Hoffman, 2014; Khachaturian et al., 2017). Comprehensive care delivery for PLWD may begin with the leveraging of both healthcare providers and community resources.

Purpose Statement

The purpose of this study is to examine community perceptions on communication gaps regarding dementia-specific health resources and services in Northeast Tennessee and explore how communication may shape perceptions concerning the acceptability, accessibility, affordability, and availability (the 4A's) of dementia-specific resources and services for people living with dementia and their caregivers. The study intends to survey community organizations that serve older adults to evaluate existing dementia-specific health resources and services. The data will be analyzed and reported with descriptive statistics. Secondly, classic grounded theory (CGT) will be used to conduct one-on-one recorded interviews with organization leaders, caregivers, and healthcare providers to determine common categories that address acceptability, accessibility, affordability, and availability (the 4A's) and develop an applicable framework for understanding participants' perceptions of communication's influence on care efficiency. Lastly, the researcher will use the data collection and perform a gap analysis to pinpoint opportunities that may lead to improving access to and communication regarding these resources and services.

Research Questions

- 1) *What dementia-specific health resources and services exist in Appalachian communities in Northeast Tennessee and how are they impacting community access?*
- 2) *What are the perceptions of communication gaps that occur among healthcare professionals, caregivers, and dementia service organizations when caring for people living with dementia and their caregivers in Appalachian communities in Northeast Tennessee?*
- 3) *How can communication impact access to dementia-specific health resources and services for people living with dementia and their caregivers?*

Significance of the Problem

Many factors relate to the need for improved communication and resources regarding healthcare in Appalachian communities. In comparison with other United States regions, Appalachia is one of a few areas with high rates of mortality due to ADRD (Obisesan, Yorrick, & Gillum, 2011). Further impacting this community is the lack of healthcare professionals available to caregivers. Northeast Tennessee is home to several Appalachian communities. According to the Tennessee Department of Health (2016), Northeast Tennessee counties have a shortage of primary care providers in some counties and a shortage of mental health professionals in all counties. Elders residing in rural areas often have higher needs for mental health services while rural areas have the highest levels of health professional shortages and lower access to health resources (Lane et al., 2012).

Even in cases where access to healthcare, health education, and research may be available, there remains an opportunity to strengthen connectivity and reliance among organizations with resources. Multiple barriers affect access and underutilization of healthcare resources (Dautovich et al., 2014). Increasing awareness in rural populations through access to available resources and collaboration may help increase the quality of care and life (Wiese, 2013). Initially gaining community buy-in through trust, partnerships, and community awareness is the strategy expected to be most impactful (Fuller, Johnson-Turbes, Hall, & Osuji, 2012; Presley, 2013).

This study is significant because it aims to address resource disconnect and underutilization in a geographical area that would benefit from the resulting awareness. It

signifies the value of applying public health strategies to address ADRD issues that may, directly and indirectly, impact Americans, their communities, and the United States economy.

Assumptions

1. Resource information from organizations is up to date and accurate on websites;
2. Participants fully understand the purpose of the interview;
3. Participants respond truthfully during the interview process; and
4. The use of CGT and its theory generating criteria will be enough to reflect the social processes of the community and organizational leaders in Northeast Tennessee.

Definitions of Terms

The following definitions of terms were used:

Dementia. Dementia is a general term for a set of thinking and social symptoms that exhibit in a person when they experience a descent in mental ability interfering with daily routine (National Institute on Aging, 2015). There are multiple types of dementia, but the most commonly diagnosed are Alzheimer's disease, Vascular, Lewy bodies, Mixed, and Frontotemporal.

Alzheimer's Disease. AD is a fatal, irreversible, progressive neurodegenerative disease that begins in specified locations of the brain designated for memory and thinking processes, which can later impact an individual's abilities to perform activities of daily living (Alzheimer's Association, 2017a, 2019b; Alzheimer's Foundation of America, 2016; Alzheimer's Tennessee, 2016; Meloche, Compton, Rosario, & Brown, 2016; National Institute on Aging, 2015, 2016, n/d-a; Office of Disease Prevention and Health Promotion, 2015).

Appalachian Region. The Appalachian Regional Commission defines the Appalachian region as an Appalachian Mountains geographical region spanning 205,000 miles from New York to Mississippi with 42 percent of the region classified as rural (Appalachian Regional Commission, 2016).

Resource. A resource is an asset or a source of help or information available for use by a person or organization to function effectively (Oxford University Press, 2017).

Caregiver. A caregiver is a paid or unpaid person that provides others with needed assistance to complete any level of activities of daily living (Alzheimer's Association, 2017a).

Theoretical sampling. The collection of data to create patterns derived from concepts. It is meant to maximize concept development first by surfacing the various valuable properties each contains and identifying the relationships that may exist between them (Corbin & Strauss, 2008). By sampling the raw data and using the constant comparison method, the concepts surface and can be used for theory generation (Glaser, 1978).

Chapter Summary

This chapter discussed the need for addressing ADRD in Appalachian communities in Northeast Tennessee by investigating the quantity and quality of disease-specific resources, with particular emphasis placed on the identification of communication gaps between healthcare and community organizations as well as caregivers involved in the care of PLWD. The statements of the problem, the purpose of the study, significance, assumptions, and definitions of terms were included. The available and relevant literature on ADRD will be discussed in the next chapter.

CHAPTER 2

LITERATURE REVIEW

The overall purpose of this study is to gain substantial insight from the Appalachian community of Northeast Tennessee regarding dementia care access and communication gaps and delve into how communication may shape acceptability, accessibility, affordability, and availability (the 4A's) of dementia-specific resources and services. The review of pertinent literature focuses on ADRD, economic and caregiver burden, rural populations, barriers to healthcare access in the Appalachian regions, health resources, and health communication relating to ADRD care.

Alzheimer's Disease and Related Dementias

Most commonly occurring in adults over 65 years of age, dementia serves as an overarching term used to describe a syndrome of common symptoms when abnormal cognitive, physical, and social functions progressively deteriorate, which tend to be overlooked in earlier stages (Alzheimer's Association, 2019b; Alzheimer's Tennessee, 2016; Boustani et al., 2003; Meloche et al., 2016; National Institute on Aging, 2015; Stewart et al., 2014; Tilly, Wiener, & Gould, 2014; World Health Organization and Alzheimer's Disease International, 2012). Additionally, the brain compensates for the abnormal changes, allowing PLWD to continue functioning at normal levels. Only when specific symptoms occur, depending on the type of dementia, can it be detected. However, symptoms of cognitive decline begin years after the disease progresses when the brain cannot compensate for abnormalities any longer (Alzheimer's Association, 2017a). Beginning slow and progressing with time, dementia symptoms are often

viewed as a normal part of aging but indeed are not (Alzheimer's Association, 2016c; Meloche et al., 2016; National Institute on Aging, n/d-b; Weiler, 1987). Subtle memory decline or forgetfulness can occur with age and are often confused with dementia making it hard to detect.

Initially, the clinical manifestation of AD was vaguely known. Shared symptoms among the various types of dementia make diagnosing a challenging task (National Institute on Aging, 2015). For diagnostics, an individual must experience significant impairment in two or more of these mental functions: memory, communication and language, focusing and paying attention, reasoning, judgment, and visual perception (Alzheimer's Association, 2016c; Stewart et al., 2014; U.S. Preventative Services Task Force, 2016). Also, challenges in conversation, misperception of time or places, misplacing items and the inability to retrace steps, and frequent agitation often occur (Alzheimer's Association, 2017a, 2017b; Neitch et al., 2016). In addition to the number of possible symptoms, behavioral and psychological symptoms of dementia vary among individuals and may manifest in some more than others adding to the difficulty in making a diagnosis.

Epidemiology. Public health practitioners, healthcare providers, and policymakers can no longer ignore population growth and longevity (Lathren, Slone, Hoyle, Zimmerman, & Kaufer, 2013; Weiler, 1987). AD is a significant contributor to poor health outcomes, including disability and death. Based on the disability-adjusted-life-years metric, AD had advanced from 25th in 1990 to 12th leading cause of disease burden in 2010. Moreover, using the years of life lost and the years lived with disability metrics, AD advanced from 32nd to ninth and, 17th to 12th leading cause of disease burden and disability, respectively (Alzheimer's Association, 2015).

Incidence. In 2017, it was estimated that someone began developing AD every 66 seconds, and by 2050 that timeframe is projected to be every 33 seconds (Alzheimer's

Association, 2017a). In 2019, it is estimated that 487,000 people over 65 years will develop Alzheimer's dementia (Alzheimer's Association, 2019a). If a medical breakthrough does not occur before 2050, the projected number is anticipated to increase two-fold, and the number of cases is expected continue to increase until an effective treatment is determined (Alzheimer's Association, 2015; Sg2, 2016).

Prevalence. Higher prevalence rates will accompany the growth of the U.S. aging population (Boustani et al., 2003). In 2017, it was reported that one in 10 persons over 65 has AD (Alzheimer's Association, 2017a). As of 2019, it is estimated that 5.8 million Americans have AD (Alzheimer's Association, 2019a). It is expected that by 2025, AD prevalence will reach 7.1 million people over the age of 65, and by 2050 it is projected to reach 13.8 million in the same age group (Alzheimer's Association, 2017a; L. E. Hebert, Weuve, Scherr, & Evans, 2013; Meloche et al., 2016).

PLWD live years with progressively declining health and have additional complications when ADRD is paired with other chronic health conditions (Alzheimer's Association, 2017a; Khachaturian et al., 2017). Due to the slow progression of the disease, AD diagnosed individuals can survive between two and 20 years, but on average live four to eight years beyond diagnosis (Alzheimer's Association, 2015; Miller & Boeve, 2009). Likewise, the variation in disease duration impacts the prevalence rates, which may explain the influx in prevalence for the oldest population groups.

Risk Factors. Factors outside of medical care that extensively contribute to health include societal factors, genetics, and health behaviors influenced by social factors (Hartley, 2004). For PLWD, age, general health, existing medical conditions, culture, race, ethnicity, SES, social support network, personalities, and outlook all influence their ability to function and

determine the type of care they need (Maslow, 2013). Above all, age is the most influential and frequently studied risk factor for AD (Alzheimer's Association, 2017a; Boustani et al., 2003; Neitch et al., 2016; Stewart et al., 2014). Family history accounts for 10-30% of risk (Neitch et al., 2016). Early onset is linked to the involvement of genetic factors, and late-onset is a combination of brain changes influenced by numerous factors related to genetics, environment, and lifestyle (Meloche et al., 2016). In an attempt to understand genetic risk factors of AD, researchers have identified the Apolipoprotein E (APOE) gene on chromosome 19 in 1993 and now include it as a genetic component of risk (Alzheimer's Association, 2016b). Even though APOE e4 increases a person's likelihood of developing AD, merely having the gene does not suggest one will have the disease (National Institute on Aging, n/d-a).

Mild cognitive impairment (MCI) is a condition in which an individual becomes concerned due to an increase in memory problems when compared to others their age, but the ability to complete activities of daily living remain intact (Alzheimer's Association, n/d; National Institute on Aging, 2016; Neitch et al., 2016). Older adults with MCI have an increased risk of developing AD (Alzheimer's Association, 2017a; National Institute on Aging, 2016). There is no research suggesting memory lapses associated with normal aging progress into MCI, but there is evidence supporting the progression of MCI to ADRD (Alzheimer's Association, 2017a; Neitch et al., 2016).

Research suggests that health, environment, and lifestyle factors may influence disease development and progression. Other risk factors include diabetes, tobacco use, education level, head traumas, substance abuse, depression, economic status, social support, and learning disabilities (U.S. Preventative Services Task Force, 2016). Modifying risk factors through primary prevention can abate progression (Neitch et al., 2016). Alzheimer's disease shares many

of the same health risk factors that are commonly monitored through primary care such as cardiovascular health including hypertension, physical activity, and diet, all of which are known to influence brain health (Alzheimer's Association, 2015, 2016c; U.S. Preventative Services Task Force, 2016). The ongoing investigation between cognitive decline and vascular health shows a correlation between vascular health risk factors and their influence on cognitive health (National Institute on Aging, n/d-a). To this point, research suggests that primary care prevention should target those risk factors profoundly impacting the heart as they affect brain health as well.

Morbidity & Mortality. Death records make it difficult to determine the precise numbers of AD-related deaths. The World Health Organization defines *cause of death* as a “disease or injury which initiates the train of events leading directly to death” (2004). ADRD are only listed as the cause of death if the underlying cause of death is solely due to ADRD alone. Acute conditions are often listed as a cause of death, therefore altering the record keeping which may not account for the death due to AD with any additional health complications. While there may be an unrelated cause of death, many of those diagnosed with ADRD will die from the disease, or a disease complication; most commonly pneumonia (Alzheimer's Association, 2016a, 2017a). Despite these variables, the Medicare data show ADRD accounts for one-third of deaths among all older adult deaths (Alzheimer's Association, 2017a).

The National Center for Health Statistics published data on deaths in the United States for the year 2014, and AD ranks 6th among other causes of death (Kochanek, Murphy, Xu, & Tejada-Vera, 2016). For those over 65, it is ranked as the 5th leading cause of death (Alzheimer's Association, 2017a). Adults over 85 years have higher mortality shown in Figure 1 with AD related deaths accounting for over 65% of the total (Kochanek et al., 2016).

Number of AD Deaths in 2014 by Age Group

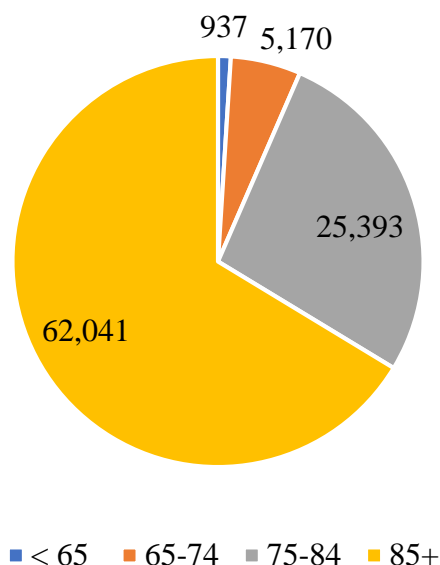


Figure 1. Number of AD Deaths in 2014

From the same dataset, Table 1 shows the 2014 age-adjusted death rate of 25.4 per 100,000 was higher than 2013's 23.5 per 100,000. Further supporting the variation in age groups, those over 85 years have an exponentially higher death rate when compared to other age groups (Kochanek et al., 2016).

Table 1

Death Rates by Age and Age-Adjusted per 100,000

	55-64	65-74	75-84	85+	Age adjusted
<i>2014</i>	2.1	19.6	185.6	1006.8	25.4
<i>2013</i>	2.2	18.1	171.6	929.5	23.5

Tennessee. As awareness increases, the number of deaths accurately documented as well as the number of deaths attributed to ADRD is expected to increase (Alzheimer's Association, 2015). The annual ADRD mortality rate per 100,000 in 2017 and 2019 for Tennessee (40.8 and

52.4) and nearby states were reported respectively as Kentucky (34.5 and 39.6), Virginia (21.3 and 30.1), and North Carolina (32.6 and 41.9) (Alzheimer's Association, 2017a, 2019a).

According to the 2015 Community Health Status Indicators (Table 2), the Northeast counties of Tennessee (NETN) are all listed above the U.S. median values with morbidity due to ADRD deaths (Centers for Disease Control and Prevention, 2015). When compared to nationwide peer counties with community similarities, the NETN counties rank moderate or worse than their peers for ADRD morbidity and age-adjusted mortality.

Table 2

Community Health Status Indicators for NETN Counties

	Population	65+ (%)	Morbidity (%)	Peer County Comparison	Age-Adjusted Mortality/100,000	Peer County Comparison
<i>U.S.</i>			10.3		27.3	
<i>Carter</i>	57,355	18.5	13.0	Worse	43.9	Worse
<i>Greene</i>	68,819	18.6	10.8	Moderate	28.5	Moderate
<i>Hancock</i>	6,720	17.8	15.1	Worse	42.9	Worse
<i>Hawkins</i>	56,587	18.0	10.9	Moderate	32.6	Moderate
<i>Johnson</i>	18,095	19.4	10.2	Moderate	29	Moderate
<i>Sullivan</i>	156,786	19.5	11.8	Worse	36.5	Worse
<i>Unicoi</i>	18,235	20.6	13.5	Worse	32.9	Moderate
<i>Washington</i>	125,094	16.0	11.3	Moderate	34.7	Moderate

Comorbidities. Comorbidities are two or more simultaneously occurring chronic diseases or health conditions (Thomas, 2016). The CDC's National Center for Chronic Disease Prevention and Health Promotion (2018) reported that one in four adults have more than one chronic condition, which increases to three in four for adults over 65 years. Dementia complicates chronic conditions as it is a comorbidity effect multiplier (Boustani et al., 2003;

Khachaturian et al., 2017). When paired with other chronic diseases, dementia hinders patients and their ability to deal well with previously manageable health issues like diabetes. Chronic health conditions can throw off the body's ability to regulate itself, which creates ideal conditions for additional health issues to develop (Khachaturian et al., 2017; Office of Disease Prevention and Health Promotion, 2015). The existence of comorbidities in PLWD generates extreme challenges when delivering care, thereby intensifying the need for adequate resources, hands-on care, and treatment options intended to renew an individual's quality of life (Centers for Disease Control and Prevention, 2013). An increase in dependency ignites burden on the PLWD, loved ones, and the economy (Boustani et al., 2003; Stewart et al., 2014; Weiler, 1987).

Burden of Alzheimer's Disease and Related Dementias

Dementia has a high global economic impact and inflicts a burden on the patient, caregivers, providers, and the healthcare system. Dementia can occur in individuals younger than 65 years of age, but it occurs predominately in older adults (Alzheimer's Association, 2015; Katzman, 1976; Weiler, 1987). Across the globe, countries are witnessing an increase in the proportion of adults over 65 years of age and expect this age group to double in size (He, Goodkind, & Kowal, 2016). In the United States, this increase exists because of life longevity and a birth influx post World War II. Americans born between 1946-1964, the "Baby Boomer" generation, present the most substantial aging concern for the future (Center for Generational Kinetics, 2016; Colby & Ortman, 2014; Ortman et al., 2014). A U.S. Census population projection estimates the national population will increase from 314 million in 2012 to 400 million in 2050 (Ortman, 2012). Figure 2 displays the population projections highlighting this Baby Boomer generation trend (United States Census, 2014). The 65 and older age group is

expected to be 83.7 million in 2050, surpassing the 2012's 43.1 million (Ortman et al., 2014). Age groups over 65 will show the most significant percentage change compared to all age groups with an expected increase of 64% in the 65-69 age group and 208% in the 85+ age group between 2012 and 2060 (Ortman, 2012).

In the U.S., the median age of death exceeds 75 years of age. The U.S. must prepare for growth before it occurs because the proportion of adults over 85 years of age is projected to double by 2030 (He et al., 2016; R. Hebert, Fowler, & Arnold, 2007; Ortman et al., 2014). The 60 and over population growth in Tennessee is higher than other age groups and is projected to reach approximately 24% of the state's population by 2030 (Substance Abuse and Mental Health Services Administration & U.S. Administration on Aging, 2012). In 2016, it was estimated that 15.7 % of TN's 6,651,194 population was over 65 years of age (United States Census Bureau, n/d). Compared to the nation's 2050 projections of 20.9% for the over 65 age group distribution of total population, NETN sits around 30.8% (Haslam College of Business, 2015; Ortman et al., 2014). The dementia epidemic presents issues for providers and community-based resources as they try to meet needs while dealing with rising costs for diagnostics, assessments, management, and treatment of diseases (Khachaturian et al., 2017).

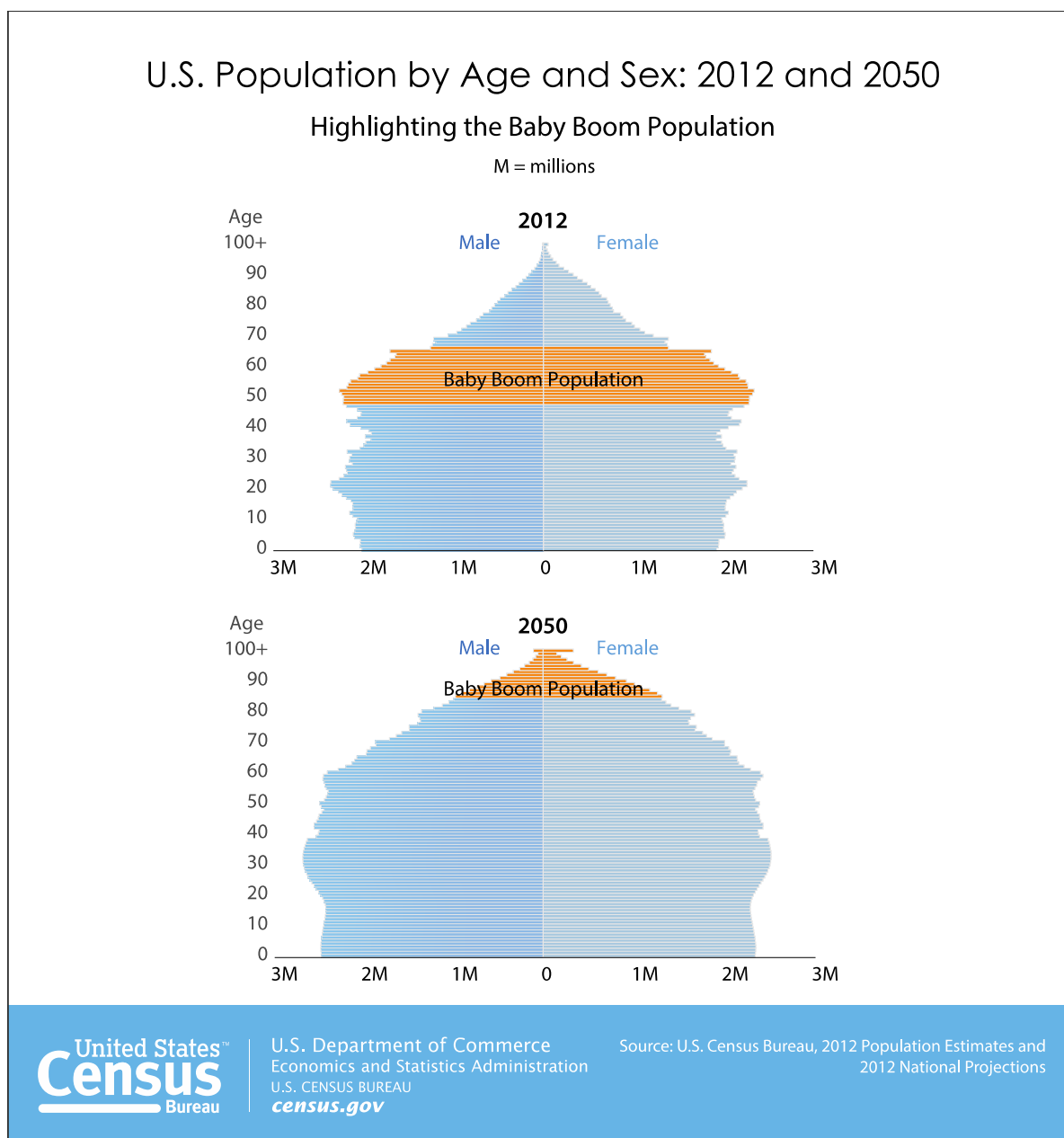


Figure 2. U.S. Population by Age and Sex: 2012 and 2050 (United States Census, 2014)

Due to an increase in prevalence, life longevity, and associated healthcare expenses, the societal financial impact of illness and dependency will heighten with disease severity; therefore there is a call to address the need for cost-effective and high-quality care to alleviate burden (Galvin et al., 2014; L. E. Hebert et al., 2013; Meloche et al., 2016; Sivananthan et al., 2013).

The financial burden and care dependency will rise exponentially with care demands (Galvin et al., 2014). Influxes in older Americans and the cost of caring for them will potentially exceed allocated funds. Indirect costs from loss of work days due to informal caregiving and direct costs of outsourced services are approximately \$100 billion annually (Boustani et al., 2003). A study conducted in 1999 on a random sample of Medicare beneficiaries found that dementia-associated total expenditures were 3.3 times higher than in non-dementia patients, with 54% of the adjusted costs due to hospitalizations (R. Hebert et al., 2007). In 2011, the annual cost of care was estimated to be \$183 billion, mostly covered by Medicaid and Medicare (Alzheimer's Association, 2011). Financial stress caused by expensive medical, long-term and end-of-life care is on average six times higher for those with dementia than someone of similar age without dementia (Stewart et al., 2014).

Care costs can be high and inconceivable at times, particularly for families struggling to gain financial support or assistance benefits (Alzheimer's Association, 2011). End-of-life care requires family caregivers and a need for external support services such as hospitals and nursing homes (R. Hebert et al., 2007). Caregiving is vital for individuals diagnosed with ADRD. As the loss of cognitive function progresses and interferes with activities of daily living, PLWD become entirely dependent on others for care until their passing (National Institute on Aging, 2016; Sivananthan et al., 2013). Majority of care scenarios occurring in the home are informal; either completed or paid for by family (Hoffman, 2014). Many families may be financially unable to provide a paid caregiver or enroll loved one into a long-term care facility; therefore, the caregiving becomes a single or collective family duty. More than 16 million loved ones take on the role of caregivers without any pay for over 5 million Americans struck with dementia (Alzheimer's Association, 2019a). The emphasis on caring for the caregiver makes a topic that

requires more extensive research and future accommodations. While they assume the role as primary caregiver in many circumstances, the health of the caregiver must be factored into and addressed in the care of the person living with dementia.

With a central concern placed on diagnosed individuals, the effect of the disease on family and friends is of high importance as well because both parties experience mental distress. (Alzheimer's Association, 2015; Weiler, 1987). The progression of dementia robs a PLWD the ability to express themselves or communicate their needs to others (Robinson et al., 2014; Sivananthan et al., 2013). This creates a loss of independence and feelings of burden towards others. Moreover, this dependency can take a toll on caregivers, especially unpaid loved ones that become financially and emotionally distressed from the new reality of caring for a PLWD (Boustani et al., 2003; Galvin et al., 2014; Neitch et al., 2016; Stewart et al., 2014). Physical and psychological distress accompanies an amplified need for caregiving and external support (R. Hebert et al., 2007). As dependency increases, the need for personal care grows. This troublesome effect provides an opportunity to incorporate loved ones throughout diagnosis and treatment while providing extensive support and resources throughout the disease's progression. In recognition of the role of caregivers, healthcare for PLWD is transitioning into a team effort for care focused on culturally, economically, and racially diverse support to encourage a family-centered feel (Snyder, 2016). A caregiver's understanding is fundamental to providing superior clinical and personal care to the diagnosed individual. They cannot adequately plan without an accurate diagnosis and external professional support to understand various aspects of ADRD.

Rural Populations and Alzheimer's Disease and Related Dementias

Place of residency influences lifestyles, availability, and access to health resources, providers, and appropriate level of care (S. L. Williams, Haskard, & DiMatteo, 2007). There are geographic variations in resource availability and accessibility, distribution of poverty, education, ethnic and minority groups, and vulnerable age groups, whereas such variations can influence the quality and type of health care received. When combined with barriers affecting access and underutilization, such as increased travel distances, time, and transportation difficulties, health care delivery and utilization become impacted (Dautovich et al., 2014). Population trends show that rural areas are increasingly comprised of older adults (Dautovich et al., 2014). In a study by Russ, Batty, Hearnshaw, Fenton, and Starr (2012), AD prevalence and incidence was found to increase in rural locations.

Rural communities are experiencing unpreparedness when attempting to address the problematic care needs of PLWD (Alzheimer's Association, 2011). Health Professional Shortage Areas (HPSA) experience a shortage in primary care health services, dental services, and mental health services (Health Resources and Services Administration, 2016; Tennessee Department of Health, 2016). Based on provider/population ratios, all counties in NETN are considered to be an HPSA in some fashion (Health Resources and Services Administration, 2016; Tennessee Department of Health, 2016). Hawkins County's entire county and low-income populations as well as the entire county of Hancock and Johnson Counties experienced primary care provider shortages in 2016 (Tennessee Department of Health, 2016). In 2017, low-income populations in Sullivan, Washington, Unicoi, Carter, and Johnson, as well as the entire county populations in Hancock, Hawkins, and Greene Counties, experienced mental health services shortages (Tennessee Department of Health, 2016). In addition to shortages, older populations' mental

needs are often higher, particularly in rural areas, where there is a lack of mental health resources (Dautovich et al., 2014).

Appalachian Region. Spanning from New York to Mississippi, 42% of the Appalachian population lives in rural areas. Poverty and outdated care delivery continue to shadow the region (Lane et al., 2012). Tennessee's Appalachian region experiences a poverty rate of 18.6 %, which is higher than the national average of 15.6 % (J.L. Marshall, 2017; J. L. Marshall et al., 2017). Although poverty shadows much of the region, culture, traditions, and rooted values continue to stay ingrained in all aspects of life (Bushy, 2008). Historically, struggling communities rely on inside assistance due to distrust of outsiders, independence/self-reliance, and choosing to interact with locals only (Bushy, 2008). Therefore, culturally appropriate care requires a full understanding of shared cultural patterns for tailoring care plans to target health disparities unique to regions (J. Williams, 2013). Without such, patients may feel that providers are unconcerned or inadequate to provide proper diagnosis or care (Presley, 2014).

Personal differences can impede care delivery (S. L. Williams et al., 2007). Culture influences how and to what extent individuals' value preventative care and treatment adherence. A strong Appalachia culture of family barricades the use of services in fear of insulting, letting down, or degrading the PLWD. In the Appalachian culture, it is essential to establish patient-provider relationships with mutual trust (Presley, 2013). Good standing between providers and caregivers enable an ideal matchup of services for PLWD (Harris, Chodosh, Vassar, Vickrey, & Shapiro, 2009). In addition to building good relationships, Presley (2013) found that Appalachian populations hold a present-time view where healthcare needs are expected to be addressed as soon as a problem arises. Inadequately met needs make it difficult for scheduling appointments and follow-ups and inconsistent follow-ups for chronic conditions. Therefore, to

deliver optimum care, it becomes beneficial for providers to competently engage patients through culturally appropriate methods (Bushy, 2008).

All of Northeast Tennessee resides within the Southern Appalachian Region (Appalachian Regional Commission, n/d). Geographically and culturally, it has a mix of southern city, country, and mountainous lifestyles. Collectively, the PLWD and caregivers' needs may vary, but the region's resources and services remain the same. More importantly, barriers among residents vary, including SES, education attainment, and income. To address these barriers, the healthcare industry in NETN must incorporate methods that are not only sensitive to culture, but also accommodating to health barriers commonly occurring in the region.

Managing Alzheimer's Disease and Related Dementias

AD, the most common form of dementia, is the only leading cause of death that cannot be prevented or cured, and those affected require a way to alleviate the burden and chronic suffering on individual, community, and societal levels. Serving this population, therefore, becomes complicated and requires collaboration to address these needs (Hoffman, 2014). Dementia requires a high level of care involvement with notably long-term, labor-intensive, and expensive care (Khachaturian et al., 2017). Additionally, the management and resource requirement for both PLWD and their caregivers intensifies with time and extends from a wide array of agencies. Deb and colleagues indicated that with disease progression, there is a related increase in required care such as medical treatment, prescriptions, home safety modifications, personal care, adult day care, and, residential services to name a few (Deb et al., 2017).

Communication. Clear and comprehensive communication is required when interacting with patients experiencing a form of dementia (S. L. Williams et al., 2007). Communication barriers in dementia care involve the abilities of providers and allied health professionals to coordinate care to meet the needs of PLWD and their caregivers (Alzheimer's Association, 2011). During the aging process, communication with knowledgeable providers and service organizations must be sensitive and built on strong relationships with providers to serve as a supportive foundation for quality care delivery. Communication can be strengthened by the right connection of people and systems compiled of professionals in various stakeholder groups, which gives care teams the confidence to adequately educate, support, and train (Stewart et al., 2014).

Person-centered care takes into account individual variations and converts them into a unique care plan that works best for each PLWD (Maslow, 2013). Combining person-centered care and communication as a professional transdisciplinary team allows for more comprehensive delivery of care based on the preferences of the patient instead of the provider or organization (Maslow, 2013). Patients would have the choice to participate in care plans to improve their care by cooperating with the interprofessional team (S. L. Williams et al., 2007). A provider's investment in communication, knowledge, and application of the recommended practices positively influences individuals who require dementia care at any level. Ensuring consistent communication across the continuum of care serves dementia patients best during their aging transition (S. L. Williams et al., 2007). Moreover, if a patient residing in NETN trusts a provider that makes these communication investments, the follow-up and patient satisfaction may be positively impacted and encourage continuous engagement throughout the care continuum.

Care Coordination. Primary care providers are frequently involved in the diagnosing process and bear the weight of the continuum of care (Alzheimer's Association, 2015; Lathren et al., 2013; Stewart et al., 2014). Routine visits to providers permit monitoring and addressing cognitive, functional, and behavioral challenges (Stewart et al., 2014). After a PLWD or caregiver address cognitive ability concerns, a provider must monitor cognitive, functional, and behavioral changes, which requires regular attention and presents a challenge to providers without help coordinating the care (Sadowsky & Galvin, 2012).

Coordinating care is nearly impossible without primary care serving as the hub for resources (Bodenheimer, 2008). Most providers acknowledge their lack the confidence to assess individuals with geriatric-specific conditions and wish to enrich their skills to improve care delivery (Harris et al., 2009). Higher levels of knowledge in dementia and dementia care have been associated with higher provider referrals, whereas the lack of referrals could negatively influence care delivery for PLWD (Harris et al., 2009; Lathren et al., 2013; Reuben et al., 2013; Sivananthan et al., 2013). Inadequately detecting and managing PLWD concerns rids providers of suitable psychosocial interventions, monitoring, or a multidimensional approach to lessen the cognitive and functional challenges that follow brain changes (Sivananthan et al., 2013). Utilizing others' expertise can also allow the provider time to meet with patients and families to address their care needs individually (Galvin et al., 2014). Often disregarded as additional work, referrals to community-based resources are essential in transitional care (Bodenheimer, 2008; Next Step in Care, 2013).

While the availability of services exists, there is a lack of the provider-based response (Judge et al., 2011). Providers are crucial to managing dementia care; they serve as the medical hub for care from detection to disease management. A provider must be knowledgeable in

ADRD to initiate referrals to diagnostic specialists and to determine best-fit community resources that will enhance the PLWD's quality of life. Some providers recognize their abilities to assess and manage PLWD to be insufficient and trust they could be improved to enhance patient care (Harris et al., 2009). However, training providers in the available community resources and referring patients may present a better, less burdening option to providers as they seek to improve the care they are capable of delivering to the aging population (Lathren et al., 2013).

Therefore, the complexity of ADRD warrants a multidimensional approach. Providers are essential to this approach but spend limited time with patients and feel there are limited treatment options available (Neitch et al., 2016; Reuben et al., 2013; Stewart et al., 2014). Despite a lack of a thoroughly effective treatment, active management is consistently being shown to improve the quality of life for individuals with any stage of dementia and their caregivers. A thorough treatment would encompass active management for those with dementia as well as incorporate caregiver involvement by continuously maintaining cognitive stimulation from social cognitive engagement and self-care.

Accessing Health Resources. The complex, pluralistic U.S. health system creates unnecessary hardships around care coordination (Bodenheimer, 2008). Often, PLWD get clustered into a box by providers, health services, and the general public but not all dementia cases are the same. Fragmented coordination makes it difficult for PLWD and caregivers to determine suitable resources to meet patient needs accurately (Bodenheimer, 2008).

Connections with resources eliminate the additional stressors created by the uncertainty around the availability of community-based resources. Also, early access to community-based resources can help PLWD live at home longer by avoiding hospitalization and institutionalizing (Gaugler,

Kane, Kane, & Newcomer, 2005; Next Step in Care, 2013). Dismissing a continuum of care denies PLWD and family caregivers the use of potentially benefitting services (Sadowsky & Galvin, 2012).

After a PLWD receives a diagnosis, overwhelming concern arises. Unprepared caregivers require support as well. Attaining education and affordable services can help ease some of the burden caregivers face when assuming the primary role of unpaid caregiving (Alzheimer's Association, 2011). Caregivers can become frustrated from the discomfort that dementia can cause PLWD and those around them and a battle to understand the disease ignites troublesome feelings. Knowledge of support services within the community can help families plan and manage symptoms (Fortinsky, 2014). The issue then becomes a matter of whether or not to use these services. Ninety-five percent of counties experiencing impoverishment are located in rural areas, have lower educational attainment, and are uninsured for more extended periods, making individuals less likely than urban populations to seek out services due to their inability to pay (Dautovich et al., 2014). With limited access to support services, rural areas are not equipped to adequately address the projected increase in older adults, specifically those with ADRD (Alzheimer's Association, 2011).

Dementia generates daily challenges where comfort and dignity-filled days are a top priority for caregivers and providers. As difficult as it may be to provide such quality of care, connecting with community support services is essential for filling the gaps in care required to provide this quality of life (Fortinsky, 2014). The demands for comprehensive dementia care significantly constrain the limited available resources nationwide. Unfortunately, the expected need will only intensify, with the expected increase in 65 and older age group (Khachaturian et al., 2017).

A lack of partnerships between health providers and community-based resources often results in underutilization due to lack of physician awareness (Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2008; Lathren et al., 2013; Reuben et al., 2009). Community-based resources can support the delivery of healthcare to PLWD by coordinating care and supporting caregivers (Reuben et al., 2013). Health systems ability to deliver care and tap into community-based resources to create a system of care will create quality improving relations. Such partnerships will help in eliminating unnecessary hospitalizations and decrease the expenditures experienced during the last years of life (R. Hebert et al., 2007).

Multiple studies stress the need to not only have primary care providers as the foundation for community-based resources, but stress the importance of utilizing a collaborative, interdisciplinary care team for comprehensive care planning and coordination (Bodenheimer, 2008; Galvin et al., 2014; Next Step in Care, 2013; Stewart et al., 2014). Collaborative relationships among them invite the opportunity to provide exceptional care (Robinson et al., 2014). As practitioners, it is a duty to guide caregivers with patient-appropriate knowledge and ways to use the information to better care for a loved one (Neitch et al., 2016). Involvement in a collaborative relationship empowers direct and thorough communication with staff and family members and improves confidence in their comprehension of ADRD and their caring abilities (Robinson et al., 2014).

A variety of studies explore care coordination and utilization of community-based resources (Lathren et al., 2013; Paskett, Harrop, & Wells, 2011; Reuben et al., 2009). To the best of our knowledge, no study has used the classic grounded theory as an approach for obtaining a comprehensive understanding on how stakeholders in the care of PLWD work together to ensure that resources are available to and being utilized by PLWD and their

caregivers. Notably, research on dementia-specific resources and services in NETN is not available. In this study, the researcher aimed to address this gap in the literature and add to the body of information available to enhance the coordination of care for PLWD.

The 4A's of access to care is acceptability, accessibility, affordability, and availability. Adapted from McLaughlin and Wyszewski (2002), the definitions used for this study are as follow:

Acceptability: the quality of openness to acknowledge potential use of and comfort level of ability to see out appropriate education, health services, and health professionals;

Accessibility: The quality of being able to physically reach out, obtain for use, or understand resources and services;

Affordability: the ability or willingness to pay for services; and

Availability: the capacity of being able to be use, the ease of access to timely and appropriate education, health services and reliable health professionals.

Classic Grounded Theory

Classic grounded theory (CGT) was used in this study to provide a rationale for the needs listed above. Developed from the methodological notes of Glaser (2009b), Glaser and Strauss, two sociologists, sought to describe qualitative research better than existing ways with a technique to improve the understanding of social behavior through enriching the meaning of data by going beyond numerical values or conversations (Cohen & Crabtree, 2006; Glaser, 2009b; Glaser & Strauss, 2009). They sought to visually represent how a study's components relate to one another, and as a result, an applicable theory emerged (Glaser, 1978). The original research study was published in their book, *Awareness of Dying*, in 1965, and in 1967 they described the

theory's discovery in the published work *Discovery of Grounded Theory* (Glaser & Strauss, 1965, 2009).

After presenting CGT to theorists alike, it has been adopted worldwide by those that value the newness and the naturalistic construction of theory. Disciplines including but not limited to education, political science, and business have all come to accept its nontraditional methodology (Glaser, 1978). The possibility of generating a theory to explain a pattern hooks researchers in search of creative ways beyond traditional descriptive research methodology (Creswell, 2007). Judith Holton, Grounded Theory Review's former editor, suggests that researchers consider using CGT for its ability to conceptually summarize the impending question by grounding interpretations and urging researcher reflection (Glaser, 2014). Exploring with CGT may not align with traditional scientific methods, but it can exceed the legitimate needs in the field (Simmons, 2012).

CGT focuses on understanding the questions being asked and deciphering meaning as additional information flows in (Creswell, 2007). It is an attractive methodology where data is systematically used to conceptualize data patterns for manufacturing accumulated ideas into a workable theory (Glaser, 1978, 2014; Glaser & Strauss, 2009; Martin & Gynnild, 2011; McCallin, Nathaniel, & Andrews, 2011). Glaser describes the substantive theory's purpose as an explanation of a behavior pattern in its simplest abstract form (2014). When applicable, grand touring questions morph to dive deeper into comparative-worthy information. Researchers choosing CGT must keep in mind that with each analysis, the information is never proven, rather it gets compared and modified for future use (Glaser, 2014). Researchers are required to stay grounded in and guided by the data.

Both inductive and deductive thinking take place with data collection and theory creation. As an experiential inductive methodology, the researcher will only truly learn by doing and feeling through the processes (Corbin & Strauss, 2008; Martin & Gynnild, 2011; McCallin et al., 2011; Rhine, 2010). Deductive logic helps to derive the induced codes into conceptual working codes with an ultimate aim of theory generation (Glaser, 1978). Conceptualized patterns clarify over time and construct a theory providing the much needed explanation beyond the words of participants (McCallin et al., 2011). Glaser strongly emphasizes simple appreciation for collected data and not to dwell on any absence of information (Glaser, 1978). Results may not be as expected, and it is imperative to permit that the data control the direction. By doing so, the process strengthens and gains reassuring support of doing CGT.

By using the constant comparison method, CGT induces codes naturally throughout the study (Glaser, 1978). Two types of coding, substantive and theoretical, make up the formation of CGT building blocks for creating a theory. Like other components of the CGT process, substantive and theoretical coding co-occur. Substantive coding discovers the codes within the data while the theoretical codes integrate the continuous analytical memo writing (Glaser, 1978; Glaser & Holton, 2004). Plainly, the substantive codes grasp observed material whereas theoretical codes conceptualize interactions between and among those substantive codes about the developing theory.

Perspectives & Misunderstandings. CGT is misperceived as a simple method, but it is not, because it commits to discovering a theory pertinent to a selected study as opposed to existing theoretical assumptions and confinements while requiring the persistent and concurrent performance of rigorous and tight procedures (Glaser, 2014). However, the variation in CGT interpretation has created modified variations of GT that steer away from the original version

(Glaser & Strauss, 2009; Martin & Gynnild, 2011; Simmons, 2012). Glaser and Strauss created the original CGT. Glaser continued to study CGT (aka Glaserian GT) while Strauss broke away with Corbin to create the first remodeled version (Corbin & Strauss, 2008). In addition, Charmaz (2006) took a constructivist approach, Clark (2005) created a situational approach, and Goulding (2002) and Locke (2001) utilized grounded theory for management and business approaches (Corbin & Strauss, 2008; Locke, 2001). These modifications do not fully align with CGT as originally constructed. CGT requires a researcher to possess the unique abilities to conceptualize, organize, and connect abstract thoughts while remaining open to change, tolerant of struggles, and trusting in the preconscious processes and emergence of patterns (Glaser, 2009b).

Additionally, the theoretical perspectives such as ontological and epistemological are not applicable for CGT. Rather, the patterns from the data grounded through conceptualization are pertinent (Glaser, 2014). Misunderstandings arise when comparing or trying to incorporate traditional qualitative data analysis (QDA) with CGT methods in regards to rigor and vocabulary descriptions (Glaser, 2014).

CGT does not neglect literature searches and is not descriptive or phenomenological. The procedures are adaptable to the data and are not a step-by-step methodology (Glaser, 2014; Suddaby, 2006). CGT is not a onetime application of a method, but rather a concurrent sequence progression of data collection and analysis interconnected by conceptualization. Stressed by Glaser, “All is data” means what the research is experiencing is exactly the data that requires maximum use (Glaser, 2012, 2014; Glaser & Holton, 2004). All is data refers to every piece of data take on a significant role with CGT. Therefore, it is vital to stay open, let the data guide, and avoid the described perspectives that may lead to irrelevant conclusions from CGT misuse

(Glaser, 2014). To combat these misunderstandings, an initial solution would be to stay true, open, and focused. The researcher needs to stay open to the data during coding until saturation and relevancy are reached. They would also need to stay focused on the categories emerging out of the coded data while accepting continual input from the data. This highlights the constant emergence of any patterns and opportunities to make notes of such alterations. Further, sampling is not pinpointed on a hypothesis, but rather categories and the relations to one another. These relations are used to detect the finest fit and what works best with the incorporation of applicable data (Glaser, 1978). Ultimately, let the data guide. Other studies have been published to show how letting the data guide will provide exactly what is needed. While this is true, a small amount of studies has been published to describe how communication can influence access to health resources.

Classic grounded theory was chosen to answer this study for its permitting and enabling abilities for emerging a pertinent theory. Among all theories available for use in public health research, CGT's experiential opportunity and exploratory nature marks it as most applicable to adequately address this study's aims. CGT's abilities to aid the gathering and understanding of responses and community needs increase the rigor of a study's design (Creswell, 2007). The researcher wanted a chance to describe a public health need through the perceptions of those involved in the dynamic care of PLWD and their caregivers in the organizational settings whom are responsible for education, care, research, and treatment.

CGT emphasizes autonomy, capacity to remain open to new research methods and ideas, and conceptualization (Glaser, 2014). Applying CGT to this study allows for a theory to develop around communication. Each person involved in the process has unique perspectives. When all

is data, the anticipated influx of information reminds the researcher to stay true, focused, and open.

Chapter Summary

In this chapter, the relevant literature on ADRD was discussed. Gaps in care coordination and communication relating to the care of PLWD were identified. Opportunities for collaboration between community-based organizations and healthcare systems were also discussed. The classical grounded theory approach was introduced, and a rationale was provided for its use in this study. In the next chapter, the study's methodology is described.

CHAPTER 3

METHODOLOGY

This chapter presents an overview of the methodology used in this study.

Aim 1

Research question 1. What dementia-specific health resources and services exist in Appalachian communities in Northeast Tennessee and how are they impacting community access?

Aim 1. To identify dementia-specific health resources and services that exist in Northeast Tennessee and to evaluate their accessibility, availability, acceptability, and affordability.

Sample. The sample included organizations with locations in any of the Northeast Tennessee counties of Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, and Washington. Organizations had to serve the senior population at some capacity, largely offering dementia-specific resources and services that may be of direct or indirect benefit to PLWD and their caregivers.

Sampling began with the 2017 First Tennessee Area Agency on Aging and Disability (FTAAAD) Directory. Contact information and organization service area data were pulled from the directory. A list of organizations known for offering dementia education, awareness, and health services included residential communities such as assisted livings, nursing homes, skilled nursing facilities, adult day care centers, senior centers, home health organizations (medical and non-medical), respite, and hospitals with geriatric-psychiatry units. Organizations had a business address located in one of the eight Northeast Tennessee counties and extended their service reach to at least some of these counties. Those excluded were hospitals (except for those with a geriatric-psychiatry unit), local and regional health departments, services specific to

veterans, disability-specific organizations, and national organizations that provide dementia-specific education but do not have a local chapter in Northeast Tennessee.

Collection and procedures. The researcher sought to gather representative data of the community's access to organizations addressing dementia-specific health resources and services. Data collection began by examining the organization descriptions provided in the 2017 FTAAAD Directory. The researcher explored each organization's website, if available, to identify applicable information before contacting via phone to follow-up with the organization to create a comprehensive description of the possible dementia-specific resources and services in Northeast Tennessee. To speak to a representative, the researcher had to schedule phone appointments with a majority of those organization that did advertise offering dementia-specific health resources and services. Case managers, administrators, registered nurses, and education coordinators were frequently the point of contact. When the researcher attempted to contact an organization three times and was not connected to a representative or did not receive a returned phone call, no additional contacts were made, and the organization was excluded.

In March 2018, the researcher worked with a committee member to construct the questions used to address the 4A's for multiple organizations. To meet Aim 1, questions branched from the following: 1) Is the service reaching the intended population that need/could benefit from the offered services [accessibility]?, 2) Are the services being accepted by the intended population [acceptability]?, 3) Is the intended population able to pay for the services [affordability]?, and 4) Are the services meeting the demand of the service area [availability]? Each of the 4A's had multiple questions to address the overall view of each. If an organization offered dementia-specific health resources and services beyond referrals, the point of contact was asked to volunteer a response for the remaining questions focused on the 4A's used to address

access to services. Those excluded from further questions were the organizations whose point of contact did not report offering dementia-specific health resources and services at any capacity. To ease data entry, the researcher created a Google Form for information gathered from each organization's website and during phone conversations. Data was gathered from April 2018 to September of 2018. Appendix A shows the Aim 1 Questions used for creating the Google Form to gather information from each organization and variable codes for analysis. The applicable data included organization type, services offered, access methods, targeted audience, costliness, referrals, and collaboration efforts.

Analysis. Each response was entered into the Google Form that created a spreadsheet for outcome results. This enabled the use of column filters to find applicable frequencies, and the organizations reported values that were compiled as frequencies which will be discussed in Chapter Five. Organizational awareness of other dementia-specific organizations was also documented to see if those serving were able to share knowledge of other organizations that may meet the needs of PLWD or caregivers. Collective responses were organized and filtered to determine categorical frequencies of organizations offering dementia-specific health resources and services, target audience of offered resources and services, how the targeted audience accessed and accepted the dementia-specific resources and services, referrals, and support.

To visually represent the geographical concentration of resources and services, the organizations were mapped based on physical addresses using Maptive, a mapping software that utilizes Google Maps, and can be found in Chapter 5. All results exclude organization names and other identifiers. The addresses are public records; therefore, the use of addresses does not violate any privacy.

Aim 2

Research question 2. What are the perceptions of access and communication gaps that occur among healthcare professionals, caregivers, and dementia service organizations when caring for people living with dementia and their caregivers in Appalachian communities in Northeast Tennessee?

Aim 2. *To describe the perceptions of access and communication gaps that occur among healthcare professionals, caregivers, and dementia service organizations when caring for people living with dementia and their caregivers in Northeast Tennessee.*

Sample. Including a diverse group of community members to better understand the cultural details of sensitive aging topics helps to create valuable understanding (Zanjani & Rowles, 2012). The targeted participants were caregivers, health educators, healthcare providers, state agency representatives, and administrators from senior care agencies, assisted living, nursing homes, senior centers, and healthcare facilities. Inclusion criteria was being over 18 years of age, involved in dementia care to some capacity, and located within the selected Northeast Tennessee counties. A non-probability purposive sample served as the initial sampling method to obtain relevant insight from community members heavily involved in dementia care. The researcher utilized the snowball technique and encouraged participants to share the invitation with others in similar positions that may be interested in participating. More importantly, theoretical sampling, a CGT sampling method, was used to gather additional participants that were best fit for the creation of the resulting theory. Defined in Chapter One, Glaser's description of theoretical sampling emphasizes the elicited coding of raw data through constant comparative analysis (1978). Sampling and analyzing coexist at all stages. The

analysis can be strengthened if it occurs during the sampling stage (Glaser, 1978). Instead of seeking verification from previous concepts, CGT sampling creates a point of inspection for concepts that surface over time (Glaser, 1978).

Recruitment. Participant recruitment took place by email, phone, in person, and by word of mouth from other participants. Using the 2017 FTAAAD Directory and websites of organizations gathered during Aim 1, the researcher compiled an email list of readily available potential participants. If no response was received, the researcher followed up one week later. Each email invitation had the *Recruitment Materials*, Appendix B, attached in addition to the study description. If contacts from Aim 1 met the inclusion criteria for Aim 2, they were invited to participate in an interview via email to dive into their perspectives of dementia-specific care. After interviews, the researcher stated that if the participant knew of others that may be a good fit for the study to please share the researcher's contact information with others. To recruit caregivers, the researcher received committee encouragement and permission to attend a support group meeting offered by an organization known for education and awareness. Two attendees expressed interest while one ended up participating. The other caregiver was recruited via word of mouth. One participant took the initiative and shared the email with providers across the region and ended up getting consent to share their contact information with the researcher.

Once each participant expressed interest and willingness to participate, a follow-up email, including a calendar invite, was sent to confirm the interview date and time, excluding the three that confirmed via phone. Those recruited by phone received a confirmation phone call an hour before the meeting time. Each participant recruited via email received an electronic copy of the informed consent document (ICD). All interviews took place in safe, public locations such as

local coffee shops, professional workspace, and community centers with private space allowing for recorded conversations.

Collection and procedures. This study focused on gathering perspectives on communication, access, and dementia care, which called for a framework that is applicable, values the participants' voices, and adds value to the literature. By valuing a participant's words, researchers can understand the community needs from an insider's perspective (Creswell, 2007). CGT drove this section of the study because of its exploratory nature with recommendations to stay exceedingly grounded in the data and absorbing participant perspectives while remaining aware of any preconceived ideas that may influence data collection. Please note, the use of CGT emphasizes data collection and analysis to co-occur and reported similarly. For the sake of uniformity and clarity, this study's data collection, procedures, and results are in the traditional dissertation format required by Georgia Southern University's College of Graduate Studies.

Pilot testing took place in March 2018 to verify question structures, comprehension, and flow. Interviews were conducted from June 2018 to September 2018 using a CGT framework to guide data collection and analysis with sixteen participants personally or professionally involved in the care of PLWD.

Each interview began with a review of the ICD to ensure the participant understood the study and expectations. Participants were asked to sign and date the researcher's copy as well as initial if consenting to be audio recorded. After obtaining consent, the researcher read a short paragraph on the *Instrument*, Appendix C, to reiterate the purpose, emphasize the ability to withdraw at any point, and conclude with a verbal consent to audio record the interview for transcription and analysis. With each interview led by the researcher but guided by the participant, the timeframe occasionally varied beyond the normal 30-45-minute limit as the

researcher wanted the participant to fully express thoughts and concerns freely without feeling pressured by time. The researcher addressed each question but allowed the participant to expand on any necessary points.

The interview script approved by the Georgia Southern University Institutional Review Board was used as the interview guide while using probing questions when needed. However, participants were able to expand on thoughts and concerns following a quiet pause before either the participant or researcher spoke. Probing questions helped expand the meaningfulness of answers and provided for questions addressing the 4A's. If a participant was unsure of the question, the research repeated the question and asked them to interpret it in a way he or she saw fit. The researcher used these open conversations to address the questions and gain answers, but also genuinely wanted the participant to feel in charge and valued for the provided insight. Each participant provided an abundance of information that was further built upon by the following interviews. Following each interview, the participant completed the *Participant Demographics* questionnaire, Appendix D, that was later used to describe the sample. Each participant received a printed copy of the ICD and a \$5 Pal's Sudden Service gift certificate for volunteering his or her time.

The interviews were recorded using the Voice Recorder application purchased from Apple AppStore. Both the phone and the application required fingerprint recognition to access the data. Immediately following each interview, the researcher used the built-in transcription features to transcribe the interview into a written document. However, ensuring transcription accuracy required the researcher to listen to each recording, modify any mistakes made during initial transcription, and organize the interview into a workable Google Docs document. The interview was then imported into NVivo 12, a qualitative data analysis software program. If insufficient

transcription were to take place, the emerging data would not fit or even work to create a well-developed theory. Recording interview sessions between the researcher and participant aids in category saturation by allowing referrals back to the interview but is only useful if multiple researchers will be analyzing the data together (Glaser, 1998, 2009b). This format enabled the researcher full visual access to examine the data as well as share with the committee chair. Glaser (1998) discourages verbatim transcription, however, with the novice researcher learning the process, there was a need to verify coding methods after data collection for consistency by reviewing a subset of generated codes against the final codebook. Also, Glaser (1978) discourages the use of external coders and believes that coding should only be completed by those directly involved in the data gathering process because there is an inability to develop a list of codes before data collection or transcription. External coders are incapable of coding without a structured set of codes and to do so goes against the CGT process while removing the intimacy of immersing oneself into the data. Thus, the researcher interviewed all participants, transcribed and analyzed all data, and created a codebook based on interview results. The researcher shared the NVivo file with the supervising committee chair for feedback on analysis. The chair selected two interviews, coded them using the constructed codebook, and calculated a Kappa Agreement score to verify coding agreement between raters. The level of agreement was above the 0.80 benchmark for all nodes.

Memos. Due to the diversity of the sample, each interaction with participants was vastly different, and the researcher needed to capture this variation in perception and experience. It was vital to memo throughout because the memos supported the coding process as they took place the entire length of the study. All interview memos and notes were kept in the same ringed binder. The researcher wrote memos during data collection and on observations that may be

used as supplementary data to further enhance quality. Glaser and Holton (2004) explain that sorting and writing up the resulting theory is done on the conceptual level, not the raw data level. Memos generated during theory generation advance the theory to become more concise. A researcher, not a computer, performs theory-generating techniques more effectively, as he or she is capable of sharpening, relating, and integrating the concepts on an abstract level while incorporating information drawn from persistent memo writing (Glaser, 2007; Glaser & Holton, 2004). This capability and tie to the data is only possible with a researcher fully immersed in the data throughout the entire process.

Conceptualization. Conceptualization is the deriving of data to generate codes, develop categories, and verify patterns. This process begins after the first moment of data gathering. A baseline for data comparison evolves from the first data piece and continues to be revised or modified into workable concepts. Concepts form after the data has traveled through the conceptualization process (Glaser, 1978). This cycle will continue until full saturation, and continuous resolution towards the central category is integrated into the set of concepts resulting in the theoretical assembly (Corbin & Strauss, 2008; Glaser, 2014).

The culture of participants and researchers influence the way they give and receive communicated information. In combination with culture, past participant experience affects their willingness to speak up and their interactions with others. The researcher will be able to grasp what is meaningful to the participant if they have an awareness of this influence (Gubrium & Sankar, 1994). Despite the tediousness, CGT's emphasis on conceptualization invites a thorough way to incorporate the participant's culture into the analysis and theory emergence.

Coding. Researchers complete the analysis during and after data collection (Glaser, 1978). Data collection occurs with four fluid stages: codes, concepts, categories, and theory. The data analysis takes place in all four of these stages too. Starting as a researcher's interest, codes are identified from the data which in turn promotes concept transformation into categories that ultimately become a comprehensive theory. Any change within the data initiates change in the resulting concepts (Corbin & Strauss, 2008; Gubrium & Sankar, 1994). A new theory results from a thorough integration of data by conceptualizing and structuring it to illuminate what is going on and how it can be explained based on scientific principles and procedures (Glaser, 2014). Procedurally, coding focuses on new words while patterns develop from codes. Glaser and Holton (2004) state that a researcher must ask the following questions while processing the codes: *What is the data a study of? When examining field notes, what category does this incident indicate? What is actually happening in the data?.* The purpose of these questions is to ensure that the theoretical sensitivity is carried out through analysis collection and encoding of data (Glaser, 1978). By continuously asking these questions throughout, the researcher stays engaged with the data and gains a deeper understanding while steering the process.

Initially, open coding guides direction, which in turn influences the sample by permitting the researcher to become selective and fixated on the emerging problem (Glaser, 1978). This begins the process of raw data transcription and extensive inspection. Due to open coding's capability of identifying variables and focal points for the forthcoming theory, data relevancy becomes impacted by breaking down the data into manageable components that may develop into conceptual ideas (Cohen & Crabtree, 2006; Glaser, 1978). Data concepts based on the constant comparison analysis may or may not develop further into the categories that create the theory. Codes can further arise into the different conceptual thoughts based on whether the

experiences allow for a continuous analysis and ideal theoretical sampling. The conceptual outcome is dependent on the continuous review of incoming data.

Delimiting the collection assists researchers by decreasing the overwhelming sense of fear caused by mass delivery of data in the coding procedure (Glaser, 2009b). The search for relevance and workability of gathered data starts here. The fit of data is tested for appropriation by constantly comparing the emerging concepts. Being concept-driven, a deep exploration of the rising theory's developing concepts heighten the discovery of relevancy (Corbin & Strauss, 2008). The process of analyzing data immediately after each interview permits the collected data to converge to generate purposeful emerging categories requires continuous refinement of categories for the duration of theory creation (Guthrie & Lowe, 2011). Cross-examination of relations must be considered for theory growth. Categories must appear throughout the data collection process and must be logical, consistent, and free-flowing so abstract ideas can be pulled from the data.

The resulting theory and categories within the theory must be malleable for future researchers. As data is gathered and analyzed, each potential category will be assessed to meet the criteria listed above to begin the process of theory development. As required, the categories must represent growth capacity through the determined interrelated concepts with advanced analysis and development (Corbin & Strauss, 2008). A central category, or core variable, in an emerging theory must meet the criteria to be deemed appropriate and will account for a sizable portion of variation existing around the main problem (Glaser & Holton, 2004). After choosing the central category, the major categories must relate back (Corbin & Strauss, 2008). Each interrelationship is foundational for the next. Conceptual codes of underlying patterns serve as

the relationship between the data and the theory it creates. Further supporting CGT, this discovery is based on data, not preconceptions (Guthrie & Lowe, 2011). It is said that patterns of behaviors enable understanding. Hence, latent patterns must emerge without the researcher's force. Requiring simultaneous gathering and analyzing data results in a noteworthy fashion that drives continuation until saturation. It is fundamental for the researcher to stay present and ahead of the data filtering in (Gubrium & Sankar, 1994). These vital behaviors minimize overwhelming feelings experienced with large amounts of data and make for a more efficient process.

Saturation. Sampling continues until saturation and theoretical understanding are reached (Gubrium & Sankar, 1994). The saturation is not based on a completed number of interviews, but rather a researcher's confidence in the data stating the truth behind what has been gathered from participants. Once the researcher determines categories as fully saturated, and is convinced summative conceptual framework delivers accuracy, a theory is considered complete (Glaser & Strauss, 2009). Strauss and Corbin state that by asking the basic questions of what, when, where, and why, a well-integrated theory will result to explain the targeted issue (2008). Resulting theory will only be as correct as the gathered data. Thus, the theory must be modifiable to make way for newly constructed components further evolved out of new data (Glaser, 1978).

Theoretical Model. Creating a theory is condensing extensive raw data that form concepts responsible for explaining an issue in a logical and systematic manner (Corbin & Strauss, 2008). Constructing the theory is only possible through the multi stages of coding, memo writing, and sorting ideas (Glaser, 1978). A key take away is that the emerging theory

guides all steps along the way including data collection, coding, category integration, memo generation, and theory creation (Glaser, 1978). Analyzing during collection creates theoretical connections built inductively from the stages of theory development (Glaser, 1978). Developing a theory with related patterns and concepts will form a framework built on relationships able to explain an issue (Hage, 1972). Creating a theory allows the researcher to be systematic and remain open and connected to the data (Glaser, 1978, 2009b). Drawing upon the gathered and accumulating information aids in the ability to gain and understand further useable knowledge where the researcher will be more successful at depicting appropriate conclusions (Corbin & Strauss, 2008). Ending results will be optimal if the researcher maintains the ability to be in tune to clearly identify issues apparent to participants.

Analysis. To answer research question 2, the researcher sought to generate a theory using CGT to help find new ways to clarify the question at hand and present possible conclusions. The analysis took place in tandem with data collection and following the final interview. By doing so, the delimiting process allowed the researcher to not become overwhelmed by the excessive amount of data at any one point in time. The researcher was able to remain submerged in the data by conducting, listening while transcribing, and generating codes for each interview. The closeness influenced the ability to witness participants' concerns and perspectives and transfer that into resulting codes. While tedious and time-consuming, the continuous modification and analysis of incoming data enabled the researcher to develop a theory relevant, yet modifiable, for future studies.

Beginning the analysis process, it was imperative to first understand the data just as it was and not allow the emotions, concerns, and hope illuminated from transcribed interviews to

interfere with the process. Placing great value in the internal view and having high regard in using the participants' thoughts, the researcher added these aspects after coding. The first stage of CGT's substantive coding consisted of opening coding, the first dive into each raw transcribed interview. After importing each interview, the researcher began coding the raw data by examining responses to identify the applicable emerging code based on the point. The codes showed to be continuous and similar in thought; key concepts continued to appear.

After the initial open coding of each interview, the codes were evaluated from within to ensure that any newly placed content fit with the existing codes. The constant comparison created a cross-check of data within the codes to verify the correct placement. If there was a conflict, the information was either placed into a more aligned node or made into its own. This process continued throughout the first step of each interview. Analytical memos created at each coding generation reinforced data reflection.

The researcher used the constant comparison method to process each interview and test it against other concepts for fit and relevancy. Certain concepts kept appearing in the selective coding process, which flagged the researcher to pay attention, explore in greater detail, and seek to recruit other participants that may have similar vital input. Testing the fit by comparing it upon itself drove much modification by evaluating the direction and how well it represented the data. The developing concepts steered the categorization and connected the pieces.

After determining the central category, the researcher reflected on the dense categories that related back by using the knowledge gained from interviews, interactions with participants, and the open coding to decipher strategies or possible consequences of the strategies taken by people living with dementia and their caregivers. At this point, the results of the other categories neared saturation by comparing them with other concepts relating to that category. After

concluding the data collection, the researcher examined the codebook to identify the most frequently referenced concepts. The research printed out all of the codes from each of the concepts and reread them to again ask, “*What is this data a study of?*” and “*What is actually happening in the data?*” This allowed the researcher to compare and restructure the selected concepts to focus on and become categories. The researcher prioritized the categories into the selective categories that revolved around the core by identifying the relationships and searching for the emerging data patterns. These relationships helped ground the other categories with the core by generating theory. Theoretical coding incorporated memos for the comparison of related saturated categories and pieced together the concepts to understand the process of accessing dementia-specific resources and services and how communication influences that process.

The researcher repeatedly drafted these connections into a visual representation to explore the relational patterns illustrated by the data. After many trials, the researcher pulled together a workable theory made of the categories and relationships they have with each other. Glaser’s criteria for a generated theory is it to be centered, extensively relates to other categories and accounts for variation in patterns (Glaser & Holton, 2004). The theory is one that shows the impact of access and communication regarding dementia-specific resources and services. However, with the larger vantage point, the constructed theory design is not only relevant and fit with the data, but it also works and can be modified to fit the flow of new data and research fields.

Aim 3

Research question 3. How can effective communication impact access to dementia-specific health resources and services for people living with dementia and their caregivers?

Aim 3. *To determine how effective communication among stakeholders impacts acceptability, accessibility, affordability, and availability of dementia-specific health resources and services.*

Sample. Aim 1 flagged the state of dementia-specific resources and services, the avenue of marketing available resources and services, and targeted audience of the resources and services. Aim 2 concluded with improvement questions focused on addressing access improvement, communication improvement, and communication's improvement on access. These questions encouraged participants to discuss areas they believe needed addressing by envisioning ways to eliminate foreseen barriers around the 4A's. The interview questions used were

- Access improvement- "How can access to dementia-specific health resources and services be improved?",
- Communication improvement- "How can communication regarding dementia-specific resources and services in Northeast Tennessee be improved among all stakeholders (people living with dementia, caregivers, healthcare providers and dementia-specific organizations)?", and
- Communication improving access- "How can effective communication among stakeholders improve access to dementia-specific resources and services?"

The participants discussed their perspectives on the 4A's as well as ways they believe the 4A's of dementia care could be improved. Afterward, these three questions were clustered together in an NVivo 12 "improvement" node for Aim 3's future target data.

Collection and procedures. Gap analyses offer opportunity to create change through action items. Aim 3 analysis created a comparison of what currently exists (Aim 1) with what participants addressed as opportunities for improvement (Aim 2). The gap analysis assessed performance deficiencies by identifying short-term goals to bridge a performance gap in dementia care. To do so, the researcher used data gathered up until this point to find the most important opportunity for improvement.

Analysis. The gap analysis identified potential opportunities for communication improvement. Using CGT encourages the researcher to let the data guide and to incorporate all forms of applicable data. Therefore, Aim 1 data played an equally significant role in Aim 3 as Aim 2. The researcher began by taking a critical look at the current situation of dementia-specific health resources and services by benchmarking Aim 1's access methods that affect the organization's involvement and methods to disseminate the organization's information in the community. Further, the researcher identified the goal state based on the interviews from Aim 2. The outcome for Aim 2 specified vital points that influence dementia care delivery. The researcher asked each participant to share his or her perspective on improving access and how communication could be a part of that process. These analyzed results are incorporated and used as the comparison goal. The researcher cross-referenced by exploring the connection and tying together how dementia care is affected by communication and how this influences the 4A's of care delivery. Each participant was asked how communication could be improved as well as how communication can improve access to dementia-specific health resources and services. These responses were incorporated in the Aim 2 dataset.

Aim 1 results stated that employees were the targeted audience for education and awareness. Often times, PLWD and caregivers received informal information directly provided by the knowledgeable staff. Aim 2 results showed two points that carried over into Aim 3: readiness and starting point. Readiness included the preparedness to advocate and educate for the best possible dementia care. Starting point included the first connection to dementia care continuum where an advocate would serve the primary role of navigation. Collectively, if Aim 1 and Aim 2 data served as an opportunity to identify a way to bridge the identified gap. Also, to explore the best practices for dementia care, a literature search for relevant evidence-based practices, guidelines, and innovative ways to address and care for PLWD and their caregivers from a community perspective determined the action plan for Aim 2.

The gap between the current state and the proposed community needs validated its existence. It is not enough to only identify where the community stands but to include where community members feel it should be to meet the growing needs of dementia care. To reach the goal state, a form of movement is required. The proposed action items incorporated participant suggested improvement processes with information gathered during a literature search of pertinent information regarding the selected action. The action item is supported by evidence-based practice from other healthcare fields. While the health conditions vary, the purpose and principles in the action item are the same, satisfying a public health issue and a healthcare need.

Validity and Reliability

Traditional research methodology stresses reliability and validity. CGT critics make a note of this, but there are ways a Grounded Theorist can emphasize the soundness of his/her work. Despite the differences from traditional ways, the constant comparison method enables

CGT to meet the standards of fertile research. With regards to study validity, CGT's uniqueness evaluates validity based on the fit, relevance, work, and modifiability of data (Schroth, 2013). The fit is how well the selected concepts fit with the data. This must be a natural occurrence, or it contradicts the CGT requirement of emerging concepts verses forcing them. Use of theory helps to deliver this interpretation of data (Glaser & Strauss, 2009). Relevance is the researcher's capability of identifying real concerns. A researcher must be open to exploring the real situations and allowing that information to flow inward freely. Workability is when the created theory elucidates the issue addressed at the study's start. The researcher must explain what happened in this process and attempt to bypass any preconceived ideas that may have potentially interfered with the emergence. Modifiability is a vital criteria component, despite being a criterion added after original discovery. Modifiability of a created theory infers that the theory must be malleable with new data (Glaser, 1978; Schroth, 2013). In sum, for a CGT produced theory to be a respectable one, it must fit, be relevant, work, and be modifiable. In sum, this study may be more reliable than valid based on its design. Instead of verification from previous concepts, CGT sampling creates a checkpoint for appearing concepts (Glaser, 1978). Rigor and credibility, however, are two validity concerns. CGT combats these with its conceptualization and innovative application of procedures leading to an emergent theory (Glaser, 2014). Researchers can use CGT to better understand their own research instead of pressuring their data to meet the criteria of other theories.

The researcher's use of CGT served as a supportive measure to grasp a complex health care delivery issue. The conceptualizing techniques used in this study, have validity verification procedures built into the process itself. Triangulation improves the validity and reliability of a study by using multiple research methods to examine the same issue. This study's design set up

the opportunity to examine access and communication from both organizational and individual community member viewpoints. CGT emphasizes the "all is data," which uses the other forms of data in Aims 1 and 3 to further support the findings determined in Aim 2. The chosen theoretical approach limits generalization of study results due to the nature of qualitative information from a specified group of participants. Further, the Aim 1 sample represents organizations in Northeast Tennessee and may not represent the perspectives of organizations from other geographic locations. However, the initial purposive sampling for Aim 2 was used to gather the maximum amount of information from those initial participants whom are heavily involved in dementia care and community events. Also, non-respondents often differ from respondents (Gordis, 2009). The respondents for Aim 1 and Aim 2 may have varied from those that declined or did not respond. This is to be acknowledged because with CGT, a theory is modifiable and is only as good as the gathered data. Therefore, if a researcher were to reevaluate the constructed theory with new or more respondents, the results may vary.

Reflexivity. The researcher is aware of how personal connection and perceptions can influence data collection, analysis, and reporting. Therefore, it is essential to acknowledge this influence. Dementia-specific resources and services were the chosen topic because of two reasons: personal connection with a grandpa passing from Alzheimer's disease and professional connection created from previous work was a nursing assistant at a local hospital. Both of these reasons are highly impactful and have created a purpose-driven mission to understand and help to alleviate burden. Also, the researcher was a student volunteer with a dementia work group with about one-fourth of the participants and built rapport before the interviews took place. Therefore, their interest in participating could have partially been initiated by an already established professional relationship. This may have influenced the openness during the

interviews too, which would have enabled comfortability to share thoughts and concerns. Some participants were the point of contact for Aim 1 data. The researcher's previous email and phone conversations could have influenced their willingness to participate and the structure of their responses. Contrastingly, the researcher may have negatively influenced the data by the researcher persona for those that have not previously spoke to the researcher. Most of the participants had a personal connection to dementia. It is a highly sensitive topic dealing with vulnerable older adults and loved ones. The researcher attempted to avoid being viewed as an outsider by setting the tone as informal and safe to create an environment for open conversation. However, participants may have been hesitant to share true perspectives and concerns due to being identified as a researcher and not an insider. Appalachian culture incorporates the present time view, and the researcher acknowledges that being a part of a community for over 15 years may possibly impact the expectations of urgency to finding solutions. Thirteen of the 16 participants discussed a starting point, the central category, that emphasizes the idea of urgency. Also, the researcher strongly believes in collaborative approaches and working towards common goals. Multiple participants mentioned the communication barriers across the care continuum and started more collaboration and working in teams could help alleviate some of the miscommunication. The researcher acknowledges that this, too, is a shared belief among participants and the researcher.

Since the researcher has a professional connection to some participants due to volunteer work, the influence on the study outcomes is well acknowledged. On the other side, this study has further solidified the researcher's interest in solving the dementia care access in NETN. The researcher recognizes that when one works within a field, it cannot be assumed that others know

what you know. If it is not addressed or explained, they may never find out, which creates a lost opportunity.

Protection of Participants

For the protection of organizations, the results do not contain any identifiable information such as community partnerships or organizations' names. For the protection of interview participants, the results do not contain personal information that may tie the shared responses to the individual. Contact information for Aims 1 and 2 were kept in separate Google Sheets files and were also separated from related research data. The demographic form they completed included a category they self-identified their affiliated connection to dementia care. This category does not contain organization information or personal connection and was used when describing the demographic results in Chapter 5. Also, each interview took place in the individual's place of work or a community setting such as a community center or local coffee shop with a private room that allowed for recorded interviews. Recorded interviews were stored long enough to transcribe the data and then were deleted. It is the researcher's responsibility to protect the participants by maintaining their confidentiality. This study's data will be kept securely for five years from the date it was gathered. After May 2024, the data files will be destroyed. This study was approved by the Georgia Southern University Institutional Review Board.

Potential Concerns

Ethical considerations can be amplified in qualitative research due to relationship building and an exchange of personal time and effort between the interviewer and participant (Creswell,

2007). The researcher resides in NETN and is personally connected to Alzheimer's disease because of her grandfather and attends dementia and aging events in the community. Being an insider researcher has its advantages, such as having an understanding of the geographical barriers than can impose of seeking care, maintain a mutual understanding by speaking the same lingo as participants, and recruiting participants to participate in the study. Having an emotional connection to dementia can increase the level of importance with pertaining topics and health issues. The researcher had to reflect on this issue when trying to contact organizations and participants that were less than interested in participating. Being involved in the community and knowing of the dementia related organizations and resources required the researcher to maintain a standardized system for Aim 1 data collection. Contrastingly, being a member of this community, the participants may have expected the researcher to know everything they do about the local health and community-based organizations, events, and providers. Additionally, the researcher's closeness may have been a disadvantage and made it difficult to see all aspects of data, perspectives, and the overarching picture.

A novice researcher's eagerness can also impact the CGT process and he or she may swiftly analyze the data, which can obstruct the quality of analysis by imposing on the data. The researcher must be aware of this potential problem and continue to remind oneself of staying grounded in the data (Glaser, 2009b). Grounded Theory does not have interchangeable terms, or jargon, with qualitative data analysis (QDA) and attempting to do so invites avoidable concerns into the CGT process. Jargonizing is the use of methodological phrases without providing a real meaning that are used to mislead others into perceiving that the researcher is knowledgeable in an area with little experience (Glaser, 2009a). Despite the inability to eliminate jargonizing, it can be explained and identified for its incapacitating ways on formally conducted Grounded

Theory (Glaser, 2009a). The researcher hoped to address these concerns listed by being professional, open to the data, and true to the process throughout the study.

Chapter Summary

In this chapter, the researcher presented the methodology used in this study. The research question, sample population, collection and procedures, analysis, and potential concerns were included. The study results are presented in the next chapter.

CHAPTER 4

RESULTS

Aim 1

Research question 1. What dementia-specific health resources and services exist in Appalachian communities in Northeast Tennessee and how are they impacting community access?

Ninety-eight of 119 organizations (82.4% response rate) answered questions about their organizations. Nine declined and voicemails were left for twelve administrators. Of the 21 excluded, fourteen were known to offer resources and services but either declined (5) or did not return voicemails (9). Seventy-three of the 98 contacted organizations (74.5%) offered dementia-specific resources and services in some capacity and reported having staff knowledgeable in communicating and interacting with PLWD. Of the 73, 60 (82.2%) of these organizations reported collaboration efforts such as working with one of the dementia-specific non-profit organizations for education, community awareness, participation in fundraising events, or referring PLWD and caregivers to them for additional information. Of these 73, the following data reported below and represented in Table 3 to illustrate information on dementia-specific resources and services in NETN.

Cost. When asked about affordability, the fees for general services were mostly unclear and the means to pay varied from the private pay to government support. Also, many organizations stated the fees they charge were not due to dementia-specific care delivery, but rather the general care their organization would provide to anyone seeking services where

tailoring of care was dependent on the patient/client needs. However, assisted livings did express a price variation for providing locked and secured memory care units.

Education. Sixty of the 73 offer dementia training for employees while 51 (69.8%) target PLWD and caregivers. Ten assisted living facilities offer in-house employee education either enforced by corporate requirements or annual continuing education computer-based learning modules. All home health (medical and non-medical), hospitals, and nursing home and skilled nursing facilities (SNF) and six out of 7 hospice and 16 out of 17 assisted living facilities responded by offering dementia training for employees to ensure they have the knowledge for direct care delivery. Two of the eleven senior centers in Northeast Tennessee offer dementia care in the facilities for members and caregivers as health education. All agencies and awareness and education organizations stated the benefiting party of their services were not employees but rather PLWD and their caregivers. They emphasized what their organizations gives to the community instead of internal trainings offered to employees, in part because many of these responsible for education and awareness are reaching the community with limited staff. Organizations that outsource the employees' education do so through one of the non-profit dementia-specific organizations in Northeast Tennessee that focus on awareness and education.

Referrals. A total of twenty-six organizations (35.6%) reported a physician referral as a requirement to access their services. Two of the three state agencies primarily offer referral and funding while one offers services to the community.

Services Offered. Seventeen of the assisted living facilities offer dementia-specific resources and services. Similarly, thirteen medical and eight non-medical home health organizations offer resources and services. Two hospitals stated offering resources and services

to employees and detailed information for PLWD and their caregivers upon discharge. Of the nursing home facilities, all stated offering resources and services to employees, PLWD, and families.

Support. Concerning PLWD and caregivers support, twelve assisted living facilities offer educational sessions or support groups. Two of the medical focused home health organizations have extensive support for the PLWD and caregivers not provided during direct care. All six of the awareness and education organizations offer education classes, but three of them offer regularly scheduled support groups in Northeast Tennessee.

Table 3

Frequencies of Organizations & Targeted Audience (%)

<i>Organization Type</i>	Total in NETN N (%)	Offering dementia- specific resources and services N (%)	Employees N (%)	PLWD & caregivers N (%)
<i>Agency</i>	3 (2.5)	3 (4.1)	0	3 (5.9)
<i>Assisted Living</i>	24 (20.1)	17 (23.3)	16 (26.7)	17 (33.3)
<i>Awareness/ Education</i>	8 (6.7)	6 (8.2)	0	6 (11.8)
<i>Home Health (medical)</i>	20 (16.8)	13 (17.8)	13 (21.7)	2 (3.9)
<i>Home Health (non- medical)</i>	16 (13.4)	8 (11)	8 (13.3)	5 (9.8)
<i>Hospice</i>	9 (7.6)	7 (9.6)	6 (10)	1 (2)
<i>Hospital</i>	3 (2.5)	2 (2.7)	2 (3.3)	0
<i>Nursing Home & SNF</i>	25 (21)	15 (20.5)	15 (25)	15 (29.4)
<i>Senior Center</i>	11 (9.2)	2 (2.7)	0	2 (3.9)
<i>Totals (%)</i>	119	73 (74.5)	60 (82.2)	51 (69.8)

To explore a little further, the researcher asked questions to address the 4A's, and to address access specifically, the question "How are dementia-specific resources and services accessed by the intended population?" received varying responses. Resources and services were generically labeled because each organization's scope of practice varied. The questions were meant to be general yet specific enough that the organization's point of contact would speak to the resources and services his or her organization offers the community.

Table 4 shows the organizations' access to education and dementia care. Online access is due to organizations requiring their staff to complete computer-based learning modules or lay individuals accessing published information on an organization's website. Many organizations aim their education efforts towards those providing direct care, which was stated to be accepted and well received by the staff. Education was either completed through onboarding and continuous education from other staff, outsourced to one of the nonprofit dementia organizations, or completed on the computer with a required annual renewal. A large portion of the organizations that offer dementia-specific resources and services did so directly by the staff.

Table 4

Access to Education and Care (%)

<i>Organization Type</i>	Access			
	In person N (%)	Online N (%)	Materials N (%)	Provided by staff N (%)
<i>Agency</i>	1 (2.1)	2 (4.2)	2 (7.4)	3 (5.6)
<i>Assisted Living</i>	14 (29.8)	11 (22.9)	9 (33.3)	12 (22.2)
<i>Awareness and Education</i>	6 (12.7)	2 (4.2)	6 (22.2)	4 (7.4)
<i>Home Health (medical)</i>	4 (8.5)	9 (18.8)	2 (7.4)	11 (20.4)

<i>Organization Type</i>	Access			
	In person N (%)	Online N (%)	Materials N (%)	Provided by staff N (%)
<i>Home Health (non-medical)</i>	4 (8.5)	5 (10.4)	3 (11.1)	8 (14.8)
<i>Hospice</i>	4 (8.5)	6 (12.5)	-	4 (7.4)
<i>Hospital</i>	2 (4.3)	1 (2.1)	-	-
<i>Nursing Home/SNF</i>	10 (21.3)	12 (25)	3 (11.1)	10 (18.5)
<i>Senior Center</i>	2 (4.3)	-	2 (7.4)	2 (3.7)
<i>Total</i>	47	48	27	54

A variation in marketing tactics ranged from passive brochures and newspapers to meeting with providers and attending community events. Only four organizations stated experiencing difficulties marketing or delivering information on the dementia-specific resources and services their organization offers. Five of the organizations stated the resources are somewhat accepted by the targeted audience, primarily the PLWD and caregivers. All of these five expressed concerns of acceptance and stated that the barriers of accepting resources and services such as denial appeared to be more disease-related and not necessarily the offered assistance.

Figure 3 presents the Maptive generated map (2018) to represent the 73 organizations who stated offering resources and services. Organizations are concentrated along Interstate 26 between Johnson City and Kingsport. The map of plotted dementia-specific resources and services illustrate the maldistribution of services in the region. Serving the region would require either a staff member to drive to homes or a patient to drive into the high populated areas to access resources and services. Transportation is an additional barrier PLWD and

caregivers may face when seeking dementia care from dementia-specific health resources and services in NETN.

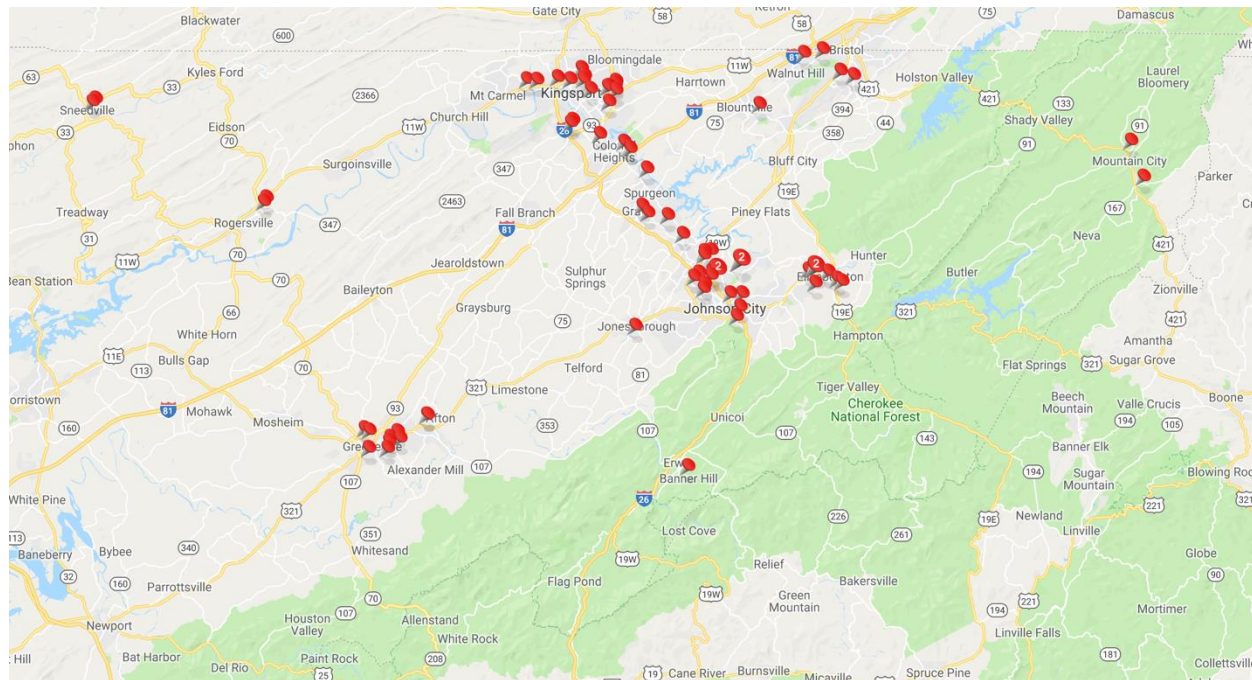


Figure 3. Map of Dementia Organizations in Northeast Tennessee (Maptive, 2018)

Aim 2

Research question 2. What are the perceptions of access and communication gaps that occur among healthcare professionals, caregivers, and dementia service organizations when caring for people living with dementia and their caregivers in Appalachian communities in Northeast Tennessee?

Forty-one individuals were invited to participate in one-on-one interviews. Sixteen interviews took place between June 2018 and October 2018 (39.0% response rate). Four participants were recruited with snowballing techniques, one in-person during a support group meeting where the researcher shared printed recruitment flyers, one by word of mouth, and the

remaining ten via email. Age ranges included five 18-30 years, three 31-40 years, five 41-50 years, two 51-60 years, and one over 61 years. All participants were white non-Hispanic, and fourteen were female (87.5%). Thirteen participants have been Northeast Tennessee residents for over twenty-five years (81.3%), one for 20-24 years, one for 10-14 years, and one for 5-9 years. The classic grounded theory approach was used to pull emergent categories from the data and construct a theory. After concluding the data collection, the researcher identified which ones were the most frequently referenced concepts. “Personal characteristics”, “awareness of availability”, “point of initial contact”, “providers & organizations” under advocacy preparedness, “navigation”, “collaborative approach”, “competency”, and “delivery and presence” appeared as the opportunities for saturation by having anywhere between 27 to 95 initial code references each. Influential data from the concepts “aware of availability”, “navigation”, and “where to get started” generated the main concern into the central category, *starting point* because thirteen of the sixteen participants repeatedly mentioned it as a key concern with accessing resources and services.

Theoretical Model. The generated theoretical model shown in Figure 4 is a visual representation of combined perspectives on dementia care, resource and service utilization, and communication regarding them. While complex, the model is rooted in the categories generated through the CGT approach. These categories are bolded in the model to show placement and their roles in the process. The communication arrows indicate a flow of information while the remaining arrows indicate process and direction.

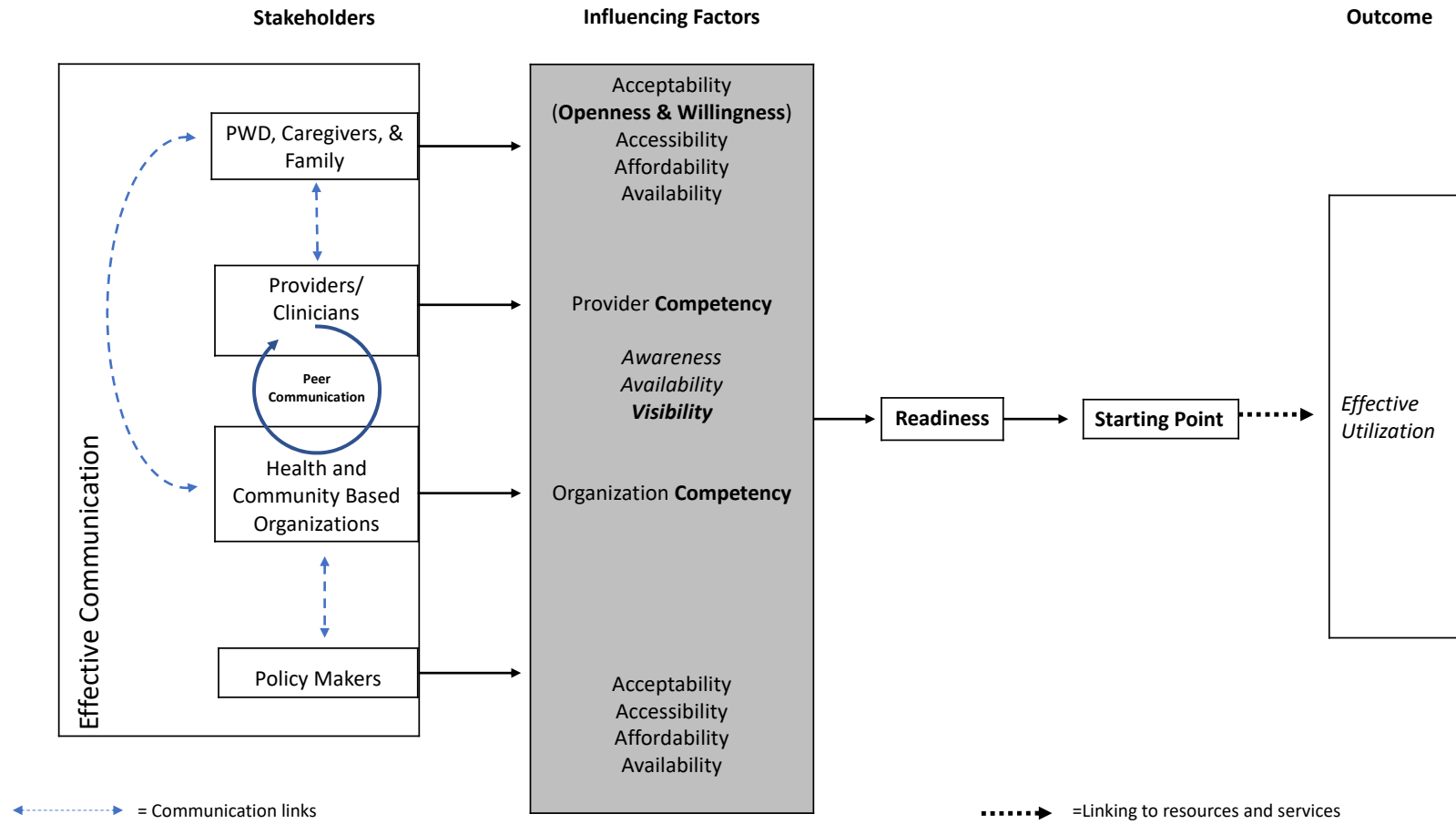


Figure 4. Theoretical Model

Stakeholders. Stakeholder groups each hold a vital position in the model leading to effective utilization of health resources and services. PLWD, caregivers, and families reside at the top of the stakeholder groups. Their involvement in dementia care is first in line and without this group, the remaining theory would not exist. Providers are the second stakeholder group. They are involved in the direct care of PLWD across the lifespan. Their involvement can become crucial for PLWD as providers diagnose, treat, and refer patients to community resources. Next, health and community-based organizations, follow closely underneath providers. They serve as an extended arm of the provider when addressing PLWD needs. Lastly, policymakers reside at the bottom of the stakeholder group. Their involvement can create lasting change to care protocols, methods, and funding sources available for PLWD use to pay for resources and services and for health and community-based organizations ability to have the opportunity to serve.

Effective communication involves the stakeholder groups because it must support all groups and take place before the remaining model can progress. Dotted lines signify two-way communication links between stakeholder groups. Noticeably different, the communication between providers and organizations is solid and continuously flowing to and from providers and health and community-based organizations. This significantly represents the importance of effective communication to and from providers and organizations. Their communication can positively or negatively affect the PLWD, caregivers, and family. The study participants emphasize the importance of the existence and strength of this communication link and how vital it is to have and maintain to ensure PLWD, caregivers, and family receive the applicable care. Peer communication between providers and organizations would include patient care needs pre and post diagnosis. Lastly, policymakers are a key stakeholder as supporting policy for

dementia care is vital to assuring access to quality care. Their role includes adequate advocacy, funding, and implementing policies to make dementia a priority at the national and state level to trickle down funding, support, and incentive to create sustainable change in dementia care.

Influencing Factors. From the PLWD, caregivers, and family's perspective, utilization of dementia-specific resources and services is influenced by all of the 4A's: acceptability, accessibility, affordability, and availability. Acceptability, or acceptance of the disease and the need for additional support, serves as a primary barrier to utilization of resources and services. Accessibility, the physical ability to obtain resources and services for use, affordability, willingness or ability to pay for resources and services, and availability, a resource or service's presence in a community and capacity to be used by community members, collectively influence the utilization of dementia-specific resources and services.

Open & Willing. As a CGT category within acceptability, this category was defined as the individual barriers that influence a PLWD or caregiver's decision to seek resources and services. Personal beliefs and willingness are the collective influences that may impact individuals' abilities or willingness to seek (or not seek) understanding, help, or care. Some examples include denial, stigma, betrayal, and maintaining autonomy, control, and independence. Personal beliefs can cause internal conflict and influence one's decision to use health resources and services. Also, someone that has been self-reliant can find it excessively difficult to relinquish control. Participants focused on the individual barriers of accessing resources and services while emphasizing the long-standing independence. They acknowledged cultural influence too. Participants were able to address a portion of the inhibition to seek resources and services caused by the patient's self-reliance or relying on close family to provide

care. However, those with positive external support such as an adult child or spouse that believes in accepting assistance are more inclined to seek services.

One participant, born and raised in Northeast Tennessee, who was a senior care administrator for a local community-based health organization noted that in her position, she worked with a wide range of patients and their families. From her experience she found that despite the struggle of personal barriers, they can be overcome, often with family support. She stated:

“Part of the concern I see working with families is that there may be a barrier to, a psychological barrier, that they may not be accepting of the fact that their loved one has dementia. There is a struggle of accepting this type of help, primarily from the one facing the condition, even in the early stages. ‘I don't need help.’ ‘I am completely fine.’ ... When it comes to the point to where there may be something. There may be a trigger and or not being able to dress oneself. It may be a pride thing. It may be a loss of dignity. There may be a moment of clarity to where they're willing and able to accept the help, but it's mostly initiated by the loved one.” (Senior Care Administrator 2)

Participants expressed sincere concern for families caring for PLWD and noted that the process not only affects the PLWD, but all parties involved. Often serving as a supportive initiator of service utilization, loved ones also experience denial. This can impede on their ability to support the PLWD or become the primary caregiver. When a spouse assumes the role of primary caregiver, life can become jumbled and stressful. Sensitive approaches may be needed.

One participant, a recent graduate and long-standing resident of NETN who had joined healthcare as a medical provider in a local hospital pinpointed a barrier providers and organizations frequently see:

“You know, whether the patients are in denial that they have any kind of memory impairment and don't need the help or when it does come to the caregiver having to step in, and they think that they can do it themselves and they don't need the help. I think there's a negative stigma on assisted-living and nursing homes. And families and caregivers feel like if they put them in those types of facilities, then they're doing them a disservice or failing them.” (Provider 2)

Another participant, a long-standing resident of NETN and retired female assumed the role as a primary caregiver for her husband for multiple years. Due to their height differences, she was unable to physically care for him as the demand increased. She was able to move him into an assisted living facility where she had additional hands to provide him the care she felt he deserved. It was a tough decision, but as a family, they accepted the disease progression and care demand in front of them.

“I'll be honest, maybe some of it is my fault. Maybe I have had enough, put my head in the sand some. My kids tell me 'you have to be proactive you can't just,' but when you're with the person suffering it is a harder thing. In addition to the person suffering from dementia, the families suffer just as much. Most people with dementia are in denial that they have memory issues and the family doesn't want their loved one labeled with that diagnosis. There's definitely still a stigma out there.” (Caregiver 1)

It is important for PLWD and caregivers to understand the progression of ADRD and that the length of time between first signs and symptoms and death can be long-lasting. Without a current cure, the constant level of aging with cognitive decline will require an influx of care (Deb et al., 2017). Understanding the specifics of ADRD allows all parties to begin the process towards planning and preparation.

Competency. Competency is the knowledge, skills, and attitudes of healthcare providers/clinicians and health and community-based organizations. Competent providers and organizations impact the ease of access to health services through timely reliable care.

On the frontlines of care, primary care providers have an opportunity to bridge the gap by encouraging the use of dementia-specific resources and services by PLWD and caregivers. Healthcare provider competence can be enhanced through knowledge and direction to appropriate resources about dementia-related care. One participant emphasized the importance of the competency of both providers and health or community-based organizations. This provider is a long-standing NETN resident that works in geriatrics at a local healthcare facility. Unfortunately, she was distraught on her knowledge of dementia-specific resources and services available in the community. She stated:

“I deal with that population so much that I feel like I would know, you know. I would know about it if they are reaching out and they were coming to us... Knowledge is so powerful to me and like I said I just think education to all parties involved all stakeholders is the biggest thing that we could do. So, I guess just communicating, marketing those resources, and making sure that the people, the providers, in Northeast Tennessee know that this is what we have available...I don't know a whole lot of providers that are scared to ask for help or ask for resources if they know they're there.”

So, I think the first step is just communicate, communication from the resources to say 'Hey, we're here and this is what we offer.' Yeah, because I really have a hard time believing that if the providers know if there's something to be offered that they would just ignore that." (Provider 3)

As a previous caregiver for a recently deceased spouse and a direct care provider in a local hospital, one participant (Caregiver Two) noted that even within the healthcare system, her knowledge of available resources and services was limited. Unlike the other caregiver, her husband was born in the home across the street, and she knew he would not want to pass anywhere but home. Tirelessly, she, cared for him the best she could. Home health was available at the end of life, but she relied on family and close friends to stay with him earlier on while she remained working. Unsure if she would go back and change it, caregiver two stated; *"If there are more organizations out there, they need to communicate that with the primary care doctors."* Knowing the external support is there can provide comfort and ease while leaving the choice to the PLWD and their loved ones.

Visibility. Visibility is the community presence of resources and services to those that may passively or actively be seeking specialized health services. It also involves how the information gets out to the public and into the right hands, or the dissemination of information. Do people in the community see the organizations that may help them solve a problem?

Primary care providers are often at the forefront of the diagnosing process. One participant, who had been a NETN resident for over 25 years and currently a nursing home administrator, stressed a provider's workload and how vital knowledge of available organization can be when caring for patients:

“You got a lot of organizations out there, but if they don't market themselves to the hospitals, to the physicians, it's tough. It's the provider's responsibility more so to get their name out there. Physicians are people. They are thrown a lot of problems on a daily basis, and they deal with a lot of things and information passing through. Maybe their primary concern is to care for that patient but if they don't know about the resources too... I think it is kind of a marketing thing. We do have to get our names out there. We do have to get our names in front of these folks for them to remember us.” (Nursing Home Administrator 2)

Organizations offering resources and services have the ability to respond to the need and make their organizations known not only in the community but in healthcare facilities. A senior care administrator further supported the visibility of organizations to providers and stood for peer communication through collaboration by declaring:

“Tight communication, networking with them, providing events together, educational events, and just having a very steady presence and making dementia awareness a part of every single interaction... I think that's a beautiful thing.” (Senior Care Administrator 2)

One participant was a young, health educator and was very passionate about patients' needs being met and the value of peer communication in impacting an organization's ability to be visible to providers and the community. Health Educator 3 saw an opportunity to progressively move healthcare forward through advancing two-way communication and raising awareness to the providers that see PLWD and their caregivers and closing the communication feedback loop, wherever necessary:

“It's also just a lack of education for professionals as well. They don't know that we don't have those resources until someone mentions it. It's like a family's not gonna know there's not a resource for them until they're in that situation and then they don't have time to bring awareness. They're taking care of their family. Its 'refer to the social worker,' and so it refers to me. I'm not going back to the clinician and saying, 'hey I wasn't able to give them anything.' There's not necessarily a protocol for follow-up. It's like 'this is out of my scope so I'm gonna pass it on to the social worker' and then you know I'm trying to brainstorm with my peers.” (Health Educator 3)

Another participant, well aware of the different barriers the majority of organizations face including visibility, pointed out:

“One of the biggest obstacles that we even have is that people don't know we exist. If they're not able to go to places like the senior center or something like that to come to one of our health fairs they're not gonna know that we exist.” (Agency Administrator 1)

Another local agency administrator discussed some of the barriers his organization faces in today's health climate. He discussed that visibility requires creativity. As another long-standing resident of NETN, he touched on the importance of not only being competent in packaging information but knowing your target audience and selecting the appropriate platform for that particular audience:

“I think it is a marketing challenge of understanding who your target market is, and part of that is the client, but really it is the caregiver. How you best reach that target market and that sounds fundamentally simple but fundamentally is very complex. While we are providing the services in Northeast Tennessee, that caregiver could be two states away for all we know.”

(Agency Administrator 2)

There was a need to for organizations offering dementia-related resources and services to be visible to caregivers too. Assuming the caregiver role can be exceptionally difficult. However, knowing that there is help can provide comfort and give options to a family to help juggle concerns as they arise. Senior Center Administrator 1 had worked in senior care for her entire career and was able to discuss her knowledge of senior care along the care spectrum. She expressed the visibility and awareness of availability being a large component of utilization. She stated: *“Knowing that the support is there and knowing that there are services out there to help during this time.”*

Between providers and organizations, the influencing factors of awareness, availability, and visibility influence competency. A provider’s competency stems from a medical and relational knowledge and resourcefulness and an organization’s competency grows from the ability to be known in the community and tailor their marketing towards the target audience. Despite the discomfort, the ease of technology access and leaning on community organizations to help care for the PLWD are a provider’s opportunity to create bridges, decrease provider burn out, and build reliable community contacts. Organizations must be available for use and visible and a provider must be aware of the available dementia-specific resources and services. Collectively, this stresses the height of a continuous flow of peer communication between providers and organizations, acknowledging they must work together instead of mutually exclusive.

The last stakeholder group is policymakers. Their influencing factors include the 4A’s as well. Their acceptability is drastically different from PLWD, caregivers and families, in that policymakers must be accepting of dementia’s impact on population health rather than specific individuals’ health. If they are unaccepting, then they would remain unwilling to advocate.

Often times, policymakers decide the allocation of funding for organizations, how providers are reimbursed for healthcare costs, and the criteria for PLWD and caregivers to access dementia-specific resources and services. Therefore, the accessibility, affordability, and availability of these resources and services are highly impacted by hierarchical influences driven by public policies. This was not a dense category in this study, but health educator one and agency administrator two discussed the need for government support to drive awareness and the 4A's of access to dementia-specific health resources and services. These participants were individuals heavily connected to senior care and both receiving funding from state level government. Policy driven changes fluctuate their organizations' abilities to provide resources and services in NETN. Therefore, they understood and highlighted policymakers' influence on dementia care.

Readiness. When effective communication between and among stakeholder groups is in place and the influencing factors are addressed, the model continues with readiness, the preparedness to advocate for and educate the PLWD and caregivers to obtain the best possible care. Readiness is heavily impacted by all stakeholder groups as they each serve a role in dementia advocacy and education.

Frequently, caregivers jump through hurdles to meet the needs of loved ones as well as their own. When drastic changes occur, and caregivers are left without support or assistance, they can feel alone. If a caregiver reaches out and they are ill received, they may be less inclined to continue seeking help. Caregiver 1 experienced multiple hurdles in the early diagnosis. The provider was not compassionate or empathetic and did not provide the caregiver or her husband with any resources or services. Additionally, she attempted to do it herself and reached another wall.

“At that point, it was so fresh that anytime I talked about it, you know, I just cried. So, I called and went through it, and they said “‘Oh, you need to talk to someone that’s not here. We’ll have them call you.’ Days past. I called back and same thing. So, frankly, I never talked to anybody. That was a real dead end, and I got very discouraged. I just can’t; I can’t keep doing that and going through that because back then I worked five days a week so it’s really hard to attend anything during the day and at night I couldn’t leave.” (Caregiver 1)

Healthcare providers and organizations are equipped not only with information to be able to help PLWD and their families at the time of diagnosis but must also be willing to take the time to be the advocate and create connections. Collaboratively, providers and organizations must communicate and work with each other to benefit the PLWD. To do so, a plan with shared ideas, buy-in, and commitment may send a clear message to PLWD and caregivers that healthcare providers and community organizations are working together for their best interest.

At this point in the model, PLWD and caregivers have accepted the disease and are ready to explore possible care options. To do so, Provider 2 suggested *“we need to be more proactive and making patients and caregivers more comfortable about expressing these concerns and then screening early on. It’s almost like preventative even though this disease is not necessarily preventative. To plan and it may make life a lot easier on you and everybody involved and make quality-of-life much better.”* Communication between providers and PLWD must be effective and relational. A PLWD and caregivers trust in a provider is heavily subjective to the influencing factors. Also, the communication between providers and organizations must be as well. Health Educator 3 works to help patients understand and navigate services her organization provides. However, her biggest concern is the PLWD and caregiver’s confusion

associated with why they were referred to her and why she is helping them in the first place: “Also, awareness to the families and physicians to not just come in and say ‘they’ve got dementia. Its mild to moderate, and we’ll follow up with you in two weeks and then see ya bye.’ No, we need to sit down and actually go over this diagnosis. Or here’s some literature. Take it home and read it.” Moreover, readiness can occur for each of the stakeholder groups when it is fed with effective communication and well-established connections between providers and organizations.

Policymakers must exhibit readiness as well. Their readiness impacts the effective utilization of dementia-specific resources and services by PLWD, caregivers, and families. They serve as advocates to increase funding, reallocate resources and services, and establish partnerships to decrease the costs for dementia care. Without the readiness of policymakers, all other stakeholder groups will experience top-down barriers that impede and dementia care utilization. Collectively, each stakeholder group should experience readiness before effective dementia resource allocation and utilization can occur. Without readiness, fragmented care would cause PLWD and caregivers, providers, and organizations to experience barriers within the influencing factors and prevent the navigation of resources and services from occurring.

Starting Point. A *starting point* is the core of this study. It is an initial connection to dementia care continuum where an advocate assumes the role of navigation. Starting point is induced and interrelated to the preceding components of the model. All portions of the model are in place to avoid PLWD falling through the cracks caused by fragmented care. Frequently mentioned throughout the interviews, a point of contact assumes the first connection a PLWD or caregiver reaches to seek dementia-specific resources and services. However, PLWD and caregivers do not know when to begin, who is a right contact person, or where to get help. Even

though every PLWD has a starting point, many times, they start in the middle of a crisis. Often times, healthcare providers and organizations know of other organizations that a PLWD could reach out to the right person to suit needs, but sometimes it is not as transparent for those with the unmet needs. Furthermore, those in the industry may or may not be aware that PLWD and caregivers are not sure where to start. There is an opportunity for those in the industry to use that to help any PLWD or caregiver reaching for help. At this point, that could alleviate stress inflicted by crisis moments and desperation. Getting plugged in with the right person early sets the foundation for care delivery. Strategies to do so include a strong support system, being plugged in with community organizations, and having a trusting relationship with a healthcare provider.

Senior Care Administrator 1 acknowledges the existing resources, but identifies the challenges by stating: *“I feel like that we have the resources there, but the knowledge of how to obtain them may sometimes be a little difficult, trying to find the right person, the right go-to person who can really get you where you need to go to get those resources, I think a struggle.”*

Starting point is fluid with other domains in the theoretical model as they are interrelated and rely upon each other. One provider in a local hospital works to provide hands-on direct care. Also, a long standing NETN resident, Provider 4 expressed:

“Most of our families are completely clueless like where to even start the process, how to obtain a sitter, how to even initiate nursing home placement, anything like that...I think that there is a lack of resources. I don't think that people really know how to even, I mean, it's not like there's a book that says 'OK, your loved one has dementia. This is the steps that you need to take.' You know? What I mean is there's just no simple way. I mean there's education on what the disease is and stuff like that, but I don't feel like

there's a lot of resources or just kind of an easy breakdown of these are the resources that are available. All of that."

Reiterating the same viewpoint, senior care admin one stated: *"people that are caregivers 24/7 and don't think they can step out and go to things like that or don't know where to get help or where to get started."* The role of PLWD and caregivers is an unbroken transition from readiness, through starting point to effective utilization.

In summary, based on the theoretical model developed as part of this study, effective utilization occurs when stakeholders are engaged and in constant dialogue, positive influencing factors are in place, stakeholders are ready to serve as advocates for PLWD, and PLWD and their caregivers have a starting point to navigate them to the right resources and services necessary for their care.

Aim 3

Research question 3. How can effective communication impact access to dementia-specific health resources and services for people living with dementia and their caregivers?

Collectively, this aim served to advance care delivery by identifying the improvement opportunities in dementia care. The researcher used Aim 1 and Aim 2 data simultaneously to illustrate the gap. Participants addressed their concerns during interviews, and their responses supported the Aim 1 findings. Represented in Table 5 are the two categories illuminating an opportunity for dementia care. Discussed further in Chapter Five, the action items are recommendations to address these public health challenges based on the results from Aims 1 and 2 and published literature.

Table 5

Gap Analysis

<i>Target</i>	<i>Interview Data Support</i>	<i>Current State (Aim 1)</i>	<i>Goal State (Aim 2)</i>	<i>Action</i>
<i>Readiness</i>	“make those connections for people”; “gonna take the medical community to become knowledgeable of resources so they could facilitate that process”	Employees are the primary audience for education, knowledgeable and trained, accepting AND organizations are partnering with each other	Providers and organizations must be aware of both <u>dementia</u> and <u>resources and services</u> AND work together to connect patients and families	Peer Health Communication Intervention [evaluate increase in awareness]
<i>Starting Point</i>	“where to get started”; “don’t know who to go to”; “unsure where to begin”; “plugged in with the right person”	PLWD and caregivers struggle to know where to find help, often times, late in the disease progression	Effective communication and guidance through navigation of appropriate care options	Patient Navigation [navigator serves as a supportive mediator between organizations, providers, and PLWD]

Readiness. Fifty-one of 73 organizations claimed employees as the primary audience, being the higher reported group to receive dementia education. Seventy out of 73 organizations confidently stated having staff that is both knowledgeable in the communication needs and trained to interact with people living with dementia properly. Out of the 42 reported responses, 31 stated the dementia-specific health resources and services were ‘very accepted’ by the targeted audience. Also, 60 of the 73 organizations stated they partner with other organizations on dementia care needs. Based on Aim 2 data, providers and health and community-based organizations must be aware of both dementia and the resources and services available plus work together in order to connect patients with resources and services. The apparent gap includes the misconnection between providers and organizations and the awareness of dementia-specific resources and services in NETN. To address *readiness*, the researcher proposes a peer health communication intervention to evaluate the potential increase of awareness of dementia and applicable resources and services in the community, health systems, and clinics while evaluating the collaboration efforts between providers and organizations.

Starting Point. Organizations were asked during Aim 1, “How soon after initial contact can a new client/patient/resident typically receive dementia-specific resources and services?” Of the fifty-five reported organization responses, fifty-two answered making initial contact with organizations in less than one week and forty-nine in less than five days. From the sixteen participant interviews, thirteen reinforced that a starting point is an opportunity for improvement by promoting navigation of dementia-specific health resources and services in some form and how it could improve the 4A’s. Also, each participant was asked improvement questions. Collectively, responses on access and communication improvement reiterated the need for

awareness, knowing where to start, and working within and across stakeholder groups to do so.

To address the *starting point*, the researcher proposes a care coordination model with patient navigators. Patient navigators would serve as a mediator between patients and the healthcare field. Historically used for cancer treatment and care, patient navigators present a way not only to increase uptake, but aid patients and families through a disheartening web of confusion. Often, by the time PLWD and caregivers reach out, they are in a crisis mode and are appreciative of any help. Implementing a care coordination model may smooth this process with earlier interventions. Participant One, an educator and long standing NETN resident, gave an excellent response for knowing when this gap no longer exists:

“Everybody involved would know exactly what exists. I think when those involved know exactly what exists, how do you access it, whom you get to access it, that will also be when major gaps are identified. And when enough people become extremely passionate about something that's typically when things will change. So, I think increasing awareness, knowing what to do and then where we need to go.”

CHAPTER 5

DISCUSSION

Access to care is a public health issue regularly targeted when aiming to improve health outcomes. AD/DRD care needs escalate with disease progression until a time when the PLWD loses all functions and abilities to care for one's self. The study determined that the number of organizations offering dementia-specific resources and services in Northeast Tennessee is plentiful yet unaccepted by some and unknown by many. PLWD and their caregivers experience multifaceted barriers making it difficult to access these resources and services. Individual belief barriers such as denial, control, and stigma impede on the likelihood of willingness to seek assistance, which is when the reliance on others can either help or hinder the quality of care. PLWD and caregivers can be unsure of where to start or whom to contact to communicate needs or access dementia-specific resources and services.

During this study, the researcher found that neither the number of organizations nor the cost of use was the primary hindrance on access to dementia care. However, the study showed that organizations are plentiful yet remain unaccepted by some and unknown by many. This presents a break in access, communication and dementia care. From Aim 2 participants, the influencing factors, *open and willing*, *competency*, and *visibility*, either help or hinder the remaining process in the model. Together, these can become potential barriers to effective communication among stakeholders. Again, within acceptability, *open and willing* represents the individual barriers that influence a PLWD or caregivers' decision to seek health resources and services. *Competency* represents the knowledge, skills, and attitudes of medical providers/clinicians and health and community-based organizations. *Visibility* represents an

organization's community presence and its dissemination of information into the community. Collectively, *open and willing*, *competency*, and *visibility* address the most influencing factors for the stakeholder groups when it comes to the use of health resources and services. *Readiness* represents preparedness to advocate for and educate PLWD and caregivers to provide the best possible care. Lastly, *starting point* represents the first connection to the dementia care continuum where an advocate assumes the role of navigation to find the best available options to suit individual needs. Additionally, the gap analysis provided two recommendations to address this public health challenge.

The results from this study are two-fold by addressing the communication gaps from both ends: provider and consumer. They emphasized the need to be timely and proactive by helping PLWD and families overcome the barriers that delay care access early in the process. The suggested means of action to address these gaps include a peer health communication intervention and implementing patient navigation designed for ADRD. Two closely related recommendations are shown to be successful in the literature. They would be tailored to address the public health challenges linked to dementia care. According to the Rural Health Hub, both health communication and patient navigation are considered strategies within evidence-based toolkits proven to work within rural settings (Rural Health Information Hub, 2019a, 2019b).

The results of this study are similar to previous studies that indicate communication and patient navigation as opportunities to address chronic health conditions and access to health resources and services. Effective communication encompasses all stakeholder groups because they all serve a vital role leading to effective utilization of dementia-specific health resources and services. Collectively, their communication would be fluid and multidirectional. However, a strong emphasis is placed on the communication between health providers and organizations

because their communication and relationships with one another become the platform for patient connection. The reliance on one another can eliminate stressors placed upon one and help spread the care demand.

Peer Health Communication

According to the CDC and National Cancer Institute, health communication is “the study and use of communication strategies to inform and influence individual decisions to enhance health” (Centers for Disease Control and Prevention, 2019). Health communication includes various tailored delivery methods to the right targeted audience for assurance of relevancy and applicability with hope to increase the knowledge of and modify attitudes towards dementia, early interventions, and the use of existing resources and services.

A thorough provider would be knowledgeable and aware of the disease process, diagnosing, best practices, and community resources available to meet patient needs. Since PLWD have variable disease progression, the care intensity, the timeline for disease progression, and accumulation of symptoms all differ, leading to diagnostic hesitations (Fortinsky, 2014). However, without a standard protocol, effective treatment, or a cure, caring for the PLWD and the caregivers can be extremely difficult for providers. Furthermore, a lack of partnerships between health providers and community organizations often stems from lack of physician awareness (Fortinsky et al., 2008; Lathren et al., 2013; Reuben et al., 2009). Without knowledge of what exists, a provider will not feel confident in their ability to deliver comprehensive dementia care that brings together healthcare and community care.

Moreover, a peer-based health communication network would connect providers and organizations to work collectively instead of siloed care PLWD and caregivers experience often.

Peer health communication would be led by a team focused on dementia care. The communication would be continuous and reliant on bringing specialties to the table. It would serve as the foundation of interdisciplinary teams, while including health and community-based organizations to offer additional resources that may be beneficial to a family such as adult day services or attending caregiver conferences.

Also, the provider's general concern for the patient's well-being can influence the patient's willingness to comply with physician recommendations because often, the provider is the first point of contact, which is particularly true for Appalachian communities where trust-filled relationships are warranted (Presley, 2014). A provider has the opportunity to use that relationship to encourage and empower patients to address memory concerns as soon as they arise. Community organizations offering dementia resources and services must continue to market themselves to increase their visibility to grow the knowledge of services. The Rural Health Information Hub (n/d) encourages a wide spread of information through multiple methods of dissemination such as websites, flyers, toolkits of training materials, and press releases all while targeting key audiences such as universities, caregiver groups, hospital organizations, and faith-based organizations. More importantly, communicating with healthcare providers and clinicians and maintaining these relationships with other organizations and providers not only helps with advertising, but these relationships can help PLWD, caregivers, and families locate the right care options. Patient navigators could mediate these relationships for providers and organizations while specializing in ADRD navigation.

Patient Navigation

Awareness and readiness to advocate and guide patients allows for diversity of care outside of traditional healthcare that can help postpone the need for institutionalizing patients and reduce the caregiver burden because providers are confident in educating and initiating referrals to community organizations that best fit the patient's needs (Harris et al., 2009; Lathren et al., 2013). Providers serve as a reliable point of contact and must be used as such. This is an opportunity for care providers to bridge the gap in care by aligning patients with navigators.

A literature review completed by Paskett and colleagues on data published from November 2007 through July 2010 found supportive evidence from 33 articles examining the efficacy of patient navigation programs for cancer screenings (Paskett et al., 2011). However, the support for follow-ups or across the continuum of care was lacking and required more research.

A report prepared by The Global Council on Alzheimer's Disease illustrated a vision for dementia care similar to this study (Freeman, Gay, Stefanacci, Michael, & Digby, 2016). They provided commonalities between cancer and Alzheimer's including stigma, complex needs, and the benefits of early diagnosis; they found patient success with timely diagnosis, establishing a care plan, and caring for the caregiver too (Freeman et al., 2016). Many of the available resources and services are used towards the end of life in the later stages of ADRD.

Implementing patient navigators would focus on the well-being of PLWD and could help decrease hospitalization and caregiver burnout while increasing the early involvement.

Davis, Darby, Likes, and Bell (2009) conducted focus groups across Tennessee to identify the needs of underserved cancer patients. They found four key themes necessary for a patient navigation initiative to meet patients' needs, which included addressing access to quality care,

emotional and practical concerns for survivorship, family concerns, and be involved across the continuum of care, starting at the time of diagnosis (Davis et al., 2009). Starting the navigation process at the time of diagnosis or probable dementia suspicion before a formal diagnosis, is a key take away that relates to the study at hand.

Meeting dementia care needs present challenges around the world. Other countries have implemented dementia navigators as the single point of contact to help eliminate the run around for exceptional care. One dementia navigator initiative provided by Alzheimer's Society of Warwickshire in the United Kingdom stated they provide early intervention and support by being a single point of contact for information, provide information on local support services and training sessions, and be emotional support for PLWD and their families (NHS Warwickshire North Clinical Commissioning Group, n/d). Though, the United States healthcare industry has focused the navigation efforts on various cancers in the past; other countries have thriving interventions for chronic conditions prevalent in the United States. A variation in culture and values may adjust the findings and should be considered.

Nonetheless, adopting methodology and modifying it to fit our communities would be worth the effort. It is an opportunity to test out the use of a patient navigation model focused on dementia care while using the cancer navigator program as a template. A dementia navigator may be a part of either home care model, a non-profit organization, or a health system. To drive independence and focus on the peer communication, the use of a non-profit or home care model may be the best fit. The funding sources would be vastly different in either model, but worth exploring and reaching out to the Aim 2 participants to gain perspectives. This may be a potential avenue for expanding the current project and exploring funding, organizational

structure, and means of establishing referral relationships with clinics, health systems, and other community-based organizations.

If we consider the study's findings, there are a large number of specialized organizations that offer dementia-specific health resources and services to some capacity but finding out about their existence and how to utilize them is where the gap lies. A peer health communication network would be made up of cohesive connections between healthcare providers and health and community-based organizations that support each other to build a strong knowledge base. Providers and organizations would be knowledgeable in dementia and of the existing dementia-specific resources and services in NETN. More importantly, PLWD and their caregivers would be connected to knowledgeable patient navigators serving as the specific point of contact to successfully navigate patients through the process of accessing community resources and services that are best suited for their individualized care needs along the dementia care continuum.

Strengths and Limitations

Like others, this study has strengths and limitations that must be considered. To our knowledge, no other research has been done on access to dementia specific health resources and services in NETN. This study was both inductive and deductive due to a methodology based on a small purposive sample from Northeast Tennessee counties. While the sampling can be seen as a limitation, the richness of participant insight provided an opportunity to examine dementia communication from health care to patients. CGT has been praised as well as criticized for reasons stemming from misunderstandings, uncertainty in the conceptualization, and deviation from traditional research methodology. Positivists criticize CGT most often by stating it lacks

alignment with standard science research requirements (Glaser, 2014; Simmons, 2012).

Contrastingly, CGT uses the constant comparison method that is a checkpoint used throughout to help combat this issue. Another strength of CGT is the exploratory nature of the study design. The use of CGT in this study placed high regard to participants' perspectives of community needs. To understand a community, you must ask the community what it needs, not tell them what it needs. A concern to note is the regional focus. This study was not intended to be generalized as the use of CGT is specific to the question at hand. This study's researcher had not received extensive training on how to how to generate a theory prior to the conduct of this study. Gynnild (2011) states this lack of knowledge in generating theories is quite common among young researchers. Due to the nontraditional means for research, finding an expert for mentoring can be difficult for a young researcher, and while mentoring is excessively important, the utilization of textbooks written by experts can be used as a source as well (Glaser, 2009b; Martin & Gynnild, 2011). The researcher read multiple books on CGT to grasp the fundamentals and worked with faculty mentors to adapt and refine the methodological approach. Glaser praises candidates for choosing CGT to conduct dissertation research and challenging themselves (Glaser, 2009b). It has been stated above that a researcher must plunge him or herself into the data project to begin to understand the true creation and methods of CGT. The researcher was willing to stay open and focused and let the data guide the study, while anticipating that by utilizing CGT, it would reinforce, and challenge applied knowledge in the field of research. CGT's applications of data and theory generation further support a foundation for understanding the opportunities ahead.

Opportunities for Future Research

This study's research revealed opportunities for additional research. First, the resulting theoretical model should be tested in future research. Second, this data represented organizations and healthcare providers; however, the data did not contain two critical groups in the dementia planning process. The researcher was unable to recruit people living with dementia plus a proxy and physicians for Aim 2 interviews. Persons with early onset of dementia play a crucial role in understanding the navigation process because they are the reason this research exists.

Perspectives of patients personally affected are vital to understanding how to improve and tailor dementia care. Physicians serve another major role in the navigation process too because they are often the first point of contact for health concerns. Future research should expand to incorporate PLWD plus a proxy, primary care providers, and other healthcare providers who address initial memory concerns with screening and referral services. Another opportunity for further research would include implementing a patient navigator intervention and evaluating the process and outcome measures for patients, families, and healthcare providers. Again, navigators have been used for increasing cancer screening and treatment. While similar, implementing navigators for a continuum of dementia care and evaluating it for efficacy would add to the supporting literature.

These two main opportunities identified in this study, peer health communication and patient navigation, could have important implications for addressing access to dementia-specific health resources and services. These opportunities may offer solutions to fill a void in patient care. Increase demand for dementia specific resources and services with an aging population plus insider insight can lead researchers to find new ways to address the health needs of our

aging population. Doing so could create a robust platform needed to construct innovative approaches to tailored dementia care.

Conclusion

Grasping the public health issue of Alzheimer's disease and related dementias is a challenge that requires extensive assistance from four distinct stakeholder groups: PLWD, caregivers and families, health providers and clinicians, health and community-based organizations, and policymakers. Portions of the healthcare industry focus on tertiary care and treating the problem when it happens. With the integration of public health, healthcare is slowly moving down the continuum towards incorporating more preventative health measures and preparation for health conditions with poor prognosis. Therefore, the vulnerability of PLWD and their caregivers require advocates to collectively stand and take the lead, not only in individual situations, but also from a policy level.

PLWD and caregivers must focus on overcoming individual barriers and addressing memory concerns as early as possible. We do not have a cure for ADRD, nor do we completely understand ways to prevent disease development or progression. However, as we have learned from years of research, various modifiable risk factors can be controlled by lifestyle and can decrease the risk of developing some forms of dementia. It is a long-term disease; therefore, the health choices made in earlier years of life can positively or negatively impact disease development. Additionally, healthcare providers and clinicians can step in by striving for prevention of chronic health conditions. The healthcare culture abandons prevention frequently. However, support staff such as dietitians, nutritionists, mental health counselors, or other community health workers can all aid a provider's ability to address prevention measures of

chronic health conditions. When it comes to diagnostics and referrals for services, providers should be trained on discussing health risk factors with patients and work to create a relationship that permits patients to feel comfortable enough to share cognitive changes. Providers should build interdisciplinary teams to connect nursing staff, psychologists, neurologists, psychiatrists, case managers, and community-based organizations to create a reliable network of professionals focused on patient safety, care, and quality of life. Contrastingly, the responsibility of establishing a care coordination team could be transferred to a patient navigator. There would be a care plan initiated earlier, PLWD and caregivers would have a primary contact for information, support, and direction, and caregivers would feel less burn out by eliminating some of the care burden from themselves. Health and community-based organizations play a crucial role as they are who patients seek but are unaware they needed them until it is too late. It is also important for organizations to continue to work towards more funding through advocacy and community awareness. As we have learned from this study, there are many organizations in NETN working hard to partner with other organizations and get their name into the community. However, the healthcare providers' awareness of resources and services and the connection with the organizations must be addressed. We know awareness alone does not create change, but the relationships and constant visibility may lift the stigma associated with dementia. Through partnerships and effective communication, provider confidence in dementia care, the care team, and organization may increase the quality of life for PLWD, caregivers, and families. Supporting this finding, policymakers should focus on the benefits and cost savings of addressing ADRD. Research shows the amount of money spent on dementia care exceeds billions, and that is only for those individuals that seek medical attention. The healthcare climate is more advanced and complex than ever before. Instead of focusing on quality, we attempt to

do more with less. Therefore, the organizations struggle to survive let alone thrive. A shift towards quality prevention and treatment must surpass the initial funding cuts. Policymakers have the opportunity to focus on cost savings from early interventions, less hospitalizations, and less nursing home placements.

The vulnerability of PLWD requires the advocates to step up and take the lead. The researcher plans to share the study's findings with the Aim 2 participants in hopes of informing potential policies, programs, or strategies that may help to eliminate the gap. This study provided insight on how communication impacts the 4A's of dementia-specific resources and services in Northeast Tennessee. The researcher hopes it will assist health professionals from various stakeholder groups to collaborate and implement interventions to help mediate the dementia care process. Health Educator 1 commented, "*some individuals probably don't have the capacity to reach out. So that's going to take the medical community as a whole to become knowledgeable of resources so they can facilitate that process.*" It boils down to the right care at the right time in the right place.

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APPENDIX A
AIM 1 QUESTIONS

VARIABLE	MEASURE	CODING
ORGANIZATION		
ORG_01	Organizational type How would you describe your organization?	1=residential 2=community 3=clinical
ORG_02	Service focus What best describes the service focus of your organization?	0=adult day services 1=advocacy 2=community engagement 3=education 4=health care 5=home health (non-medical) 6=home health (medical) 7=hospice 8=research 9=respite 10=residential community (includes memory care) 11=support groups (caregivers or people living with dementia) 12=support independence 13=training 14= training employees 15=therapy services/skilled nursing Carter=1 Greene=2 Hancock=3 Hawkins=4 Johnson=5 Sullivan=6 Unicoi=7 Washington=8 n/a=999
ORG_03	Service Area What Northeast Tennessee County(ies) do(es) your organization serve?	
ORG_04	Partnerships Does your organization work closely with other organizations to collaborate on dementia-specific resources and services?	0=No 1=Yes
ORG_05	Description of partnerships If yes- please describe the capacity of collaboration and methods	OPEN
RESOURCES & SERVICES		
ORG_06	Offer Does your organization offer dementia-specific health resources and services?	0=No 1=Yes
ORG_07	Service description If yes- how would you describe the resources and/or services offered by your organization?	OPEN
ORG_08	Use Who is able to use your dementia-specific health resources and services?	1=Anyone 2=County Residents 3=State Residents 4= employees 999=N/A
ACS_01	Delivery How does your organization deliver dementia-specific health resources and services?	1=online 2=staff lead 3=self-delivery
ACS_02	Access How are dementia-specific resources and services accessed by the intended population?	1=in person 2=online 3=distributed materials 4=directly provided by staff
ACS_03	Wait time How soon after initial contact can a new client/patient/resident typically receive dementia-specific resources and services?	1=same day 2=1-3 days 3=4-6 days 4=1-2 weeks 5=> 2 weeks
ACS_04	Referral Does the use of your organization's dementia specific health resources and services require a physician referral?	0=No 1=Yes

ACS_05	Hours	Does your organization offer dementia-specific health resources and services in the evenings/on weekends?	0=No 1=Yes
ACS_06	Advertise	How does your organization advertise dementia-specific health resources and services?	1=brochures 2=events 3=market to HC providers 4=market to community-based organizations 5=market to nursing homes/retirement communities 6=market to healthcare organizations 7=social media 8=word of mouth 9=newspaper
ACP_01	Communicating	Does your organization have staff that is knowledgeable in the communication needs of people living with dementia?	0=No 1=Yes
ACP_02	Training	Does your organization have staff that is trained to interact with people living with dementia properly?	0=No 1=Yes
ACP_03	Outreach-PLWD	Does your organization have outreach efforts to people living with dementia and their caregivers?	0=No 1=Yes
ACP_04	Outreach-HC Providers	Does your organization have outreach efforts to healthcare providers?	0=No 1=Yes
ACP_05	Outreach-Orgs	Does your organization have outreach efforts to dementia-specific health organizations?	0=No 1=Yes
ACP_06	Receive	When providing dementia-specific health resources and services, how are they received by the targeted audience?	1=not at all accepted 2=somewhat accepted 3=moderately accepted 4=very accepted
AFF_01	Cost	Does your organization charge for dementia-specific resources and services?	0=No 1=Yes
AFF_02	Fee for service	If yes- What is the fee for service?	#
AFF_03	Payment	If yes- How do recipients pay for dementia-specific health resources and services?	1=Medicaid (including CHOICES) 2=Medicare 3=Out of pocket-flat fee 4=Out of pocket-sliding scale 5=Tri-care 6= Private pay insurance 7=LTC Insurance
AVA_01	Staff duty fulfillment	Has it been difficult to designate staff to market or deliver dementia-specific resources and services?	1=not at all difficult 2=somewhat difficult 3=moderately difficult 4=very difficult
AVA_02	Staff shortages	Your organization is short staffed -for example, not enough staff to deliver dementia-specific health resources and services.	1=not true at all 2=somewhat true 3=moderately true 4=very true
AVA_03	Community	Are you aware of other dementia-specific health resources and services available in your community?	0=No 1=Yes
AVA_04	Description of community R&S	If yes, what ones do you know of?	OPEN

APPENDIX B
RECRUITMENT MATERIALS

Recruitment Email

Subject: Community Perceptions Regarding Dementia-Specific Health Resources and Services

Good morning [Good afternoon], [Name].

I hope this email finds you well. I want to invite you to participate in my research study that aims to examine communication issues that may occur for those providing as well as receiving dementia-specific resources and services. You are selected because you serve the older adults of Northeast Tennessee. Below you will find an invitation to participate in my dissertation data collection efforts.

[Insert approved Recruitment Materials]

Your participation in this study will involve a 30-45-minute one-on-one interview where I would join you in your place of business or a private community setting. Our conversation will need to be audio recorded to support data collection and analysis. Personal information will not be shared or included in the final written dissertation. Your privacy is my priority. You will receive a five dollar gift certificate to Pal's Sudden Service at the completion of the interview.

Please let me know if you are willing to participate in this study.

Thank you for your consideration, and I look forward to hearing from you.

Have a wonderful day.

Kindest Regards,



Help Improve Dementia Care

Ginger Bastian, BS, MPH
 DrPH candidate, Leadership
 C:423.534.3048
 E: rb05575@georgiasouthern.edu

Invitation to Participate in a Research Study

You are invited to participate in an exciting study! Be a key contributor in a one-time 30 to 45-minute interview to create a thorough understanding of how to enhance communication regarding dementia-specific health resources and services to further deliver quality dementia care in Northeast Tennessee.

We will examine community perceptions on communication gaps regarding dementia-specific health resources and services in Northeast Tennessee. Also, we aim to explore how communication may shape perceptions concerning the acceptability, accessibility, affordability, and availability of dementia-specific resources and services for persons with dementia and their caregivers.

We hope to recruit a diverse group of community members involved in caring for older adults as well as persons with dementia able and willing to participate with a caregiver present. Your participation will help determine opportunities for improving the care of our affected community members.

Interviews will be held from June to August in a professional location of your choice. A \$5 Pal's Sudden Service gift certificate will be provided for participation. If you are interested in participating or know someone that may be an excellent fit for this study, contact Ginger Bastian!

APPENDIX C
INSTRUMENT

INTERVIEW FACILITATOR GUIDE

Good morning [Good afternoon]! I am Ginger Bastian from Jiann-Ping Hsu College of Public Health at Georgia Southern University (GSU). You are invited to participate in my study conducted in collaboration with East Tennessee State University (ETSU) under the direction of professors Drs. Apenteng, Lawrence, Cohen, and Beatty. The purpose of this interview is to obtain your perspective on community access to dementia-specific health resources and services as well as communication among healthcare professionals and dementia service organizations when caring for people living with dementia and their caregivers in Northeast Tennessee. Your participation is voluntary. You may stop this conversation at any time if you no longer feel comfortable. As a participant, your confidentiality will be protected, and no data set or reports using information obtained from this study will use your name or identifiable information. The Institutional Review Board at GSU has reviewed and approved this research (IRB # H17028). This interview should take us no more than 30-45 minutes. There are no right or wrong answers. We will have a conversation to understand how to improve access to and communication regarding dementia-specific services and resources.

May I have your permission to audio record this interview to allow for transcription and analysis? [At consent, begin audio recording] Thank you.

All right let's begin.

GRAND TOURING QUESTIONS

1. *Please tell me a little bit about yourself and your connection to dementia care.*
2. *What do you see as the major issues concerning dementia in Northeast Tennessee?*
3. *Please tell me about the dementia-specific resources and services you are aware of in Northeast Tennessee. This can be general or specific resources and services that help persons with dementia and/or affiliated professionals in Northeast Tennessee.*
4. *How would you describe access to dementia-specific resources and services in Northeast Tennessee?*

- *Question 4 Probing Questions*

- i. *Availability*

Are there sufficient dementia-specific health resources and services in your community?

Why [why not]?

- ii. *Accessibility*

Do you feel dementia-specific health resources and services reach those that need or could benefit from them?

Why [why not]?

- iii. *Acceptability*

Do those in need or those who could benefit from dementia-specific health resources and services accept these services?

Why [why not]?

- iv. *Affordability*

Are the existing dementia-specific health resources and services affordable?

Why [why not]?

Are folks willing (or able) to pay for resources and services?

Why [why not]?

5. *How can access to dementia-specific health resources and services be improved? How do you feel awareness, education, and collaboration can be our driving forces for improvement?*

6. *What are your thoughts on communication between A) Persons with dementia (and their caregivers) and dementia-specific organizations?, B) Persons with dementia (and their caregivers) and healthcare providers?, C) Healthcare providers and other healthcare providers?, and D) Healthcare providers and dementia-specific organizations? Do you feel their perspectives on care may vary?*
 - How can communication regarding dementia-specific resources and services in Northeast Tennessee be improved among all stakeholders (persons with dementia, caregivers, healthcare providers, dementia-specific organizations)?*
 - How can effective communication among stakeholders (persons with dementia, caregivers, healthcare providers, dementia-specific organizations) improve access to dementia-specific resources and services?*
7. *Are there any issues, concerns, or considerations you would like to add that we have not addressed already?*

Thank you for participating. [Stop audiorecording]. I have a brief questionnaire for you to fill out. Once you complete it, we are finished. I sincerely appreciate the time you have taken to participate in my study.

APPENDIX D

PARTICIPANT DEMOGRAPHICS

Thank you for participating!					
Please check the box in each column that best describes you.					
You are a(n):	Age	Gender	Race	Ethnicity	Years Living in Northeast TN
<input type="checkbox"/> Person with dementia	<input type="checkbox"/> 18-30	<input type="checkbox"/> Male	<input type="checkbox"/> Asian	<input type="checkbox"/> Hispanic or Latino	<input type="checkbox"/> 1-4
<input type="checkbox"/> Caregiver	<input type="checkbox"/> 31-40	<input type="checkbox"/> Female	<input type="checkbox"/> American Indian	<input type="checkbox"/> Not Hispanic or Latino	<input type="checkbox"/> 5-9
<input type="checkbox"/> Healthcare admin	<input type="checkbox"/> 41-50		<input type="checkbox"/> Black		<input type="checkbox"/> 10-14
<input type="checkbox"/> Senior care admin	<input type="checkbox"/> 51-60		<input type="checkbox"/> Pacific Islander		<input type="checkbox"/> 15-19
<input type="checkbox"/> Assisted living or nursing home admin	<input type="checkbox"/> 61-70		<input type="checkbox"/> White		<input type="checkbox"/> 20-24
<input type="checkbox"/> Senior center admin	<input type="checkbox"/> 71 or older		<input type="checkbox"/> Two or more races		<input type="checkbox"/> 25 +
<input type="checkbox"/> University faculty/staff					
<input type="checkbox"/> Healthcare provider					
<input type="checkbox"/> Health educator					
<input type="checkbox"/> Local/State agency admin					